Navigating the Cathexis: Mothers and Daughters and End of Life

by

Pamela Anne Grassau

A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Factor-Inwentash Faculty of Social Work
University of Toronto

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2015

This dissertation begins with women’s lives and examines the experience of mothering (and daughtering) across the lifespan. Specifically, my work focuses on the cathexis, the flow of energy that moves between mothers and daughters as they navigate the meaning, significance and context of their connection as a mother is at the end of her life. Strongly informed by a feminist epistemology, this study draws on multiple conversations with five mothers and adult daughters (10 participants including one-in law pairing) as a mother is receiving in-patient or home based end of life care. Drawing on a narrative methodology and utilizing joint/dyadic interviews as my method, mothers and daughters were asked to share relational stories over time: when the daughter was young; when the daughter was a young-adult/adult; when illness arrived; in the present and what they hoped for one another in the future. Applying a narrative thematic and dialogic/performance analytic approach, end of life relational stories were examined to further our understanding of how and why experiences of end of life are performed by mothers and daughters in particular ways. Findings across the two analytic approaches reflect interwoven processes between mothers and daughters which are individual, relational and intersubjective. Individual processes address individual knowing and individual choices; relational processes reflect relational care practices between mothers and daughters, and mothers and daughters and care providers; and intersubjective processes address mutual knowing of dying and death. Implications of this study for social work practice and education strongly encourage social work
practice to expand to dyadic interviews and interventions in end of life, with an emphasis on what we can learn if we listen carefully to what, how and why people say things in particular ways. Implications for research encourage further questioning about how end of life is relational, and strongly urges researchers to explore joint/dyadic interviews as a method to explore living and dying in relationship.
Acknowledgements

“I do not at all understand the mystery of grace --only that it meets us where we are and does not leave us where it found us.” (Lamott, 1999, p. 143)

It is important to begin by humbly and gratefully acknowledging the women who participated in this study. Special thanks are extended to each of the five mothers and daughters who participated for their tremendous generosity in sharing their lives, relationships, hearts and minds with me at this particular time in their lives. This work is dedicated to each of you, and is particularly dedicated to the re-membering (Myerhoff, 1982, p. 111) of the four mothers who have died since this study began.

My doctoral work has been guided and shaped by an academic thesis committee that has grown and shifted over the years. Special thanks are extended to Dr. Adrienne Chambon for her early encouragement in my work and in shaping some of my initial explorations of mothering and daughtering outside the context of psychosocial oncology and end of life practices. Sincere thanks are also extended to Dr. Izumi Sakamoto for her supervision and support as I navigated across multiple research ethics boards, began collecting data, and worked to meet pressing academic timelines. Particular thanks are extended to Dr. Sakamoto for her encouragement to find my own voice in my writing. Dr. Charmaine Williams, a highly respected teaching mentor who I had the privilege to teach with in the early days of my doctoral studies, brought in her initial role as a second reader important reminders and reflections of who this work is for, what this work contributes and how this work can further shape social work practice. In the past year Dr. Williams moved into a supervisory role and offered a tremendous amount of time, energy and support. I am extremely grateful for how she has pushed my work epistemologically, theoretically and methodologically. Further, I am very appreciative for the new questions and insights that Dr. Eunjung Lee brought to my work about how relational dialogue is lived and performed in relationship. I would also like to sincerely thank Dr. Christina Sinding who has been involved in my work since the beginning. Dr. Sinding’s research with women living with illness, as well as those who are caring for loved one’s in end of life, has been an important beacon for me of what is possible in this area of research. Further, Dr. Sinding’s feminist praxis continues to inspire me about who we can be as teachers, researchers and as feminist women inspired to create change in the world. I would like to thank Dr. Juanne Nancarrow Clarke for her thoughtful review and insights on an earlier draft of this work. I would also like to thank Dr. Cheryl-Anne Cait for bringing her expertise, background and insights into the final examination of this work.

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Dr. Peter Lawlor, Dr. Christopher Klinger, Jo-Anne Dusseault and Maryse Bouvette who have not only welcomed me, but have allowed me to find a home for my research and practice in hospice, palliative and end of life care. I would also like to particularly acknowledge Dr. Pippa Hall and Dr. Tara Tucker for their leadership, and mentorship as co-principal investigators on varying forms of this study, as well as the larger grant that we are about to begin. Shauna Daly – I am thrilled that you are embarking on this journey with us!

I would also like to gratefully acknowledge the continual support and encouragement that I have received from my families to both begin and complete this work. Mom, thank you for being my Mom, and for being my first teacher about mothering and daughtering. Dad, my biggest cheerleader who asked me to ‘hurry up and finish”, I’m sorry you are not here to see this in person. Please know that your love and belief in me has helped me complete this work. Lynda O’Dwyer, you have been such an important part of this journey with me – thank you for teaching me about care, compassion and the importance of really being with people when they are ill. Wilfrid, Erin and family, thank you for reminding me of the importance of living (and playing) each day. Bev and Bob, thank you for your love and support, and thank you Bev for continuing to teach me about resilience, strength and compassion.

Mom-D, thank you for giving me such deep roots and for immediately and unconditionally claiming me as your ‘girl’. Having you in my life, even though for a short amount of time, offered and continues to offer me so many gifts. One of the biggest gift I have received is having Dennis (Dad-D), Nadine, Shawn, Aunt Marlene and the rest of the family in my life – in them, I see so many parts of you. Special thanks to each of you for being part of my family, and Nadine ~ life is absolutely and truly a better place with a sister!

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And last but definitely not least, Beth, thank you for loving me ‘beyond counting’ and for being my biggest and strongest cheerleader. Your ability to see all of me – is such a tremendous gift to me. My world is so much more whole with you in it – and I’m excited to see where we go from here…..
# Table of Contents

Table of Contents ........................................................................................................................... vi

List of Tables ................................................................................................................................... ix

List of Figures ..................................................................................................................................... x

List of Appendices ............................................................................................................................ xi

Chapter 1: Introduction ................................................................................................................... 1

  1.1 Mothering/Daughtering as Experience & Motherhood/Daughterhood as Institution ......... 2

  1.2 Why Focus on Mother and Daughter Relationships in End of Life? .............................. 3

  1.3 Mothers and Daughters and Relational End of Life Stories ........................................... 4

  1.4 Questions Guiding this Work .............................................................................................. 4

  1.5 The Context of End of Life and End of Life Care in Canada ........................................... 5

    1.5.1 Death and Dying Statistics in Canada ....................................................................... 5

    1.5.2 Where do Canadians die? .......................................................................................... 7

    1.5.3 Practices and Models of End of Life Care ................................................................ 8

  1.6 Organization of Dissertation ............................................................................................. 21

Chapter 2: Review of Theoretical and Empirical Literature ......................................................... 24

  2.1 Life Course Theory and Psychosocial Stages of Development ........................................ 24

    2.1.1 Central tenets of Life Course and Psychosocial Stages of Development ............... 26

    2.1.2 Families and End of Life in the Context of Life Course Theory and Psychosocial Stages of Development ........................................................................ 29

    2.1.3 Life Course Theory and Psychosocial Stages of Development’s Influence on Research and Practice in End of Life ......................................................... 32

    2.1.4 Contributions and Limitations of Life Course and Psychosocial Stages of Development to Understanding Mothers and Daughters at the End of Life ........ 36

  2.2 Stress and Coping Models ................................................................................................ 37

    2.2.1 Central tenets of stress and coping theory ............................................................... 37

    2.2.2 Families and End of Life in the Context of Stress and Coping ............................... 40
<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.2.3</td>
<td>Stress and Coping Theory’s Influence on Research and Practice in End of Life</td>
<td>47</td>
</tr>
<tr>
<td>2.2.4</td>
<td>Contributions and Limitations of Stress and Coping theory to Understanding Mothers and Daughters at the End of Life</td>
<td>53</td>
</tr>
<tr>
<td>2.3</td>
<td>Relational Cultural Theory</td>
<td>54</td>
</tr>
<tr>
<td>2.3.1</td>
<td>Central Tenets of Relational Cultural Theory</td>
<td>54</td>
</tr>
<tr>
<td>2.3.2</td>
<td>Families and End of Life in the Context of Relational Cultural Theory</td>
<td>58</td>
</tr>
<tr>
<td>2.3.3</td>
<td>Relational Cultural Theory’s Influence on Research and Practice in End of Life</td>
<td>68</td>
</tr>
<tr>
<td>2.3.4</td>
<td>Contributions and Limitations of Relational Cultural Theory to Understanding Mothers and Daughters at the End of Life</td>
<td>73</td>
</tr>
<tr>
<td>2.4</td>
<td>Summary and Conclusions</td>
<td>73</td>
</tr>
<tr>
<td>Chapter 3: Design and Methods</td>
<td></td>
<td>77</td>
</tr>
<tr>
<td>3.1</td>
<td>Distinguishing between Epistemology, Methodology and Method</td>
<td>78</td>
</tr>
<tr>
<td>3.1.1</td>
<td>Feminist Epistemology</td>
<td>79</td>
</tr>
<tr>
<td>3.1.2</td>
<td>Social Location of the Researcher</td>
<td>81</td>
</tr>
<tr>
<td>3.2</td>
<td>Narrative Methodology</td>
<td>84</td>
</tr>
<tr>
<td>3.3</td>
<td>Method – Dyadic interviews</td>
<td>86</td>
</tr>
<tr>
<td>3.3.1</td>
<td>The Dyadic Interview Guide</td>
<td>89</td>
</tr>
<tr>
<td>3.4</td>
<td>Should research happen in palliative and end of life care?</td>
<td>89</td>
</tr>
<tr>
<td>3.5</td>
<td>Settings</td>
<td>92</td>
</tr>
<tr>
<td>3.5.1</td>
<td>In-patient Palliative Care Unit (PCU)</td>
<td>92</td>
</tr>
<tr>
<td>3.5.2</td>
<td>Palliative Care Consultation Service (PCCS)</td>
<td>93</td>
</tr>
<tr>
<td>3.6</td>
<td>Sampling &amp; Participants</td>
<td>94</td>
</tr>
<tr>
<td>3.7</td>
<td>Recruitment Procedures</td>
<td>98</td>
</tr>
<tr>
<td>3.8</td>
<td>Mother/Daughter Participants</td>
<td>101</td>
</tr>
<tr>
<td>3.9</td>
<td>Data Collection</td>
<td>103</td>
</tr>
<tr>
<td>3.10</td>
<td>Data Analysis Procedures</td>
<td>106</td>
</tr>
</tbody>
</table>
List of Tables

Table 1  Top Ten Leading Causes of Death in Canada in 2009          p. 6
Table 2  Comparison of Place of Death between Atlantic and Western Provinces p. 7
Table 3  What Matters Most In End of Life Care Ranking                  p. 17
Table 4  Comparison of Core Values: Canadian Association of Social Workers and Hospice, Palliative Care p. 19-20
Table 5  Psychosocial Types of Illness                                 p. 41
Table 6  Participant Overview                                          p. 102
Table 7  Transcription Legend                                          p. 129-130
List of Figures

Figure 1  Life Course Theory and Psychosocial Stages of Development  p. 32
Figure 2  Stress and Coping Theory: Global and Situational Meaning  p. 39
Figure 3  The Role of Hospice Palliative Care during Illness  p. 42
Figure 4  Family Systems Illness Model & Individual Illness Developmental Stages, Tasks & Challenges and Family Illness Developmental Tasks (Terminal Phase)  p. 46
Figure 5  Relational Cultural Theory  p. 57
Figure 6  Overview of Epistemology, Methodology and Methods  p. 79
Figure 7  Recruitment on the In-Patient Palliative Care Unit  p. 100
Figure 8  Recruitment within Palliative Care Consultation Service  p. 101
Figure 9  Overview of Interviews  p. 103
Figure 10  Word Frequency Word Cloud  p. 244
List of Appendices

Appendix A  Information Letter and Consent Form for Participants (Version 1 and Version 2)
Appendix B  Interview Guide 1 & Interview Guide 2
Appendix C  Ruth & Sarah Thematic and Dialogic/Performance Analysis
Appendix D  Mary & Amelié Thematic and Dialogic/Performance Analysis
Appendix E  Marian & Pam Thematic and Dialogic/Performance Analysis
Appendix F  Carrie & Elisabeth Thematic and Dialogic/Performance Analysis
Appendix G  Diana & Susan Thematic and Dialogic/Performance Analysis
Appendix H  Overview of Core Findings: Individual, Relational and Intersubjective Processes
Chapter 1: Introduction

“This cathexis between mother and daughter - essential, distorted, misused – is the great unwritten story.” (Rich, 1976, p. 225)

This dissertation begins by focusing on the unique cathexis, that is the mental, physical and emotional energy that flows between a mother and daughter,¹ as a mother is receiving end of life care. Beginning with cathexis is purposeful, designed to ensure that that the energy, flow and movement within the mother and daughter relationship remains primary as I explore how mothers and their adult daughters experience end of life. Emphasizing cathexis in end of life is also deliberate, designed to ensure end of life conceptualizations of decathexis (emotional withdrawal or disengagement when someone is dying) (Connor, 2009; Poor, 2001), are broadened to understandings of energy and flow across the full continuum of life, including when someone is facing the end of their life. Starting with the experiences of women mothering and daughtering in end of life, raises new questions about how end of life is relational, how living, dying, and living while dying are experienced relationally, and how we can ensure we care for patients and their families as they approach the end of their lives. Situating this work within social work practice, education and research offers its own ‘unwritten story’, as social work as a discipline strives to build a stronger foundation for how theory, practice, and research contribute to the field of end of life care.

¹ Adrienne Rich’s use of ‘cathexis’ emphasizes the flow of energy that moves between mothers and daughters physically, emotionally and psychically. The concept of cathexis has been attributed to Sigmund Freud’s early work around psychic energy and emotional investment, which in German was called ‘Besetzung’. James Strachey, who translated Freud’s work into English, invented the word ‘cathexis’ to more accurately capture the occupied space between psychic energy and emotional investment. This said, there have been tensions around how the word cathexis is understood, and it remains a term that defies being easily categorized or quantified (Ornston, 2002; Strachey, 1962).
1.1 Mothering/Daughtering as Experience & Motherhood/Daughterhood as Institution

Over 30 years ago, Adrienne Rich (1976) wove together two central threads which have since been considered foundational to any feminist discussion of mothers and daughters. The first thread differentiated between the experience of mothering, which was grounded in women’s experiences, thoughts, and emotions, and the institution of motherhood, which reflected how women’s lives are deeply interwoven within the economic, political, medical, and social institutions operating both around and through their lives. Drawing on multiple sites and examples, Rich’s work reflects on how women’s sense of self; their bodies, roles, and relationships, and also their sense of agency and control are all highly interwoven within familial, social, and contextual worlds. Further, these worlds prescribe not only externally, but also internally who women are. The second thread addressed the complexity of the mother and daughter relationship, offering what has become one of the most cited references on mothers and daughters: “The cathexis between mother and daughter - essential, distorted, misused - is the great unwritten story” (Rich, 1976, p. 225). In weaving these two threads together, Rich ensured that the experience of mothering and the institution of motherhood were understood as being interwoven into the mother and daughter relationship.

Initial work within the area of mothering and motherhood spoke to the experiences and issues of ‘all women’ (Boyd, 1989; Gilligan & Rogers, 1993; Hirsch, 1981), but over the past 20 years, feminist women of colour have pushed to de-center the universal category of ‘woman’ and, as a result, ‘mother,’ in order to reflect more accurately the identities and locations that exist as a result of class, ethno-cultural background, sexual orientation, religion, and ability. As a way of speaking to this shift, Collins (1994) uses the term ‘motherwork’:

I use the term *motherwork* to soften the dichotomies in feminist theorizing about motherhood that posit rigid distinctions between private and public, family and work, the individual and the collective identity as individual autonomy and identity growing from the collective, identity as individual autonomy and identity growing from the collective self-determination of one’s group. Racial ethnic women’s mothering and work experiences occur at the boundaries demarking these dualities (Collins, 1994, p. 59).
I am interested in engaging directly with the stories that mothers and daughters relay together about the work that they do individually and collectively as mothers move into end of life care. Specifically, my focus is on how mothers and daughters navigate the boundaries of their lives, as they live within multiple roles, identities, and contexts. Within this shared ‘motherwork’ and ‘daughterwork’ space, mothers and daughters can define for themselves their lives as women, their individual and collective relationships to illness, their individual and collective wants and needs for living and dying, and how they both want to be remembered. Lastly, I am interested in hearing whether mothers and daughters have felt that larger institutional (i.e. social, cultural, historical, and medical) stories inform or weigh in on their own experiences, and how they have responded to or countered these stories with their own experiences.

1.2 Why Focus on Mother and Daughter Relationships in End of Life?

While there are a number of different family members who provide care, women continue to dominate the field in formal and informal caregiving (Armstrong & Armstrong, 2004; Armstrong & Kits, 2004; Baines, Evans, & Neysmith, 1998; Barnes, 2006). A growing body of literature looks at the critical role of adult daughters, and how adult daughters are a primary resource in caring for aging and ailing parents (Abel, 1986; Horowitz, 1985; Pope, Kolomer, & Glass, 2012). Literature which addresses the unique experience of daughters caring for their mothers speaks to the specific roles, costs, burdens and challenges that arise as daughters care for their aging and ailing mothers over time (Aronson, 1991; Covinsky et al., 2001; Donorfio & Sheehan, 2001; Lewis & Meredith, 1988; Ward-Griffin, Oudshoorn, Clark, & Bol, 2007). As will be discussed in more detail in chapter two, while this literature echoes some of the concerns and challenges which are addressed in the family caregiving in end of life studies, we also see a movement beyond psychological theories on stress and coping, to a context that includes broader feminist, relational, and structural perspectives. Feminist theory (Enns, 2004; hooks, 1984; Lather, 1991; Mackinnon, 2009), and specifically relational feminist theory (Gilligan, 1982; Miller, 1986), helps us to build an understanding of women’s lived experiences as different from men’s experiences, and how women’s lives are situated across and within relationships. Feminist self-in-relation and later feminist relational cultural theory (Jordan, 2004, 2008, 1997; Miller & Stiver, 1997), further emphasizes the importance of connection and relationships in the lives of
women. While many relationships are important for girls and women, underscored throughout much of the feminist mothering literature is the centrality of the mother and daughter relationship (O'Reilly & Abbey, 2000; Rich, 1976). This literature draws attention to relational images between mothers and daughters (Jordan, Walker, & Hartling, 2004; Miller, 2008; Miller & Stiver, 1995). Relational images are built from past and present experiences, and are deeply internalized understandings, meanings, and expectations of who a woman is individually and relationally; of her roles and responsibilities; and importantly how she responds to relational connection and disconnection. Examining how mothers’ and daughters’ relational images weave together into relational stories as they talk about their lives offers important insights about how end of life is experienced through a relational lens, and how and in what ways we might further support women at this time of their lives.

1.3 Mothers and Daughters and Relational End of Life Stories

As will be discussed in more detail in chapter three, this study was guided by a narrative methodology which emphasizes the centrality of narratives and stories: of how stories give shape to our experiences (Mishler, 1995; Sandelowski, 1991); and how the telling (and listening) to women’s stories can offer a profound way to really hear how women know and experience their lives. As Catherine Riessman (2008) notes, “telling stories about difficult times in our lives creates order and contains emotions, allowing a search for meaning, and enabling connection with others” (p. 10). In drawing on joint/dyadic interviews with mothers and daughters together, this study focuses specifically on co-constructed stories, on the stories that unfold relationally between mothers and daughters, as they talk about who they are as women, and as mothers and daughters in relationship. In particular, this study explores relational stories, as a form of story (and storytelling) that lives between mothers and daughters, which holds relational beliefs and understandings about: who they are as women, who they are as women in relationship over time; and who they are as mothers and daughters in the face of illness, and loss.

1.4 Questions Guiding this Work

1. What are the relational stories (beliefs, understandings) that inform mothers’ and daughters’ experiences in their relationship, and how do these relational stories inform their experiences of end of life?
2. How does the process of participating in a relational life review illuminate relational understandings of end of life, and how might this widen our understanding of shared loss and meaning at end of life?

1.5 The Context of End of Life and End of Life Care in Canada

In the following section I speak to the broader context of end of life and end of life care in Canada. After providing an overview of death and dying statistics in Canada, I address more broadly where Canadians die. In speaking to practices and models of end of life care, I describe how palliative care and hospice, palliative care is provided in Canada. Further, I speak to some of the social and cultural understandings which inform broader understandings of death, dying and end of life care. I then address the role of social work across these contexts, and I emphasize how social work has a strong historical connection to hospice, palliative care, and how there are many similarities between the core values of social workers and the core values of hospice palliative care. While there is a strong movement towards identifying and positioning all end of life care as part of hospice, palliative care, the majority of Canadians who die, do not receive any form of formalized hospice, palliative care services (Canadian Institute for Health Information, 2007, 2011). While I am a strong supporter of hospice, palliative care, and have seen the strengths of this model of care for patients who are dying and their families, it is important to acknowledge that the experience of end of life exists in multiple forms outside of medically informed systems and practices of end of life care. Until we have a system of end of life care that meets the needs of all Canadians, regardless of who they are, and/or where they live, it is imperative that we speak to end of life care as a whole and that we remember that hospice, palliative care (while growing), continues to meet the needs of only a small percentage of the greater number of Canadians who are in end of life.

1.5.1 Death and Dying Statistics in Canada

In 2011 there were 242,074 deaths in Canada, 89,195 of which were in Ontario (Statistics Canada, 2013). Table 1 outlines the top ten leading causes of death for Canadians in 2009 (Statistics Canada, 2009).
<table>
<thead>
<tr>
<th>Ranking</th>
<th>Cause of Death</th>
<th>Number and percentage of Canadians in 2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Cancer [Malignant neoplasms]</td>
<td>71,125 (29.8%)</td>
</tr>
<tr>
<td>2</td>
<td>Heart Disease</td>
<td>49,271 (20.7%)</td>
</tr>
<tr>
<td>3</td>
<td>Stroke [Cerebrovascular diseases]</td>
<td>14,105 (5.9%)</td>
</tr>
<tr>
<td>4</td>
<td>Chronic lower respiratory diseases</td>
<td>10,859 (4.6%)</td>
</tr>
<tr>
<td>5</td>
<td>Accidents [unintentional injuries]</td>
<td>10,250 (4.3%)</td>
</tr>
<tr>
<td>6</td>
<td>Diabetes [Diabetes mellitus]</td>
<td>6,923 (2.9%)</td>
</tr>
<tr>
<td>7</td>
<td>Alzheimer's disease</td>
<td>6,281 (2.6%)</td>
</tr>
<tr>
<td>8</td>
<td>Influenza and pneumonia</td>
<td>5,826 (2.4%)</td>
</tr>
<tr>
<td>9</td>
<td>Suicide [Intentional self-harm]</td>
<td>3,890 (1.6%)</td>
</tr>
<tr>
<td>10</td>
<td>Kidney disease [Nephritis, nephrotic syndrome and nephrosis]</td>
<td>3,609 (1.5%)</td>
</tr>
</tbody>
</table>

The table above demonstrates that just over fifty percent of deaths in Canada are linked to cancer and heart disease and that a little more than 10% of deaths are sudden, such as stroke, accidents or intentional self-harm. These statistics reflect that only a very small percentage of Canadians die unexpectedly.

Population projections note that by 2031 about a quarter of Canadians will be 65 years old or older, and by 2056 an estimated 1 out of 10 Canadians will be 80 years or over compared with about 1 in 30 today. As the majority of deaths that occur in Canada are people who are over the age of sixty-five (Statistics Canada, 2010) this raises significant concerns about not only how we will be able to care for Canadians as they age, but also how our system will be able to handle the increase in deaths each year. Population estimates predict that by 2036, our annual death rates will have increased by 65%, and by 2058 our death rates will have doubled (Statistics Canada, 2010). These projections also require us to think more critically about how Canadians die, and how people with different illness trajectories progress in their illnesses towards end of life and death. Statisticians have developed theoretical trajectories to categorize how varying illnesses progress, and how death occurs in Canada. Four trajectories appear: 1. sudden death, 2. terminal illness (e.g. cancer), and 3. organ failure (e.g. congestive heart disease), and lastly 4. frailty (e.g. neurological decline, other frequent causes of death in the elderly) (Canadian
Institute for Health Information, 2007). These trajectories provide theoretical understandings and projections for how patients in each illness category will require health care services before they die. Canadian patients who have been categorized as living with terminal illness often remain fairly high in functioning until they begin to rapidly decline before they die. Canadian patients categorized as living with frailty, experience much lower functioning prior to death and a much slower progressive decline towards death (Canadian Institute for Health Information, 2007, 2011). While these trajectories offer important information for thinking about patterns of health care use, and how our system needs to meet the needs of patients within each of these illness groupings, these trajectories also offer insights into how and when end of life care may be initiated for Canadians across illness categories.

1.5.2 Where do Canadians die?

Most Canadians die in an inpatient, hospital based medical ward (Wilson et al., 2009). Available statistics from Atlantic (2007-2008), and Western (2003-2004) provinces offer us, in two different datasets, comparisons between places of death. Please see Table 2: Comparison of place of death between Atlantic and Western Provinces (Canadian Institute for Health Information, 2007, 2011).

<table>
<thead>
<tr>
<th>Place of Death</th>
<th>Percentage of Canadians – Atlantic Provinces 2007-2008</th>
<th>Percentage of Canadians – Western Provinces 2003-2004</th>
</tr>
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<tbody>
<tr>
<td>Acute Care Hospital</td>
<td>62%</td>
<td>58%</td>
</tr>
<tr>
<td>Other health facilities (e.g. long term care, nursing homes, complex care facilities)</td>
<td>22%</td>
<td>42% (includes all other locations)</td>
</tr>
<tr>
<td>Home</td>
<td>14%</td>
<td>Data Not Available</td>
</tr>
<tr>
<td>All Other Locations</td>
<td>2.2%</td>
<td>Data Not Available</td>
</tr>
</tbody>
</table>

Table 2

*Comparison of place of death between Atlantic and Western Provinces* (Canadian Institute for Health Information, 2007, 2011)
More recent statistics available from 2011-2012 on the place of death for cancer patients, note that about half (45%) of Canadian cancer deaths occurred in acute care hospitals (Canadian Institute for Health Information, 2013). Home-based deaths within this data represent only a small proportion (14%) of the deaths that occur annually.

1.5.3 Practices and Models of End of Life Care

Prior to the rise of medicine, and specifically institutionalized medicine, the care of the dying was seen predominantly as the responsibility of the family and if family were not available, within religious institutions. Within families, end of life took place in the home, and family members would provide any/all care for the dying. Within religious institutions, end of life care would take place within parishes or sites owned by varying religious groups. As medical care has become more formalized, and medical institutions have become more established, there has been a notable shift towards people dying in hospital under medical supervision (Clark, 2010). The shift towards medical supervision in end of life has not been without conflicts and tensions, as “the focus of modern medicine moved farther away from the care of those at the end of life and appeared to be preoccupied with new interventions focused on cure rather than palliation” (Clark, 2010, p. 9). These tensions within the field of medicine around whether medicine as a practice focuses on curing or palliation still linger today, despite the fact that death and dying happen across all medical specialties.

1.5.3.1 Palliative Care

Palliative care as defined by the World Health Organization (WHO) is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness” (World Health Organization, 2012). This definition speaks to the overall focus of palliative care, which is an approach designed to improve quality of life for those facing the problems associated with life-threatening illness. Further, this definition addresses the people (patients and their families) of whom this approach has been designed and intended to support. Together, this definition asks us to consider complex questions which speak to: what quality of life means in the face of life-threatening illness; what improves quality of life and, more specifically, what type of care improves quality of life when people are living with a life-threatening illness; and most importantly how these elements can be addressed for patients and their families.
Palliative Care in Canada

Within hospitals, end of life care is provided primarily in general or subspecialty medical wards, with a smaller number of patients receiving specialized tertiary palliative care in a palliative care unit (Towns et al., 2012). Within specialized palliative care units, such as the one site where mothers and daughters were recruited for this study, care is delivered by a multi-disciplinary team of experts in palliative care, and models of care focus predominantly on complex hospice and palliative care needs and issues. Home based hospice palliative care is delivered to patients living at home or in a residential home, and is provided by hospice volunteer services, home care nursing services with specialized skills in hospice palliative care, and/or primary care physicians who access specialized palliative care consult team services to provide additional palliative care services and supports (Ferris et al., 2002). The second site of data collection for this study comes from mothers living at home or in a residential home, who are receiving medical care from their community based primary care providers. Within this context, primary care physicians access additional palliative care community consult services to provide specialized palliative care supports for their patients who are in need of more advanced or complex care in relation to pain, symptom management, wound care, or existential distress.

As the type and extent of palliative care can vary across medical wards and palliative care units, it is often challenging to accurately determine the percentage of patients who received some form of palliative and end of life care while receiving end of life care in an acute care hospital. With the statistics that are available we begin to see regional differences between Western and Atlantic Provinces in the estimates of how many inpatients received some form of palliative care during their last hospitalization. In Western Provinces in 2002-2003, it was estimated that about one-quarter of patients who died in hospital received some form of palliative care during their last hospitalization (Canadian Institute for Health Information, 2007). In Atlantic provinces in 2007-2008, closer to 60% are estimated to have received some form of palliative care during their last hospitalization (Canadian Institute for Health Information, 2011). Together these statistics reflect that 25% to 60% of patients (depending on region), received some form of palliative care in their last hospitalization prior to death. However, these statistics do not allow us to examine the extent of palliative care delivered. Finally, as there is a wide range of palliative care delivered to Canadians, and as patients and families move between home,
inpatient and for some, specialized tertiary sites, it is often difficult to know the extent, and impact of these models of care on how patients and families experience end of life.

1.5.3.2 Hospice, Palliative Care

The terminology used to describe end of life care practices also varies across practice sites, disciplines, and geographic locations. In the interest of building and securing a unified and system wide approach to the delivery of end of life care in Canada, there has been a strong push across local, provincial, and national levels for all end of life care practices to be subsumed under the larger term of hospice palliative care (e.g. The Canadian Hospice Palliative Care Association (CHPCA). While many would agree on the common goal of having a stronger and more accessible hospice palliative care strategy, there are a number of programs and sites across Canada describing their services as hospice or palliative care. Some of the differences which exist between programs which are run as hospices or hospice care programs versus those run as palliative care units and programs reveal how end of life care practices have become more formalized over time.

The term hospice, which has the same root as the Latin words hospes (host) and hospitium (hospitality/guesthouse) has been traced back to medieval times when religious groups offered a place of respite for weary and/or ill travelers who were intending to visit spiritual sites for healing (Bennahum, 2003). While religious groups in the 16th to 18th centuries offered end of life care for those who were suffering or alone, most people were cared for by their families and died where they lived. As the practice of medicine became more professionalized, physician practice focused predominantly on curing disease. When cure was not possible, patients who were in end of life were shifted away from physician care to sites and care practices which were predominantly offered by nursing and spiritual care providers. The modern hospice movement, seen as the immediate precursor to much of how hospice care is practiced today, is widely attributed to the work of Dame Cicely Saunders (Baines, 2011; Clark, 1999). In 1967, Dame
Saunders opened St. Christopher’s Hospice in South London, England as an in-patient program designed to care specifically for patients in end of life. Three elements were central to how care was delivered at St. Christopher’s Hospice, and these elements continue to be reflected in the aims/goals of most of the practice of hospice, palliative care today. The first element speaks to a core interest in understanding what causes pain. Over her career, Dame Saunders conducted a number of narrative-based studies which explored how patients experienced pain. From these studies, Saunders developed an understanding of pain, which she conceptualized as ‘total pain’ (Clark, 1999; Saunders, 2006; Saunders, 2003). Total pain was conceptualized as a holistic way of understanding and treating pain, whereby physical symptoms and manifestations of pain were viewed as closely interwoven with psychological, social, cultural, and spiritual aspects of pain and suffering. In order to understand and treat total pain, clinicians needed to really listen to patients and in listening they gathered a sense of the many different parts of patients’ lives which were in pain. A clinician’s ability to fully understand and treat total pain was strongly woven into the second core element, namely that patients and their family members are considered the primary unit of care. Dame Saunders felt strongly that care for patients in end of life needed to include both the patient and their family. This understanding that patients’ lives are deeply interwoven into the lives of their family members was seen as an integral part of caring for the dying as well as the living. Finally, the third element was a multi-disciplinary model of care. Having a care team at St. Christopher’s Hospice which included physicians, nurses, social workers, and chaplains was considered one of the primary ways of ensuring that total pain was both listened to and addressed with each patient and family member.

**Hospice/Palliative Care in Canada**

The beginning of hospice palliative care in Canada is linked to Dr. Balfour Mount, a Montreal based physician who specialized in urology and oncology at McGill University and the Royal Victoria Hospital. Interested in some of Dr. Elizabeth Kübler-Ross’s early writing on death and

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2 In 1969, St. Christopher’s Hospice began delivering home-based hospice care. St. Christopher’s Hospice was at the forefront of end of life care delivery as St. Christopher’s Hospice became the first hospice to deliver home based end of life care in the United Kingdom (Baines, 2011).

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dying (Kübler-Ross, 1969), Dr. Mount travelled in the early 1970s to St. Christopher’s Hospice to meet Dame Saunders and explore the applicability of the modern hospice care movement in Canada. Dr. Mount spent a week at St. Christopher’s Hospice and was inspired by the model of care that he witnessed (Ottawa Citizen, 2005). This said, Dr. Mount was dissuaded by the fact that St. Christopher’s Hospice operated predominantly by private donations. Dr. Mount envisioned a model of care that was more aligned with in-patient acute care hospitals. In 1973, Dr. Mount opened one of the first hospital-based in-patient palliative care units in Canada at the Royal Victoria Hospital in Montreal, Quebec. Dr. Mount coined the term *palliative care*, drawing on the Latin words palliare (to cover) and pallium (to cloak) as a way of describing medical care practices which focused on relieving symptoms rather than ascribing to curative medical practices. Dr. Mount believed that palliative care in a hospital based context could draw on many of the central tenets of the hospice care movement, while also being provided within the provincially funded infrastructure of acute-care hospitals.

The unique trajectories of how hospice care and palliative care have arisen over time continue to offer important insights about some of the distinctions which exist between these two different forms of end of life care, particularly in relation to funding. While hospice programs receive some provincial funding for hospice-based care, they still rely heavily on private funding for operational costs. Specialized palliative care units within hospitals fall within provincial hospital billing. Other, more subtle but powerful differences reveal how programs and services have evolved in relation to the extent and level of community engagement in the organization, and ultimately the extent that the medical model informs how care is practiced.

*An Important Note about the End of Life Care Sites Utilized Within This Study*

The mothers and daughters that participated in this study were recruited from two palliative care programs: an inpatient palliative care unit and a home based/residence based palliative care consultation services. These sites were chosen due to the fact that I had an a priori relationship with both the palliative care sites and the providers working within these sites. As most

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3 In 1973, two hospital based in-patient units were opened within a few months: St. Boniface Hospital in Winnipeg, Manitoba, followed by the Royal Victoria Hospital in Montreal, Quebec.
Canadians die in hospital (Wilson et al., 2009), and there continues to be a very small percentage of the population that receives some form of palliative care during their last hospitalization (Canadian Institute for Health Information, 2013; Canadian Institute for Health Information, 2007, 2011), this means that the women who participated in this study reflect a very specific, and distinct type of patient/family experience of end of life. This said, across all sites of dying and death there are core and essential elements about how mothers, and their adult daughters, experience end of life. As most deaths occur in hospital based settings, common across hospital based settings and within palliative care settings, is the larger context of how most end of life experiences occur in a setting which is strongly informed and shaped by a professional, medical caregiving practice and context. Beginning to understand how this broader end of life medical context informs and shapes the experiences of mothers and daughters, is the first step in understanding how women’s lives (and their experiences of end of life), are situated within these medical institutions and practices of living and dying. Findings within this study, while exploratory, are understood as only one pathway in examining the experiences of mothers and daughters in end of life. In order to more accurately reflect the wider range of experiences of end of life across the population, future research needs to expand beyond hospice, palliative care sites and programs into hospital, and acute based settings across our country. In addition, it is important to recognize the many experiences of end of life which continue to not be documented or represented within more mainstream data collection practices and health service documentation of end of life across Canada.

1.5.3.3 Broader Social and Cultural Understanding of Death/Dying and End of Life Care

It is important to acknowledge that there are a number of different beliefs, values, and knowledge claims which inform broader social, cultural and political narratives about death and dying. The most pervasive narrative which operates about death and dying is one which emphasizes the importance of not talking about death and dying. As Senator Carstairs notes, “We are a death denying society who refuses to accept that we are all going to die, and clings to the hope that our own death will be quick and painless. Yet, that will not be the reality for 90% of us” (Carstairs, 2010, p. 3). Despite strong campaigns for patients and families to talk about end of life goals of care and advanced directives with their medical care providers prior to end of life (e.g. Speak Up Campaign for Advanced Care Planning in Canada), there continue to be a
large number of Canadians who upon hospitalization do not have documented advanced end of life care plans (Heyland et al., 2013). As a result, many patients and their family members are required to make difficult decisions for themselves, and/or their loved one, at a time in their lives where there is much strain and uncertainty.

When end of life cannot be denied or ignored, further messages unfold about what makes for a good death. Clark (2002) in speaking to the history informing the medicalization of dying, and the medicalization of palliative care, presents six elements which inform what a good death in modern Western culture would include:

1. Pain-free death;
2. Open acknowledgement of the imminence of death;
3. Death at home, surrounded by family and friends;
4. An ‘aware’ death – in which personal conflicts and unfinished business are resolved;
5. Death as personal growth; and
6. Death according to personal preference and in a manner that resonates with the person’s individuality (p. 907).

Importantly, these elements circulate for patients, families, and medical care providers and can set up expectations and outcomes for dying which are not, for a wide range of reasons, possible. Varying models and frameworks have been created to conceptually understand, assess, and evaluate a good death (Emanuel & Emanuel, 1998; Hales, Zimmerman, & Rodin, 2010; Patrick, Engelberg, & Curtis, 2001). These models focus extensively on understanding what the patient and their family want in end of life, and what particular elements constitute a good death (Balducci, 2012). Understanding the broader social and cultural context of how many Canadians deny that they are going to die, and therefore have not talked about what they want in end of life care, is a critical element in thinking about how death and dying happen in Canada. Further, understanding the elements which may be informing what a good death looks like for patients and families is an important part of knowing what Canadians want and expect at end of life, and how and/or whether these outcomes can or cannot be achieved.
What does Quality Mean for Canadians in End of Life Care?

One way to assess what Canadians want and expect in end of life, is to further our understanding of what Canadians perceive as *quality* in end of life care. Two Canadian studies offer insights about the importance and meaning of quality in end of life care for patients and their family members. The first study with patients from three different sub-populations living with life-limiting illnesses, explored how patients perceived quality end of life care (Singer, Martin, & Kelner, 1999). From these patients, five elements were noted as essential in providing quality end of life care:

1. Receiving adequate pain and symptom management;
2. Avoiding inappropriate prolongation of dying;
3. Achieving a sense of control;
4. Relieving burden and;

Ensuring that pain and symptoms are well managed and that the experience of dying is not inappropriately prolonged, have been identified as primary concerns for medical and allied health professionals as well as patients living with a life-threatening illness and their family members (Canadian Hospice Palliative Care Association, 2006; Faull, 2005; Murray, 2009; Parliamentary Committee on Palliative and Compassionate Care, 2011). Establishing and upholding goals of care for each patient and family, is seen as an essential component in supporting patients to achieve a sense of control over what their end of life care includes (Canadian Hospice Palliative Care Association, 2012; Steinhauser et al., 2000). Understanding the significance of the burden for patients who are in end of life, and supporting and relieving this burden are critical elements in supporting patients and their families as needs shift and

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4 A total of 126 participants from 3 patient groups: dialysis patients (n = 48), people with human immunodeficiency virus infection (n = 40), and residents of a long-term care facility (n = 38).
change in end of life (McPherson, Wilson, & Murray, 2007). The final element speaks directly to the importance of strengthening relationships between the patient and their loved ones.

For the dying experience to be meaningful, participants desired the full involvement of loved ones in communication about their dying. At times, this meant overcoming resistance, their own and others’, to engage with uncomfortable subject matter. But even so, participants felt that the need for communication with loved ones was of overwhelming importance. When this intimacy was achieved, participants found their relationships strengthened. (Singer et al., 1999, p. 166)

Integral to strengthening relationships is not only the value and importance of family members being involved in end of life care, but that patients and their family members have the support they might need to talk about dying and to overcome varying resistances that can arise when talking about dying. Notable then, is how patients and families feel their relationships are strengthened, and how they feel there is an intimacy achieved when they are able to communicate with one another. Thus, we begin to get a clearer sense of what patients in end of life are looking for from quality end of life care, and how patients are looking for specific supports which can help them strengthen their relationships before they die.

The second study draws on data collected from patients in end of life and their designated family members, and asked patients and family members from five hospital sites in Canada to rank the elements that mattered most to them in receiving quality end of life care. The list of elements that were provided (twenty-eight for patients and twenty-five for family members), were drawn from an extensive review of the literature, discussions with key experts, and data drawn from semi-structured interviews conducted with twelve patients who were seriously ill. Patients and family members completed the surveys separately and were asked to rank each of the items in order of “How important is it: Not at all, Not very, Somewhat, Very, Extremely Important” (Heyland et al., 2006, p. 628). Patients and family members were asked to rank the importance of each element based on their own perspective and role. While the ranking of the complete list of elements is very informative, below I draw particular attention to the top ten elements that patients in end of life (N=434) and family members (N=160) noted as mattering most in end of life care. The following table, Table 3, *What Matters Most in End of Life Care*
Ranking, reflects the ranking of the top ten elements for patients in end of life and their designated family members [with emphasis added] (Heyland et al., 2006).

Table 3

<table>
<thead>
<tr>
<th>Ranking</th>
<th>How Important is it – Patients (N=434)</th>
<th>How Important is it - Family Members (N=160)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>To have trust and confidence in the doctors looking after you</td>
<td>To have trust and confidence in the doctor looking after the patient</td>
</tr>
<tr>
<td>2</td>
<td>Not to be kept alive on life support when there is little hope for a meaningful recovery</td>
<td>To not have your family member be kept alive on life support when there is little hope for a meaningful recovery</td>
</tr>
<tr>
<td>3</td>
<td>That information about your disease be communicated to you by your doctor in an honest manner</td>
<td>That information about your family member’s disease be communicated to you by the doctor in an honest manner</td>
</tr>
<tr>
<td>4</td>
<td><strong>To complete things and prepare for life’s end (life review, resolving conflicts, saying good-bye)</strong></td>
<td>To have an adequate plan of care and health services available to look after him or her at home, after discharge from hospital</td>
</tr>
<tr>
<td>5</td>
<td>To not be a physical or emotional burden on your family</td>
<td>That your family member has relief of physical symptoms such as pain, shortness of breath, nausea</td>
</tr>
<tr>
<td>6</td>
<td>Upon discharge from hospital, to have an adequate plan of care and health services available to look after you at home</td>
<td><strong>To have the opportunity to strengthen or maintain the relationship with your family member</strong></td>
</tr>
<tr>
<td>7</td>
<td>To have relief of symptoms (pain, shortness of breath, nausea, etc.)</td>
<td>To have information on your family member's illness and needs be readily available to the doctors treating him or her upon arrival at the hospital</td>
</tr>
<tr>
<td>8</td>
<td>To know which doctor is the main doctor in charge of your care</td>
<td><strong>To complete things, resolve conflict, and say goodbye to your family member.</strong></td>
</tr>
<tr>
<td>9</td>
<td>That the doctor discuss concerns relating to your illness and care with your family present</td>
<td>To receive adequate information about your family member's disease (the risks and benefits of treatment)</td>
</tr>
<tr>
<td>10</td>
<td><strong>To have an opportunity to strengthen or maintain relationships with people who are important to you</strong></td>
<td>To have trust and confidence in the nurses looking after your family member</td>
</tr>
</tbody>
</table>

Table 3 above offers us a number of important insights about what matters most to patients and their family members in end of life care. Perhaps most notable is how the top
priority for patients and their family members is to have trust and confidence in the doctors looking after them or their loved one. This shared priority speaks to the importance of not only the skill, expertise, and experience of the physician, but also of building and sustaining strong relationships of trust between patients, family members, and physicians. In addition, the similarities in the rankings between patients and family members, suggests that there are a number of very similar issues informing their perceptions of what matters most in end of life care. As we can see, the top three are identical for patients and family members and while there are differences in placement of ranking within the outlined top ten elements, the majority of the top ten elements are common across patients and family members. Of particular importance is how strengthening relationships, reflected previously in the Singer and colleagues (1999) study, is also reflected within this data, with patients ranking strengthening and maintaining relationships with people who are important as tenth in priority and family members ranking this as sixth. Within Heyland and colleagues (2006) survey, completing things, resolving conflicts and saying goodbye were noted as a separate category, and it would appear that this element closely aligns with some of the elements Singer and colleagues (1999) attributed to strengthening relationships. Patients ranked completing things, resolving conflicts and saying goodbye as fourth in importance, while family members noted it as eighth. It is important to highlight here that family members ranked these elements based on their importance for themselves, and therefore we see that family members also wanted to strengthen and maintain relationships, as well as complete things, resolve conflicts, and say goodbye to their loved one.

Together, these two studies demonstrate what quality of life and quality end of life care includes for patients and their family members. While quality end of life care includes a number of elements which relate to pain and symptom management, not prolonging death, and supporting patients to feel in control and to relieve burden, it is noteworthy that strengthening relationships between patients and family members, as well as completing things, resolving conflicts, and saying goodbye are also ranked in the top ten elements. In order to understand how we might strengthen or maintain relationships between patients and their family members, and/or support them in talking about death and dying, completing things, resolving conflicts and saying goodbye, it is essential that we have an understanding of how patients and families experience end of life together, and how and in what ways their relationship has responded to a patients’ advanced illness and end of life needs.
1.5.3.4 Role of Social Work across End of Life and End of Life Care

It has been argued that social work has a strong rationale to provide end of life care:

- Social work has always been concerned with responding to loss,
- Social work brings a whole system view – putting individual experience into a wide context;
- Social work has a concern with helping ameliorate the practical impact of change (Small, 2001, p. 962-963).

This is further demonstrated in examining how a number of the core values informing the Canadian Association of Social Workers Code of Ethics (Canadian Association of Social Workers, 2005), also closely reflect the values informing Hospice Palliative Care activities (Ferris et al., 2002). See Table 4 for a comparison of core values between CASW, and Hospice, Palliative Care

<table>
<thead>
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<th>Table 4</th>
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<tr>
<th><strong>Comparison of Core Values: Canadian Association of Social Workers and Hospice, Palliative Care</strong> (Canadian Association of Social Workers, 2005; Ferris et al., 2002)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Canadian Association of Social Workers: Code of Ethics</strong></td>
</tr>
<tr>
<td>1. Respect for the Inherent Dignity and Worth of Persons</td>
</tr>
<tr>
<td>2. Pursuit of Social Justice</td>
</tr>
<tr>
<td>3. Service to Humanity</td>
</tr>
<tr>
<td>4. Integrity in Professional Practice</td>
</tr>
<tr>
<td>5. Confidentiality in Professional Practice</td>
</tr>
</tbody>
</table>
The similarities between the core values of social workers and the core values of hospice palliative care are strongly informed by the founder of the modern hospice movement, Dame Cicely Saunders. Dame Saunders, trained initially as a nurse, then as a Lady Almoner (social worker) and finally as a physician (Clark, 1999), noted the importance of her background in social work in informing how the modern hospice movement developed. Drawing specifically on her experiences carrying out case work and family support, Saunders notes,

My own experience with the end of life problems of distressed patients and families and the many home visits this entailed had a lasting influence on the way the modern hospice developed with its regard for the family as both the unit of care and, frequently, the caring team (Saunders, 2001, p. 792).

Dame Saunders’ conceptualization of total pain as a holistic way of both understanding and treating pain, whereby physical symptoms and manifestations of pain are closely interwoven with psychological, social, cultural, and spiritual aspects of pain and suffering, also reflects a social work perspective in understanding how people perceive and experience pain.

Social work has an important history and role in hospice palliative care. The Canadian Hospice Palliative Care Association (CHPCA) formally recognizes social workers as core members of the inter-professional palliative care team in all settings of care—residential hospice, acute and long-term care facilities, cancer centres and community care. Social workers provide end-of-life care to many patients and their families across these care settings, as well as in many non-health-related situations.

(Social Work Competencies on Palliative Education - SCOPE, 2014)

Nevertheless, there has been a strong need in both the United States and Canada to clearly outline and define what social work practice includes in hospice palliative care (Bosma et al.,
This process has been seen as an important one, in both achieving consensus across the discipline of social work about the scope and breadth of social work practice, but also in ensuring that other interprofessional teams members in hospice, palliative care know what social workers do (Bosma et al., 2010).

In 2005 Health Canada's Secretariat on Palliative and End-of-Life Care funded a task group, known as the SCOPE (Social Work Competencies on Palliative Education) team, to conduct national research aimed at developing a set of core social work competencies to guide education for practice with people facing end of life issues (Social Work Competencies on Palliative Education - SCOPE, 2014). A recommended framework for describing the scope of social work practice in end of life care was developed through a modified Delphi method as well as focus groups and surveys. The eleven core competencies include: advocacy, assessment, care delivery, care planning, community capacity building, evaluation, decision-making, education and research, information sharing, interdisciplinary teamwork, and self-reflective practice. After further consultation, the eleven competencies were further developed into a curriculum that can be used in undergraduate and graduate schools of social work (Social Work Competencies on Palliative Education - SCOPE, 2014). This focus on bringing social work hospice palliative care competencies into social work curricula is one way of ensuring that social workers have a strong foundation in the knowledge and skill required to support people in end of life, loss and bereavement.

Further, it is imperative that as social workers, we continue to build new knowledge about the experiences of end of life for people in end of life, and their families. Drawing on the strengths of our social work profession in acknowledging and responding to the needs of people in end of life (and their families), I believe that social workers are well positioned to broaden the knowledge base that informs what we know about the experience of end of life and end of life care.

1.6 Organization of Dissertation

Below I provide a brief overview of each of the remaining chapters in my dissertation.

In chapter two I review three theoretical approaches which, either explicitly or implicitly, underscore most of the literature available on how families, and specifically mothers and
daughters, experience end of life. The three approaches reviewed are: 1. Life course developmental theories and psychosocial stages of development (Elder, 1998; Elder, Johnson, & Crosnoe, 2003; Elder & Shanahan, 2006; Erikson, 1950), 2. Stress and coping theories (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Lazarus & Folkman, 1984; Park & Folkman, 1997), including family illness models (Rolland, 1984, 1987, 1987, 2005), and 3. Relational cultural theory (Jordan et al., 2004; Miller & Stiver, 1995). After addressing the central tenets of each of these theoretical approaches, I provide an overview of how our understanding of families, and specifically mothers and daughters in end of life has been informed by each of these approaches. Further I highlight how each of these approaches has informed research and practice in end of life. Finally I review the contributions and limitations of each of these theoretical approaches on our understanding of mothers and daughters in end of life.

In chapter three I speak to the overall design and methods of this study, and how this study is guided by a feminist epistemology, which draws on a narrative methodology, with a specific focus on joint/dyadic interviews as my method. I address how my own social location informs this study and how this study has worked to bridge research and practice by furthering our understanding of how mothers and daughters experience end of life. In addition this study also demonstrates how research designs can integrate practice components, as this study integrated a life review ‘memoir/legacy’ document for patients and families to have at the end of the study. Within this chapter I also address the ethical issues and concerns that I believe need to be attended to within any study in end of life. I then speak to the two primary sites of palliative and end of life care practice where I recruited the ten participants that participated in my study. Further I address the procedures that I utilized in recruitment and data collection for the study. Lastly, I address the decisions that I made to utilize Catherine Riessman’s (1993, 2008), narrative analytic approaches, and further how I addressed criteria for trustworthiness and ethical validation.

In chapter four I present my findings. The first part of my findings begin by addressing who I am: my social location; my a priori connection to the two palliative care sites/practices that were involved within my study; and some of the early observations and decisions that I made as I began my study. I end this part of my findings by providing an overview of my narrative analytic approach, and I address how I transcribed and worked with the relational stories
throughout my analysis. The second part of my findings begins by introducing the five mother and daughter dyads that participated in this study. For each mother and daughter dyad I begin with a narrative overview followed by reflections of the first meetings and interviews I had with each mother and daughter. Within each mother and daughter dyad, I address two specific end of life relational stories, which speak to core aspects of their experiences as they receive end of life care. As I examine each of these end of life relational stories, I draw on both a narrative thematic and a dialogic/performance analytic approach. Specifically, I conduct a narrative thematic analysis on both end of life relational stories, and for one of the end of life relational stories I utilize a dialogic/performance analysis. After reviewing all five of the mother and daughter dyads, I offer some overall reflections, of some of the apparent similarities and differences which arose across the five mothers and daughters dyads.

In chapter five, I bring us back to the feminist epistemology guiding this study and how this study was focused on what mothers and daughters know and experience in end of life, and how and why this knowing needs to be situated within the multiple contexts in which women live and die. In reviewing the end of life relational stories across each mother and daughter dyad, I explore how these stories were produced and performed between mothers and daughters, and how these stories reflect mothering/daughtering activities, practices and understandings which are deeply woven within individual, relational and intersubjective processes. In examining the central threads of each of these processes, I address how my study findings support, challenge and add to the literature that already exists about how mothers and daughters experience of end of life. Lastly, and perhaps most importantly, I address what we learn in talking with people who are experiencing end of life and how this learning has implications for social work practice, social work education, and further social work research in this area.
Chapter 2: Review of Theoretical and Empirical Literature

Within this chapter I review three theoretical approaches which, either explicitly or implicitly, underscore most of the literature available on how families, and specifically mothers and daughters, experience end of life. These approaches; 1) Life Course Theory (Elder, 1998; Elder et al., 2003), and Psychosocial Stages of Development (Erikson, 1950); 2) Stress and Coping Models (e.g. Folkman et al., 1986; Lazarus & Folkman, 1984; Park & Folkman, 1997); and 3) Relational Cultural Theory (Jordan, Kaplan, Miller, Stiver, & Surrey, 1991; Jordan, Walker, & Hartling, 2004; Miller, 1986, 2008) have emerged within different historical contexts and are guided by distinctive assumptions, practices and concerns. After reviewing the central tenets of each theoretical approach, I examine how each theoretical approach has added to our understanding of how families, and particularly mothers and adult daughters, are conceptualized in end of life. Situating this discussion within the literature, I address the influence of each of these theories on the broader field of research and practice in end of life care. In concluding this chapter, I review the relative contributions that each of these theories have made, the inherent gaps that remain and how my study is positioned to explore these elements in a way that will enrich our understanding, and improve our care practices for mothers and daughters in end of life. Finally I address how these approaches are, or could be more woven into social work practice in end of life care.

2.1 Life Course Theory and Psychosocial Stages of Development

While the terms life course or developmental or stage are used in different ways across disciplines, I am specifically drawing together approaches that study “constancy and change in behaviour throughout the life course (ontogenesis), from conception to death” (Baltes, 1987, p. 611). Both life course and developmental life stage approaches, examine how people move across their lives from birth to death, and each approach asks different questions about how and why people behave and develop in certain ways. Inspired by sociologists studying variation in child development across social, economic and historical contexts, “Life-course theory emerged in the 1960s in response to these issues and to the challenge of an aging population and the rapid
growth of longitudinal studies” (Elder & Shanahan, 2006, p. 667). Drawing on the notion of *trajectories*, life course theorists’ focus on how:

Historical forces shape the social trajectories of family, education, and work, and they in turn influence behavior and particular lines of development. Some individuals are able to select the paths they follow, a phenomenon known as human agency, but these choices are not made in a social vacuum. All life choices are contingent on the opportunities and constraints of social structure and culture. (Elder, 1998, p 2)

Developmental psychologists, on the other hand created developmental, life stage theory in “the second half of the 20th century… theorists of the era were inspired by the power of the stage theory to illuminate patterns of development across the life span and to generate insights about the distinctive characteristics of different life stages” (Arnett & Tanner, 2009, p. 17).

Identifying stages and tasks that need to be completed across age-related categories, developmental life stage theorists, such as Erik Erikson (1950) outlined stages of psychosocial development from birth to death. This work was taken up in specific ways by others. For example, George Vaillant (Vaillant, 1998), and in his early work Daniel Levinson (Levinson, 1978), focused on stages of male adult development, Gail Sheehy (Sheehy, 1976, 1996) examined male and female adult development, while others such as Daniel Levinson in his later work (Levinson, 1996), and Carol Gilligan (Gilligan, 1982), shifted to explore female adult development. Jean Piaget (Piaget, 1985; Piaget & Inhelder, 1962) and Mary Belenky and colleagues (Belenky, Clinchy, Goldberger, & Tarule, 1986) focused specifically on cognitive development, while others such as Lawrence Kohlberg (Kohlberg, 1984, 1986) focused on moral development. While the above researchers applied their particular interests to the questions of how humans developed over the life course, Erikson’s psychosocial stages of development is the model that most explicitly addresses development across the full life course, including end of life, and as such, I focus specifically on his model.

Life course and psychosocial stages of development fundamentally underscore the knowledge and practice of end of life care with individuals who are dying, and their families. On a broader level, life course and psychosocial stages of development also inform how end of life care models have been shaped, positioned and situated within larger health and illness trajectories. The contribution of life course and psychosocial stages of development towards our
understanding of how individuals and families experience end of life is both extensive and expansive, and offers a strong foundation for furthering our understanding of how mothers and daughters relationally experience end of life.

2.1.1 Central tenets of Life Course and Psychosocial Stages of Development

Life Course Theory

A number of key concepts and principles inform life course theory. Below I address what I believe are the three most relevant concepts to my study, as well as four guiding principles which are seen as integral in informing all life course studies (Elder, 1998). The three key concepts are: trajectories, transitions (counter transitions), and turning points. Trajectories, “provide a dynamic view of behavior and achievements, typically over a substantial part of the life span” (Elder & Shanahan, 2006, p. 684). A trajectory then points our attention to a broader frame of reference, wherein our focus is on how people behave over a longer period of time. Trajectories could encompass broader periods of time such as: childhood; adulthood; or the experience of parenting over the life-course. “Transitions refer to a change in state or states…a substantial change in the course of a behavioral trajectory” (Elder & Shanahan, 2006, p. 684). Transitions then highlight changes in behavior, where a person moves or changes their behavior from one form of action to another. Examples of transitions could be: when a child leaves home; when a diagnosis shifts to non-curative or palliative care; or when someone moves into an institutional setting. Counter-transitions are transitions that are caused by the actions or events of others, such as: a daughter having a child which is the first grandchild for her mother; or a mother requiring care from her daughter to be able to live at home. Turning points, represent points in the transition, where a person understands or interprets, “some degree of change in situation, behavior, or meaning” (Elder & Shanahan, 2006, p. 687). Turning points then are points within transitions where people experience or recognize that something is shifting or changing for themselves or others. Collectively, these concepts offer a useful framework for understanding how change occurs over the life course of an individual.

In addition to the above concepts, life course theory proposes four key principles as an important framework for researchers drawing on life course theory (Elder, 1994, 1998; Elder et al., 2003; Elder & Shanahan, 2006):
1) **Historical time and place**: The life course of individuals is embedded in and shaped by the historical times and places they experience over their life-time.

2) **Timing in lives**: The developmental impact of a succession of life transitions or events is contingent on when they occur in a person’s life.

3) **Linked lives**: Lives are lived interdependently, and social and historical influences are expressed through this network of shared relationships.

4) **Human agency**: Individuals construct their own life course through the choices and actions they take within the opportunities and constraints of history and social circumstances. (Elder, 1998, p. 3-4)

These principles highlight the importance of locating an individual’s development across their life course within a specific historical time and place, and recognize as such that each individual is situated within a unique historical time period and place. Further this highlights the importance of thinking about how each individual, particularly across intergenerational families, enters into their present day context, through their own understanding of historical time periods and experiences. Timing in lives focuses our attention on how and when transitions and turning points arise, and how these elements are experienced in relation to other events and experiences. The concept of linked lives emphasizes how individual lives are interconnected with others and how social and historical elements inform and are expressed through these relationships. Finally human agency, examines how people make choices and respond to different events and experiences as a result of the historical and social context that surrounds them.

**Psychosocial Stages of Development**

Strongly informing developmental life stage theories, particularly those developed in the early 20th century[^5], is a prioritization of theories which situate development across the full life course (ontogenesis) (Baltes, 1987; Erikson, 1950; Newman & Newman, 2008). Closely interwoven

[^5]: Many developmental, life stage theorists since the late 20th century have shifted towards a developmental, life span theory, which rejects the centrality of stages within these models. (See Baltes, Lindenberger, & Staudinger, 2006; Elder & Shanahan, 2006). This said, understandings of fixed stages of development, are still widely accepted within many fields and disciplines.
with ontogenesis, is an emphasis on theories which address universal, normative understandings of how all individuals move through development. As Arnett and Tanner (2009) note about stage theorists, “although they recognized individual differences…given a reasonably normal and healthy environment, all persons would develop in a similar way through similar stages, driven by the same inherent developmental program” (Arnett & Tanner, 2009, p. 18). Within these approaches development encompasses a wide range of biological, social, emotional and cognitive domains (Baltes et al., 2006; Keenan & Evans, 2009; Newman & Newman, 2008) and stages of development are either continuous (Newman & Newman, 2008; White, Hayes, & Livesey, 2009), reflecting development which progressed slowly across the life course, or discontinuous (Newman & Newman, 2008; White et al., 2009), representing particular age-related tasks which needed to be completed at certain times. Most of the developmental, life stage theories that have really shaped the field of developmental psychology focus on discontinuous stages of development.

Within Erik Erikson’s psychosocial model of development (Erikson, 1950), the life course is seen as unfolding within specific age-related stages which require individuals to successfully complete particular tasks or challenges. Each age-related stage has a psycho-social crisis or challenge that needs to be addressed. While individuals can move to the next stage if they have not successfully responded to each crisis, these areas are considered elements that may arise as potential problems in later adulthood. Below I address how life course theories and psychosocial stages of development inform our understanding of how families, and specifically mothers and daughters, experience end of life.

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6 There have been a number of critiques about the validity of differentiating between continuous and discontinuous development, given that the focus on a particular age and stage as a discrete stage is more apt to be researcher driven, rather than a more longitudinal understanding of how development progresses across the life course. (See Baltes, Reese, & Nesselroade, 1988).
2.1.2 Families and End of Life in the Context of Life Course Theory and Psychosocial Stages of Development

In order to examine how life course and psychosocial stages of development inform our understanding of how families, and specifically mothers and daughters experience end of life, it is important to begin by centrally acknowledging how end of life, reflects the end of a life course. Dying is a part (but only one part) of our experiences of life and living… To be dead is to be through with dying; to be dying is still to be alive” (Corr & Corr, 2012, p. 143). Regardless of the breadth, depth, quality or duration of an individual’s life, end of life speaks to a finite end, at least in a physical sense, of the life course. As such, while there are particular transitions, turning points, needs and experiences that arise in end of life, this stage of life cannot be removed from its positioning as the end of a broader life trajectory. As families experience end of life, individuals who are dying are not only family members living within end of life or within a terminal phase/stage of life, but are family members who have lived across a broad and varied life course trajectory which has unfolded within a particular social and historical context. For most people in end of life, this life course trajectory has included many different life stages, transitions and turning points, all of which inform the identity of each person, as well as who this person is as a family member within the broader family system. Similarly, each family member of an individual who is in end of life is also experiencing, from their own developmental position, what it means to lose their family member, and how this also shapes and informs their own individual life course (a counter-transition, as described above).

With regard to developmental life stages, and Erik Erikson’s psychosocial stages of development (Erikson, 1950), age-related developmental stages could be considered as also woven into the experience of individuals at end of life. As my particular study focuses on mothers and their adult daughters, I review the age-related developmental tasks that are associated with adults in middle adulthood, and maturity (Erikson, 1950). Middle Adulthood, which speaks to adults who are between the ages 40-65 years of age, describes adults engaging in a central internal crisis between Generativity vs Stagnation (Erikson, 1950). Generativity, “is primarily the concern in establishing and guiding the next generation” (Erikson, 1950, p. 267), which focuses on people feeling like they are generating a connection or interest in something or someone that will continue beyond their own life course. As Erikson notes, generativity is in some ways a response to concerns about death, “A person does best at this time to put aside
thoughts of death and balance its certainty with the only happiness that is lasting: to increase, by whatever is yours to give, the goodwill and higher order in your sector of the world” (Erikson, 1974, p. 114). Of interest is how thoughts of death are presumed within this stage, and that thoughts and the certainty of death are encouraged to be shifted away with a focus on lasting happiness. Stagnation on the other hand speaks to an internal crisis of feeling stuck and withdrawn into one’s own internal world. The strength or virtue found within generativity is one that focuses on care. As will be described more fully below in the practice section, generativity is strongly woven into many end of life care practices and interventions, as an important form of care for people who are dying.

As daughters in this study also fall within the middle-adulthood, 40-65 years of age, it is also important to consider how generativity, as a way of informing the next generation, might also be operationalized for family members who are supporting a loved one who is in end of life. Family members, including daughters, relay that care practices can create a sense of closer relationships with their parents (Aoun, Kristjanson, Hudson, Currow, & Rosenberg, 2005; Hudson, 2004) and that care practices can offer a way of giving back to their parents (Grbich, Parker, & Maddocks, 2001; Stajduhar & Davies, 1999), as a way of acknowledging the generativity of their parents care. It is less clear how care practices may also be a form of generativity for daughters, in relation to a daughter’s sense of how she is contributing to the world for following generations.

Maturity, which addresses people who are over the age of 65 until their death, positions adults as living with a central internal crisis between Ego Integrity versus Despair (Erikson, 1950). Centrally woven into the understanding of maturity, Erikson speaks to the meaning that culminates in caring for self and others across the life course, “Only in him who in some way has taken care of things and people and has adapted himself to the triumphs and disappointments adherent to being, the originator of others or the generator of products and ideas – only in him may gradually ripen the fruit of these seven stages” (Erikson, 1950, p. 268). Ego integrity draws attention to who someone is within them, who they are in relationship to others, and who they are in connection to a broader understanding of humanity. Erikson links this understanding of self and connection to others as a way of responding to the fear of death:
It is the ego’s accrued assurance of its proclivity for order and meaning…as an experience which conveys some world order and spiritual sense, no matter how dearly paid for. It is the acceptance of one’s one and only life cycle as something that had to be and that, by necessity, permitted of no substitutions…the possessor of integrity is ready to defend the dignity of his own life style…for he knows that an individual life is the accidental coincidence of but one life cycle with but one segment of history; and that for him all human integrity stands or falls within the one style of integrity of which he partakes…in such final consolidation, death loses its sting. (Erikson, 1950, p. 268)

Despair, as the alternate response to the crisis of maturity is framed in fear, fear of not having enough time to be, or become who one would want one to be (Erikson, 1950). Maturity as such asks people to consider who they are, and how and in what ways this meaning informs the understanding that people’s lives are finite.

Life course theory has also been drawn on to build an understanding of how families experience their own life cycles, and how families develop and transition between and across developmental stages. Building on Erikson’s developmental work, family life cycle speaks to family level transitions and tasks of development and growth (Haley, 1986 as cited in Hoyle, 2013). Within the family life-cycle model (Carter & McGoldrick, 1989; Carter & McGoldrick, 1999; McGoldrick, Carter, & Garcia-Preto, 2010) families move through six stages which begin with a focus on single young adults leaving home, and continue through to the family life cycle stage of families in later life. Within this model each family stage is connected with a particular transition that has an emotional process, and as well as changes that need to happen within the family for the stages to move forward developmentally. The family life cycle model encourages us to think about how individual developmental age-related stages, coincide with family life-cycle stages, and how development needs to be examined within individual and family domains. This intersection of individual and family life cycles is revisited in the upcoming discussion of stress and coping theory. Figure 1 Life Course Theory & Psychosocial Stages of Development offers a visual overview of the central tenets informing this particular study.
Figure 1. Life Course Theory & Psychosocial Stages of Development

2.1.3 Life Course Theory and Psychosocial Stages of Development’s Influence on Research and Practice in End of Life.

Much of the literature available in end of life care, and specifically the literature which speaks to the experiences of families in end of life, is drawn from empirically based research studies which are practice-based in focus. This means that this literature focuses on the practice of end of life care, wherein studies explore: how patients and families experience end of life as a way of improving our understanding of needs, gaps in services and recommendations for change in practice; or are focused on current or innovative interventions and practices which are considered and/or evaluated as helpful or positive in supporting families in end of life.

Life course theories are reflected within this practice-based literature, as research studies examine how families experience end of life and bereavement as either a particular transition or stage across the broader life course (i.e. Aoun et al., 2005; Steinhauser, Voils, Bosworth, & Tulsky, 2014; Williams & McCorkle, 2011), or within sequential, follow-up or longitudinal studies which follow family members through advanced illness or end of life into bereavement.
(Gotay, 1984i.e.; Grbich, Parker, & Maddocks, 2001; Stajduhar, 2003). While life course and developmental stage theories consider the full life course in examining how a person develops and how these elements inform the experience of end of life, the actual practice of end of life care is more often than not, provided in acute care settings which are focused on present-day, illness-based concerns. Further, the primary focus in end of life care across sites (within acute care hospitals, long term care, and in the home), on pain and symptom management in end of life care, can further perpetuate a focus on end of life and death/dying as a physical and biomedical transition that is isolated and disconnected from the larger trajectory of a person’s life. This limited focus on physical and biomedical transitions and stages also means that other domains of care (i.e. spiritual, emotional, social) can be seen as less important, and other trajectories that arise across the life course, such as family trajectories, or the extensive relational trajectories that unfold between mothers and daughters are ignored or missed. While hospice, palliative care practices draw on holistic understandings that position end of life within the broader life course, the majority of sites where people die have only minimal access to palliative care trained physicians, nurses and social workers (Towns et al., 2012). Finally, the separation of end of life care from bereavement, and grief needs and experiences, means that the majority of practice sites that are providing end of life care, are rarely able to provide supports to families after their loved one has died. The separation of end of life care services, from bereavement supports for family members, is one that has been modeled on medical practices that situate disease and illness within individual bodies, and does not reflect or represent broader social and relational understandings of how illness, death and dying extend beyond biomedical concerns.

**Practice in End of Life**

In examining the empirical literature with families and end of life, life review, often emerges as a central part of end of life practice. Life review refers to an intervention that supports people in progressive return of the memories of past experience in search of meaning and in striving for emotional resolution (Jenko, 2007, p. 160). Life review is different from reminiscence or reminiscence therapy, which is focused on recounting memories and documenting events, rather than extrapolating the meaning behind people’s memories. While life review differs considerably across practices and programs, essential pieces generally speak to meaning-making, forgiveness, heritage and legacy (Ando, Tsuda, & Morita, 2007; Keall, Butow, Steinhauser, & Clayton, 2011; Steinhauser et al., 2009; Steinhauser, Alexander, Byock, George, & Tulsky, 2009). The word
‘legacy’ speaks to a growing focus within practice settings to support people who are living with advanced illness in reviewing and documenting their lives, so that they might leave behind a legacy of their lives for their loved ones (Chochinov, 2012; Jenko, Gonzalez, & Seymour, 2007; Lewis & Butler, 1974; Rubinstein, 1998). Finding ways to assist patients in telling and sharing their life story has been identified as an important process in helping patients find meaning and purpose at the end of their lives (Rousseau, 2000; Viederman, 2000).

1. Key components of life review and meaning-making/legacy have been explored in a number of interventions utilized with patients and family members in end of life (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008; Ando, Morita, Ahn, Marquez-Wong, & Ide, 2009; Chochinov, 2012; Haber, 2006; Keall et al., 2011). One of the most prominent examples of legacy work in palliative and end of life care is found in the work of Dr. Harvey Chochinov. Dr. Chochinov is a Canadian psychiatrist who after 20 years of working in the field of palliative and end of life care has developed an intervention called Dignity Therapy. This therapy is based on a theoretical and conceptual understanding of dignity and dignity-conserving practices in end of life care (Chochinov, 2002; Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002).

Dignity, which examines meaning and how patients experience meaning in end of life, is constructed as being informed by a) illness-related concerns experienced by the patient, b) dignity-conserving repertoire which speaks to patient perspectives and practices that support and foster a sense of dignity, and c) social dignity inventory, which speaks to the role of other people in how and whether a patient experiences dignity (Chochinov, 2002, p. 2254-2256). The patient-focused therapy involves an audio-taped interview which facilitates a conversation with the dying person about her or his life (e.g. times in their life when they felt most alive, roles and accomplishments they are most proud of); their hopes and dreams for their loved ones; and the learning and messages that they have for their loved ones at this time. Dignity therapy is based on the belief that the desire for legacies is tied to one of the developmental stages outlined by Erik Erikson (Erikson, 1950). Chochinov draws specifically on the middle adulthood stage of generativity versus stagnation: “Generativity refers to providing guidance for the next generation, and it becomes paramount when patients are facing a life-threatening or life-limiting prognosis” (Chochinov, 2012, p.16). Following the interview, the interview is transcribed and the transcript is moved into a ‘generativity document’ (Chochinov, 2012, p. 16). This generativity document is an edited and transformed document which is shaped and constructed
by the person who conducted the dignity therapy interview. Dignity therapy has been integrated into a number of different palliative care contexts and has most recently been tested in a randomized control trial format. In comparison to participation in a client-centred interventions and standard practice, dignity therapy has been shown to be significantly more helpful than other interventions in the following ways: increasing a sense of dignity; creating a sense of change for patients in how they feel their family and loved ones see and appreciate them; and being helpful to patients’ families (Chochinov et al., 2011, p. 753).

2. While it’s clear that dignity therapy offers benefits, it is important to address some of the assumptions that inform life review and legacy, and how there may be tensions that arise in the overall purpose of what is being documented. On one hand, life review and legacy is designed to focus on how individuals think about and make meaning from their lives. Meaning in this context could be derived from moments of great connection and learning, as well as moments of great sorrow, disconnection, and loss. Within these stories there is the potential to hear elements that reflect the best of people, through stories of strength, courage, fortitude. Likewise there may be stories that reflect the challenges, the weaknesses, the hurts and harms caused to others, which while bringing meaning to a person, may also be tied to feelings of shame, embarrassment, and guilt. Herein we find the tension between meaning-making for people who are in end of life as they reflect on their lives, and the purpose of legacy and generativity and leaving things for the next generation. As we think about the kinds of stories and narratives that are often captured in legacies, memorials, and eulogies, there can be a strong focus on capturing and telling certain parts of who people are/were, and there can be a focus on transforming challenging narratives into stories of redemption, or lessons learned, or hopes for others to not follow a similar path. The question then is how personal meaning and experience inform legacy, and how much the focus on legacy informs what life stories are included within a legacy document. This tension could be traced back to Erikson’s psychosocial stages of development as well, as Generativity vs Stagnation, and Ego Integrity vs Despair are constructed as separate distinct stages, perhaps reflecting some of the inherent differences in the tasks and challenges which are operating within each of these stages. The question then remains about how these tensions are held within these practices, and whether it is possible to both highlight these differences with participants, and/or give participants opportunities to create more than one kind of document.
2.1.4 Contributions and Limitations of Life Course and Psychosocial Stages of Development to Understanding Mothers and Daughters at the End of Life.

In summary, there are many important contributions that life course theory and psychosocial stages of developmental offer in our understanding of how mothers and daughters experience end of life. Life course and developmental psychosocial stages theories emphasize how end of life experiences are situated across the larger life course trajectory. While many studies may focus on particular needs and concerns at end of life, we are reminded that each individuals needs are interwoven within and across a broader life trajectory. Age-related stages of development focus our attention on particular needs that may arise for people who are dying, and how the tasks that are associated with a particular age and stage, may also inform the concerns that arise at end of life. Further, a family life-cycle model introduces the idea that families have cycles and stages of their own, and that there are particular transitions and processes that a family experiences which are in addition to the individual age-related stages of development.

Some of the limitations that arise are related specifically to the overriding goal within life course and developmental stage theories to explain how all people develop across the life course. The focus on universality and normative trajectories can overlook the diversity and complexity that informs development. In particular, Erikson’s psychosocial stages of development has been strongly critiqued for not addressing how girls and women develop, and for presuming that developmental frameworks drawn from empirical studies with boys, would be applicable to girls (Gilligan, 1982). Similarly the emphasis within these approaches on individual development, risks missing the centrality of relationships, and as such only explores some elements of development. Critiques of family life cycle models have also argued that the normative, white, heterosexual, married couple and children which underscore the family life cycle models do not apply to the majority of families today, and further can appear to suggest that there are normal families, and then other families that do not fit within these models (Hoyle, 2013). Lastly, situating development as a largely internal, intrapsychic process, misses interpersonal, relational and social elements which also inform development.
2.2 Stress and Coping Models

Beginning in the 1950s, investigations into how individuals experience stress, and the critical role of perception of stress and coping mechanisms began to emerge (Lazarus, 1993). While early investigations into coping examined personality traits or styles in relation to stress, Richard Lazarus and Susan Folkman examined coping responses as a process which is highly contextual, and introduced a transactional model of stress and coping that has grown to have a tremendous influence in the context of health and illness (Folkman et al., 1986; Lazarus & Folkman, 1984). Stress and coping models focus on how individuals physically and psychologically respond to stress. Stress and coping models have been drawn on extensively within end of life research and practice. Two primary and interconnected threads inform this work: 1) For people who are dying, the experience of end of life is often one of the most stressful time periods in their life; and 2) For family members, providing care to a loved one is often one of the most stressful time periods in their life. The contribution of stress and coping approaches in end of life care are therefore central to furthering our understanding of how patients and families experience end of life, and most importantly, how we can support families at this time of their lives.

2.2.1 Central tenets of stress and coping theory

A critical element of stress and coping models is cognitive appraisal, “a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being” (Folkman et al., 1986, p. 992). As the individual appraises the situation there are two levels of appraisal: primary appraisal, wherein the individuals assess the possible impact or harm that the event can cause, and secondary appraisal where the person evaluates whether or what can be done to change the impact or harm of the event (Folkman et al., 1986; Lazarus & Folkman, 1984).

Coping, “is defined as the person’s constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person’s resources” (Lazarus & Folkman, 1984). As such Folkman and colleagues (1986) note coping is process-oriented, based on what people think and do and how this changes during an experience (p. 933), contextual, based on how people understand the stress and their ability to responds to this stress, and that assessing coping requires non-judgment, as coping is not right or wrong or good or bad, it is just how people respond (Folkman et al., 1986). Further, coping has two primary approaches; emotion-focused coping, where people feel they have little control, and
therefore they work to control or regulate the stress, and *problem-focused coping*, where people feel they have control and therefore they work to change or alter the environment (Folkman et al., 1986, p. 993).

More recently, meaning and meaning-based coping has been integrated into the transactional model of stress and coping (Park & Folkman, 1997). Meaning examines how individuals perceive or understand the importance of certain elements. Two forms of meaning are proposed, global meaning and situational meaning (Park & Folkman, 1997). *Global meaning*, “encompasses a person’s enduring beliefs and valued goals” (Park & Folkman, 1997, p. 116). Specifically, global meaning are about beliefs, and how beliefs “can be organized around beliefs about the world, beliefs about one’s self, and beliefs about the relationships between one’s self and the world” (Lazarus, 1991b; Tunis, 1991; cf. McCamm, Sakheim & Abrahamson, 1988 as cited in Park & Folkman, 1997, p. 118). *Situational meaning* is, “the meaning that is formed in the interaction between a person’s global meaning and the circumstances of a particular person—environment transaction” (Park & Folkman, 1997, p. 116). Three main elements inform situational meaning: 1) appraisal of meaning, 2) search for meaning, 3) meaning as outcome (Park & Folkman, 1997, p. 121-122). *Appraisal of meaning*, refers to how people evaluate the importance of the stressor at the beginning; *search for meaning*, examines how people work to find meaning or significance of the stressor; and *meaning as outcome*, examines the meaning/significance after the stressor has happened (Park & Folkman, 1997, p. 121-122).

*Figure 2 Stress and Coping Theory: Global and Situational Meaning* displayed on the following page provides a visual display of the relevant elements of situational meaning outlined in the above discussion. This is a modified model of the model provided in (Park & Folkman, 1997, p. 117).
As stress and coping theorists worked to address how people in relationship experience stress, new conceptualizations, particularly within spousal relationships, of relationship-focused coping emerged. Relationship-focused coping, focuses on interpersonal elements between individuals, rather than the internal psychological elements which inform emotion and problem-focused coping (DeLongis & O'Brien, 1990; Kramer, 1993; Lazarus & Folkman, 1984). Two specific forms of relationship-focused coping are particularly important for this study. Active engagement, where people in relationship work to talk about the situation and engage collectively around problem solving; and protective buffering, where people in relationship work to hide, or deny the stressors and work to protect the other from further distress. (Coyne, Ellard, & Smith, 1990, p. 136). While much of the literature in end of life has focused on the stress and coping of caregivers, in the sections that follow I work to illuminate how stress and coping and family models of chronic illness can deepen our understanding of how families and specifically mothers and daughters experience end of life.
2.2.2 Families and End of Life in the Context of Stress and Coping

Building on the life course models which were presented in Section 2.1., illness trajectory models, particularly in the area of chronic illness, began to be developed, to speak to how illnesses progressed and intersected with the life course (i.e. Corbin et al., 1984; Paterson, 2001). Woven into the growing interest in how chronic illness unfolded across the life course, were theorists who were interested in examining the experience of chronic illness within individual and family systems. The *Family Systems Illness (FSI) model* (Rolland, 1984, 1987, 1987, 2005), is one such model which works to address both the life-course illness trajectory, as well as the timing of illness, and how these elements intersect with patient and family experiences of chronic illness. Although the language of the FSI model seems to reference developmental theories, it can be understood as a way of framing the specific stressors associated with various types of illnesses and the types of coping that are then required of individuals and families living with those illnesses.

With a specific focus on the issues and concerns that may arise for mothers and daughters, I address the three primary dimensions that inform the FSI model: 1) *Psychosocial Types, Typologies and Timing of Illness*; 2) *Developmental Phases, Stages and Tasks in End of Life (Individual & Interpersonal; Family)*; 3) *Family/Multigenerational Legacies of illness and loss, and Health Beliefs* (Rolland, 2005, p. 2585).

*Psychosocial Types, Typologies and Timing of Illness*

*Psychosocial types* or *typologies* examine specific types of illness with a focus on the variance that can occur across each stage of illness. These stages are important, as they address how the illness trajectory unfolds and, how the responses and outcomes of each stage, inform what patients and families are experiencing. See Table 5, *Psychosocial Types of Illness* (Rolland, 2005, p. 2585-2586).
Table 5

*Psychosocial Types of Illness (Rolland, 2005, p. 2585-2586)*

<table>
<thead>
<tr>
<th>Stage</th>
<th>Possible responses/outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Onset</strong></td>
<td>Acute or Gradual</td>
</tr>
<tr>
<td><strong>Course</strong></td>
<td>Progressive, Constant or Relapsing/Episodic</td>
</tr>
<tr>
<td><strong>Outcome expected</strong></td>
<td>Illnesses which do not effect life span</td>
</tr>
<tr>
<td></td>
<td>Illnesses which are progressive and fatal</td>
</tr>
<tr>
<td><strong>Incapacitation</strong></td>
<td>Extent, kind and timing of impairment (Cognition, sensory, mobility etc.)</td>
</tr>
<tr>
<td><strong>Level of Uncertainty</strong></td>
<td>Predictability of the way or rate an illness will progress</td>
</tr>
</tbody>
</table>

Woven into each of these stages are varying psychosocial responses and outcomes which raise different needs, coping styles and family demands. Having an awareness of these stages offers a way to examine how families are experiencing each of the stages individually and collectively. This broader model of illness is useful and can as Rolland (2005) notes, guide further research and practice. While types and trajectories can offer a normative understanding of how most families arrive in end of life, most critical is how patients and families understand each of these stages, and what these stages mean. Prior to meeting each family, one cannot assume that knowing the stage of illness means that one knows the specific end of life concerns that will be operating for each family.

The second dimension in the FSI model, attends to the developmental phases that arise within three specific times of illness. These phases: *crisis, chronic* and *terminal* speak to particular developmental tasks that arise for patients and families within each phase (Rolland, 2005). Underscoring these specific times of illness is a developmental model that reflects how patients and families move across these phases as they move through the illness trajectory. Hospice and palliative care models of practice, draw on a similar model as a way of
demonstrating how hospice, palliative care shifts across these phases as well. See Figure 3, The Role of Hospice Palliative Care During Illness (Ferris et al., 2002)\(^7\)

\[\text{Figure 3. The Role of Hospice Palliative Care During Illness (Ferris et al., 2002).}\]

While it is important to acknowledge that illness trajectories vary\(^8\), and that even within normative grouped understandings there is variance and unpredictability, the premise behind this model, is to offer a sequential trajectory which situates hospice, palliative care along a continuum of: Presentation/Diagnosis of acute/crisis illness (on the far left of the model), where the focus is on therapies to modify disease; to Illness – Chronic (in the middle), where therapies may be about modifying disease, but may also include therapies that are focused on relieving suffering and/or improving quality of life; to Patient’s Death /Terminal and Bereavement (on the far right of the model) where therapies are completely focused on hospice, palliative care. The dashed line within the model is to suggest that therapies to modify disease could be received at

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\(^7\) As Noted in Ferris et al (2002), this model was adapted from: Expert Working Group on Integrated Palliative Care for Persons with AIDS to Health and Welfare Canada Federal Centre for AIDS. Caring Together. Ottawa, ON: Health and Welfare Canada, December 1987: 29. Permission to reproduce is acknowledged in the copyright acknowledgements section.

\(^8\) For example, Murray et al. (2005), demonstrate three types of illness trajectories towards end of life: 1. Short period of evident decline (e.g. cancer); 2. Long term limitations with intermittent serious episodes (e.g heart disease); and 3. Prolonged dwindling (Alzheimer’s Disease) (Murray, Kendall, Boyd, & Sheikh, 2005).
the same time as therapies to relieve suffering and/or improve quality of life. While this model is limited to an illness trajectory, the focus on specific transitions within the illness trajectory (from acute diagnosis to bereavement) is outlined to show progression, and to show how therapeutic care moves along this continuum.

Developmental Phases, Stages and Tasks in End of Life

Before addressing how the Family Illness Model conceptualizes the developmental phases, stages and tasks in end of life for families, it is important to review the major threads that inform our understanding of how individuals experience dying. After reviewing the individual and interpersonal stages and tasks of dying, I will review the developmental phases that are outlined for families experiencing end of life.

Individual & Interpersonal

Two primary theories and models address how individuals, who are dying, developmentally experience end of life. Again, despite the emphasis on developmental processes, I argue that this literature is organized around a belief that dying is a stressor within which individuals and their families must cope by completing certain processes or tasks. The first and most widely known theory is from Elisabeth Kübler-Ross (Kübler-Ross, 1969), a preeminent psychiatrist known for her work with people who were terminally ill. While later versions of Kübler-Ross’s work (Kübler-Ross & Kessler, 2005) were extended to include people who were grieving a loss of a loved one, her early work focused specifically on people who were dying. Within this work, Kübler-Ross described a series of five stages of dying, which were developed to try and normalize the ways that a person may respond when they receive a terminal prognosis.

These five stages of dying are:

- **Denial** - the initial response to a person being told that they are going to die and is one of disbelief and shock

- **Anger** – the frustration and anger that can come as individuals question “why me?”

- **Bargaining** – the middle-ground of trying to bargain around when and how death happens

- **Depression** – the stage of awareness that death is going to happen
Acceptance – the place of acceptance or letting go that death is going to happen.


While there have been a number of misinterpretations of how Kübler-Ross conceptualized and operationalized these stages, this work strongly informs many present day understandings of dying and grief. The second model draws on a task-driven model developed by Charles Corr (Corr, 1991-92; Corr & Corr, 2012), which outlines specific tasks individuals who are dying need to address. The emphasis within this model on tasks is important as it, “identifies what a person is trying to do in his or her coping, the specific effort that he or she is making to achieve what is required or desired” (Corr & Corr, 2012, p. 156). Tasks are associated with four specific domains:

**Physical:** To satisfy bodily needs and to minimize physical distress in ways that are consistent with other values

**Psychological:** To maximize psychological security, autonomy, and richness in living

**Social:** To sustain and enhance those interpersonal attachments that are significant to the persons concerned and to maintain selected interactions with social groups within society or with society itself

**Spiritual:** To address issues of meaningfulness, connectedness, and transcendence and, in so doing, to foster hope.


Emphasized within the above tasks is a wide range of domains that extend well beyond the individual, and internal stages of dying that are reflected within Kübler-Ross’s stages of dying. Of particular interest is the social domain which speaks to relatedness between individuals who are dying, those who surround them, and society as a whole. Within the task model, the social tasks outlined have “to do with sustaining and enhancing the interpersonal attachments valued by the coping person” (Corr & Corr, 2012, p. 159), while also narrowing and disconnecting from others, “Dying individuals often narrow the scope of their interests…. they may increasingly focus on issues and attachments that involve a progressively smaller number of individuals”
The process of disconnection that a person who is dying makes from others around them, has in varying contexts, been referred to as *decathexis* (Connor, 2009; Poor, 2001). This dual process of sustaining, enhancing relationships, while also narrowing is an important recognition of how the task work for people who are dying involves a range of connections and disconnections, which while individually based, are also interpersonal. Further as Corr & Corr (2012) note the social task involved for the person who is dying, and those around them, “is that each person involved will have at least two sets of tasks: one conducted on his or her own behalf and another conducted in relation to the interests of others who are involved” (Corr & Corr, p. 159). Within this task model, the tasks of dying and coping with dying are individual tasks that people who are dying and those who surround them are individually and interpersonally experiencing.

*Family and Relational Developmental Tasks*

As was noted earlier, the second dimension within the FSI model (Rolland, 1984, 1987, 2005), attends to the developmental phases that arise within three specific times of illness: *crisis,* *chronic* and *terminal.* While in the previous section I addressed the developmental tasks that have been prescribed for individuals who are dying, the FSI model outlines developmental tasks for families within each of these phases. An important element of the FSI model are the transitions and *re-evaluations* that inform how families move from one phase to another (Rolland, 2005, p. 2588).

*Family/Multigenerational Legacies of Illness and Loss, and Health Beliefs*

The third dimension of the FSI model, examines specifics about how a family over multiple generations has its own *multigenerational history* (Rolland, 2005, p. 2588), and how this history informs how each family member and the family as a whole appraises, experiences and copes with illness, as well as how grief, loss and other stressors and challenges are conceptualized and understood (Rolland, 1987, 2005). Further it is important that each family member is asked about varying beliefs that exist within themselves and within the larger family about: how the family copes and experiences illness; what beliefs circulate about what causes illness and whether these beliefs can be influenced or changed; and how social, cultural, and religious beliefs may also inform the experience of illness (Rolland, 1987, 2005). Ensuring that illness experiences are situated within multigenerational understandings allow one to understand how
individuals and family members have understood past illnesses, and how these experiences or family stories about these illnesses inform present experiences and understandings of illness. Engaging families about varying health beliefs and meanings also ensures that particular beliefs about why illnesses happen, or how individuals and family members believe they should respond to an illness based on their familial, social, cultural or religious beliefs are understood as integral elements in understanding how a family is appraising and coping with illness.

The FSI Model reflects the many different elements that inform how families experience illness, chronic illness and end of life across the life course. For families experiencing end of life, and specifically mothers and daughters as an important dyadic relationship within the family, it is clear that there are many different elements that inform how mothers and daughters experience end of life. Within Figure 4. Individual Illness Developmental Stages, Tasks & Challenges and Family Illness Developmental Tasks (Terminal Phase) Family Systems Illness Model, offers a visual overview of the central tenets informing this particular study.

2.2.3 Stress and Coping Theory’s Influence on Research and Practice in End of Life to end of life

The primary focus within the literature on families and end of life, is on describing the significant costs, stressors, challenges, and burdens that arise for family caregivers providing end of life care for their loved one (i.e. Andershed, 2006; Funk et al., 2010; Hudson, Aranda, & Kristjanson, 2004; Stajduhar et al., 2010). Well documented are the extensive difficulties that arise for family caregivers in providing instrumental, daily living care for a loved one who is dying (Funk et al., 2010; Stajduhar et al., 2010). Most critically, family caregivers feel unprepared and do not feel like they have the skills, information and knowledge (particularly about pain and symptom management), to provide the care that their loved ones require (Funk et al., 2010; Hudson, Aranda, & Kristjanson, 2004; Rose, 1999). As a family member’s illness advances, there is also evidence of an increase in distress, anxiety and burden for family caregivers (Aranda & Hayman-White, 2001; Carlsson & Rollison, 2003; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Ladner & Cuellar, 2003; Meyers & Gray, 2001; Payne, Smith, & Dean, 1999; Waldrop, Milch, & Skretny, 2005). While it’s clear that providing end of life care for family caregivers is challenging in the home (Axelsson & Sjoden, 1998; Carlsson & Rollison, 2003; Payne & Grande, 2013), or within hospice, palliative care (Carlsson & Rollison, 2003; Haley et al., 2003; Ladner & Cuellar, 2003; Meyers & Gray, 2001; Waldrop et al., 2005), or in hospital based settings (Dunne & Sullivan, 2000; Hebert, Schulz, Copeland, & Arnold, 2009; Rogers, Karlsen, & Addington-Hall, 2000), there is also evidence that family caregivers can find positive and meaningful elements which arise as a result of providing end of life care to their loved one. Positive meanings and appraisals are associated with family members experiencing: closer relationships with their loved one who is dying (Aoun et al., 2005; Hudson, 2004; Jo, Brazil, Lohfeld, & Willison, 2007; Koop & Strang, 2003); care provision as an opportunity to return care to a loved one who cared for them (Grbich et al., 2001; Koop & Strang, 2003); feeling pride about the quality and proficiency of their caregiving skills and abilities (Aoun et al., 2005; Grbich et al., 2001; Jo et al., 2007; Koop & Strang, 2003; Stajduhar & Davies, 1998); and lastly caregiving providing a meaningful opportunity to support and share in the end of life experience with their loved one (Koop & Strang, 2003; Stajduhar, 2003; Stajduhar & Davies, 1999).
Of interest in reviewing the significant challenges, and some of the noted positive experiences, is how most of the negative elements speak to task-based, instrumental care, while many of the positive elements speak to the purposes and meaning behind the caregiving. Seminal work by Barbara Bowers (1987) on intergenerational caregiving offers important insights into how the caregiving literature in end of life care could be expanded to more closely examine how families, and mothers and daughters experience caregiving. Drawing on an extensive number of interviews with both parents and adult off-spring (most of whom were women), Bowers work centrally positons the purposes of care as far more important for family caregivers than the tasks of care. This said, purposes of care are not observable, but rather require an understanding of why certain forms of care are provided, and what this care means for the caregiver and/or the care receiver. Within Bowers work she presents five unique but interconnected categories of caregiving: protective, anticipatory, preventive, supervisory, and instrumental care (Bowers, 1987). Of central importance is that only one of the five forms of caregiving is linked to the physical acts and instrumental tasks involved in care provision. “The other four types, while not defined by or directly associated with observable behaviors such as tasks, are processes crucial to the intergenerational care experience and to our understanding of how families care for their elderly relatives” (Bowers, 1987, p. 25). Each of these forms of caregiving would expand our understanding of the purpose and meaning behind care provision and would bring us closer to understanding not only what care daughters provide, but why.

Protective caregiving – is focused on protecting the parent from elements of aging and or illness “which were considered threats to the parents’ self-image or to the establishment of the parent-child relationship” (Bowers, 1987, p. 27). In Bowers study, protective caregiving was considered adult caregivers “most significant work and the most frequent and powerful source of stress” (Bowers, 1987, p. 27). In thinking about mothers and daughters, this would invite us to think about the varying elements of advanced illness that daughter’s may perceive as potentially or definitely threatening her mother’s self-image. These elements could be related to a mother’s care needs and abilities (independence); a mother’s ability to make her own decisions (autonomy) and a mother’s needs and wants about where she wants to die (control). As the central role of adult children is to provide and sustain emotional support, questions circulate about how daughters’ continue this support at a time that is emotionally taxing on both mothers and daughters? Further as part of the protective aspect of caregiving, elements of care that may
be perceived as threatening the adult/child (mother/daughter) relationship are also addressed. This means there is recognition that daughters may be focusing on care practices that secure and support their relationship with their mother by avoiding care practices or processes that could threaten their relationship or situations or relationships that could be perceived as undermining the relationship. This could, as a result, centrally position daughters as at odds between supporting their relationship with their mother, while also acknowledging the role and responsibilities of care providers in how they provide care for their mothers. Understanding how protective caregiving is actualized could for example, shift a health care provider’s focus from labelling a daughter as uncooperative or obstructionist, towards a more situated understanding of how mothers and/or daughters may be perceiving the outcome of certain care practices and decisions, and how these outcomes could impact the relationship between mothers and daughters.

**Anticipatory caregiving** – examines what adult caregivers (offspring) do, and/or the decisions they make based on what they think their parent’s needs might be. This speaks to all the planning and thinking processes that adult caregivers engage in, as they work to examine and attend to all of the possible negative outcomes that could occur. Bowers notes how this speaks to adult children working to think about and cover all the possible things that could happen -“just in case” (Bowers, 1987, p. 27). Working to anticipate possible care needs, or anticipating all of negative outcomes which could occur within the context of advanced illness and end of life becomes more difficult as illnesses progresses with less and less certainty. Within this context, mothers and daughters have less and less control of what might arise in the future. In relation to mothers and daughters in end of life, this would address all of the caregiving work that daughters do in relation to what they anticipate might happen as their mothers’ illness advances and she becomes closer to the end of her life.

A particularly important point about anticipatory caregiving is how Bowers found that this form of caregiving “is also rarely talked about openly between parents and their offspring…it is intentionally invisible” (Bowers, 1987, p. 26). Adult caregivers in Bowers study felt that attending to and anticipating possible needs for their parent was their responsibility, and that they would not share this with their parent, for fear of being seen as not supporting, or worse still questioning or threatening a parents’ ability to cope and take care of themselves.
Preventive caregiving – includes all of the concrete things that adult children do, “for the purpose of preventing illness, injury, complications, and physical and mental deterioration…[and] generally involves more active monitoring and supervising than anticipatory caregiving” (Bowers, 1987, p. 26). With mothers and daughters this would examine what daughters do to try and ensure that their mother’s stay safe and well, for as long as possible. As with anticipatory caregiving the difficulty in the context of advanced illness and end of life is that there are so many elements during this time that are uncertain and are unable to be prevented. Further still, the element that daughters may be working to prevent the most, such as her mother’s suffering, or her mother’s death, are elements that are not within the daughters’ control, regardless of how much a daughter may work to try and prevent these things from happening.

Supervisory caregiving – examines the caregiving that happens as adult children try and observe and supervise their parents care for themselves, or the care that is provided to them by others. Adult children may be involved in following-up with their parents about whether they took their medication, or whether a particular form of care was provided by a health professional. With mothers and daughters, daughters may be watching and observing how much their mother is eating, whether the care provider in a health institution gave them a bath, or if the mother is receiving care services in the home, whether these services arrived when expected. Closely woven into supervisory caregiving are anticipatory and protective caregiving as daughters are making sure that their mother’s needs are continually being met. The potential risk, and/or the actual experience of their mothers’ needs not being met, can mean that daughters feel that it is their responsibility to continually supervise and oversee their mothers’ care.

Instrumental caregiving – is the form of caregiving that is most often referenced in the caregiving literature, as it speaks to the actual activities of care. This speaks to the actual caregiving practices of doing things with and for another, such as supporting parents with daily living activities such as preparing meals, bathing, dressing, and as needs progress, potentially assisting parents with using the toilet, eating or getting in and out of bed (Bowers, 1987). “The purpose of this care is to maintain the patient’s physical integrity and health status” (Bowers, 1987, p. 26). For mothers and daughters, this includes all of the care practices that a daughter actively supports and assists her mother with, whether her mother is living at home, or within a health institution. For many daughters, instrumental caregiving is a core part of their relationship
with their mothers, even when these care practices may also be provided by professional caregivers. Of importance within Bowers study was that, “While this is the type of caregiving that is most often studied … it was considered by family caregivers as the least important type” (Bowers, 1987, p. 26). Instrumental caregiving was seen as less important for family caregivers as they felt that their most important caregiving role was one which focused on the emotional well-being of their parent (Bowers, 1987). As end of life care focuses fundamentally on the physical well-being of the mother and the care of her body, daughters may be in a different position from some of the caregivers in Bowers study, as daughters in end of life often become quite involved in providing instrumental, nursing and medical care. This said, the purpose of providing instrumental care for daughters may be quite similar to the purposes of instrumental care at earlier stages of the illness, as daughters work to ensure that their mothers’ emotional well-being is supported and cared for within these forms of care.

Widening the scope to how protective, anticipatory, preventive, supervisory, and instrumental caregiving underscore the care practices between mothers and daughters in end of life, would offer a way to both acknowledge the centrality of instrumental task-needs, while also ensuring that the purpose and meaning behind care practices are also understood. These areas of caregiving have not been addressed in the end of life literature, and would further illuminate not only what caregiving practices daughters are providing, but also how and why these practices may either strengthen meaning-making between mothers and daughters, or further escalate isolation, stress and burden.

**Practice in End of Life**

Stress and coping approaches strongly inform assessments, and interventions in end of life. As patients and families move into end of life care, whether in the home or within a care facility, there is often a strong emphasis within medical and end of life care team assessments, to assess both the needs and symptoms of patients, as well what patients and families understand these symptoms mean. Underscoring this assessment practice is a critical understanding of the importance of meaning and perception of meaning, in how patients and families experience stress and burden. In assessing patient and family needs it is paramount to consider the needs and concerns of the individual patient, the family, and the physical and social resources that are available to support the family during end of life and bereavement.
As “research indicates that carer resources, rather than patient diagnosis or illness severity, are the primary predictors of carer burden and other carer outcomes” (Hudson, 2013, p. 581), interventions have focused their attention on building carer resources. In conducting a systematic review of psychosocial interventions for family caregivers, Hudson, Remedios & Thomas (2010) reviewed the literature from 2000-2009 which specifically targeted psychosocial outcomes for family caregivers. Fourteen articles met their inclusion criteria, and the goals of the interventions included, “psychosocial support, psycho-education, carer coping, training in patient care (symptom management), sleep promotion and family meetings” (Hudson, Remedios, & Thomas, 2010, p. 3). A critical area raised by family caregivers is the lack of information and support that is available to help them as they move into providing end of life care (Andershed, 2006; Aoun et al., 2005). As a result of the need for information and support, a number of interventions have been created as psycho-educational programs to try and provide the information that family caregivers require so that they feel they have the resources/information they need, while also receiving the psychosocial support they require. Information and resources offer caregivers information and support about: caregiving roles, caregiving practices (managing symptoms, pain management etc.); physical signs of dying and what happens when someone is imminently dying; as well as self-care strategies for reducing stress and burden during caregiving (Hudson & Aranda, 2013; Hudson, Aranda, & Hayman-White, 2005).

One psychosocial intervention which includes the whole family, and begins during the time when a patient begins receiving end of life care and extends into bereavement, is an intervention called, “Family-Focused Grief Therapy” (Kissane et al., 2006). This program is a brief intervention that includes four to eight sessions over a time period of nine to eighteen months. The intervention, “aims to prevent the complications of bereavement by enhancing the functioning of the family, through exploration of its cohesion, communication (of thoughts and feelings), and handling of conflict” (Kissane et al., 2006, p. 1209). Drawing upon previous research with families in end of life, Kissane and colleagues, (Kissane et al., 1996; Kissane, Bloch, Burns, McKenzie, & Posterino, 1994) worked to create a typology of three types of families to describe how family functioning, family cohesion, conflict and communication inform the overall functioning of families in end of life and bereavement. Family focused grief therapy has been designed for families with moderate levels of impairments (cohesiveness, conflict) and higher levels of psychosocial morbidity. Within a randomized clinical trial, “Family
focused grief therapy reduced the complications of bereavement, with a greater reduction of
general distress over thirteen (13) months and a significant reduction of distress and depression
for the ten percent (10%) of family members with high baselines scores (Kissane et al., 2006, p.
1215). Further these results emphasize the importance of bereavement supports beginning
during end of life care, and that families who are determined at risk, could become the primary
focus for this form of therapeutic intervention (Kissane et al., 2006, p. 1215).

2.2.4 Contributions and Limitations of Stress and Coping theory to
Understanding Mothers and Daughters at the End of Life

Stress and coping theories are typically evoked to speak to how patients who are dying
experience stress and coping; how family caregivers experience stress and coping; how patients
and/or family caregivers perceive stress (on primary and secondary levels); how coping
responses are problem-focused or emotive-focused; and outcomes of caregiving coping
(Folkman et al., 1986; Pearlin, Lieberman, Menaghan, & Mullan, 1981). From this literature we
take away important messages about the significance of how patients and caregivers cope, both
as a process in how they think and respond to stressors, as well as the context of how they
experience the stages, tasks or demands that arise in end of life, and the resources which they
feel are available to them (Folkman et al., 1986). While tremendously important in offering us
insights about how patients and family caregivers cope and respond to the stressors which arise
in end of life care, this literature also constrains our ability to examine more situated and
relational understandings of end of life, which move beyond the confines of how family
members experience caregiving. As Stajduhar and others (2010) note in their review of 125
studies with home-based caregivers in end of life, “The focus for analysis is overwhelmingly the
individual, and to a lesser extent, the caregiver–patient dyad; in far fewer studies, researchers
considered broader or more contextual features of caregiving, including variables representing
relationships between care recipients and caregivers” (p. 578). Missing from this literature on
patients who are in end of life, is an understanding of how patients and families experience end
of life relationally, how end of life issues, concerns and stressors come into the relationship, and
how patients and families respond individually, collectively and communally to what end of life
means to who they are. Further still, stress and coping models while offering a variety of
appraisal styles, and forms of coping which draw on meaning on global and situational levels,
these models can suggest that there are normative ways and styles of coping, and while not explicitly part of the model, can carry an implied hierarchy that some forms of coping are more effective than others. Within more traditional end of life literature, such as the early work of Sigmund Freud in Mourning and Melancholia (Freud, 1957) focused on the intrapsychic elements of grief and loss, and directly labelled some forms of grief as depressed or maladapted, it seems paramount that there is caution in creating normative or universal understandings of grief and loss. Further still, there is a significant gap in understanding how gender and/or social and cultural contexts inform stress and coping. Lastly, as much of the literature on stress and coping and caregiving looks specifically at the experience of end of life, this focus on a particular stage and time of life, misses how caregiving and relationships exist across the life course, and as such, may be better represented in models which appreciate the continuous nature of these relationships on how mothers and daughters experience end of life.

2.3 Relational Cultural Theory

Drawing on feminist developmental work arising from the Stone Centre for Developmental Services and Studies at Wellesley College in 1981, relational cultural theory centrally positions women’s development within relationships and cultural contexts. Recognizing that psychosocial developmental stages theories were built on evidence drawn primarily from empirical studies with boys, feminist developmental theory offered a critical turn in exploring how relationships and processes of connection and disconnection inform development. Further, relational cultural theory advanced the understanding that connection and disconnection occur on individual and social levels. This theoretical entry offers a way to think critically about how women in relationship experience end of life on individual and social levels, and how conceptual understandings which are framed relationally, may broaden our understanding of how women experience this time of their lives. Although feminist relational cultural theory has not been taken up broadly in the context of end of life practice and research, it introduces some very important concepts that could strengthen our understanding of how families, and specifically mothers and daughters experience end of life.

2.3.1 Central Tenets of Relational Cultural Theory

Originally known as the ‘self-in-relation’ model (Jordan, Kaplan, Miller, Stiver, & Surrey, 1991) and later as the Stone Center relational model (Jordan, 1997), the Stone Centre writings
examined how girls and women move between connection and disconnection within their relationships. Central to the practices and processes of how girls and women built their relationships were relational images, which informed not only how and why disconnection happened, but also the meaning behind disconnection and how this informed women’s sense of self in relation to others.

Relational images

Underscoring the concept of relational images is the understanding that as girls and women long for connection within their relationships and yet experience disconnection, powerful internal images begin to develop which reinforce and replicate not only their fears and vulnerabilities around wanting and needing connection and not receiving it, but also underlying meanings about why disconnection happens and what this means for future relationships (Miller & Stiver, 1995, p. 214). As these meanings become more and more entrenched, they also begin to take on a predictive quality as “they [not only] determine our expectations about what will occur in relationships, they then guide our actions” (Miller & Stiver, 1995, p. 214). Most importantly, relational images and meanings create a framework for women which will “determine not only her expectations about relationships per se; they determine her total sense of herself - her sense of what she is and what she can do” (Miller & Stiver, 1995, p. 215). Ultimately internal relational images are both powerfully descriptive and prescriptive, as they inform not only how girls and women understand who they are and what they need in relation to others, but also who they are, and what they are able to do within the multiple relationships and contexts within which they live.

As the Stone Centre writings continued to grow, more emphasis was placed on how difference and diversity connected with gender and development. Beginning with “Women’s Growth in Diversity” (Jordan, 1997) and “The Complexity of Connection” (Jordan et al., 2004), a significant shift took place in the renaming of ‘relational theory’ into ‘relational-cultural theory.’ This shift “follows from increased recognition that relationships do not exist as atomized units, separate and distinct from the larger culture. Indeed, relationships may both represent and reproduce the cultures in which they are embedded” (Jordan et al., 2004, p. 3).

Three relational processes are seen as unfolding within women’s relationships: relational competence; relational resilience; and relational awareness (Jordan et al., 2004).
Relational competence explores a woman’s “capacity to move another person, to effect a change in a relationship, or effect the well-being of all participants in the relationship” (Jordan, 2004, p. 15). Relational competence is important as it offers insights about how a woman feels about herself and her abilities to connect with another person, and whether she believes she can influence the other person, or her relationship with this person. Framed somewhat differently, Jordan (2004) defines relational competence as, “the ability to participate in growth-fostering relationships…the ability to “move” someone or a relationship on the emotional, cognitive and behavioral realm” (Jordan, 2004, p. 15). Centrally woven into the process of building relational competence, and developing growth fostering relationships, are two relational activities: mutual empathy and anticipatory empathy. Mutual empathy speaks to a process or movement between women, as it addresses how “caring and learning flows both ways” (Jordan, 2004, p. 15), and the importance of this form of connection in building and sustaining growth fostering relationships. Similarly, anticipatory empathy also speaks to a process or movement between women, as it focuses on the “noticing and caring about our impact on others” (Jordan, 2004, p. 15), and how women work to anticipate the impact of their thoughts, feelings and actions on another person. While relational competence is located within women’s relational images, and within their relationships with others, it is important to highlight how women’s relational competence is strongly informed by social and cultural contexts which often silence, ignore or threaten women’s knowing and relational practices. As such it is imperative that understandings of relational competence are understood as being widely informed, and influenced by broader social, cultural, historical and institutional contexts.

Relational resilience examines how women in relationship respond to disconnection, isolation and suffering, and “the relational dynamics that encourage the capacity for connection” (Jordan, 2004, p. 28-29). Relational resilience works to shift the focus from individual resilience factors, such as sense of control and positive appraisals of stress, towards broader understandings which position resilience within and through relationships. In positioning resilience within relationships, women are encouraged to reach out to others, particularly in times when they are feeling isolated and alone, as a way of shifting towards understandings of vulnerability which can be supported and shared with others. Critical to the shift towards relational resilience is an understanding that social support within relationships includes mutual involvement, where support is both given and received (Jordan, 2004, p. 34). Mutual involvement expands our
understanding of social support from what individuals ask for and receive, to an understanding where support is relationally conceptualized as involving giving and receiving as a form of relational resilience.

*Relational awareness* focuses on shifts and changes within relationships and “includes an awareness of our patterns of connecting and disconnecting…and includes personal awareness, awareness of the impact of oneself on the other, the effect of other on oneself, and the quality of energy and flow (i.e. cathexis) in the relationship itself” (Jordan, 2004, p. 53-54). Relational awareness then builds an individual and relational understanding of how and why women respond in the ways they do, and how patterns of relating, may actually prevent women from being in relationships that foster growth. As relational images strongly inform relational patterns, it is important that links are made between the relational patterns that women reproduce within their relationships with broader social and cultural messages of how women *should* respond and relate to one another in particular ways and within particular relationships and contexts.

See *Figure 5*, Relational Cultural Theory for an overview of the central tenets informing this particular study.

*Figure 5*. Relational Cultural Theory (Jordan et al., 2004; Miller & Stiver, 1995)
2.3.2 Families and End of Life in the Context of Relational Cultural Theory

A relational-cultural theoretical perspective on families and end of life calls for an approach which focuses on both relationships and social-cultural contexts. While relational cultural theory has not been drawn on in understanding the experiences of families, or specifically mothers and daughters in end of life, there is literature guided by feminist theory, and social-cultural, relational theory that can guide us towards central issues and concerns that may be experienced by mothers and daughters in end of life. As I address this literature, I will focus specifically on how this literature echoes central tenets of relational cultural theory, and how this literature can inform further work with mothers and daughters and end of life.

Feminist, relational understandings of relationships, connection, illness and care.

From a broader feminist, relational literature base I address three primary areas: Relational development across the life course; Meaning-making between mothers and daughters; and Relational patterns between mothers and daughters.

Relational development across the life course

Building on the work of the Stone Center, and relational cultural theory, Carol Deanow (2011), proposes a new relational model of development wherein age clusters (age-related stages), are identified across the life course, and each cluster is recognized for its “capacities and possibilities as well as its challenges and obstacles” (Deanow, 2011, p. 125) in supporting girls and women to develop growth fostering relationships. Each cluster within Deanow’s work speaks to relational, developmental tasks. While Deanow presents eight age clusters across the whole life course, two specific age clusters would apply to mothers in end of life and their adult daughters: Dexterity/Imbalance and Sustainment/Abandonment or Withdrawal. Below I review the central opportunities and challenges of these stages and then I explore how these stages might inform how families and specifically mothers and daughters experience end of life.

Dexterity/Imbalance (Throughout Adulthood) – Women across adulthood, are often actively involved in a wide range of relationships. These relationships which may involve spouses/partners, children, aging parents, friendships, and work colleagues, and are relationships which involve a wide range of needs, concerns and responsibilities (Deanow, 2011). Attending
to and meeting the variety of needs across each of these relationships involves dexterity. “Dexterity involves the skill of being relationally present and engaged in all these sectors” (Deanow, 2011, p. 133). This dexterity speaks to attending to relational shifts and changes with children as they develop and move into adulthood, as well as adult children attending to shifts and changes with their parents as they begin relating to one another as adults (Deanow, 2011, p. 134). As parents age and their needs increase, they may need to ask for more support from their adult children, and adult children may need to take on different tasks and roles with their parents. “Most frequently, it is women in families who take on these caretaking roles” (Deanow, 2011, p. 134). Further other relationships such as friendships and work relationships are also centrally important for adult women at this time of their lives. The central challenge for women “is to find the time and energy to engage in all these mutually enhancing relationships without experiencing imbalance. Imbalance, in this regard, suggests that the demands of one (or several) of these relationships take over, leaving little time or energy for other important relationships” (Deanow, 2011, p. 134). Finding a way to balance all of these competing can seem unattainable for many women, carrying the risk or concern that some relationships may not be able to be repaired and connection within these relationships may not be possible.

For families and specifically mothers and daughters, the age cluster of dexterity/imbalance speaks to the multiple relationships that mother and daughters often are navigating as they experienced advanced illness and end of life. For mothers who need more support, it can be very difficult for mothers to ask their daughters for more support if they are already aware of how their daughters are struggling to meet the needs of the many relationships within their daughters’ life. The awareness and empathy that mothers have of their daughters lives, and the impact their needs may have on their daughters’ lives demonstrates how mutual empathy and anticipatory empathy can shift how needs are represented and brought into the relationship. Further, daughters who are aware of their mother’s physical decline and are anticipating the care needs that her mother may be experiencing, can be challenged if some of these needs are protected from her, or if she questions whether her mother is fully communicating her needs. These issues have been reflected in the literature within research studies with mothers and daughters, where mothers are frail, aging, or living with dementia (Aronson, 1991; McGraw & Walker, 2004; Sheehan & Donorffio, 1999; Walker & Allen, 1991; Ward-Griffin, Bol, & Oudshoorn, 2006; Ward-Griffin et al., 2007).
**Sustainment/Abandonment or Withdrawal** – As parents’ age and care needs increase adult parents, and adult children, often need to negotiate continual changes in their relationship. Aging parents are often in a position of needing to ask for increasing levels of support from their adult children, and can find themselves in a position where these needs cannot be hidden or protected from their children. Many aging adults also begin to withdraw socially from larger social support networks, and this withdrawal may mean that adult children are not only primary caregivers, but are also one of the few social supports that aging parents have in their lives. Adult children at this time of their lives can often be shifted into providing levels of care that are progressively more and more demanding. This level of care may be demanding physically as well as emotionally and psychologically as adult children move into providing care that is progressively more involved as parents are no longer able to care for themselves. Primary obstacles that are raised within this age cluster relate to the difficulties and levels of disconnection that can occur as women age and as needs increase. While these levels of disconnection can be expressed on individual and relational levels between mothers and daughters, this disconnection also speaks to broader social and cultural levels, as social norms about aging, advanced illness and end of life are treated as parts of life to be avoided at all costs. “To the extent that society still fears aging and practices ageism, especially stigmatizing ‘‘old women,’’ some elderly women experience abandonment by their families and communities” (Deanow, 2011, p. 135).

For families in end of life and specifically mothers and daughters, the age cluster of sustainment/abandonment and withdrawal is particularly apparent as a mothers’ health needs continue to increase and her daughter continues to provide and meet her mothers’ needs. How daughters sustain this level of care, while also caring for their other relationships, over extended periods of time, often means that daughters worry about abandoning their mothers, when they need to take care of other relationships needs. As mothers’ are at the end of their life, there can also be an emphasis for daughters’ on ensuring that they are present and with their mothers when their mother dies. The importance for daughters of being there at the end, can speak to a daughters’ need to ensure that she has done everything for her mother, and that she has fulfilled any or all promises to be with her mother until the end. The challenge with the unpredictability of the end of life, is that while some daughters are able to be with their mothers’ when they die,
other daughters may not be able to be there, which can leave these daughters with feelings of guilt or remorse for not being there, or having abandoned their mothers’ at a time of great need.

*Meaning-making between mothers and daughters (relational competence/resilience)*

While much of the caregiving literature between mothers and daughters has focused on the instrumental tasks of aging and caregiving, there is a growing literature that has focused on furthering our understanding of how mothers and daughters collectively make meaning of their relationships as a mother moves into later stages of her life (Walker & Allen, 1991). This literature focuses on how mothers and daughters create connection and meaning in the context of aging, frailty and illness. Alexis Walker & Katherine Allen (1991), in a study with 29 widowed mothers and their caregiving daughters, explored how mother and daughter dyads conceptualized the costs and benefits that come from caregiving. Three types of relationships were seen as unfolding between mothers and daughters, which addressed varying levels of rewards, costs, conflict and concern for the other partners’ outcome:

*Intrinsic mother-daughter relationships* – within intrinsic mother and daughters relationships, mothers and daughters experienced joint rewards with relatively few costs. There was an absence of conflict, or a limitation of conflict, and both mothers and daughters expressed a mutual concern for the outcome of each other (Walker & Allen, 1991).

*Ambivalent mother-daughter relationships* – within ambivalent mother and daughter relationships, while mothers and daughters experienced joint rewards, there were also significant costs to these rewards for at least one of them within the relationship. Further, joint activities were rarely seen as activities that both mother and daughter found rewarding. Mothers and daughters within ambivalent relationships experienced a lot of conflict, and the concern for the outcome of the other, was primarily experienced by one of the partners, but not both of them. (Walker & Allen, 1991).

*Conflicted mother-daughter relationships* – within conflicted mother and daughter relationships, mothers and daughters experienced very few rewards and extensive costs. Mothers and daughters did not engage in activities that were rewarding to both of them, and there was a great amount of conflict within their relationship. Lastly, with regard to concern for outcomes, mother
and daughters were concerned about their own outcomes, but not each other’s (Walker & Allen, 1991).

This review of types of mother and daughter relationships, expands our understanding of the wide range of elements that inform how a mother and daughter experience both individual and collective rewards and costs, and how activities may be jointly rewarding, or rewarding for only one of them. Furthering our understanding of rewards, costs and conflicts, can help us understand how relational competence, and relational resilience are experienced within mother and daughter relationships at the end of life.

Relational Patterns between mothers and daughters (relational awareness)

Lori McGraw & Alexis Walker (2004), in their study with thirty-one aging mothers and their caregiving daughters, explored how aging mothers and their caregiving daughters negotiate issues of connection, autonomy, and conflict (McGraw & Walker, 2004). Drawing on videotaped interactions a number of relational themes emerged. Relational themes included: attending and responding to one another’s circumstances, preserving mother’s autonomy, and managing conflict and tension (McGraw & Walker, 2004, p S326). In developing these themes, McGraw and Walker found three patterns of relating emerge between mothers and daughters: (a) symmetrically connected, (b) asymmetrically connected, and (c) symmetrically constrained. Central to their findings was the role of attentiveness, autonomy and connection. The three patterns of relating are described below:

Symmetrically connected – for mothers and daughters who showed patterns of relating which were symmetrically connected, mothers and daughters were, “comfortable being near each other, both physically and emotionally…sat close to one another and touched affectionately” (McGraw & Walker, 2004, p. S328-9). Further they found that these mothers and daughters laughed often together, seemed to really enjoy being with one another, and really seemed to demonstrate that they trusted one another (McGraw & Walker, 2004). Mothers and daughters who displayed symmetrically connected patterns of relating, “exhibited high levels of attentiveness and responsivenes, encouraged mother’s autonomy, and handled conflict in positive ways” (McGraw & Walker, 2004, S329).
Asymmetrically connected – for mothers and daughters in asymmetrically connected pairs, there were many similarities with the mothers and daughters in symmetrically connected relationships. These similarities were reflected in daughter’s trying to maintain their mother’s autonomy, and in mothers and daughters working to manage conflict in a positive way. The differences between these two patterns of relating were reflected in how attentiveness and responsiveness between mothers and daughters were not reciprocal. “Daughters were more attentive and responsive to mothers than the reverse. Mothers did not ignore daughters’ explicitly stated needs or comments; however, interactions were more subtly focused on mothers’ needs” (McGraw & Walker, 2004, p. S329).

Symmetrically constrained – for mothers and daughters in symmetrically constrained patterns of related, there were differences between “what daughters and mothers said and what their nonverbal behaviors revealed” (McGraw & Walker, 2004, p. S329). Mothers and daughters were not as attentive to the needs of each other, and daughters were less apt to preserve her mother’s sense of autonomy. An important finding within this study was that, “when relationships were troubled, mothers’ autonomy seemed to be in jeopardy” (McGraw & Walker, 2004, p. S329).

McGraw and Walker’s study offers some valuable insights into how mother and daughter patterns of relating can be expressed in both verbal and nonverbal behaviors. Drawing on videotaped interactions, McGraw and Walker were able to examine how and when nonverbal and verbal behaviors may be dissonant with one another. Further, understanding how these relational patterns emerge, offers us concrete examples of how relational awareness between mothers and daughters unfolds, and how these elements inform their relationship.

Situating Mother and Daughter Relationships with Relational, Social-Cultural Contexts

As noted in the introductory chapter, there are a number of different beliefs, values, and assumptions which inform broader social and cultural narratives about death and dying. The most pervasive narrative which operates emphasizes that conversations about death and dying should be denied or ignored. Varying understandings and interpretations of what a good death means, circulate for patients, families, and medical care providers and can, as a result, set up expectations, outcomes and judgements that may collide with each other. Stu Farber, Thomas Egnew and Annalu Farber (2004) suggest that instead of referring to a good death that we
consider using the term “a respectful death” (Farber, Egnew, & Farber, 2004, p. 103). A respectful death, “emphasize[s] a nonjudgmental relationship between parties…that acknowledges differences and allows for a shared process of integrating differences into as coherent a whole as possible” (Farber et al., 2004, p. 105). Drawing strongly on the importance of respect, this model focuses on exploring a process with patients, family members and care givers about what the patient and family believe in and value, and what their goals are in end of life, versus defining normative, prescriptive understandings of what a good death looks like for everyone (Farber et al., 2004). Ultimately then, a respectful death would encourage a respectful process and dialogue between patients, family members and health care providers, wherein the focus would be on exploring the goals of the patient and family for end of life, and then developing a care plan, that ensures that these goals are respected.

In their seminal work on death and dying in hospital based care, Glaser and Strauss (1966) observed how patients, family members, and providers built an awareness of how death and dying occur in different contexts. Examining and defining different types of ‘awareness contexts’ (p. 10), Glaser and Strauss described different types of awareness (i.e. closed, suspected, mutual pretense, and open) and how these types of awareness unfolded relationally between people. While this work focused specifically on how awareness of death and dying is experienced relationally, it did not address how the experience of dying was shared relationally and socio-culturally over time.

While there are many different studies about experiences of end of life, there is very little in the literature which examines specific relational, socio-cultural aspects of end of life. Drawing on a select few studies, I explore how relational and socio-cultural aspects have been conceptualized and operationalized, and how these aspects may inform the experiences of families, and mother and daughters in end of life.

Relational Conceptualizations of End of Life and End of Life Decision-Making

Alex Broom and Emma Kirby (2013) conducted a study with twenty patients in a palliative care unit, to understand how patients experienced end of life, in relation to the needs and wants of their family members. Interviewing patients alone, patients shared how family relationships created, “pressures and strains on families and patients; differentiation in family responses to and involvement in the dying process; and tensions between individual and family preferences/
desires” (Broom & Kirby, 2013, p. 499). A key focus on the narratives from patients focused on their perceptions and understandings of the pressures and strains that health and illness needs had put on their families. Critical within these narratives was an understanding of how the decision to move into an in-patient unit was guided by family coping concerns, and how patients felt guilty for being such a burden on their families (Broom & Kirby, 2013). As a result, in-patient care offered a way of alleviating the burden on their family, while also offering more challenges, as patients worried about family members having to watch a long drawn out death (Broom & Kirby, 2013).

Differentiation in family responses to and involvement in the dying process reflected that there was a wide range of family responses, from family members who were very involved with the patient and provided extensive and amazing support, to other families who experienced extreme conflict where patients felt isolated and alone (Broom & Kirby, 2013). This finding was suggested as an important counter to more predominant narratives in the literature, which can suggest that most patients and families in end of life have strong or positive connections. There is instead a wide range of family responses, and what is probably most common, is that family variability is to be expected (Broom & Kirby, 2013). Finally, in relation to preferences and choices for dying, “much of the family dynamics discussed within the interviews centred on the relationality of dying preferences and the degree to which dying was situated within a dialectic between individual preference and collective desire. That is, family wanted the person to ‘hang around’ and ‘make the most of it’ whereas some participants desired a quick death” (Broom & Kirby, 2013, p. 508). This finding strongly reflects the importance of understanding how patients and family members understand their own preferences in end of life, as well as their understandings or perceptions of each other. Underscoring this is the importance of understanding how patient preferences may be strongly informed by what patients think their families need or want to hear. “The maintenance of stoicism and to ‘fight’ for the benefit of family members was frequently revealed as an important element of preserving relationships at a time of considerable tension and stress” (Broom & Kirby, 2013, p. 508).

This study raises the importance of understanding how mothers and daughters in end of life experience and understand the pressures and strains that end of life is placing on both of them at this time of their lives. Understanding the trajectory of illness, and how care needs have been met in the past, offers important insights about how and why mothers may be receiving in-
patient or home-based care, and importantly how mothers and daughters perceive the positive or negative aspects of this situation. Further it highlights that there is a lot of variability around how mothers and daughters may respond to the needs and issues that arise at end of life, suggesting that some families may be very involved in end of life, while other families may not be able to be available, or may not be able sustain connection with the mothers at this time of their life. Lastly this study raises the importance of understanding how individual and family preferences inform end of life decision-making, and how mothers may make decisions for their care, and their goals of care, based on what they think their family members prefer or want on their behalf.

The nonlinear, fluctuating nature of clients’ sociocultural experience

Within Carol McWilliam et al.’s (2008) study, an ethnographic method was drawn on to investigate, “the culture of home-based palliative care as experienced by people older than 65 years who are dying of cancer” (McWilliam, Ward-Griffin, Oudshoorn, & Krestick, 2008, p. 339). Drawing on home-based visits to four participant’s homes, the findings reflected how participants navigated a journey that was active and shifting between “living while dying/dying while living” (McWilliam et al., 2008). This journey was one that was marked by the tensions between “seiz[ing] the opportunities and interpersonal relationships of ‘living while dying’ and confront[ing] the challenge of ‘dying while living’ through: ‘celebrating life/grieving losses’; ‘connecting with/detaching from others,’; ‘resigning to/accepting life circumstances,’; and ‘holding on to/moving beyond life in the present moment’” (McWilliam et al., 2008, p. 338). Each of these elements will be discussed below:

celebrating life/grieving losses – participants celebrated life by appreciating the time they had and living each day at a time, while also mourning and grieving the losses that were also impossible to ignore (McWilliam et al., 2008). While celebrations of life within these findings were tied to broader social messages about how dying should be performed by patients, and how these roles align with broader constructions of a good death, the experience of isolation, and extreme separateness from others was interpreted as part of the process of meeting and confronting death (McWilliam et al., 2008, p. 341-342).

connecting with/detaching from others - participants reflected on the importance of connecting with others and making strong connections with loved ones, while at the same time withdrawing
and detaching from other people and roles that no longer fit for them. Connecting with others was also seen as aligning with a good death while detachment was connected to the person’s experiences of isolation and separateness, as well as some of the developmental elements connected to end of life (McWilliam et al., 2008, p. 342-344).

**resigning to/accepting life circumstances** – participants resigned themselves to what was happening and worked to cope with what was happening in ways that were private and contained, while also moving between spaces of accepting and coming to terms with what was happening. Coming to terms with what was happening was seen as coming to some form of resolution about the meaning of dying in their lives (McWilliam et al., 2008, p. 344-345). Resigning to death, was linked by the authors to Phillipe Aries (1974) conceptualization of ‘tamed death’ wherein the person, “did not embarrass others nor evoke strong emotions but instead took place privately and secretly, a death more tolerable to survivors” (McWilliam et al., 2008, p. 344). Accepting life circumstances was linked to Elisabeth Kübler-Ross’s stages of dying, and in particular her final stage of accepting death and dying (McWilliam et al., 2008).

**holding on to/moving beyond life in the present moment** – participants talked about wanting to hold onto the present moment and not wanting to die and living as long as they could, while also shifting into accepting that death was going to happen, and embracing what life after death could involve (McWilliam et al., 2008). Holding on was connected sociologically to participant’s sick roles in patients believing that if they follow medical directions they can live longer. Moving beyond life was connected to a social construction of a good death, and Kellehear’s (1990) notion of “dignified death”, in supporting family members to believe that there is a final meaning and dignity that comes out of death (McWilliam et al., 2008, p. 345).

McWillliam et al. (2008) discuss how their participants narratives reflect, “through their own personal values, beliefs, behaviors, and actions, both shaping and shaped by their immediate and larger sociocultural contexts” (McWilliam et al., 2008, p. 346), how personal narratives are also sociocultural narratives. These findings are very relevant for families and mothers and daughters in end of life, as they highlight how experiences in end of life are active and changing, and as such narratives between mothers and daughters may also reflect this movement. Further, the links McWilliam et al. make to broader sociocultural understandings of a good death, a tamed death, and a dignified death offer an important context in understanding how mothers and
daughters may work to find and attribute broader meaning to their actions and experiences in end of life.

2.3.3 Relational Cultural Theory’s Influence on Research and Practice in End of Life

Although there has not been a substantial focus on applying relational cultural theory to end of life or palliative care, there are ways in which a relational-cultural lens aids in reading the existing literature and identifying its contributions and limitations. These are detailed below within the following subsections: Starting with Women, Women/Daughter as Carers, and Mothers.

Starting with Women

Most research in psychosocial oncology and palliative and end of life care has focused on patients’ experiences of care as separate and distinct from family members’ experiences. Growing steadily over the past two decades is an interdisciplinary body of literature and research that focuses on the unique experiences of women as they are diagnosed and treated and what occurs as women move into end of life care (e.g. Chunlests kul, Carlson, Koopmans, & Angen, 2008; Rees & Bath, 2000; Webb & Koch, 1997).

Women/Daughters as Carers

Literature on outcomes of caregiving focuses on the negative physical and emotional costs of caregiving, with an emphasis on the ‘burden’ and ‘strain’ of caregiving. Much of this literature has come about as a way of identifying the invisibility of work that is associated with caregiving. Rising from feminist literature, as women are primary caregivers in both personal and professional domains and further are seriously underpaid and undervalued in both contexts, this work has moved to address a wide range of inequities and has worked to make ‘visible’ the social, cultural and economic aspects of caregiving in families.

While caregivers for people who are requiring end of life care can be young or old, most (77%) are women (Carstairs, 2010, p. 33). As women are the ones shouldering the majority of the physical, emotional, social, and economic aspects of care, and as caregiving has been
strongly shaped and constructed across gender, familial, social, racial, medical and economic domains, many women intrinsically believe that they are, and should be the ones providing this care. These relational images echo a larger body of literature with daughters that addresses the sense of ‘filial duty’ that many daughters experience as their parents age and require care (Aronson, 1991; Donorfio & Sheehan, 2001; Lewis & Meredith, 1988; Ward-Griffin et al., 2007). In order to comprehend what women bring individually and collectively into the experience of end of life care, it is important to understand how relational stories have integrated into mothers’ and daughters’ self-perceptions of who they are, what they can and should provide, and how they feel (and think they should feel) about providing care.

Read and Wuest (2007) in Newfoundland/Labrador Canada conducted a study examining the needs of daughters of parents approaching end of life. Twelve daughters were interviewed about their experiences taking care of either their mother or father while their parent was dying. The study focuses on the experiences of daughters and does not involve any of the parents receiving end of life care. Using a grounded theory approach, the authors generated a theory of ‘relinquishing’ which addressed how daughters “keep vigil, navigate systems, face loss, and come to terms” (Read & Wuest, 2007, p. 935) with their parents’ death. The core challenge experienced by daughters revolved around ‘turmoil,’ which had emotional, relational and societal dimensions. Emotional turmoil was created by “personal ideals, a lack of prognostic or practical information about dying, a belief that the parent was suffering, a sense that nothing could be done, a perceived sense of isolation, and a lack of experience with death and dying” (Read & Wuest, 2007, p. 935). Relational turmoil included unresolved elements and often revolved around family expectations. “Family expectations emerged from the data as the intensity, type, and quality of expectations family members have of one another, and particularly the daughters in the family” (Read & Wuest, 2007, p. 937). Societal turmoil reflected how structures outside the family impacted the daughters’ ability to care for their mothers. “We discovered that societal demands are a reflection of the paucity, fragmentation, lack of universality, accessibility, and comprehensiveness of services from diverse sectors in place to help these families” (Read & Wuest, 2007, p. 937).

Many of the elements which Read and Wuest relay about the emotional, relational and social aspects of turmoil are informed by each daughter’s relational images with regard to attitudes, expectations, and previously constructed meanings about what a daughter should
provide to their parent. These relational images showcase how health care and care provision have been downloaded onto the family, and structurally how current care models rely on family members to provide end of life care. It is estimated that Canadian families are carrying 25% of the total cost of palliative care by providing care in the home (Canadian Hospice Palliative Care Association, 2012). In 2004, the federal government instituted the Compassionate Care Benefit thru the Employment Insurance Program. The compassionate care benefit offers 6 weeks of paid leave (over an 8 week time-period) for those who are caring for an ailing family member. While this benefit is an important way of validating the needs and expense of caregivers, it is far from adequate in addressing the true needs, costs and duration of time required for those who are providing end end of life care to their family members.

*Mothers*

There are very few studies in palliative and end of life care which have been designed to address the experiences of *mothers*. While one can assume that many patients in palliative and end of life care are mothers as well as patients, the role of being a patient is seen as much more important and/or relevant, than the role of being a mother. While the medical role of patient may be the most apparent within health care contexts, we know that identity and sense of self are interwoven in the relationships and contexts within which we live. Just as women who are patients receiving care do not become genderless, culture-less, asexual beings, mothers who are receiving end of life care do not stop being women, who are mothers, who are mothering their daughters in ways that may be similar or different from how they have mothered across their lives. Nor do their daughters stop being women who are living and relating to their mothers as daughters in ways that may be similar or different from how they have been in relationship across their lives. Most importantly, mothers and daughters are living as mothers and daughters, within the broader medical and social context of knowing that the mothers are going to die and that the mother and daughter relationship will never be the same.

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9 Search strategies in PubMed, OVID Medline using MeSH keywords ‘mothers’ and ‘palliative care’ and ‘end-of-life care’ bring up literature where mothers are caregiving their infants, children, or youth in end-of-life care.
Practices in End of Life

For families

A relational-cultural lens on practice suggests that practices in end of life for families need to focus on supporting all members of the family at this time of their lives. Practices and interventions for families in end of life may focus on: information; family-centered counselling; regular assessments of daily living needs; financial and health insurance resources and supports; legal resources; community resources; and on-line supports:

- Information may be needed about many different aspects of end of life, such as illness progression, grief and loss, as well as after death information about what happens when a loved one dies, how funeral homes are contacted and what happens when they arrive, to how to plan a funeral, how to write an obituary etc.

- Family centered counselling practices can address a wide range of issues being experienced by the family around end of life. Specifically counselling may focus on how the family is coping with anticipatory loss, and how family members are individually and collectively responding to current losses and grief and bereavement.

- Regular assessments of shifting care needs can ensure that assistive devices and additional supports are available as illnesses progress and needs for more assistance increase. Advocating for these assessments regularly ensures that patient safety and quality of life are prioritized and that families have the supports they need to support the autonomy of the patient as much as possible.

- Support in accessing varying financial supports through provincial health insurance coverage, employee health insurance, or other government assistance to reimburse costs for assistive devices. Support may be required in submitting the required documentation for compassionate caregiving benefits or medical or family caregiving leaves. Further support and information may be required in accessing legal supports for advanced care directives, wills, power of attorneys etc.

- Community supports – for family members to access additional supports which may be illness specific (such as cancer support groups, or programs for people living with or caring for people living with particular illnesses (such as the Parkinson’s Society, or Alzheimer Society) as well as supports that are non-illness related, such as community
health centres, community recreation centres, faith communities. Further ensuring that families have access to mental health supports, crisis-lines and counselling centers can provide families with resources ahead of time, and can ensure that resources are available in the case of an emergency.

- On-line information and supports – for family members to access additional support and information that are available on-line for family members living with advanced illness and end of life, or for people who are supporting loved ones. In addition there are a number of websites that assist families in creating social network pages to keep extended family and friends updated around daily or weekly updates, as well as legacy based websites that offer families and friends the ability to post photos, and other inspirational messages.

For adults daughters who are losing or have lost their mothers

While it’s clear that adult daughters who are losing their mothers, or have lost their mothers have particular concerns and issues, there are relatively few interventions that focus specifically on the experience of daughters and loss. One example within the literature which does address daughters’ experience of loss is an educational workshop that was designed by three social workers who had lost their mothers. Catherine Foote, Mary Valentich and Leslie Gavel (1996), in experiencing the illnesses and deaths of their mothers, realized as they:

> talked of the meaning of our mothers’ lives and deaths to us…that most of our family members sought closure in the conversations. We, however, yearned to keep our mothers alive, if only as central characters in our stories. We wanted to keep talking and believed we might not be alone. (Foote, Valentich, & Gavel, 1996, p. 148)

Drawing on the value and support that came from talking together about their shared experiences of illness and loss, Foote and her colleagues created a two hour educational workshop entitled, ‘When Mothers of Adult Daughters Die’. Initially offered at a feminist helping professional conference, the workshop has since been offered within varying social work courses. The workshop addresses a) the societal context of grieving, b) an understanding of mother and daughter relationships, and c) central dynamics of mother loss. Daughters who participated in the workshop felt that the workshop was very important for them, to both connect them with the
significance of their own grief and loss as a daughter, as well as to connect them with other daughters who are also in the process of losing, or have already lost their mothers.

2.3.4 Contributions and Limitations of Relational Cultural Theory to Understanding Mothers and Daughters at the End of Life

Relational cultural theory encourages us to situate the experience of end of life within relationships and within social cultural contexts. Focusing on the mother and daughter relationship over time allows us to ensure that the life history/life course informing mother/daughter relationships is recognized as a critical element of experiences of dying and grief. Emphasizing how connection and disconnection have been experienced between mothers and daughters, also offers a way to understand how mothers and daughters have navigated challenges, conflict and distance. These elements become important factors in supporting mothers and daughters to navigate the differences and challenges that are happening in end of life. Relational cultural theory encourages widening our frame to a broader context of grief and loss, and it offers a way to honour the experiences of mothers and daughters as a unique and special relationship between women that is different from other relationships, and that unfolds in a social, cultural and political context with specific implications for women. While there are many benefits, relational cultural theory also has limitations. While a relational perspective offers insights about how women in relationship experience illness, a relational perspective on its own is not sufficient. Specifically in examining women’s experiences in end of life, it is essential that stages of illness, psychosocial types of illness, and family life-cycles are also woven into relational approaches, or these elements of experience may be simplified or ignored. Further, it is essential that ideas about women, and mothers and daughters and what they need are recognized as emerging within their own cultural context, and as such need to be reviewed and examined for inherent biases and assumptions that may be operating within these contexts.

2.4 Summary and Conclusions

In summary, it is apparent in reviewing each of these theoretical approaches, that each approach offers an important contribution in furthering our understanding about how families, and specifically mothers and daughters experience end of life. As Neimeyer, Prigerson and Davies (2002) notes:
Grief as a human experience is both a natural and constructed event. On one hand, core features of our response to loss reflect our evolution as biological and social beings, rooted in the disruption of attachment bonds required for our very survival. On the other hand, we respond to bereavement at symbolic as well as biological levels, imputing significance to the symptoms of separation that we experience as well as the changes in personal and collective identity that accompany the death of a member of the family or broader community. (p 235)

Life course and developmental psychosocial stages focus our attention on how end of life experiences are situated across the larger life course trajectory, and while many studies may focus on the particular needs and concerns at end of life, these needs to be understood as interwoven within a broader life trajectory. Age-related stages of development focus our attention on particular needs that may arise for people who are dying that are connected to their particular age and stage, and how these stages and their related challenges and tasks may also inform the concerns that arise at end of life. Stress and coping theories, which dominate most of the literature available on family experiences end of life offer an important overview of the extensive and inherent challenges that arise for individuals and family caregivers in end of life. It is absolutely imperative that these challenges are recognized and supported and that end of life care is recognized as a particularly stressful time for both people who are dying, and their family caregivers. For people who are dying, there are a number of supports that can be put in place to support them as they address the varying stages and tasks that come in end of life. Most important within these supports is to ensure that these practices are led by the needs of the person who is dying, and are guided by a person’s understanding of their needs at this time of their life. For family caregivers, while there are a number of interventions that exist that have focused on supporting them around their knowledge and support needs during end of life, it is important that these programs are evaluated so that there is an understanding of how these programs support family caregivers at this time in their lives. Relational cultural theory, while not reflected in most of the literature with families in end of life, offers a critical entry to examine how family members, relationally experience end of life. Drawing on the centrality of relationships and culture, we can then examine how relational images, and relational competence, relational resilience and relational awareness inform the experiences of mothers and daughters in end of
life. Further, thinking critically about the relational and sociocultural elements of end of life, push us to broader understandings of illness, a good death, respect and dignity.

While each of the three approaches reviewed above offers a distinctive entry and understanding of how families experience end of life, there is also overlap across these approaches as each approach centrally works to address how people in end of life experience and make meaning at this time in their lives. The strength in drawing on all three approaches is how together they collectively address the many different and competing needs and issues that arise for individuals and families at this time of their life.

Regardless of where a social worker practices, it is likely that their practice will be touched by end of life, loss and bereavement. For social workers working with people receiving end of life care, Monroe (2010) notes that the, “core social work task concerns the social and psychological health of the patient, family, friends, and carers, before and after death” (p. 185). Each of the theoretical approaches reviewed above inform a number of core social work tasks and practices related to assessment and intervention. In assessment, life course theory and psychosocial stages of development strongly inform an assessment approach that situates the experience of end of life within a larger life trajectory, wherein the current experience of end of life is one transition, across a lengthy trajectory. Further, family life cycle approaches inform an assessment practice that examines how the family has moved across developmental stages, and how the psychosocial tasks connected with each family stage have been met both individually and collectively within the family. Understanding how individuals and families have responded to the stressor of end of life, and how the stages or tasks of dying have been, or have not been addressed by individuals who are dying offers important insights for assessment and possible future interventions. Drawing specifically on the Family Illness Model (Rolland, 1987, 2005), social workers can examine: how each family is experiencing psychosocial types of illness and disability (i.e. onset, course, expected outcome etc.); major developmental phases in their natural history, such as the stage of illness, and what the particular needs and concerns may be for terminal care; and finally the key family system variables such as multigenerational history, and health beliefs that may be important for assessing needs, as well as mapping out areas of focus for practice in the future. Weaving relational cultural theory into social work practice in end of life, ensures an entry into practice that acknowledges and understands that women as mothers and daughters have particular needs and concerns in end of life that are specific and unique to
who they are as women, and as women who have been in relationship with one another across their lives. Further, addressing the broader relational and social cultural context of how women experience end of life within specific families, relationships, cultures, religions and social contexts, ensures that the meaning and experience of death and dying is considered as living and dying within and across these domains.

In the study that is presented in the following chapters, I call attention to how the specifics of womanhood and women in relationship influence the experience of end of life. Specifically, my focus is on how mothers and daughters navigate the boundaries of their lives, as they live within multiple roles, identities, and contexts. Understanding these boundaries offers room for a woman living with an illness to speak to how she feels about requiring physically intimate care and receiving it from caregivers who may include her daughter; as well as make space for a daughter’s concern about her roles as a daughter, woman and ‘mother’ as she cares for her mother. Within this shared ‘motherwork’ and ‘daughterwork’ space, mothers and daughters can define for themselves their lives as women, their individual and collective relationships to illness, their individual and collective wants and needs for living and dying, and how they both want to be remembered. Lastly, I am interested in hearing whether mothers and daughters have felt that larger institutional (i.e. social, cultural, historical, and medical) stories inform or weigh in on their own experiences, and how they have responded to or countered these stories with their own experiences.
Chapter 3: Design and Methods

Within this chapter I begin by addressing the epistemological tenets and assumptions that inform the methodology and methods of my study. Drawing on the importance of distinguishing between epistemology, methodology and methods (See Carter & Little, 2007; Crouch & McKenzie, 2006; Harding, 1987; Sprague, 2005), I address how a feminist epistemology provides a foundation for my work, and how this informs both the narrative methodology that I draw on, as well as the specifics of how and why I utilize dyadic interviews as my method. Further I address how my own social location as a feminist, palliative care researcher and social worker also informs the epistemology, methodology and methods of this study. Building on the growing recognition of the value of life review, narrative and legacy building practices for patients in end of life (Ando et al., 2007; Chochinov, 2012; Chochinov et al., 2011; Jenko, Gonzalez, & Seymour, 2007; Keall et al., 2011), this research design works to bridge research and practice by offering participants an opportunity to leave the study with a recording as a form of ‘legacy’ that may offer further support as mothers and daughters approach end of life and bereavement.

This chapter also addresses the following components of methodology:

- I address some of the ethical issues and concerns that I believe need to be attended to throughout the course of any study in end of life care;

- I speak to the two primary sites of palliative and end of life care practice where I recruited the ten participants that participated in my study.

- I review my sampling procedures and I specifically address the theoretical, biographical, and methodological rationale for including five dyads, which includes four mothers and four biological daughters, and one mother [in-law] and one daughter [in-law]. Herein I purposely work to both respect how family roles and relationships differ across family contexts, while also complicating and pushing at the boundaries of how women define and create their own understandings of who they are in relationship to one another.

- I review the specific procedures that surrounded recruitment and data collection for the study; and
• I address how I analyzed my data, specifically how I made decisions about how to work with Catherine Riessman’s narrative thematic analysis and narrative dialogic/performance analysis (Riessman, 1993, 2008) and how I addressed criteria for trustworthiness and ethical validation.

3.1 Distinguishing between Epistemology, Methodology and Method

While the term *methods* is often used as an overarching term to describe everything that a researcher has done to conduct her study, it is important for researchers to take the time to differentiate between the epistemology, the methodology, and the method(s) informing their study (Carter & Little, 2007; Crouch & McKenzie, 2006; Harding, 1987; Sprague, 2005). Below I address what each of these “fundamental concepts” (Carter & Little, 2007 p. 1319) includes within my study, and most importantly, how these concepts work together to inform the overall design of my study. Guided by Carter & Little (2007), I have integrated and slightly modified their flowchart as a way of demonstrating and applying how each of these concepts have been applied within my study. See Figure 6. Overview of Epistemology, Methodology and Methods for a visual overview of the elements informing this study.

*Figure 6. Overview of Epistemology, Methodology and Methods (adapted from Carter & Little, 2007)*
3.1.1 Feminist Epistemology

The word epistemology, derived from the Greek word *episteme* meaning to know, and *logos* to account or explain, focuses our attention on the science or theory of knowledge and what this knowledge means (Chia & Rasche, 2010; Flyvbjerg, 2001). In thinking specifically about mothers and daughters and end of life care, a number of different and seemingly disparate theories and forms of knowledge seem to arise which speak to: mothers and daughters; death and dying; and specifically mothers who are dying and their adult daughters. On one end are strongly embedded biomedical and scientific understandings which objectively position the experience of death and dying within medical contexts, and locate death and dying within a specific physical, ailing body. On the other end are feminist theories and understandings which position women’s knowing as located within women’s bodies; situated within and across women’s roles and relationships; and embedded within and across the multiple contexts in which women live and die. Here the experience of dying and death, like other stages of life, are part of the life course that all women will experience. In between these two more dominant landscapes are less explored terrain, of how women as mothers and daughters navigate advanced illness, and how mothers and daughters relationally experience end of life.

While the term *feminist epistemology* speaks to a range of perspectives, assumptions and knowledge claims (i.e. Belenky et al., 1986; Brooks, 2007; Butler & Scott, 1992; West & Zimmerman, 2002), common is an examination of how gender informs and influences what is considered, understood and valued as knowledge. Most centrally, feminist epistemology is focused on “a situated knower, and hence of situated knowledge: knowledge that reflects the particular perspectives of the subject” (Anderson, 2012, p. 2). Situated knowledge as Anderson notes, is embodied, personal, emotional, relational and gendered (Anderson, 2012, p. 2-7). Sandra Harding (1987) argues the importance of thinking critically about the answers that might arise in answering the following three epistemological questions. Below I walk through each of these questions with a specific focus on what each of these questions and answers builds in our understanding of how mothers and daughters experience palliative and end of life care.

1. Within the context of palliative and end of life care, “**who can be a knower (can women?)** (Harding, 1987, p 3).
Thinking critically about who is authorized to be a knower, and who is not, offers important insights about who is allowed and authorized to know in a certain situation, and conversely who is silenced and marginalized. Further we widen our understanding of who is and who is not allowed to be a knower by asking questions such as not only Can women know?, but Can women as mothers and/or daughters know?; What would it mean if the knowledge of mothers and daughters was integrated into our understandings of death and dying?; and finally, How can this knowing help other mothers and daughters? These questions highlight the importance of listening to women’s knowing, of recognizing the multiple roles and relationships that women live within, and of privileging this knowing, particularly at a time in their lives when women’s voices may be becoming softer, slower and more difficult to understand. In ensuring that all women’s voices are heard, we legitimate and privilege women as knowers until the end of their lives.

2. Within the context of palliative and end of life care, “what tests beliefs must pass in order to be legitimated as knowledge (p. 3).

Thinking critically about what tests exist, both explicitly and implicitly, to validate and legitimize what can be known, is imperative if we are to understand not only what parts of women’s experiences are considered legitimate and relevant, but to whom and in what contexts. Further, questions arise such as: Does personal experience of dying legitimize a mother’s knowing – to herself, to her family, to her care providers?; Does a daughter’s personal experience of watching her mother die legitimize her knowing – to herself, to her family, to her mothers’ care providers?; and finally Are some beliefs more legitimate than others, and if so, how or why? These questions emphasize not only how knowledge is tested or evaluated, but also how this knowing is positioned in relationship to others, and how and why in some contexts and relationships certain knowing is considered true, valid and legitimate, while in others it is evaluated as false, partial, and worst still, irrelevant in the treatment and care in end of life.

3. Within the context of palliative and end of life care, “what kinds of things can be known (can “subjective truths” count as knowledge?) (p. 3).

Lastly, and perhaps most importantly, are questions around what kinds of things can be known, and how this knowing counts in our understanding of how mothers and daughters
experience end of life. Is our focus on empirical truths only, knowing that can be seen, pointed at, and shown evidence of? Can personal, subjective, embodied, sacred and spiritual truths, also count as knowledge? Expanding our understanding of what can be known through multiple forms of knowing, can create space for mothers and daughters to share and teach us about the aspects of death and dying that are highly emotional, intuitive, partial and often difficult and/or impossible to fully verbalize to others.

Given the relative absence of literature which addresses women’s experiences of end of life, and further still the absolute dearth of literature which addresses women’s relational experiences of end of life, this study focuses specifically on how women experience end of life as mothers, as daughters, and as women in relationship. A feminist epistemology privileges the knowing that lives between mothers and daughters, while ensuring that this knowing is located and situated within the wide range of contexts within which women live. Focusing on how mothers and daughters understand and experience the end stage of life, and how they collectively co-construct meaning, offers important insights about how the experience of living, and living while dying, is experienced relationally between women. A feminist epistemology also provides a way to bridge between the personal and the political, as personal experiences are situated within a wide range of social and political discourses about motherhood and daughterhood, advanced illness, death and dying, and care practices.

3.1.2 Social Location of the Researcher

Feminist epistemology also emphasizes the importance of researchers both reflecting on, and acknowledging to others, how their own social location informs not only the trajectory that has unfolded in moving towards a specific area of study, but also how their social location shapes their knowing, and how these elements inform the research questions, methodology, methods and analysis (Lather, 1991; Nielsen, 1990; Olesen, 2011). I begin therefore by speaking to my location as a social worker and palliative care researcher, and I then move to how I have come to my specific work with mothers and daughters in end of life.

While my academic background is firmly positioned in social work, both through my undergraduate degree and my graduate degree in social work, I have often felt like my trajectory through social work has been one that has been situated between and across some of the disciplinary divides that exist between clinical social work with individuals, families and groups
and community, policy, planning and organizations. Having initially practiced social work within community based settings in mental health, and then in communities developed to support adults living with a range of developmental abilities and mental health needs, my social work praxis has seemed to reflect a melding of clinical social work, with broader community and planning initiatives, as I worked on community needs assessments, community economic development projects, and community based research.

After I completed my graduate degree, I worked for three years with an interprofessional research team, focused on the ethical, legal and social implications unfolding in genetic testing for breast, ovarian and colon cancer. Within this research team I developed strong research skills and learned an enormous amount about how research unfolds; how research networks and partnerships sustain research; and ultimately how research can and should inform clinical practice. It was through this research experience that I decided to reconnect with my social work background and training and start my PhD. As I began my PhD I was also really privileged to begin working with a newly formed community based research group that was focused on working with women who were living with breast cancer, who were often marginalized in mainstream breast cancer research. It was through this research team, and specifically my work on a study focused on young women living with breast cancer, that my particular interest in working with mothers with advanced illness and their daughters really began to develop. As part of this research team I travelled across Canada and ran focus groups with young women diagnosed with breast cancer. We defined young women, as women who were under the age of forty-five at the time of diagnosis; seventy young women participated. Focus groups were designed to connect with specific sub-groups of young women: women who did not have children; women who were not partnered; women with young children; and women with adolescent children. This research study (Gould, Grassau, Manthorne, Gray, & Fitch, 2006) was particularly formative for me, and influenced why and how my doctoral work focuses on mothers and daughters and end of life. As I travelled across Canada, three themes stood out for me and continue to inform my current research:

First, the women I met made it clear that their experiences of cancer were completely interwoven into the relationships that surrounded them. Stories of diagnosis and treatment were woven into their love/concerns for their partners, their children, and their own and their families future. Second was an understanding that women who were mothers had particular concerns
about their daughters. Some of this concern was connected to genetics, a worry about passing on genetic mutations, or possible risk factors. Much of the concern revolved around how young daughters had shifted into significant caregiving roles, which while welcomed by some mothers, was also worrisome as mothers saw how their daughters focused on their needs and not their own. At the time of the focus group, many of the mothers were three years post diagnosis. For many of these mothers it was notable how many of their daughters had only recently begun to share poems/songs/stories that expressed the depth of their daughters’ fears. This showed mothers how all of their family had been touched by cancer and it also showed them how the experience of cancer lived on in these relationships well after diagnosis, treatment and into their present day. Third was how the experience of living with advanced or recurrent disease is isolating precisely because it is the part of living with cancer that (at least in North America), socially, culturally we work to ignore - the fact that cancer ends lives. Living this reality, living with advanced disease is terrifying for women who receive this news, but it is also terrifying for other women who have had earlier stage diagnoses, and are now trying to trust in a future that will remain cancer free. As I ran each focus group, this awareness, watching as women met each other, and seeing the subtle ways that women with advanced disease were living a separated, marginalized experience stayed with me. These women were living with an experience that does not get represented in our everyday lives, a place where the collective drive to conquer cancer is too late, as women are already dying of this disease. These three elements: 1) How the experience of illness was embedded in family relationships, 2) The particular concern that mothers had for their daughters and what their illness meant for their daughters, and 3) How research and practice tended to neglect the experiences of dying and death led me to focus my doctoral research on how mothers and daughters navigate the cathexis at the end of life.

For the past four and a half years I have been working in palliative care education and research. Within a research manager position, I work on education and research projects with medical and allied health learners, and I also work on research projects with patients and families on the palliative care unit. My doctoral work has been strongly informed by my experiences on the palliative care unit, as I have met and continue to meet mother and daughters who are relationally experiencing end of life.

‘Cathexis’ is a concept that I discovered in my exploration of the mothering literature. Adrienne Rich specifically addressed how the mother-daughter relationship had its own specific
energy/flow, and how this relationship can be caught within the interplay of personal, individual, social, cultural, and historical narratives. My own experiences of mothering and daughtering have never really fit into any of dominant stories that circulate and represent the relationships between mothers and daughters. “From June Cleaver to Murphy Brown, television has obviously had a powerful impact on how maternal roles are valued and played out” (Abbey, 2003, p. 7). My identity as someone who was adopted complicates my understanding of biology, identity, and family. My identity as a daughter to my mother, the mother who adopted me and raised me, and who is now widowed and living with many different chronic health concerns, informs some of my understanding of daughtering - but there are other parts of who I am, as a feminist, as a queer woman that further complicate what daughtering means to me. This is further textured by my experience of meeting my birth mother and two half-siblings over seven years ago, wherein I experienced mothering and daughtering in a way that made me reconsider my position on nurture versus nature understandings of identity, relationships and sense of place in the world. Here I found healing and connection and sadly more loss, when my birth mother died suddenly over a year and a half ago. As I have met more mothers and daughters, I discovered that the dominant storyline of mothers and daughters, which I knew was definitely not mine, turned out not be a lot of women’s experiences.

3.2 Narrative Methodology

While there are a number of different methods and procedures one might draw on to access how mothers and daughters experience end of life, I was motivated to find a methodology which could embrace feminist, relational understandings of care, dying, and bereavement. Given the absence of literature which addresses both mothers and daughters experience of end of life, I was compelled to find a methodology which offered a way to hold a situated, relational, and complex understanding of end of life. Feeling drawn towards Bruner’s (1984) distinction between “life as lived (reality), life as experienced (experience), and life as told (expression)” (Bruner, 1984, p. 7; 1986), I was interested in finding a qualitative strategy which worked to explore how mothers and daughters experienced end of life together (relational experience), how they talked together about these experiences (relational, narrative expression), and how mothers and daughters accessed their shared lived experience (relational, narrative reality) while mothers were receiving palliative and end of life care.
Narrative methodology, is conceptually and methodologically informed by a number of different disciplines; sociologists from the University of Chicago in the 1930s and 1940s drew on life history as a form of case study (Denzin, 1970p. 219); psychologists have made links between life narratives and the early work of Sigmund Freud and his psychoanalytic analysis of individual case studies (Atkinson, 1998), and in anthropology, the collection of life histories and life stories is tied to folklore and early ethnographic work (Atkinson, 2001). Drawing on basic tenets of biography (e.g. Roberts, 2002; Smith, 1994), life history (e.g. Cole & Knowles, 2001; Hagemaster, 1992); ethnography (e.g. Hammersley & Atkinson, 1995, 2007; Van Maanen, 1988, 2011); and oral history (e.g Leavy, 2011; Plummer, 1994), narrative methodology examines how individuals narrate and contextualize their life experiences through stories and narratives (Berg, 2004; Berg & Lune, 2011; Clandinin & Connelly, 1994; Creswell, 1998, 2013; Tuchman, 2005).

Catherine Riessman (1990, 1993, 2008) addresses what stories and narratives do and why people tell stories. Drawing specifically on difficult times (e.g. divorce, infertility, chronic illness), Riessman argues that narratives are particularly important for people who are experiencing difficult times or disruptions. “Telling stories about difficult times in our lives creates order and contains emotions, allowing a search for meaning, and enabling connection with others” (Riessman, 2008, p. 10). Narrative within this context offers a way to both create order and facilitate meaning-making, while also offering a mechanism for connection with others. In one-on-one narrative interviews, connection with others is facilitated through the telling of one’s narrative, as the person shares their narrative with an interviewer or researcher. Further still the researcher may give the narrative back to the participant in a text or audio-based format and the narrative could then be shared more broadly with others in the participant’s life. The narrative told then moves more broadly as these narratives are shared with others, either through the text or through presentations and publications. Joan Didion a prolific writer who has written extensively about narrative, loss and experience relays that “we tell stories in order to live” (Didion, 2006, p. 185). Perhaps we could also say that we tell stories in order to die, and for those of us left behind, such as Didion and four of the five daughters that participated in this study, we also tell stories in order to continue on living after the loss of a loved one. I believe as a result that drawing on a narrative methodology which seeks narrative and stories to build understanding and meaning-making, is the most appropriate choice for my study as it offers me a way of centrally holding a feminist epistemic viewpoint, while furthering our understanding
about death, dying and end of life. As text and audio based narratives can often be important for participants after they have participated in a narrative interview, and as there is evidence that this is also important in end of life practices, I have integrated this into my study, as a form of legacy that mothers and daughter can have after the interviews are completed.

3.3 Method – Dyadic interviews

Drawing on narrative methodology, I was guided to find a method which would allow me to access shared, relational accounts and narratives between mothers and daughters. *Dyadic or Joint interviews* are defined as interviews where two or more participants are interviewed at the same time (Arksey, 1996; Morgan, Ataie, Carder, & Hoffman, 2013; Sakellariou, Boniface, & Brown, 2013; Seymour, Dix, & Eardley, 1995). Within this study, I use the term dyadic interviews. Used predominantly within research studies with couples or other family relationships, dyadic interviews offer the opportunity to hear relational accounts between participants, while also offering the ability to see the interaction that unfolds as these accounts are shared (Bjornholt & Farstad, 2014; Seymour et al., 1995). When used within couple and family research studies, dyadic/joint interviews are noted as offering ethical advantages, as partners or family members may prefer to be interviewed together, and being interviewed together ensures that the interviewing process does not raise concerns about potential or possible conversations raised in confidence during one-on-one interviews (Bjornholt & Farstad, 2014; Seymour et al., 1995). Further still, it is argued that richer and fuller accounts are shared within dyadic interviews, as missing elements can be filled in, if one person is unable to fully recount a particular experience or event (Arksey, 1996; Bjornholt & Farstad, 2014; Seymour et al., 1995). Although there are important differences between dyadic interviews and focus groups, such as participant numbers and pre-existing relationships, many of the strengths inherent in focus groups also operate within dyadic/joint interviews (Morgan et al., 2013). Drawing on his extensive background in focus groups, David Morgan, reflects on how the central elements of *sharing* and *comparing* found within his work with focus groups (Morgan, 1996, 2012) also extend to dyadic interviews,

Sharing allows each participant to extend what the other has said, and comparing involves a process of differentiation that moves the discussion in alternative directions. Taken together, sharing and comparing allow researchers to hear interesting similarities and differences in what the participants think…This process of sharing and comparing
also occurs in dyadic interviews, as the participants respond to each other. Thus, what focus groups and dyadic interviews have in common is not just the broader equivalence of relying on interaction but also the specific processes that make this interaction of interest to researchers. (Morgan et al., 2013, p. 1277)

Further still, as part of the sharing that unfolds within focus groups and dyadic interviews, there is the potential to access what Sue Wilkinson (1998) argues is one of the most important elements of drawing on focus groups with people who are living with illness, and that is to access how participants understand and make meaning of their experiences (Wilkinson, 1998). Specifically, Wilkinson outlines how central tenets of group conversations can support and encourage interviewees to talk about topics that are difficult; to talk about the issues that are most important to them; and to take the time they need to really talk about their experiences (Wilkinson, 1998, p. 334-338).

Of particular interest within Wilkinson’s work is her focus on what she refers to as “co-construction of meaning” in action (Wilkinson, 1998, p. 338). Specifically, Wilkinson focuses on how people make meaning about their experiences, with and in relation to others. “Critically, then, focus groups offer an opportunity for researchers to observe how people interactively construct the meanings attributed to health and illness: how opinions are formed, expressed, defended and (sometimes) modified within the context of discussion and debate with others” (Wilkinson, 1998, p. 338). Drawing on dyadic interviews with mothers and daughters enriches our understanding about the “co-construction of meaning” of not only mothering and daughtering practices, but also death and dying; and how mothers and daughters make meaning as they experience end of life. Lastly, there are strong practice implications for drawing on dyadic interviews with mothers and daughters in end of life care. Adult daughters are frequently at their mothers’ bedsides as their mothers are receiving end of life care. Furthering our understanding of how mothers and daughters relationally experience end of life can offer important insights about how mothers and daughters can be supported together as they approach the end of life.

There are of course, also disadvantages of using dyadic interviews, and these elements do need to be addressed. Most problematic, is the possibility that one voice within the dyadic
interview overshadows, overpowers or worse still, silences the voice of the other participant (Arksey, 1996; Seymour et al., 1995). Compassionate, clear and direct research interviewing skills are critical in being sensitive and attentive to how dialogue is shared, how verbal and non-verbal expression may be informing or constraining conversation, and attending to how both voices share the conversational space between them. In the privileging of the relational narrative, individual elements which might further explain or contextualize participants’ thoughts and actions may be left outside of the relational narrative. Similarly, another disadvantage is that certain conversations and discussions may not be raised within the dyadic interview, as one or both of the participants may not feel comfortable or able to talk about these issues collectively. While this element importantly raises that not all issues and concerns will be raised within a dyadic/joint interview, the focus of this study is on furthering understanding of how relational knowing informs experiences, thereby respectfully recognizing that there may be many aspects of end of life which are not raised within these discussions.

Feminist epistemology also informs how I draw on dyadic interviews as my method, as it is important that I utilize these methods in a way that is guided and evaluated by feminist principles. As Carter & Little (2007) suggest, this means centrally acknowledging how relationships are built between myself as the researcher and the participants. Most critically for me throughout the course of the study was the importance of building genuine, compassionate connections with each mother and daughter that I met. While I met each mother and daughter under the formality of conducting a study, my focus across the course of the study, was on making sure that the needs of each mother and daughter were respected and prioritized over the research outcomes. This meant taking the time to really listen to women, to witness and hear about their lives, and to fully hear and support how they were experiencing and making meaning of this time in their lives. Recognizing my own knowing as subjective and situated, this also meant as a feminist researcher, that across the study that I acknowledged my role, identity and relationship with each mother, daughter, and mother and daughter and how this also informed and shaped the data and the findings. Critical to the study then, was adapting a number of mechanisms to ensure that my findings were as trustworthy and credible as they could be (See Trustworthiness and Ethical Validation Section 3.11 below).
3.3.1 The Dyadic Interview Guide

The focus within this study was on developing situated, relational understandings of how mothers and daughters experience end of life. The interview guide was informed by many of the key principles guiding relational cultural theory and feminist research (i.e. mutuality, relationality, reciprocity), and the focus of the interviews/conversations was on understanding how mother and daughter relationships had shifted across time. Asking mothers and daughters to share stories about their relationship across four points in time (e.g. early stories, later stories, stories of illness, present stories), created space for the contexts surrounding mothers and daughters to come to the surface and allowed the history of the mother and daughter relationship to arise. As mothers and daughters talked about different stages of their relationship, a wide range of stories emerged, together with more complex understandings of how relationships shifted and changed over time. Understanding how mother and daughter relationships have shifted and changed over time also ensured that present day experiences were situated within the relational and historical context of their relationship and their lives. Narrative research with people living with illness often begins the narrative at the onset of illness (e.g. Frank, 2002; Kleinman, 1988; Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010). While these illness narratives provide a deep and rich understanding of illness, I believe that starting with illness misses critical elements about participants’ lives that inform and transform how people experience illness. Specific elements of the interview process and questions are presented in section 3.9.

3.4 Should research happen in palliative and end of life care?

Prior to moving into the settings that were involved within my study, it seems important to address the broader context of what it means to be conducting research within palliative and end of life care. Most central is the question of whether one should do research with patients and families in end of life care. This question raises important ethical and philosophical questions of the intent of research, and how researchers justify and account for the goals of research, with patients and families living with a terminal illness. The majority of research conducted in palliative and end of life care works to address larger clinical and biomedical questions, such as pain, symptom management (e.g. nausea, constipation, fatigue), treatments, and practices, and draws on methodologies which involve large samples and experimental and/or randomized
clinical trials (e.g. Grond, Zech, Diefenbach, & Bischoff, 1994; Higginson et al., 2003; Steinhauser et al., 2000). Within most of these studies, the specific patient and family context is not under study, and in fact the intent of these studies is to de-contextualize the experience, such that all patients and families are essentially the same. While the findings of many of these studies will not extend the life of the research participants, and one could reasonably question the likelihood that there will be any improvements in their quality of care, the most common rationales for this research concern the advancement of knowledge and supporting the greater good. Ethical concerns which are raised within clinical and biomedical studies tend to focus less on the research goals or questions, and more on issues of consent, risks, benefits, and anonymity or confidentiality. As Koenig, Back and Crawley (2003) suggest, it is somewhat ironic how institutional review boards consider the ethics of research with patients who are dying (and their family members):

Phase I drug studies, for example, have the intention of evaluating the maximal safe and tolerable dose of a new compound. It is generally terminally-ill patients who have failed all previous therapies who are invited to participate in these trials…This same group of patients—those for whom no cure is likely—are at the same time deemed by some Institutional Review Boards to be in need of special “protection” from researchers whose goal is to improve the quality of dying. (p. S46)

Clearly reflected within these radically different assessments of risks and benefits for research participants is an understanding of how ethics of beneficence (benefit others) or nonmaleficence (do no harm) shift according to study type or study focus, and how these differences inform how decisions are made within the research ethics board.

In contrast are qualitative studies built on epistemological understandings which believe that researchers can only come to know the experience of end of life if they engage directly with patients and families who are living with a life-limiting illness. Researchers focus on building relationships so that the researcher, patient, and family can work together to understand more fully how each patient and family member experiences end of life. A wide range of qualitative paradigms and their methods are available (e.g. narrative, ethnography, phenomenology) which directly situate patients and families within their specific life experiences and contexts. There is a growing literature base within palliative and end of life which draws on strong qualitative
designs (e.g. Donorfio & Sheehan, 2001; Gardner, 2008; Read & Wuest, 2007), which have worked to witness and support patients and families while also furthering our understanding of how patients and their families experience end of life. Similar to larger clinically-based quantitative research, most qualitative researchers narrow their discussions about ethics to patient recruitment, voluntary consent, and how confidentiality will be upheld throughout the study. Missing within quantitative and qualitative studies in end of life are deeper concerns about how ethics lives within and across studies that are focused on people who are currently experiencing end of life. Louise de Raeve (1994) strongly argues that qualitative researchers in end of life, need to attend directly to how power, relationships, vulnerability, choice, and benefit are woven throughout their studies in end of life. de Raeve’s questions are challenging and call for continual re-examination of the intent of research, the process, supports, and extent of the relationships and supports that one can provide in a research study, and ultimately how one justifies doing research with patients and families in end of life (de Raeve, p. 304). Many of de Raeve’s concerns followed me throughout the course of my study and informed my decision to think critically about “relational integrity” (Wright & Flemons, 2002, p. 267) as an ethical practice within my study.

Relational Integrity as Ethical Practice

Wright and Flemons (2002) writing about their research with patients in end of life, propose a concept called relational integrity, as a way of ensuring that integrity is addressed across all research relationships, within a research study. Relational integrity is reflected:

In our interactions with each other and our colleagues, with our research participants, and with our data – gathering it, textualizing it, going into it (analyzing), and going beyond it (extrapolating) – we hold relationships to be inviolable. That is, we make sure we don’t impose ourselves on the person or thing with whom or which we are in relationship (a colleague, an informant, the data, an idea), and, recognizing that what we report in our research is the story of our participation in the project. (p. 267)

Within their description of relational integrity, Wright and Flemons touch on a number of important relational elements, both conceptually and methodologically. The use of the word ‘imposing’ suggests some kind of force, whether through size, power, or position, that is being used on something or someone else to change or transform it. Here Wright and Flemons speak
not only about how they consciously focus on not imposing on other people, but also about how they are mindful of not imposing themselves on the data, on an idea. Relational integrity then becomes a relational process which is actualized within relationships, including the relationships we have with the data we collect, with the ideas that emerge, and the findings that accumulate. Lastly, Wright and Flemons stress that when they report their findings, this report or ‘story,’ as they call it, reflects their full participation as relational beings with their informants/participants, with each other, and with the data. The use of the word ‘participation’ is an important one, as it centrally acknowledges that what we present in our findings is our experience of participating in the study. Their findings are not distant, objective measures, nor are they direct representations of others' experiences, but rather our own understanding of what we have learned, developed, and created by participating in the research. I move forward then with relational integrity as something which will flow across and through my research design, as both an epistemological and conceptual foundation, as well as an ethical and methodological guide.

3.5 Settings

Within this study I originally designed my study to recruit mothers and daughters from one site, an in-patient palliative care unit (PCU). Shortly after beginning my study, the in-patient care unit modified its admission criteria, so that patients, who would have normally been admitted to the PCU, were instead being triaged to other sites. The rationale behind this shift was that the in-patient palliative care unit, which has a highly specialized interprofessional care team, could focus on patients with particularly advanced and complex end of life care needs. As a result of this shift in admission criteria, a large percentage of the patients that were admitted while I was recruiting, did not meet my initial inclusion criteria. As I approached the end of my third month of data collection, I decided in concert with my committee to expand my data collection to two palliative care programs that were institutionally affiliated. In the end, the women that I recruited were in either the In-Patient Palliative Care Unit (PCU), or were receiving home based palliative care, via the Palliative Care Consultation Service (PCCS).

3.5.1 In-patient Palliative Care Unit (PCU)

The in-patient Palliative Care Unit (PCU) site for this study is a large (31 bed) unit affiliated with a university research hospital in a mid-sized Canadian city, which offers a range of end of life care for patients and families living with advanced disease. Approximately 550 patients
come to the PCU annually, and the median length of stay is 16 days. An increasing number of patients come to the PCU for pain and symptom management and are discharged for home-based end of life care when patient symptoms are under control.

Data collection on the PCU for this study occurred over four and a half months (March 29th – August 10th 2013). As institutional patient level statistics are collected quarterly (Q2-April 1st to June 30th 2013, and Q3 - July 1st to September 30th 2013), data presented below will be compiled for these quarters. Between April 1st and September 30th 2013 there were 251 new patients (including readmissions) admitted to the Palliative Care Unit (Q-2=121 pts, Q-3=130 pts). The majority of admissions to the PCU during these two quarters, 181 patients (72.1%) were from acute care hospitals, while patients admitted from home, 66 patients (26.2%) reflected just over a quarter of the admissions. Other admissions to the PCU included one patient (0.04 %) from long term care, and 3 patients (1.1%) admitted from ‘other’ institutional designations. Other as an institutional designation is used to speak to admissions from retirement homes, complex care units etc. The average length of stay on the PCU was just over twenty days (20.6 days), and the median length of stay was 12 days. Across these two quarters, approximately 79.8% of the patients died on the PCU, while 11.7% were discharged to other complex care and end of life care sites, 6.8% were discharged home, and 2.4% were discharged to acute care sites.

3.5.2 Palliative Care Consultation Service (PCCS)

Outpatient data collection took place within a palliative care consultation service offered to family physicians and their patients and families, to provide home/residential based palliative and end of life care.

There were 196 new patient referrals to the palliative outpatient service between July 1st and September 30th 2013. Of these referrals, 68 (34.6%) were from hospitals, 15 (7.6%) from Long-Term Care, 42 (21.4%) from primary care physicians, 42 (20.9%) from Community Care Access Centres /Community Nursing, 10 (5.1%) from Academic Family Health Teams, 15 (7.6%) from residential homes and 5 (2.5%) from hospices. Of the 196 patients referred, 62% had cancer diagnoses and 38% had non-cancer diagnoses. Further, within this time-frame there were 199 bedside visits and 1,363 telephone consultations and case management calls (Medical Chief, 2014).
3.6 Sampling & Participants

“Sample size depends on what you want to know, the purpose of the inquiry, what's at stake, what will be useful, what will have credibility, and what can be done with available time and resources.” (Patton, 1990, p. 184).

Guided by a feminist epistemology and narrative methodology, the purpose of this inquiry is to explore and further our understanding about how mothers and daughters relationally experience end of life. The study design was focused on building a rich and thick understanding of how each mother and daughter experiences and makes meaning of this time of their lives, and what these experiences teach us conceptually about the relational experience of end of life. As such, “the work of linking interview accounts – continually analysed – and conceptual frameworks – under construction throughout the research – clearly requires small sample sizes so that all the emerging material can be kept in the researcher’s mind as a totality under investigation at all stages of the research” (Crouch & McKenzie, 2006, p. 495).

According to Luborsky and Rubinstein (1995), one way of structuring sampling in qualitative studies is to think about “sampling for meaning” (p. 101). Sampling for meaning has four primary elements that need to be addressed within the sampling design. Below I address each of the four elements of sampling for meaning (Luborsky & Rubinstein, 1995), with a specific focus on what sampling for meaning would mean within my own study. The first element speaks to context and meaning, which means focusing on both the context of where and how mothers and daughters were receiving palliative and end of life care, but also the meaning that this context has on how mothers and daughters talk about their lives. The second element speaks to the individuals being interviewed and how they may be working to understand, contextualize and integrate their experiences. As patients and families are in end of life, there may be a particular focus on some meanings more than others, and there may be attention on revising or modifying some meanings, before someone dies. The third element attends to the process of being part of an interview, and how mothers and daughters may not have thought about, or interpreted some aspects of their experience before the interview, and therefore their understandings and interpretations emerge in relation to the interviewing process (Luborsky & Rubinstein, 1995, p. 101). Lastly, the fourth element speaks to how meaning and understanding that arises within the interview, links participants’ personal knowing with community and
broader social cultural forms of understanding. Sampling within this context accesses a wide range of meaning and knowing regardless of how many participants participated in the study.

With sampling for meaning in mind, I used a convenience sample, where my focus was on gathering together a sample of mothers and daughters that could support an in-depth relational examination of how mothers and daughters experience end of life. As there were no specific guidelines for sample size with this type of design, I initially decided to seek out eight mother-daughter dyads. Drawing on eight mother and daughter dyads, with multiple meetings and at least one-to-two recorded relational interviews for each dyad, seemed capable of providing sufficient opportunity to draw on multiple interview points of data to offer a thick, rich, and detailed account of how mothers and daughters experience end of life. As will be noted below, I was not in the end able to recruit eight mother and daughter dyads, and ultimately had a sample size of five mother and daughter dyads. The broader context and rationale of drawing on a sample of five mother and daughter dyads (including on mother in-law and daughter in-law pairing) will be discussed below.

**Inclusion Criteria**

For those mothers who were receiving care on the PCU, it was important that they were given time to transition onto the PCU before being screened to participate in this study. Transitioning into the PCU can mean a tremendous amount of change for patients and family members as they acclimatize to new spaces, care team, and routines. The study design required that mothers needed to have been on the PCU for a minimum of three days before they were asked if they would like to hear about the study. This also gave time for the patient’s health status to become clearer. A small number of patients who are admitted to the PCU are imminently dying, and this excluded them from the study (see Exclusion Criteria below). Mothers who were recruited from PCCS were receiving palliative care at home and therefore transition time was not required. Similar health status screening applied for mothers from the PCCS to ensure that mothers were able to participate. Both mothers and daughters needed to be able to communicate in English, and both needed to be able to read and understand the consent form and provide informed consent.

*Inclusion criteria in relation to mother [in-law] and daughter [in-law] pairing*
The study was designed to include a mother receiving palliative and end of life care and her adult daughter. Mothers were defined as women who parented their daughters from a young age and this included daughters who were biologically related, daughters who were adopted, as well as daughters who were woven into their lives through other life-partnerships and connections. As one dyad includes a mother [in-law] and daughter [in-law], it is important to share the rationale for why this dyad conceptually fits within the overall design of this study. Below, I draw on a rationale that is informed theoretically, biographically and methodologically.

- **Theoretically**: Feminist and relational cultural theory (O'Reilly, 2004; Okin, 1989; Satz, 2013), speaks to the importance of women defining for themselves who is part of their family. Expanding beyond biology and heteronormative understandings of the nuclear family, feminist theorists and clinicians have focused on the importance of women defining for themselves who is part of their family and of recognizing family forms that extend to adoptive, lesbian, blended, and polygamous families (Arnup, 1995; Park, 2013).

- **Biographically**: For four of the five dyads, the biographies of the two women had been intertwined since the birth of the daughter. For the fifth dyad, there was an extended life history connection which began when the daughter [in-law] was a teenager and has extended over the past forty years. The specific context of how this particular mother [in-law] and daughter [in-law] came together, when the daughter [in-law] was an adolescent, and the fact that early on in this relationship the daughter [in-law] was involved in caregiving with the mother [in-law], means that this relationship had been developing over the past forty years. At the time of the interview it was clearly noted that the mother [in-law] and daughters [in-law] saw one another as ‘daughter’ and ‘mother’. In relation to feminist, developmental tasks, this mother [in-law] and daughter [in-law] have relationally moved through a number of developmental life stages together, building their own understanding of mothering and daughtering for themselves (Deanow, 2011).

- **Methodologically**: As this study focused on hearing narratives between one mother and one daughter (and not multiple daughters), there were four families where the mother and daughter needed to choose which daughter participated in the study. This process of ‘choosing’ – meant that there were ‘other’ daughters within the same family units that were left outside the scope of the study. It was important for me that the mothers and daughters that I met had the ability to choose who participated. This felt like one way of
ensuring that the role of ‘mother and daughter’ was constructed by each family, and not based on more traditional understandings of caregiving which focus on proximity to the patient and/or number of hours providing care. For one family, the daughter who participated in the study was chosen by the mother. In this case, the daughter that participated was not the daughter that lived locally and provided most of the day-to-day care for her mother. For the second family, the daughter that participated was the daughter that was the most actively involved in her mothers’ care, and the other daughters were estranged from their mother. Within the third family, the daughter that participated in the study was the daughter that happened to be present on the day of recruitment, as she and her sister shared the responsibility of being with their mother while she was on the palliative care unit. Within the fourth family, the daughter that participated in the study was the daughter that was actively involved in overseeing her mothers’ care, and the other daughter was less ‘close’ due to some family conflicts around the estate. In the fifth family, the daughter [in-law] and mother [in-law] chose to participate together and I respected their self-identification as a mother/daughter dyad. While respecting this choice by the participants and its demonstration of their relationship, I also recognized the importance of analyzing their contributions with awareness that there may be particular concerns and issues that arise with mothers-in-law and daughters-in-law that are quite different from daughters that were born into or raised with their mothers.

Exclusion Criteria

The following potential participants were excluded from the study: mother and daughter dyads where one member did not want to participate; mothers and daughters who were not able to communicate in English and/or not able to understand the consent form and provide informed consent; and mothers and daughters who were too ill to participate in the study. As energy levels and health symptoms/situations can shift rather quickly at end of life, there was a focus on having the series of interviews happen within a short window of time. While the intent of the study was not to have anyone participate who was imminently dying, it was possible that health status might shift during the study, and a mother could become too ill to participate. As the focus of the study is on relational understandings of end of life, it was imperative that the primary interview involved both mothers and daughters. If the mothers’ health shifted after the
first interview, I consulted with the daughter to assess the daughter’s interest/ability to continue to participate on her own for the remainder of the study. These conversations prioritized the needs/wishes of the mother/daughter dyad over the needs of the research study.

As data collection progressed, it became apparent that recruiting mother-daughter dyads able and willing to participate in the study was an arduous task (details of this process are presented in sections 3.7 and 3.9). As I participated in the interviews, I came to realize that my sampling for this study was less driven by the need for a specific number of cases/people, and more by the need to sample “states arising within a field of a particular set of circumstances” (Crouch & McIntyre, p. 493). Within this study I was interested in studying the specific states and experiences arising for mothers and daughters as they were dealing with end of life together. Therefore, determinations about the sufficiency of my sample were based on the depth and the breadth of the “cases”, and not on the number of dyads that I interviewed. My committee and I eventually decided to stop recruitment after completing interviews with five dyads. Acknowledging that the decision to stop recruitment at this point reflected some pragmatic concerns about the time available for data collection, I am also clear that it was based on my analysis of the data as it was collected, and my certainty that my data was sufficiently rich and of sufficient depth and breadth to attend meaningfully to the research questions of the study.

3.7 Recruitment Procedures

All research projects on the PCU and PCCS must be reviewed and approved by the institution’s Research Ethics Board, as well as the affiliated university’s Research Ethics Board. At the PCU site, to address ethical concerns about coercion and patient autonomy, the Division of Palliative Medicine at the affiliated university has created a template for how patients and family members on the PCU can be recruited into a research study. A researcher is not allowed to directly approach a patient and/or family member about a research study. Instead an intermediary step has been created, whereby a care team member asks patients and family members if they are interested to hear (or not) about a possible research study happening on the PCU. Institutionally it was decided (and approved by the related Research Ethics Boards) that one care team member, an advanced practice nurse, could ask the patient and family member whether they would be interested in hearing about a study on ‘mothers and daughters.’ If the patient or family member said ‘yes,’ I followed up to describe the specifics of the study. If the patient or family member
declined to participate, the conversation about the study with the patient ended and no other mention of the study was made to the patient or family member.

**Mothers and Daughters who met my inclusion criteria**

**In-Patient Palliative Care Unit:**

**Screening of Interest by the Advanced Practice Nurse N= 12**

In the four and a half months of data collection on the Palliative Care Unit, twelve mothers were considered eligible to participate. Of the twelve mothers who met the eligibility criteria, eight relayed that they would be interested in hearing more about the study and four declined. Reasons for declining were noted as: two mothers and daughters together said they were not interested; one mother noted on her own that she was about to be discharged and did not want to participate as a result, and one mother noted on her own that she was too fatigued to participate. *Figure 7* below reflects how screening of interest and recruitment unfolded in the Palliative Care Unit.

**In-Palliative Care Unit**

*Figure 7. Recruitment on the In-Patient Palliative Care Unit*
Palliative Care Consultation Service

In the three weeks that I collected data within the Palliative Care Consultation Service, three mothers met my eligibility criteria, and all three noted that they would be interested in hearing about my study. *Figure 8* below reflects how screening of interest and recruitment unfolded in the Palliative Care Consultation Service.

**Screening of Interest by the Palliative Care Consultation Service: N=3**

*Figure 8*. Recruitment in Palliative Care Consultation Service

**Mothers/Daughters who agreed to hear more about my study**

**Palliative Care Unit**

Of the eight mothers/daughters who said that they were interested in hearing more about my study, four agreed to fully participate in my study. Of the four mothers/daughters that declined to participate, two mothers/daughters declined to participate at the initial meeting, and two mothers/daughters initially agreed to participate, and then after further conversations declined before moving into the interview. Of the two mothers and daughters that declined at the initial
meeting, one mother declined as she was leaving the PCU rather hastily against physician orders, and one declined as the daughter felt that she was not really a caregiver\textsuperscript{10} and therefore the study was not applicable to her and her mother. The other two mothers and daughters who initially agreed to participate and then declined, provided a number of important insights about how mothers and daughters may perceive research studies with mothers and daughters and end of life. Field notes taken from these conversations will be drawn on later in the dissertation.

**Palliative Care Consultation Service**

Of the three mother/daughters that said they wanted to hear more about the study, one mother and daughter did not meet my inclusion criteria as the mother was not able to verbally communicate. The other two mothers and daughters agreed to participate, but only one mother/daughter dyad was able to fully participate in the interview. The second mother and daughter provided consent but decided to withdraw at the time of the interview as the mother found talking too challenging/fatiguing due to nerve pain on her neck, the site of her cancer.

### 3.8 Mother/Daughter Participants

**Palliative Care Unit & Palliative Care Consultation Service**

Of the five mother/daughter dyads: three of the mothers (Ruth, Mary, Marian) were receiving in-patient palliative care on the palliative care unit. The fourth mother (Carrie) was receiving residence based palliative care consultation services. The fifth mother [in-law] (Diana) was receiving in-patient palliative care on the palliative care unit. Table 6, *Participant Overview* provides a participant overview and general demographics of each of the mother and daughter dyads that participated.

\textsuperscript{10} This mother and daughter were told that this study was not specifically on caregiving between mothers and daughters, but rather the focus was on mother and daughter relationships more generally.
### Table 6

**Participant Overview**

<table>
<thead>
<tr>
<th>Dyad</th>
<th>Age of Mother</th>
<th>Age of Daughter</th>
<th>Diagnosis</th>
<th>Days on PCU/# of consultation visits</th>
<th>Mother/Daughter living situation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>In-Patient Palliative Care Unit</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ruth &amp; Sarah</td>
<td>85-94</td>
<td>55-64</td>
<td>Myelodysplasia</td>
<td>64-70 days (10 weeks)</td>
<td>Daughter lives in a different city than the mother</td>
</tr>
<tr>
<td>Mary &amp; Amelié</td>
<td>85-94</td>
<td>45-54</td>
<td>Metastatic head and neck cancer</td>
<td>15-21 days (3 weeks)</td>
<td>Mother and daughter lived together prior to move onto the PCU</td>
</tr>
<tr>
<td>Marian &amp; Pam</td>
<td>65-74</td>
<td>35-44</td>
<td>Parotid gland tumor, Metastatic bone and lung cancer</td>
<td>8-14 days (2 weeks)</td>
<td>Daughter lives in the same city</td>
</tr>
<tr>
<td><strong>Palliative Care Consultation Service (Home/Residence based care)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carrie &amp; Elisabeth</td>
<td>75-84</td>
<td>55-64</td>
<td>Polymyositis</td>
<td>PCCS was initiated on Jan 31st, 2013 and was extended for five consultations which extended across seven months.</td>
<td>Daughter lives in the same city</td>
</tr>
<tr>
<td><strong>In-Patient Palliative Care Unit</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diana &amp; Susan</td>
<td>75-84</td>
<td>55-64</td>
<td>Bradycardia, heart disease</td>
<td>15-21 days (3 weeks)</td>
<td>Daughter-in law lives in the same city</td>
</tr>
</tbody>
</table>
3.9 Data Collection

Field Notes

Field notes were taken throughout the full study. These notes include a wide range of elements, including an account of the varying conversations that took place with each mother/daughter dyad, as well as notes and reflections both before and after each recorded interview. While on the PCU, I spent my time both observing and gathering information about who might be a possible candidate for my study, as well as initiating and building rapport with possible participants. Approximately 60 field notes of varying lengths were taken over the four and a half month window of data collection. My field notes focused on capturing and reflecting on connections with: a) staff on the PCU that arose during conversations about patient eligibility and study screening, and b) possible study participants after they offered initial assent to hear more about the study. While not considered part of the participant data accrued, the questions and concerns raised by possible study participants who declined to participate after hearing about the study offered a number of important and critical insights about how mothers and daughters both collectively and individually think about and experience palliative care and research.

Field notes were also taken in cases where I continued to have connection with the mothers and daughters after the interviews were completed, the transcripts returned and thank-you notes given. Due to both my own feminist, relational sensitivity of building and sustaining relationships, and the context of uncertainty and relational vulnerability that exists during end of life, I felt it was important to be available for continued connection and conversation with mothers and their daughters while the mothers were on the Palliative Care Unit. For the two mothers on the PCU who were discharged home, this meant regular visits with the mothers and/or daughters before the mother left the PCU. For the two mothers who participated in the study and died on the PCU, this meant expressing openness to continuing and sustaining connection with both the mothers and daughters beyond the interview aspects of the study. Field notes were taken during this time to document my reflections and thoughts about my own connections and conversations with each mother and daughter dyad, and my own experience of relational shifts with both the mothers and daughters, when the mothers’ health shifted to a point where the mothers appeared non-responsive and ultimately died.
In the Palliative Care Consultation Service (PCCS) site, my field notes documented conversations that I had with the care team going into the patient homes, as well as my phone conversations with possible mother/daughter participants. Field notes were also taken both before and after the interviews with the mother/daughter dyad living in the community.

**Interviewing Schedule**

Two to three meetings were planned with each Mother/Daughter dyad. If the energy/strength of the mother/daughter dyad was limited, Meeting 1 and Meeting 2 were combined. If patient and family member availability/ability was limited, all three meetings happened within a brief time period (the briefest interval for all interviews to be completed was three days). *Figure 9* provides an overview of the interviews.

![Figure 9](image)

**Figure 9. Overview of Interviews**

**Pre-Interview** – Meeting to talk about the study, review the consent form, provide a general introduction to the study and build rapport with mothers and daughters. This stage of the
interview was absolutely critical as it set the tone for how the interviews and discussions would unfold, and how mothers and daughters were witnessed and heard throughout the study. This interview was also foundational in that it marked the beginning of the relationship that was being built between me and the mothers and daughters interviewed. This stage also acknowledged and supported the everyday aspects of how mothers and daughters were currently feeling physically, emotionally, and spiritually. Attending to non-verbal cues around fatigue, fluctuating pain levels, and distress were paramount, as I wanted to ensure that interviews were not extending mothers and daughters beyond their consent and/or their capacity.

Meeting 1

The interview guide that I used for the first interview utilized four primary guideposts which framed the primary purpose that guides this study.

**Rapport Building Questions:** The first set of questions in the conversation/interview focused on building rapport between me and the mothers and daughters. This focused on asking mothers and daughters to tell me about why they both agreed to participate, who they are as mothers and daughters, and what elements are central for me to know about them as mothers and daughters.

**Contextualizing the Mother-Daughter Relationship:** This was comprised of a loosely constructed timeline, where mothers and daughters were asked to share early stories, later stories, and illness stories that reflected their relationship over time. In focus was a sense of how mother and daughter relationships shifted over time, and how mothers and daughters navigated these shifts both individually and relationally. The constructed timeline was drawn from a review of the theoretical and empirical literature.

**Present Day:** This section asked mothers and daughters to talk about their experiences in the present, to share what they thought this time (end of life) might be like, and how it might be similar or dissimilar from what they think other mothers and daughters might experience at end of life.

**Looking Ahead:** This section moved the conversation to looking ahead and explored what mothers and daughters hoped for one another and what learning they would like to pass on to each other.
Meeting 2

The second interview further explored the conversations that were raised in the first meeting and worked to deepen my understanding of the context of each mother and daughter relationship. Further we talked about any other concerns that mothers and daughters might have had about the future. Lastly, we talked about mothers and daughters overall thoughts on participating in the interview.

3.10 Data Analysis Procedures

My work aligns with a feminist perspective (Charmaz, 2004; Lather, 1991; Olesen, 2011) whereby the objective of analyzing the relational data is not to move towards a unified truthful account of mothers and daughters, but rather to explore the complexity of mother and daughter dyads as they experience end of life. Interwoven with this perspective is the acknowledgement that as the researcher I am part of the analysis, and the importance of attending to my own reactions, thoughts and experiences throughout all phases of the study. A project field journal was kept from the outset of the study to document the process/my analytical thinking as I moved through the project (Padgett, 1998). This also ensured a rigorous audit trail.

Analysis of the qualitative data began while the data was being collected (Creswell, 1998, 2013; Miles & Huberman, 1994). Textual transcribed interview data were imported and analyzed in NVivo 10 (Bazeley, 2007; Morse & Richards, 2002; Richards & Richards, 1994). Narrative analysis, “refers to a family of methods for interpreting texts that have in common a storied form” (Riessman, 2008, p. 11). Catherine Riessman (2008) breaks down narrative analysis into four analytic methods: 1) thematic analysis, 2) structural analysis, 3) dialogic/performance analysis, and 4) visual narrative analysis. Each analytic method focuses on different elements of narrative and as such answers different research questions and results in different narrative outcomes. My study draws on both a narrative thematic analysis as well as a narrative dialogic/performance analysis.

Narrative thematic analysis focuses on the specific content of what participants say within an interview (Riessman, 2008, p. 54). While the parameters of a narrative or story in thematic analysis can vary, within this study I organized the relational stories across a life-course...
perspective that draws on the four time-periods that were used within the interview guide: 1) when the daughter was young, 2) when the daughter was an adolescent/young adult, 3) when illness arrived, and 4) present day. Further, relational stories that were shared about the future were also thematically analyzed. Each of the mother and daughter dyads were coded separately, so that the stories for each mother and daughter could be examined both within each mother and daughter dyad, as well as across each of the chronological time-periods. Analytically I worked with Riessman’s (2008) thematic narrative analysis exemplar where she drew on the research of Gareth Williams and his narrative work with people who had been diagnosed with rheumatoid arthritis (Williams, 1984). My analytic steps consisted of:

1. Reading the interviews multiple times and creating a map/outline for how each interview unfolded
2. I began reading and re-reading the transcripts to identify what was happening thematically within each narrative, and the “underlying assumptions”(Riessman, 2008, p. 57) that seemed to be informing the narrative around mothering/daughtering practices; care practices; illness practices; life lessons. I then began coding the narrative stories to capture these elements, and other themes that emerged in and across the narratives.
3. After coding each transcript, I created a table to outline on multiple levels of detail, what the central elements were that were arising within each dyad, and within each time period.
4. I mapped out overall relational practices and processes that were operating within each dyad, and how and in what ways these elements were reflected across mother and daughter dyads.
   a. In the interest of ensuring that differences between the mother [in-law] and daughter [in-law] dyad were respected and attended to, I coded this dyad separately and delayed integrating this dyad into the overarching table, until I had completed the process for each of the other dyads.

Narrative Dialogic/Performance, works to examine how dialogue between participants in a dyadic interview is created relationally, and how narratives and stories are performed (Riessman, 2008). While different parts of narrative and story can be drawn on within
dialogic/performance analysis, the narratives selected for this analytic approach were narratives which addressed specific aspects of end of life. This decision was guided by my research questions and the importance of accessing relational understanding and meaning-making between mothers and daughters of end of life. Guided by Riessman’s (2008) dialogic/performance exemplar with a study that she conducted with a man living with advanced multiple sclerosis (Riessman, 2004); as well as Lyn Mikel Brown’s study with preadolescent girls (Brown, 1998) my analytic steps included:

1. Reviewing each mother and daughter dyad for narratives related to end of life and extracting each oral narrative and modifying it according to linguistic features (direct speech, asides, repetition, expressive sounds, verb tense performativity).
2. Separating narratives into specific time periods and noting (where possible) final codas.
3. Identifying how and where the dialogue touches on the broader context of family, community and social cultural context with respect to motherhood/daughterhood, death/dying
4. Outlining how and in what ways the broader contexts are being performed within each narrative and how these may be similar or different from narratives performed within other mother and daughter dyads.
5. Weaving myself in as a ‘co-narrator’ within the narratives and considering how my own role/identity as a social worker, palliative care researcher, daughter are reflected within the narrative performances.

Memos, annotations and field notes were used extensively to document non-verbal and contextual factors which also helped to illuminate how various elements of the text related to one another within each dyad, as well as across mother/daughter dyads (Miles & Huberman, 1994; Montgomery & Bailey, 2007).

3.1.1 Trustworthiness and Ethical Validation

While differences continue to circulate within the broader field of qualitative research about how and/or whether truth(s) can be captured within qualitative research, and whether there can or should be fixed criteria to normatively assess the quality of all qualitative research, there continue to be elements of trustworthiness that are regarded as important in assessing the worth
and value of qualitative research. Yvonne Lincoln and Egon Guba (1985), defined trustworthiness as, “How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention, worth taking account of? What arguments can be mounted, what criteria invoked, what questions asked, what would be persuasive on this issue?” (Lincoln & Guba, 1985, p. 290). Further Lincoln & Guba (1985), addressed how the worth and trustworthiness of qualitative research can be evaluated, through four different forms of evaluative criteria. Below I address how my study actively draws on three of these criteria: credibility, transferability and confirmability.

Credibility speaks to the confidence and believability in how closely the findings of a study correspond with, or resonate with the meaning and experiences that have been shared by the participants. Credibility can be established through particular activities and actions by the researcher such as “prolonged engagement (which) is the investment of sufficient time to achieve certain purposes: learning the “culture,” testing for information introduced by distortions of the self or of the respondents, and building trust” (Lincoln & Guba, 1985, p. 301). My decision to recruit mothers and daughters from the Palliative Care Unit (PCU), and later on in my recruitment, from the Palliative Care Consultation Service (PCCS) was strongly informed by the fact that these were contexts and/or program sites where I was familiar with the practices and process within each care site and/or I was closely connected with the medical care providers within each program. Having worked as a research associate in palliative and end of life care for the past four years, I had worked closely with many of the palliative care physicians on the PCU and in the PCCS. Throughout this work I had met a number of the medical, nursing and allied health care providers, as well as the palliative care management team. This said, I am sure that most of my significant connections and relationships were really developed the year before I began my doctoral study, as I had been recruiting patients and families on the PCU, in a qualitative, arts-based study about patients’ and family members’ experiences of care. Through this study, I was often engaging with patients, families and care providers, and it was during this time that I felt my role shift from being recognized as a known outsider, to a recognized member of the care team. This insider (emic) (Headland, 1990) status seemed to be built through building trust and engaging in authentic connections with varying care providers, patients and families, as well as through the experience of being connected and involved as patients became more ill and ultimately died on the PCU.
As building rapport and trust with mothers and daughters was very important for the epistemology, methodology and methods guiding my study, I had planned that that I would meet each mother and daughter at least once before beginning our first recorded interview. My actual experience of these meetings was such that I often met with mothers or daughters multiple times, before we had our first recorded interview. These meetings while not recorded, offered important forms of connection and dialogue and prolonged my connection with each mother and daughter both well beyond, and often after, the one to two recorded interviews that took place with each mother and daughter dyad. As I was aware that I was engaging in building a new relationship/connection with mothers and daughters at a time in their lives of often great flux, uncertainty and vulnerability, I felt it was important that if mothers and/or daughters wanted to stay in touch with me beyond the scope of the study, that I was able to sustain this connection. All mothers and daughters were given my contact information at both the initial meeting and again when they were given their legacy folder. For mothers and daughters who were on the PCU beyond the scope of the study, I checked-in regularly with them while they were on the PCU to offer further connection and support if this was something that they desired or required.

Having the experience of being on the PCU and working with care providers, and mothers and daughters on the PCU and/or the PCCS for a prolonged time, also strongly informed how I drew on “persistent observation” (Lincoln & Guba, 1985, p. 304), as a technique to further establish credibility. “The purpose of persistent observation is to identify those characteristics that are most relevant to the problem or issue being pursued and focusing on them in detail. If prolonged engagement provides scope, persistent observation provides depth” (Lincoln & Guba, 1985, p. 304). Through persistent observation I was able to focus my attention on not only all of the relational connections that I was involved in with mothers and daughters, but I was able to fine-tune my focus on observing how interactions shifted in different contexts, across different times of the day, with varying care providers, and in moments of relative ease, as well as moments of crisis or great suffering. Further to establishing credibility I drew on “peer debriefing” (Lincoln & Guba, 1985, p. 308), as I shared my methodological and analytic process with my supervisor and varying committee members. This offered me the ability to explore the believability and confidence that my findings relayed to audiences that were both familiar and less familiar with palliative and end of life care settings and practices. At two different stages of my analysis I brought together a wider group of colleagues (physicians, nurses, social workers,
chaplains, and bereavement/loss clinicians), as well as members of a local storytelling who work with people receiving hospice care, to read my initial narratives and early findings and to engage with early versions of my discussion chapter. This wider group of colleagues offered an additional level of confidence in my findings as clinicians reflected on how my findings resonated within their own clinical practice, and further how my findings resonated with their own experiences of losing, or having lost their mother.

Within this study I was not able to draw on member-checking as a way of furthering credibility. As I was interviewing each mother and daughter at a period in their lives when the mothers’ illness was quite advanced, I felt that the burden of reviewing findings would be too great for mothers’ whose health status was precarious, and/or daughters who were newly grieving the loss of their mothers. A similar decision to not do member-checking or return findings has been documented in the literature by other researchers working with participants whose health status is poor or potentially unknown at the time of the availability of the study findings (Koch & Harrington, 1998).

Transferability, the second criteria outlined for evaluating trustworthiness, examines how findings can be applied or fit within and across other contexts and draws on “thick description” (Geertz, 1973; Lincoln & Guba, 1985; Muecke, 1994). “Thick description analytically explores, compares, and contrasts diverse perspectives and sources of information in the corpus of field data. It tests links and adjusts inferences to form a coherent interpretation that engenders understanding of differences” (Muecke, 1994, p. 196). Throughout my study I took extensive field notes, which worked to describe my thoughts, feelings and behaviours.

Confirmability, speaks to an audit trail mechanism which highlights how the research unfolded (Lincoln & Guba, 1985; Morse, 1994; Padgett, 2008). “Careful documentation of the conceptual development of the project should leave an adequate amount of evidence that interested parties can reconstruct the process by which the investigators reached their conclusion” (Morse, 1994, p 230). Drawing on Padgett’s (2008) recommendation, within this study I kept a project journal which included “raw data as well as memos noting decisions made during data collection, coding, and analysis” (Padgett, 2008, p. 191). Further my field notes included my analytic thinking as I worked through what was unfolding within my interviews with each mother and daughter dyad. This project journal, along with the audit trail that is
captured and developed within NVivo 10 (QSR International Pty Ltd., 2012), offers an extensive overview of how the study unfolded.

Finally, I also think it is important to draw on Maureen Angen’s (2000) argument of examining ethical validation. Angen positions validation as a process that continually unfolds within and across a study and she argues that, “all scientific endeavors should contribute to our ability to carry on in an ethical way…with its aim of more fully understanding the meanings involved in our everyday existence” (Angen, 2000, p. 387). Ensuring that studies have an ethical component whereby research is evaluated on its ability to further our understanding and practice in the world seems to be a critical component of both feminist and social work research. In addition, ensuring that researchers are prepared in their research to “provide some practical answers to the so-what question” (Angen, 2000, p. 388), ensures that research findings are presented in a way that they can be integrated into not only further research, but also into practice. What are the practical questions of this work – how does a relational understanding invite new understandings and actions, and how might our assessment of quality of studies shift, if we were, “to evaluate the ability of a research study to transform our actions” (Angen, 2000). Strategies for ensuring ethical validation were woven through my process of data collection and sharing the work with others, as I have been deliberate in linking the research to the context of practice with families at end of life. This will be addressed in detail in the discussion chapter.
Chapter 4: Findings

Drawing on the centrality of narrative and storytelling within this study, I have chosen a narrative style and approach to address my study findings. The first part of my findings begin by addressing who I am: my social location; my a priori connection to the two palliative care sites/practices that were involved within my study; and some of the early observations and decisions that I made as I began my study. My goal within this section, is to offer you - the reader – a way to see who I am, and importantly, to see the parts of me that are relational, that are inviting you to journey with me, as I/We explore how end of life is experienced by mothers who are dying and their adult daughters. The last part of this section provides an overview of the narrative process that I utilized in transcribing and analyzing the narratives that unfolded within the multiple conversations that I had with mothers and daughters. Within this section I address the process that I utilized in determining the textual boundaries (Riessman, 2008, p. 97) of each narrative, and how I specifically worked with what I have conceptualized as relational stories within my analysis. The second part of my findings begins by introducing each of the mother and daughter dyads that participated in this study, followed by my narrative insights and impressions from my first meetings and first interviews with each of these dyads. Within each mother and daughter dyad, I examine how mothering and daughtering is experienced and positioned, and I explore how their relationship has unfolded across a relational continuum: from when the daughter was young; to their present experience of end of life; to their thoughts on the time ahead. In building on what has been learned about each mother and daughter relationship over time, I address two specific end of life relational stories, within each mother and daughter dyad, that speak to core aspects of their experiences as they receive end of life care. As I examine each of these end of life relational stories, I draw on two narrative analytic approaches, thematic analysis and dialogic/performance analysis (Riessman, 1993, 2008). Drawing on thematic analysis, I examine what mothers and daughters shared within each of these relational stories and how this content offers us important insights about the relational experiences of each mother and daughter in end of life. Looking to deepen a focus on relationships and how mothers and daughters perform and produce accounts of mothering and daughtering in end of life, I closely examine one relational story within each mother and daughter dyad with a dialogic/performance approach.
analysis. Highlighting and examining key performance genres\textsuperscript{11} utilized by Catherine Riessman (2008), I then examine how individual, relational and dialogic voices and multiple layers of context emerge within each performance. My analytic approach investigates how each of these analytic approaches offer conceptually and theoretically different understandings, which together offer a more interwoven account of how mothers and daughters relationally experience end of life. After reviewing all five of the mother and daughter dyads, I offer some broad reflections overall, of some of the apparent similarities and differences which arose across the five mothers and daughters dyads, and I particularly attend to any differences that were apparent between the four biological daughters and their mothers, and the one daughter [in-law] and mother [in-law] who also participated.

4.1 Me, You and Narrative Analytic Process

Woven through feminist theory, narrative methodology and dyadic methods, is a strong emphasis on relationship and reflexivity (Carolan, 2003; Mauthner, 2000). I believe that each relationship I am in, is both informed (and constrained), by my ability to be reflexive and to think critically about who I am, and how I use my voice, power, and location. Within this study this means that it is very important that I am reflexive about my own experiences of end of life, and how these experiences have informed this study, either directly through my engagement with each mother and daughter dyad, or indirectly through my analysis and write-up of the findings. Building on my own reflexivity, I invite you as a reader to think about your own stories: of family, of relationships built over time, of being parented and/or parenting, of being mothered and/or mothering. Perhaps images or stories come to mind – of moments when you were a child; stories when you were a young adult; stories from more recent times - stories which may house a wide range of thoughts and emotions of connection, resonance, belonging, and/or stories of disconnection, independence, and absence. Within these same stories I invite you to think about either your real-life experiences, or imagined thoughts of these same relationships shifting as a loved one experiences a decline in health, of frightening diagnoses, prognoses, and uncertainty. Further how things may shift within your relationships with your loved one as their needs

\textsuperscript{11} Performance Genres utilized: direct speech, repetition, asides and expressive sounds/cues. While Catherine Riessman also draws on historical present as a distinct performance genre, this was not apparent/applicable within my own data, so this was not examined within this analysis.
increase for assistance in completing daily living care, and of multiple losses as the person you love loses fundamental parts of who they thought they were. It is within and amongst these multiple layers of stories that my work begins.

This entry into my work is purposeful, guided by a central belief and understanding that to really hear and hold the voices and experiences of others who are in end of life, that we need to be able to hear our own stories – stories of love and connection with a parent that also hold the edges of loss and sorrow if this person is no longer physically sharing one’s world. Stories of holding on as tight as we can to those we love in end of life, while also seeing the need and importance of loosening our grip, for them, and for us. Stories of the unspeakable pain of watching someone you love be confused, anxious or agitated, that also mysteriously seem to hold moments of oasis where there is warmth, connection, and presence. It is all of these stories, your stories, my stories, the stories shared by the five mothers and daughters that participated in this study, that shape this work – encouraging us, daring us, inspiring us to further our understanding of how families experience end of life.

Researcher insights and connection to end of life care practices sites

In chapter three I talked about my connection to social work practice and research, and my specific background in psycho-social research around genetic testing for familial cancer, and my community based work in working with women living with breast cancer, and more recently my research with patients and family members receiving end of life care on a palliative care unit. All of these elements have informed my interest in how mothers and daughters experience end of life. This said, I also have my own personal connection to end of life care, as over the years I have had the experience of witnessing and sharing in the experience of close family members and family as they have received care across a number of different end of life care sites. My earliest connection to end of life care came when I was a teenager as a very close family friend, and mentor of mine, was dying of cancer. Jane, a vibrant, compassionate, enthusiastic lay minister, was someone that I looked up to, and she was a personal confidant of mine as I worked through my own layers of sense of self and identity, in relationship to being adopted. As Jane had her own connection to adoption and family, she helped me build important understandings of my own experience, she trusted me to find my way, and she offered me an important foundation of how relationships can hold connection, disconnection and difference. Jane’s diagnosis and
prognosis confirmed an advanced and progressive form of cancer, and despite treatment, it was evident that Jane was not going to survive. Jane’s gift to those around her was her tremendous capacity to share her experiences genuinely, authentically and relationally throughout this time of her life. As Jane’s health deteriorated and her symptoms became progressively worse, she offered me the ability to continue to see her, and connect with her even when her physical needs and ability to communicate were quite impaired. The last time I saw Jane she was receiving end of life care on a palliative care unit, and our visit was full of tender moments, humour, profound gratefulness, and sadness. Jane died a few months later. After Jane died I replayed the many different conversations and connections that she and I had, both when she was well, as well as when she was ill, and I continue to find strength within these stories, as she risked and I risked with her, to talk candidly about living life without her physical presence in my life.

Since this time I have had a number of close family members and friends move into end of life care, both within hospital intensive care unit settings, as well as within hospice and home-based end of life care settings. As an extended family member I have witnessed the process of end of life through the care practices of an intensive care unit, where the provision of care maneuvers between acute care practices of sustaining life at all costs, coincide with medical assessments and evaluations which determine and account for what artificial life-sustaining treatments should be provided, for how long, and at what point these supports need to be withdrawn. Further, I have respectfully witnessed the process of close family members making the decision to stop life-sustaining supports, and allow a loved one to die. As a friend, I have been honoured to be part of a caregiving circle, where we collectively worked together to provide end of life care at home, so that a friend might die at home with her kids by her side, and not within an institution. As a volunteer, I have worked within a hospice, connecting and engaging with people living with and dying of HIV/AIDS, and now in my work, I am connecting with patients and families on a palliative care unit. On a personal note, the two deaths/losses in my immediate family that have had the most impact, my dad in 2006, and my birth mother in 2012, reflect end of life experiences that were both very sudden, and neither involved end of life care. My dad died of a heart attack in my brother’s home one Sunday afternoon in March, and my birth mother died of a heart attack in the middle of the night in her home, in November. In both of these experiences I was not present when my loved one died, and I heard about their deaths afterwards as each of my siblings called to tell me what had happened. These
experiences, both of which happened during my PhD have been important personal reminders of the variability, uncertainty and presence of grief and loss, and how each of us will have our own stories of how those closest to us have died, and what these losses mean to us.

My own trajectory across end of life care practice sites and grief and loss are important, as these experiences mean that I have my own biases, values and assumptions about how end of life care is (or is not) practiced. While I clearly prioritize care practices that create space for patients and families to focus on what is most important to them in end of life, and I strongly value end of life care practices which are holistic in their approach and ensure patients and families are cared for and treated with compassion, humility and grace, I also know that experiences of end of life are personal, situated and complex. As such, there are no certainties, or predictions of where the best deaths occur, rather my focus has been on trying to ensure that wherever someone dies, that we understand what services and supports need to be in place to support each person and their family at this time of their lives.

As I have a previous connection with both the palliative care physicians, and advanced practice nurses who work across both of the palliative care sites that I utilized for this study, it is important to briefly address this a priori knowledge and how this history informs how my doctoral study unfolded.

Previous history with the Palliative Care Unit (PCU)

For the past four and a half years I have been working in research and education in palliative care in a non-acute care facility and research institute. This work has focused on research projects and education programs with both medical and allied health learners, as well as patients and families on the PCU. In 2011, I was involved in a research project on the PCU, entitled, Engaging Patients and Families about their Experiences of Care (Voices). Drawing on an

12 ‘Engaging Patients and Families about their Experiences of Care’, a qualitative arts-based research study funded by an internal research incentive grant, was conducted on the Palliative Care Unit from 2010-2011. I was a co-investigator on this study and I was actively involved in the data collection as well the lead in the data analysis. (Hall et al., 2012)
arts-based qualitative design, we interviewed patients and families about their experiences of care, and asked them to show us and describe to us, what their experiences of care looked like, and how this wide range of care experiences (i.e. good, poor, bad, fantastic) informed their experiences overall. In this study I was involved in recruitment of patients and families, interviewing and collaborative art-making, as well as leading a team-based collaborative coding approach and analytic framework to analyse the data. While prior to this study I was often on the PCU for varying meetings and educational programs, it was only in actually conducting this patient and family study that I really began to develop a deeper connection to the PCU environment overall, and the many care providers who work on the PCU. Below I will address some of the specifics of the PCU site and my connection with varying care providers, and how this a priori connection helped me conduct my own doctoral study.

Critical learning about the PCU site/environment

Finding one’s way around a specific unit or floor of any medical institution often involves learning and really integrating a number of visual, spatial and physical cues. Perhaps this reflects my own spatial abilities (or perhaps more accurately my lack of spatial abilities), but I find that I need to be on a floor a number of time before I start to feel like the room numbers and wings on a floor have any real concrete meaning. While care providers who have been working on a floor for a number of years can talk about Mrs. B in Wing B, in room 120, I found it was quite some time before I could hear the name of a person, a wing and a room number and know confidently where I needed to go. An important part of learning about the layout of a floor is also learning about how space is used relationally, which spaces are shared spaces, which spaces are private spaces, and further still which spaces are for care staff and not for patients and families. Having a strong understanding of the layout of the space was vitally important in not only finding my way around the space, but also in helping me learn about how care practices unfold across this space, and how the PCU had its own routines and rhythms. These routines reflect everything from when meals are delivered, to when rounds occur, to more tacit understandings of when and how to engage care providers, or further still how to read cues about when family members may be looking for connection, versus other moments when patients and families may want more privacy. While for many research studies this level of knowing may seem beyond the scope or practice of a qualitative narrative methodology, the reality of conducting a study with patients and families in end of life requires that there is a deep respect
and understanding for both the practice of end of life care, and the experience of end of life. Integral to developing strong rapport with care providers and/or patients and families, is an understanding of how sensitive, vulnerable and dynamic end of life care is, and how situations, symptoms and availability can shift on a moment to moment basis. This context means that researchers need to be both flexible and adaptable as there is not the ability, luxury or predictability to know in advance how someone may be feeling later in the same day, much less the following day, or the day after. Interactions with care providers and patients and families revolve around present understandings, with a shared understanding that these understandings shift and change as illnesses progress. From my experience of working on the *Voices* study, I learned the importance of checking-in regularly with care providers and patients and families, and how scheduling interviews often required an ability to work through a number of attempts before finding a window of time that worked for patients and families to participate. While this time, could have been seen as time-consuming and wasted, I found that this time provided a way for me to communicate my respect and understanding for the lived experience of each person, and as such found that when I did sit down with each patient or family member for an interview, that we had already built a connection that allowed the conversation to shift more deeply into how people were feeling. I brought this learning into my doctoral work as well, as I built in extra time so that I would be able to build the relationships that I needed to recruit mothers and daughters to my study.

*Relationship building with the Palliative Care Team on the Palliative Care Unit (PCU) and in the Palliative Care Consultation Service (PCCS)*

Part of really entering into the world of palliative and end of life care, is also about understanding explicit and implicit understandings of membership and team. As a non-clinical team member I had felt prior to conducting the *Voices* study that while I was part of the palliative care research team with most of the physicians, that for many of the care providers on the PCU I was still an outsider. This is not to suggest that I wasn’t welcomed into the space or that individual care providers were not friendly or personable, more I felt that there was an inner interprofessional clinical care team that included a range of care providers (from physicians, nurses, ward clerks, porters, cleaners). My sense was that this inner group shared a particular bond or shared understanding that linked them to the opportunities and privileges that come in providing end of life care, with the challenges and difficulties that also arise in providing this
form of care. In recruiting patients and families for my earlier study, I was on the PCU a lot, and during this time, I felt that my membership as outside of the group shifted, when a nurse asked me to help with something. Part of the sign that I was now part of the group, was the ability of this particular care provider to ask for my help, and as such for our relationship to develop to forms of connection that were reciprocal and shared. This relationship development was such that care providers learned that I could be approached as another team member, and that I was open and interested in who they were and how they were doing. Further it was clear in my work, that I was also deeply concerned about how patients and family members were doing, and that I would extend what I could to support the general care that was provided on the PCU. From my experience on this earlier study, I believe that I was able within my doctoral study, to be much more integrated into the team on the PCU, and as such that I could cross over into provider spaces on PCU (such as the nursing stations, or physician reporting areas), and that my presence was considered respectful and welcome. Further, while I was not part of the Palliative Care Consultation Services (PCCS) prior to my doctoral work, the palliative care physicians that worked on the PCCS team, were physicians that I knew from the PCU and from our larger medical division. In terms of data collection on the PCU, this meant that I knew about patients and family members who might meet my inclusion criteria well in advance, and that there was a lot of support and encouragement for me to recruit patients and families into my study. While this support was tremendously welcomed, I also as a result was even more cautious with patients and families about ensuring that consent to participate was fully voluntary. It was important to me that patients and family members did not agree to participate in my study because of my connection with their palliative care physician, or one of their other care providers. In terms of my data collection through PCCS, this meant that palliative care physicians and advanced practice nurses that were screening patients for eligibility for my study were also well connected with me, and if they had any questions about eligibility they were able to communicate directly with me, and we were able to sort through these questions together.

4.1.2 Early Observations & Decisions

Early on in my data collection there were three elements that I observed that I decided I wanted to attend to throughout the course of this study. The first element addresses how death and dying existed within the PCU site, and how the experience of death and dying is woven into the PCU physical space, into care practices (on the PCU and the PCCS), and into patient and family
narratives. The second element speaks to my intention to focus on verbal and non-verbal forms of care, connection and relationships, as non-verbal connection is often an integral part of end of life care. The third element speaks to my own decision as a feminist social worker and researcher to attend to relationships, and to ensure that if I was opening up and initiating relationships with patients and families in recruitment, that I was also attentive to offering further support, beyond and outside the parameters of the research study. I will describe each of these below.

Death is everywhere and nowhere

As the context of in-patient and home based palliative care is an integral part of the experience of end of life, I spent a great deal of time in my field notes documenting my observations. Within my field notes I worked to document the things that I saw in detail, and I focused on documenting how these things made me feel. I worked as much as possible not to go to the analytic part of my brain around what these things meant, as I wanted to focus more on the parts of narrative methods which are about observing and gathering, rather than immediately interpreting and analyzing. I was in most respects successful at this, although there were moments when I noticed that the analytic part of me was sometimes a rather handy and easily accessible coping strategy. I would find myself in these moments interpreting an event or experience, critiquing why structures were the way they were, or why more support was not available, rather than fully feeling the suffering, the loss, and the grief that permeated particular moments. As these things happened, I tried to capture them as well, as I think these shifts in thinking are tightly woven into how I have learned as a woman to cope, and to distance and protect myself. My own individual coping mechanisms are a response to my own relational beliefs and understandings of how as a feminist social worker I should practice, of how and what I think and believe my capacity with others should be, and how I often prioritize others over myself. I believe these elements are tightly woven into the tacit learning of care providers generally, and while in end of life care there is a growing awareness on the importance of addressing care giver needs, and self-care and compassion fatigue and burn-out, there are still many biases and assumptions when it comes to caregivers admitting that they are not coping well.
In end of life care the experience of death and dying exists in both overt and covert ways. Depending on where people are in the illness and dying trajectory, there may be direct and explicit signs of people who are in the very last stages of their life. These signs may be reflected in how patients are positioned in bed, or in facial features and expressions, or in sounds that can accompany dying such as wet breathing, or what is sometimes referred to as the death rattle. These physical sights and sounds can be particularly difficult to witness, as they are often woven tightly into worries and concerns about pain, and suffering. These signs of death and dying exist in end of life care, at the same time as other signs of life and living are also on display. Sometimes when people come on the PCU they are surprised to see care providers laughing with patients, patients and family members having coffee in the communal kitchen and reading the paper, or children and grandchildren running down the hall. Across this wide range of experience is the experience of end of life – and each person and their family member will experience this trajectory in their own way.

On my first day of data collection on the PCU I had just come onto the floor, and the ritual ‘bell’ rang. This bell, which I suspect sounds slightly different for everyone who hears it, is part of a ritual that has been practiced for the last number of years on the PCU. The bell is rung when the funeral home staff are removing a patient’s body from their room. When the bell rings, all care providers stop what they are doing and stand in the hallway as the funeral home staff push the gurney carrying the covered patient’s body to the elevator to take them to the funeral home. The ritual bell was instituted on the PCU a number of years ago in response to a family complaint about the lack of a formal response when a loved one was removed from the PCU. The bell then marks this transition, for the family and for care providers, and is seen as a way of respectfully acknowledging that we are all part of his larger life trajectory.

Day One of Data Collection

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**Field Note – Day 1**

I am just on the PCU when I hear the bell. The bell chime reminds me of some of the chimes that are used to mark transitions in meditative ‘sits.’ Chimes in this sense are markers to come back, invitations to transition from a meditative internal space to the physical room I’m in, the cushion I’m sitting in, the people around me. Here the chime represents a different transition, an ending of a life, a life that was until recently lived on the PCU. As I stop where I am and I lean against the wall I see the black trench coat of the first funeral home staff, his face is somber, serious and he and his colleague are navigating the gurney. The body, the person, the outline of
the person in the body bag is so small; it is as if the body is lost in such a massive bag on top of the gurney. My first instinct is I should know who this is, the name of the person, how it seems wrong to witness this, without knowing at least something about who this is. I look up briefly into the faces of some of the care providers around me in the hallway, and then look away, as if my glances are inappropriate, that I should allow them to have their own personal moment of grief and loss. As all of these thoughts fly through my head, I see a woman about my height, following the gurney. She is older than I am, I don’t know why her age is important, but I register that she is middle age. I wonder if this is my way of…stop analyzing, just write what you saw, what you felt. Her face is wracked in pain, grief, loss. Her face is quite red, her eyes puffy, her pain and her exhaustion are palpable. Other family members follow her, and they head into the elevator. As the elevator doors close, everyone around me begins to move, some quickly, some slowly, and the activities of the PCU resume. For a moment there was a pause, and now everyone is back. There is something about this being Day One of my study that feels important, a reminder somehow, of what this study is about.

I decided after this experience that it would be important for me to closely observe how death and dying manifest on the PCU both directly, such as with the ritual bell, or in witnessing and experiencing the death of mothers who participated in my study, but also to attend to moments and care practices (on the PCU or in patient homes through PCCS), where the experience of death and dying may be more indirect, less explicit, and perhaps even ignored or shielded from view. Attending to the multiple and perhaps conflicting ways that death and dying may exist, offers important insights about the variability within end of life, and how patients and families may be situated within and across different understandings and experiences of end of life, and what death and dying mean.

*Daily living – Engaging with what is verbal and non-verbal*

Recruiting patients who are receiving palliative and end of life care into a research study requires a high level of respect and *care* for how people are living with very advanced illness. This means attending to how illness is lived in an everyday kind of way, as well as how illness is lived within either an in-patient context or in the home with multiple care providers. For each of the mothers and daughters that I met, there were constantly shifting needs and experiences. Intense experiences of ease, energy, joy, and contentment could be followed by experiences of pain, exhaustion, worry, and grief and all reflected where mothers and daughters were at a given point in time. Understanding and ‘journeying’ (Wolfelt, 2003) along with mothers and daughters, involved holding and witnessing raw emotion and profound moments of connection, while also respecting and appreciating the importance of silence, humor, and touch. Within these conversations I felt like I was being invited not only to hear about each mother and daughter
relationship, but I was also being offered the rare opportunity to actively see how mothering and daughtering lives within and between mothers and daughters. Mothering and daughtering were reflected in how they talked to each other, heard each other, looked at each other, touched each other, cried together, and laughed together. Attending to verbal and non-verbal forms of care between mothers and daughters, ensures that women’s way of connecting and relating are prioritized and respected, and that all forms of care are examined as mothers and daughters relate and connect with one another, at this time of their lives.

Building, sustaining and maintaining relationships

As the experience of being on a palliative care unit or receiving palliative care at home can be one where patients and families can feel quite isolated and alone, it was important to me as a feminist researcher, to be mindful and attentive to the relationships that I was building with each mother and daughter. While there is often a lot of emphasis within qualitative research on how to build rapport and trust with participants (Berg & Lune, 2011; Charmaz, 2004; Lather, 1991), I believe that more attention needs to be placed on ensuring that researchers leave these relationships mindfully and respectfully, and that participants do not feel opened and abandoned after the interviewer collects their data. I decided as such that I would be open and attentive to all of the relationships that I built with mothers and daughters throughout this study, and that I would stay engaged and sustain relationships with any of the mothers and daughters (if this was something one or both of them was looking for), whether they participated in my study or not. This decision became more and more relevant as I reflected on how much time I spent connecting with mothers and daughters prior to them either agreeing to participate in the study, or alternatively deciding not to participate in the study. Further for the two mothers that died on the PCU, this also meant that I was available to the daughters, as their mothers’ illness progressed, and as their mothers died. While for one of these families I was not involved with the family outside the scope of the study, for the other family, I was quite involved with the daughter, and after her mother died, she left a note for me, to share her mothers’ final moments before she died.

Narrative analytic approaches
Prior to introducing the mothers and daughters that participated in this study and beginning to examine my narrative findings, it is important to take a moment to further reflect on how stories and narratives unfold within interviews. As noted earlier in my methods chapter, it was very important to me that I was sensitive to really hearing and holding the stories and experiences that each mother and daughter shared about who they were, how their relationship had unfolded over time, and how they were experiencing end of life. Within each interview there were a variety of different story types and forms of narrative and conversation that occurred. Within the actual interviews, my attention was directed to relationally building an understanding of how each mother and daughter talked about their lives, and on following and participating in the flow of how varying stories and experiences were shared within the interview. In shifting into narrative analysis, there is a need to not only understand and be aware of the different styles of storytelling (i.e personal narratives, illness narratives, family storytelling) and the many different forms and types of stories (i.e. classic family stories, story fragments, pre-narratives (Langellier & Peterson, 2004), it is also important for the researcher to decide how these stories are transcribed, and how these different styles and forms will be woven into the analysis. After the audio recordings of each interview were transcribed, I reviewed the transcripts multiple times. It became evident that some of the stories shared between mothers and daughters easily met more commonly accepted understandings of what narratives include; in that the stories offer some form of order (Riessman, 2008), and explanatory sequence (Ochs & Capps, 2001), and are set within a particular time, space and/or location (Horsdal, 2012; Riessman, 2008). These stories, which I conceptualized within this study as relational stories, were stories that mothers and daughters co-constructed together within the interviews. While sometimes these stories were co-constructed in a way that the relational story unfolded in an interwoven and overlapping format between mothers and daughters, other times the relational stories were shared primarily by one of the women, where the other person listened and clarified or built onto the story, as a way of further enriching and texturing the relational understandings and meanings that were located within each relational story. While these stories were told by either a mother or a daughter, the response of the daughter or the mother to the original story, was such that these stories were also ‘relational’, and as such I categorized these stories also as relational stories. Across these relational stories there were often fairly clear boundaries of when the narrative began and when it ended, and I felt as a result that I could confidently articulate and defend my decision-making about what I examined in my narrative analysis, and what I left out. Catherine Riessman argues “there are no
clear rules for determining boundaries, but the analytic decision is important, for it shapes interpretation and illustrates once again how we [as researchers] participate in the construction of the narrative that we analyze” (Riessman, 2008, p. 41).

More difficult were stories and accounts within the transcripts that clearly reflected important meaning and understanding for mothers and daughters, but seemed to be presented less in an narrative or story form, but rather as conversation threads, or relevant pieces or fragments (Riessman, 2008) which while important, did not really align with the more commonly understood parameters of what a narrative should include. Some of the differences in narrative form and structure may have been related to the fact that my interviews included more than one narrative teller, and there were often multiple threads in the conversation, and at some points multiple conversations occurring at once. All of this meant that the narrative form and more traditional boundaries of stories were often very difficult to isolate or contain. As Riessman (2008), notes, transcripts with multiple speakers, can reflect narrative stories in very different ways from personal narratives, such that narratives “emerge in fragments…group stories typically lack the neat boundaries – beginnings, middles, and ends – more likely to occur in research interviews” (Riessman, 2008, p. 123). As I explored narratives and different types of narratives, I also learned more about family narratives as a specific form of grouped narrative, that are often quite unique, as families often have their own culture, narratives, narrative styles and approaches that are quite distinct from other groups (Langellier, 2002; Langellier & Peterson, 2004). In thinking critically about the fact that the narratives that I was hearing were not only family narratives, but narratives of women within families, it also became important to think about how gender plays a role in how narratives are storied, and how women, share and co-construct stories with one another, in ways that are different than men (Langellier & Peterson, 1992). As my focus within this study was to examine the relational accounts between mothers and daughters, I knew that it was critically important to not extract any of the voices, in order to try and represent a relational story that was more clearly defined. I decided to explore the idea of relational stories, as a conceptual grouping of all of these forms and types of stories. Within this broader grouping I could examine relational stories with more definitive boundaries, as well as stories that unfolded across a wider span of threaded conversation and text, and I could also attend to how stories were narrated and performed, and how mothers and daughters heard and responded to each of these stories. Ultimately what emerged within this process, was the
importance that I respectfully attend and listen to what, how and why women story their lives in particular ways and styles, and that in trusting the women that I met (and myself), that this broader category of relational stories would have everything I needed to explore and examine how mothers and daughters relationally experience end of life.

*Approach/Application of Thematic Analysis*

As the focus within narrative work is to “keep a story ‘intact’ by theorizing from the case rather than from component themes (categories) across cases” (Riessman, 2008, p. 53) I began my narrative, thematic analysis by building a relational chronological table for each mother and daughter dyad. Drawing on the five specific time-periods¹³ that I asked mothers and daughters to speak to within our conversations, I began filling-in on a very detailed level the specific relational stories that mothers and daughters shared with me, within each of these time-periods. Wanting to attend to the co-constructed and relational elements of how relational stories unfold within relationships, I worked to highlight and acknowledge the primary messages or concerns within each story which were raised by each mother, and the elements raised by each daughter. After reviewing and examining the relational stories that unfolded across the relational chronology for each mother and daughter dyad, I then worked to identify two primary relational stories within each dyad, which offered insights about how each mother and daughter were relationally experiencing end of life. Staying within each mother and daughter dyad, I closely examined both of the selected ‘end of life relational stories’, and I focused on identifying the underlying assumptions, beliefs and understandings which were operating within each relational story (Riessman, 2008). Emerging from the thematic analysis was a greater understanding of how mothers and daughters experience end of life through intertwined processes that are individual, relational, and intersubjective. The specifics of each of these processes will be explored further within this chapter, and throughout my discussion chapter.

*Approach/Application of Dialogic/Performance analysis*

¹³ The five time periods are: When the daughter was young; When the daughter was an adolescent/young adult; When the mothers’ illness arrived (if it hadn’t arrived at an earlier stage), Present day, and the Future/Time Ahead.
While a full dialogic/performance analysis of both end of life relational stories for each mother and daughter dyad was beyond the scope of this study, I decided to draw on a dialogic/performance analysis approach on one end life relational story, for each mother and daughter dyad. This approach provided me with the opportunity to closely examine how mothering and daughtering practices were actively performed and produced within each mother and daughter dyad. As the dialogic/performance analysis followed the thematic analysis, I selected the first relational story within each dyad, to utilize for this analytic approach. In moving from the thematic analysis to a dialogic/performance analysis, I shifted my attention from what mothers and daughters were saying thematically, to an exploration and examination of dialogue and context within and across each relational story performance. Specifically I focused on identifying ‘who’, a speech turn or dialogue appeared to be performed for, and ‘when’ and ‘why’ certain elements were performed within each performance (Riessman, 2008, p. 105). Further I examined how I was also centrally woven within each performance as a co-performer, and how this informed and shaped each of the relational stories/performances under review. In reviewing the transcripts carefully, I specifically worked to examine the context informing the dialogue between mothers and daughters and myself, and who these performances were performed to (i.e. to each other, to me, to a general public), and what each of these performances reflected about how mothers and daughters experience end of life. As a first step in following a dialogic/performance analysis I listened to the audio recordings multiple times, as a way of identifying, in concert with the transcript text, subtle shifts and transitions in the relational story/performance that was under review. Specifically I listened for different voices and messages being displayed and produced across the relational story/performance, and I transcribed each of these voices as stanzas. Each stanza represented different voices, layers and messages, which collectively informed and created the larger performance. I then went into each stanza to see how varying “performances genres” (Riessman, 2008, p. 112) were exhibited with the text. Specifically I worked with: direct speech, in highlighting text that included direct speech; asides, as parts of the dialogue that stepped outside of the primary story to provide background, or to ask the audience a direct question; repetition, in examining words that appear repeatedly throughout the performance; and expressive sounds or cues, which reflected sounds as well as shifts in voice pitch (higher voice pitch, or lower voice pitch) or quality or tone (Riessman, 2008, p 112-113). While Riessman (2008) draws on historical present as an additional performance genre that marks shifts in how verbs perform or shift between past,
present and historical present, I did not draw on this within this study, as verb performance across performances were too variable, given the multiple voices within each relational story/performance. After identifying and labelling the performance genres emerging within each stanza I then shifted into the next stage of the dialogic/performance analysis. Prior to outlining these next steps, I offer below a brief overview of the transcript conventions that I have used within this part of my analysis. See Table 7, *Transcription Legend*.

*Transcription Legend utilized within excerpts of relational stories within this chapter*

Transcription conventions used in the dialogic/performance analysis excerpts are modified from those used within Elinor Ochs and Lisa Capps (2001) text, *Living Narrative: Creating Lives in Everyday Storytelling*. These conventions offer a way to represent speaker and speech turns which occur within the relational stories/performances, as well as how the dialogue moves between speakers (i.e. interruptions in speech or overlap in speech). In the interest of working with Riessman’s (2008) performance genres, I have added these to this legend as well.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Interviewer</td>
</tr>
<tr>
<td>M</td>
<td>Mother</td>
</tr>
<tr>
<td>D</td>
<td>Daughter</td>
</tr>
<tr>
<td>-</td>
<td>shows an overlap or interruption in the speech turn</td>
</tr>
<tr>
<td>word</td>
<td>reflect an emphasis on this word in the speech turn that is different from other words used in the same speech turn</td>
</tr>
<tr>
<td>WORD</td>
<td>reflects a very strong emphasis on this word within the speech turn</td>
</tr>
<tr>
<td>[motion X]</td>
<td>reflects nonverbal signs/cues/motions</td>
</tr>
<tr>
<td>(.)</td>
<td>brief pause,</td>
</tr>
<tr>
<td>(pause)</td>
<td>reflects lengthier pause where this is a noticeable silence of more than two seconds.</td>
</tr>
</tbody>
</table>

**Performance Genres (Riessman, 2008)**

- **[G- Direct Speech]** Represents the performance genre of direct speech, and involves highlighting direct speech lines performed within the passage
- **choices** Represents the performance genre of repetition in words (phrases) that are used repeatedly within the passage
- **[G-Aside]** Represents the performance genre of asides, where information is shared within the performance that provides background that is
outside of the main story or performance

[higher/lower pitch] Represents the performance genre of expressive sounds within the dialogue which in this study includes how voices move higher or lower in pitch/tone in relation to speech.

The next step of analysis examined two specific areas of dialogical interaction and performance: *Voices in Dialogue* and *Context*. *Voices in Dialogue* closely examines what voices were most apparent within each performance, and whether these voices were performed as voices of self (or other), or further still a generalized ‘other’, and *who* each of these voices seemed to be *performing to* within the larger performance. In some relational stories/performances the general purpose of the performance was directed to me as an interviewer to learn and understand critical elements that informed each mothers’ and/or daughters’ experience. In other relational stories/performances, mothers and/or daughters performed to each other, looking for affirmation, further clarification, about who each of them were, or what they were experiencing. In still other relational stories/performances, my voice emerges, sometimes protectively, sometimes cautiously, performing my own understandings of how communication, connection and relationships unfold in end of life experiences. *Context*, on the other-hand examines a number of different types of perspectives and situations that also inform how and why certain elements are performed within each relational story/performance. The first context that I examine revolves around me, and how my identity is both performed (and performed in relation to), as an interviewer, as a palliative care researcher, as a social worker, as a woman, as a daughter, and as someone who has lost and grieved a parent, and more recently my birth-mother. This emphasizes how important it is for me to examine how my own interview voice and performance of identity interacts and performs certain meanings and understandings, and how these elements of identity may also inform/cause/produce certain performances in return, from each of the mothers and daughters that participated within this study. The second form of context that I examine is around the end of life care site or practice that each mother and daughter dyad is receiving. Specifically this means examining how end of life care practices (and sites), reflect or reproduce particular understandings and messages about end of life that also inform how mothers and daughters and I as an interviewer perform end of life and relational understandings of end of life. The third form of context focuses on the social, cultural context, and how women’s performances of end of life are woven into and around broader understandings, assumptions and meanings of how women as mothers should die, and/or how daughters should care for their mothers at this time of their lives. While relational voices and
context are woven directly into dialogic/performance analysis, these elements are also centrally linked to the feminist epistemology that guides this study, in addressing women’s voices and experiences, and how women’s lives are situated and embedded within social and cultural contexts. By drawing on transcripts that have been formed in dialogue between mothers and daughters and myself, there is an opportunity to centrally explore how relationships and social cultural contexts are performed within these relational stories, and how in exploring the purposes behind these performances we may come to a more informed understanding of how mothers and daughters relationally experience, and perform end of life and end of life care.

Developing from the dialogic/performance analysis was further evidence of how mother and daughter experiences of end of life are not only lived, but performed, through individual, relational and intersubjective processes. Importantly we also see how these processes, while lived and performed between mothers and daughters, also powerfully “represent and reproduce the cultures in which they are embedded” (Jordan & Walker, 2004, p. 3).

4.2 Mothers and Daughters and their relational accounts

Below I introduce each of the five mother and daughter dyads that I had the opportunity and privilege to meet in my study. All names have been changed to first name pseudonyms, and potentially identifying elements have been modified to ensure confidentiality. For each mother/daughter dyad, I offer a brief narrative overview, followed by narratives of my initial meetings with each mother and daughter. These narratives are offered as a way for you as the reader to ‘meet’ each mother and daughter, to feel as if you too are in the room with us, observing, gathering, connecting, and reflecting as each mother and daughter shares who they are, what brings meaning to their lives, and how they are living in the context of dying. I then address more broadly how mothering and daughtering as experience (Rich, 1976), and motherhood and daughterhood as institution (Rich, 1976) are woven across and through each mother and daughter dyad. I then shift to explore each mother and daughter dyad over their relational continuum, offering relational stories and understandings that reflect each mother and daughter’s experience of when the daughter was young, when the daughter was an adolescent/young adult, the entry into illness and end of life, and thoughts on the future ahead. The relational continuum for each mother and daughter dyad offers a strong foundation to then shift into the two end of life relational stories which were selected for further analysis. For each
mother and daughter dyad I examine the first end of life relational story, using a thematic analysis, followed by a dialogic/performance analysis. The second end of life relational story for each mother and daughter dyad is analysed solely with a thematic analysis. Following the thematic and dialogic/performance analysis section for each mother and daughter dyad, I provide a summary, which outlines some of the key findings which emerge from the thematic and dialogic/performance analysis for each mother and daughter dyad.

Within the appendices, there are a number of documents compiled to further support and represent the analytic work I conducted within this study. Within the appendices, each mother and daughter dyad has their own grouped appendix which includes the thematic and dialogic/performance analysis data for each dyad (e.g Appendix C – Ruth and Sarah).

Each mother and daughter dyad appendix includes two sections:

1. *Relational Story/Performance Overview Table*

   - Displays the relational stories[^1] that were shared with each dyad, and how these relational stories correlate with the chronological, time-periods that each mother and daughter were asked to reference within the interviews.[^2]
   - Highlighted are the two end of life relational stories drawn on for thematic analysis.

[^1]: Wanting to attend to the co-constructed and relational elements of how relational stories unfold within relationships, I have highlighted and acknowledged the primary messages or concerns within each story which were raised by each mother (identified with an M – and red font), and the elements raised by each daughter (identified with a D – and blue font). As some of the relational stories that were shared were narrated primarily by either the mother or daughter, these relational stories are reflected as stories that are identified with one of them, and not both of them.

[^2]: While all mothers and daughters were asked to share relational stories about each of the five time-periods, not all time-periods were addressed within each mother and daughter dyad.
Highlighted is the one end of life relational story/performance used for the dialogic/performance analysis.

2. Dialogic/Performance Analysis

- The specific dialogic/performance analysis which was conducted on the relational story/performance excerpt, followed by an overview of the performance genres found within each excerpt.
- An additional copy of the transcription convention legend to ensure ease in reviewing each analyzed excerpt.
4.2.1 Ruth & Sarah

Ruth & Sarah

Ruth has spent her life living in a number of multilingual countries across Europe, as well as in the USA and Canada; she is in her late eighties. Ruth was born in Poland, and important parts of her experience, identity, and history come from her experience surviving the Holocaust. Ruth has been married for almost 70 years, and has two daughters. Sarah, Ruth’s youngest daughter, was born in Canada and raised primarily across Europe; she is in her late fifties. While Ruth loves both of her daughters, her bond with Sarah is particularly strong, as it took two miscarriages and seven years of worry and concern for Ruth to be able to carry to term a second child. Sarah went to a boarding school at the age of 13, and while it was difficult for Ruth when Sarah left home, it was also very important for her that both Sarah and her sister be well-educated and independent. Ruth and her husband felt it was absolutely critical that Sarah and her sister know fully and in detail about the atrocities committed against them, their families, and the wider Jewish people during the Holocaust.

Most of Ruth and Sarah’s relationship has been from a distance, as Sarah has often lived in a different city from her mother and father. After attending graduate school, Sarah married and had her own children. Sarah stayed in close phone contact with her mother and father, and would visit her parents a number of times throughout the year. Sarah’s older sister lived in the same city as her parents, and would often call Sarah when she needed support in taking care of their mother and/or father.

While Ruth noted that for most of her life she had been physically strong and quite independent, she also shared her ongoing struggle with depression, including two instances when she wanted to die. Ruth noted that it was her doctor’s care and treatment that “pulled her through.” A number of years ago, Ruth was diagnosed with a blood disorder (myelodysplasia) which required repeated infusions and then transfusions. After a number of years of treatment, Ruth decided that she was finished with treatment and that she would allow her illness to progress. Ruth felt at this time that she had lived well for many years, “But now I’m a ruin...so what am I doing here?”

Ruth’s decision to stop treatment was quite difficult for Ruth’s husband and her elder daughter to accept, as there was concern that Ruth’s struggle with depression may have been informing her decision to stop treatment. Sarah fully supported her mother’s decision to stop treatment, believing that this decision was in line with her mother’s personality and reasoning, and that her mother should have the ability and right to decide whether she continued treatment or not.

I met Ruth and Sarah after Ruth had been on the Palliative Care Unit for just over a month. Living in another city, Sarah would come to the palliative care unit for a number of days in a row, and then she would go home and spend time with her children and husband. My first interview with Ruth and Sarah was filled with many stories and experiences, and over the following month, I had a number of conversations with Ruth. Our second recorded interview happened just after Ruth had been on the PCU for two months, and took place with Sarah alone, as Ruth was too ill to participate. Ruth died on the unit seven days later, on her 70th day on the PCU.
My First Meeting

It’s about 4 p.m. when I walk into Ruth’s room on the Palliative Care Unit (PCU) to meet Ruth and Sarah. Ruth’s room is a shared room with two patient beds, and Ruth’s bed is closest to the door and to the shared bathroom. There is a pale yellow curtain that hangs between Ruth’s bed and the other bed, and I am struck by how artificial this division is. Ruth is in bed and the head of the bed is slightly raised. Ruth has a full, round face, a large and slightly inquisitive smile, and white wavy hair. One of Ruth's eyes is piercingly clear and bright and the other eye, as a result of a stroke, remains slightly closed. Ruth's face and hands are heavily lined and spotted with the tell-tale 'liver' spots of age. Sarah, Ruth’s daughter, is sitting on the seat of her mother’s walker, just to the left of her mother’s bed. It’s clear, even while sitting, that Sarah is a tall woman, with broad shoulders and a sturdy frame. The shape of her face and her smile share many similarities with her mother. There are many personal items on the bedside table, a digital frame with photos, cards, a vase with a flower, as well as a comb and papers. Ruth and Sarah are having an animated conversation, and I am struck by the intimacy and tenderness in Sarah’s voice as she responds, “But Mamalish....”

As I knock on the door and slowly walk in the room towards Ruth’s bed, the conversation between them ends and both Ruth and Sarah turn to look at me. After introducing myself and relaying that I’m the researcher conducting a study with mothers and daughters, I ask them if they want to hear more about the study. Sarah begins by saying yes, that they might be interested, but that they would like to know how long the interview would take. I respond that the interview will be 30-45 minutes, but that we can see how this feels for both of them. As Sarah and I are talking, Ruth asks Sarah, “What is she saying?” Sarah paraphrases back to her mom, “...it’s a lengthy interview Mamma, 45 minutes, it’s a long time, I don’t know if you are up to that....” Ruth interrupts Sarah, “Why wouldn’t I want to talk, I want to talk.” Ruth’s response is direct and clear, and Sarah smiles and turns to me and says, “Okay we are going ahead.” Sarah says to me, “So it’s daughters and mothers, I have a sister, there are two daughters in our family, so do both of us do this, or one of us?” I respond that the study is about the relationship between mothers and daughters, and that the focus of the study is on the relationship between one daughter and one mother. Having two daughters participate would add other dimensions to
the interview, as it would then offer a sibling narrative that is outside the scope of the study. I begin to say that they as a family could decide which daughter participates. Ruth nods and points at her daughter and says, “No, this is the one...this is the one that should do it.” Ruth continues, “I love both of my children, but this one...this one here, she is the apple of my eye.” I quickly glance at Sarah to see her response, and it seems to me that Sarah’s face softens, she seems both surprised and touched, and there is a moment of respectful silence that follows.

First Interview

I arrive on the PCU at our pre-arranged interview time, and I see that Ruth is in the chair lift in the hallway, on route to the large spa/bath-tub. Sarah arrives shortly afterwards and we negotiate that I will come back in an hour or so. When I go back to their room an hour later, I see out of the corner of my eye that a priest is praying at the bedside with the other person/patient in the room. Ruth is lying in bed in her nightie and dressing gown, her face is a bit flushed and her hair is still a bit wet from her bath. When I come into the room, Ruth starts to move to get up and she asks Sarah to help put on her socks and slippers. Ruth’s legs are quite swollen and she has trouble lifting or moving her legs without help. Sarah’s process of helping her mom get dressed is intimate, seemingly co-constructed as Sarah gently but firmly lifts Ruth’s legs, and Ruth wiggles her toes and the rest of each foot into thick socks and fuzzy slippers. As I watch Sarah with her mom, I am struck by the two sacred, relational acts being performed in this room.

Ruth (M) and Sarah (D) – Relational Continuum over time

Mothering/Motherhood, Daughtering/Daughterhood

While the focus within this study is on Ruth and Sarah’s relationship as mother and daughter, Ruth’s experience as a young woman living in Poland during WW II, who was forced into hiding at the age of seventeen, and lost her family, deeply permeate Ruth’s understanding of family, relationships, and her subsequent experiences of mothering and motherhood. This broader context is made apparent from the very beginning of our interview, as Ruth begins the interview talking about the day that she and others were liberated, April 15th, 1944, and then works backwards to talk about the beginning of the war and her experience of being forced into hiding. Many of the stories that Ruth shared about the Holocaust were times when her life was threatened, and she witnessed and experienced intense brutality and terror. Ruth’s experiences
of the Holocaust and liberation from the camps also inform her experiences of fertility, pregnancy and family planning as she needs to make very difficult choices around her first pregnancy. The impact of these choices threads through Ruth’s challenges with fertility, as she is able to have one healthy daughter, and then experiences seven years of infertility and difficulties in carrying two separate pregnancies to term. Sarah’s birth which follows after these multiple years of infertility and consecutive miscarriages, is warmly welcomed by Ruth, and is treated as a miracle. Sarah’s experience of daughtering is also woven into the experience of the Holocaust, as Ruth and her husband ensure that both of their daughters knew about their experiences during the war and the atrocities that were committed. This multigenerational connection to the Holocaust powerfully weaves through Ruth and Sarah’s mother and daughter relationship, albeit in different ways. Mothering and Daughtering also shift into the next generation, as Sarah marries and becomes a mother herself to her two children. Sarah’s experiences of being mothered by her Mum, strongly inform her own mothering practices, “because of the way I remembered Mum being a mother to me, I wanted to very much be the same kind of mother to my kids”. For Sarah, this means making decisions to stay at home with her kids, despite the response from others in her life who suggest that she is wasting her graduate education. As Ruth moves into end of life, Sarah is very present in her Mum’s life, travelling back and forth from her home in a different city with her husband and children, to her Mum on the PCU, and her dad in his residence. In focus in the relational stories and discussions below is how these experiences between Ruth and Sarah’s relationship over time, inform how Ruth and Sarah are relationally experiencing end of life. Shifting back to the relational continuum, I begin with the relational stories that Ruth and Sarah shared about their relationship when Sarah was young.

When Sarah was young

Relational stories shared between Ruth and Sarah when Sarah was young relay the importance that Ruth placed on being present for her daughters, and how an important memory for Ruth is Sarah coming home in the door from school and calling out for her, and how Ruth was always there for her daughter. While Sarah does not remember calling out for her mother when she arrived home, she does know that her mother was always there for her. Sarah’s experience of her mother’s presence and availability are strong factors in Sarah’s decision to stay home to raise her sons. As Sarah reflects on her experiences with her mother when she was young, she shares
one particular story of how her mother supported her when she had to do painful rehabilitation exercise at home.

D: One of the stories that, that I like to tell and Mum will also remember it, is that when I was, um, again, I don't know how old, probably around 10, I was diagnosed with a, with a little bit of a, of a back -- not a deformity, but something that the doctor wanted me to march, to march up and down with a, with a pole, you know, so that I would be walking like this [motions upright position]. And then my feet were growing pretty quickly and they hurt, and so he wanted me to march up and down with marbles under my heels.

I: Oh my goodness –

D: And I hated this. I just hated this. And Mum would park herself – we had a very long hallway – and Mum would park herself on a chair at the end of the hallway and keep me company while I marched up and down, hating my marching. And she was always there to ease the way, make it more bearable, I suppose.

I: Lovely.

D: Remember, Mamalish? And she used to sing to me.

M: The marbles, yes!

This story captures for Sarah, a time when her Mum shared in an activity that Sarah absolutely hated. Sarah’s Mum’s willingness to be with Sarah during her marching, provided ease for Sarah, as “she was always there to ease the way”, and ultimately her presence helped make Sarah’s pain and suffering more bearable. Understanding the context and meaning behind stories of care that daughters may have experienced from their mothers when they were young, can offer important insights for daughters as they struggle to find ways to support their mothers in difficult times. As Ruth reflects further about Sarah’s childhood, she shares how important it was for her that she was involved in Sarah’s education, and how because her own parents were teachers, Ruth spent a lot of time “prodding” Sarah with her lessons, and being involved in her learning. Sarah remembers this time of her life quite fondly and enthusiastically shares how important this time was, and how she remembers her mother reviewing her material with her and helping her prepare for her tests in school.

*When Sarah was an adolescent*
An important part of Sarah’s adolescence is how at the age of thirteen, she left home and attended a private boarding school. The decision to leave home and go to boarding school was a decision that the whole family made together, and Sarah was part of this decision. While Ruth found Sarah leaving very difficult, she didn’t hinder this, as she felt that it was very important for Sarah to be educated. As Ruth and Sarah talk about Sarah’s education, Ruth shifts the conversation to the importance that Sarah and her older sister were fully educated about their Jewish history, culture and identity. Education for Ruth includes academic learning as well as a broader focus of education about the world, about history, culture and identity. Ruth and her husband decided together that they would consciously and explicitly share their experiences of the Holocaust with their daughters. This choice to share their experiences, both verbally throughout the years and in a written memoir written by Ruth, was an important and active decision, and was made even though Ruth and her husband knew of other Jewish parents who protected their children from really knowing what happened. The sharing of the Holocaust experience with the next generation offered an important living link to what happened, and was a strong active voice against the threat of annihilation that Ruth and her husband and the Jewish community lived with both during and after the war.

Sarah’s experience as the daughter of parents who survived the Holocaust is quite different from her parents’ experiences. The difference between Ruth and Sarah and their relationship to the Holocaust unfolds slowly in our conversations, as initially what is most apparent in our connections is how Sarah takes care of her mother during these conversations. As Ruth begins talking about the war, Sarah reaches out and holds her mother’s hand and moves between actively listening and affirming her mother’s experience, and co-constructing some of her mother’s stories, filling in missing pieces, clarifying moments, or offering narrative links so that I would more fully understand her mother’s narrative. Strongly apparent within these conversations is Sarah’s role in acknowledging, supporting, and affirming her mother’s narrative of what happened during the war. As we talk more about the mother and daughter relationship between Ruth and Sarah, it becomes clear that for Ruth, the experience of the Holocaust is interwoven with not only her experiences of her life but also with her relationship with Sarah. For Sarah, though, the experience of the Holocaust is in the past, and she does not see this informing her experience or understanding of their mother and daughter relationship.
I: I appreciate so much you sharing. (M: mmm?) I appreciate so much you sharing this with me –

M: Yeah, because everything is linked. It’s not “this happened then, and then later.” Everything is sharing. I can’t separate one thing from another.

D: Mamalish, I think Pam wants to hear more about the mother-daughter relationships as opposed to the history.

M: It entwines, you know? One goes into the other. I can’t separate one from the other.

For Ruth, it is absolutely vital to explain how the context of the Holocaust and her experiences in the Holocaust completely interweave with her present day experiences and her relationships with her family. For Sarah, her understanding of this context is different, and while she respects and values her mother’s connection to the past, she also sees this context as outside her relationship with her mother.

When I ask Sarah about the role of the Holocaust in her life, she speaks to her interest in history generally, and her amazement at how her parents were able to live very normal lives after traumatic, disastrous, and indescribable experiences. For Sarah, the strength of character they needed in order to put a lot of what happened to them behind them is evidence of how amazing they have been as parents. Sarah recounts:

I: So how do you, how does your mom’s history and your dad’s history, how does that inform your experience?

D: Quite a lot, just in terms of my feelings about, my interest in history in general, my amazement at how they were able to live what I would consider very normal lives after the war, in spite of all their experiences, traumatic experiences, disastrous experiences, you know, there are no pejoratives that start to describe…they’ve been amazing as parents. And in some way they’ve had the strength of character to put a lot of that stuff behind them and live normalized lives.

Again we can see in Sarah’s remarks that the Holocaust context, while respected and acknowledged, is also something that she experiences as part of the past.

_When Sarah was an adult_

A critical point for Ruth in her relationship with Sarah happened when Sarah was at University, and reflected some very important differences between them about how each of them connected to the broader context and meaning of Ruth and her husband being Jewish and having survived
the Holocaust. As Ruth shares this relational story, the unfolding of the story happens rather abruptly, as Ruth seems to dovetail onto a reference that Sarah makes about the time in her life when she was getting married. The larger context that unfolds within the story (although sparingly), is that when Sarah was in University she had fallen in love with a man who had grown up in a Protestant household, and for Ruth and her husband, having one of their daughters marry someone who was not Jewish, particularly after their experiences of the Holocaust, was unthinkable. For Ruth what is emphasized in this story is what Sarah said to her when she and her husband had a strong reaction to Sarah’s choice. Within the specific conversation that Ruth recounts, Sarah said to her mom that, while she would listen to her parents, she would never forgive them if they did not accept her choice of partner. For Ruth this was a turning point. As soon as Sarah said she wouldn’t forgive her, she decided that she would support her daughter’s decision. Notable is how vivid this conversation is for Ruth, and how Sarah doesn’t remember the conversation at all.

D: That’s right. That’s why, that’s why I say that after the age of 13, I actually never really lived at home. Their home was in X country, While they were still living there, I was in a boarding school in x country, at university A in City B and then at University B in city C, doing X degree and when they came back to Canada, I was just getting married.

I: Oh, really?

D: So that’s, that’s why –

M: And we were very much against, because for us Jews who were left, so few, it was unthinkable that our children should marry out of faith.

D: My husband’s not Jewish.

M: And I tried, here, talking to him, talk to my son-in-law, whom I love dearly, and to her. But (daughters’ name) said, “At the end, I will listen to you, but I will never forgive you.” And that’s what broke my resistance.

D: I don’t remember, I don’t remember that – I’ve either blocked it out, or, you know, I don’t remember.

M: Yes.

M: As I said to myself, I don’t want her to come to the point where she would only forgive us. She loves him, he loves her, the family was wonderful. We made a beautiful wedding. And that was it.
Given Ruth’s experience of losing her whole family in the Holocaust, and her identity as someone who is Jewish, it was unthinkable for her that her daughter would marry someone who is not Jewish. Given the atrocities of the Holocaust, there is also a sense that Sarah marrying someone that is not Jewish is another possible traumatic loss for Ruth, as this would sever the living links between Sarah and Ruth as survivors of the Holocaust, as well as mothers and daughters. The threat that Sarah would never forgive her, however, is another form of separation, and this emotional form of separation is also unthinkable for Ruth. Having Sarah not forgive her is prioritized over Ruth’s sense of responsibility and connection to her own history, culture and community. Hearing about Ruth’s process of navigating across potentially divisive and core elements of her faith, family, community, and identity offers us profound insights into how Ruth and Sarah’s relationship holds both a deep understanding of trauma and the threat of loss, but also a strength to hold difference and disconnection in a way that doesn’t threaten the core of who they are. Notable for Ruth and Sarah’s relationship is how Ruth’s decision to accept Sarah and her husband and their relationship in turn seems to have created the space for Sarah and her husband to re-define the elements of Jewish history and culture that they wanted to integrate into their family, and to leave out the parts of Judaism that did not fit for Sarah. In this new and reclaimed space, Sarah has found that being Jewish is increasingly important to her and her family.

D: When I think about it, especially because Mum and, Mum and Dad’s experiences and being Jewish was important to me, I’m actually a little bit surprised, in retrospect, that I, that I, fell in love with a non-Jew. That’s just the way it happened. And interestingly, since then, being Jewish has become, actually, increasingly important to me. So we’ve definitely, I mean, we run a Jewish household. My husband is very supportive. Um, both my sons were circumcised and have had Bar Mitzvahs, although we’ve been very fortunate. In City B, there are many options, many flavours in which you can find your space and the, um, the denomination to which we belong is actually a secular and cultural version of Judaism. It’s not a religious version whatsoever.

M: It’s a non-denominational case. They don’t recognize God or church –

D: We’re basically a bunch of atheists, but we’re really Jewish atheists. So what’s important to us is Jewish history and culture ethics and values, but, (not) you know, whether or not you’re praying in the right place and the right time … it’s absolutely wonderful. And we’ve been very fortunate to have found this particular place and, um, to have revelled in it.

Sarah’s re-creation of her connection to Judaism and the history and experiences of the Holocaust is an important part of her life, both within her family, but also in her broader work
and community context. It is also an important part of her relationship with her mother. In an unexpected interruption during our recorded interview, a visiting priest sees us sitting in one of the communal family rooms on the PCU, comes over, and begins to make conversation. After he says hello, Ruth says to the priest, “...we are Jews. I am Jewish, my daughter is Jewish, so are her family.” Ruth’s very clear and direct grouping of identity, “we are Jews,” is an important part of Ruth and Sarah’s relationship, and in light of their differing understandings of the context of the Holocaust and their connection Judaism, reflects a strong shared identity and connection that lives on between them. This connection is also sacred, protected and differentiated from other families and faiths, for as much as Ruth has created a clear understanding of who she and Sarah are, she is within this exchange with the priest, also making it clear that they are separate and distinct from others. A number of important messages are relayed in the above story about how differences are navigated between Ruth and Sarah. While this difference between Ruth and Sarah could have been divisive and ruptured their relationship, Ruth’s ability to weigh the emotional loss of her daughter with her responsibility and her resolve to protect and sustain the link to the Holocaust and the Jewish community offer both Ruth and Sarah the opportunity to create for themselves their own shared connection to Judaism, as well as a revised understanding of how difference is integrated into their connection to each other. These elements build a multi-layered account of how Ruth and Sarah have navigated difference between them, and how their relationship is situated within a complex system which weaves together individual, relational, social, cultural, and historical understandings of who they are and what they mean to each other. Of interest, then, is having a sense of how Ruth and Sarah navigate potential differences that may arise between them as Ruth moves closer to death.

Present Day

As Ruth and Sarah begin to share how they are both doing in the present, Ruth shares her struggle in trying to bridge her understanding of who she was, when she was healthy and able and well, and who she is today. The difficulty she has in bringing these different parts of herself together, leave her thinking of herself as an outsider, looking in on the person she is today.

M: Before I was ill, I was so healthy. It’s, today I say -- it’s me? Sometimes I think of myself as an outsider, looking at me.

I: Really –
M: Who are you? I’m not, I’m not the woman I was for 89 years.
I: Yeah, right, so it’s really shifted how you see yourself –
M: Completely, completely. I don’t see myself as sick. I see myself as able and well. And now, now look at me. I can hardly walk, but, but that’s it, but I’m very realistic. I know what’s coming and I’m prepared for it.

While Ruth is able to talk about the difficulties she has in holding these radically different and conflicting parts of who she was and who she is, and the many things that she is no longer able to do, these difficulties also seem to be subsumed within a broader understanding of the reality of dying, and the importance of being ‘very realistic’. The dramatic shift in Ruth’s narrative from her inner struggle, to being ‘very realistic’ suggests that there are tensions between Ruth knowing what end of life looks like and being prepared, and the actual lived (and perhaps dying) experience, and the elements of end of life that are more difficult to be realistic about. Sarah’s experience in the present day demonstrates how she is living between two different cities and navigating a variety of different and potentially competing family care needs. Since Ruth was admitted to the PCU, Sarah has been driving from the city that she lives in with her husband and children, to the city where the PCU is located, and the city where her dad resides.

D: So I’m with them 24/7 when I’m with them. And, um, and now that Mum’s ill, I mean, I’m actually travelling back and forth an awful lot. You know, I’m here for a week and I go home for a week and I’ll come back for four days and I’ll go home for ten days, and I’ll come back for a week. You know, so it’s [pause] and again, I’m lucky to be able to do that because not every family and work situation would, would allow for that.

In speaking to her experience travelling back and forth, while Sarah does acknowledge that she is travelling back and forth ‘an awful lot’, the focus for Sarah is in naming her sense of privilege in being able so spend her time this way, and how many others may not have the family or work situation that would allow this to happen.

Future

In the interview with Ruth and Sarah, I intended to ask both Ruth and Sarah about their wishes or hopes for each other in the future. I directed my question initially to Sarah, and while Sarah started to answer my question, Ruth interrupted her daughter, answering on Sarah’s behalf, relaying confidently and directly, that Sarah’s hope was that Ruth would not suffer. Sarah further answers that her hope is that her Mum’s time will be short, because that’s what she wants.
I: So…are there any things that you’re wishing for, hoping for, in the time that’s left for your Mum?
D: Um, I’m hoping on her behalf that –
M: I won’t suffer --
D: -- that her time will be short because that’s what she wants –

This shared and co-constructed dialogue, of what Sarah hopes for her mother, Ruth’s response on Sarah’s behalf, and further how Sarah’s hopes are woven into Ruth’s hopes, reflects how closely connected their thoughts and hopes are for end of life, and how Ruth feels able to answer on behalf of her daughter, and similarly Sarah is able to clarify and add to her Mum’s response. Many families can find it quite challenging to talk about their hopes and wishes for their loved one in the time that is ahead. In each of the interviews with mothers and daughters I was sensitive to how I framed this question, as I did not frame the question about “time left”, if I felt that this way of speaking about end of life had not already been raised by the mothers and daughters themselves. How Ruth and Sarah responded to my question collectively and collaboratively seemed to suggest that this was a topic that they had both talked about in the past, and both of them felt able to speak directly to what the other person was wanting or hoping for. The conversation above, offers an important lead-in, to examine more directly, two specific end of life relational stories that arose within Ruth and Sarah’s interviews that offer us further insights about how both of them were relationally experiencing end of life.

Examining End of Life Relational Stories

Two end of life relational stories from Ruth and Sarah’s interviews are examined below. Each of these relational stories addresses two very different aspects of end of life and end of life care. The first relational story, which appears in two parts (Part A and Part B) speak to Ruth’s transition into end of life, and specifically Ruth’s choice to stop life-sustaining/acute treatments. Together this relational story offers important insights into the multiple meanings that are ascribed to individual choice and agency, and how personal choices are connected to appraisals of stress, coping and meaning. Further we see how individual choices shift into relational domains as family members assess and evaluate their loved ones ability to make competent, end of life choices for themselves. The second relational story speaks to the limits that can arise in
end of life communication, and how difficult it was for Ruth to articulate to herself, her family, and her care team, the depth of her fear about dying. Within the broader context of preparing for death and being realistic about death and dying, this reminds us how patients and family members may be challenged to articulate to others, the depth, and intensity of their fears about dying, and how these fears may come to the surface in indirect ways. Supporting documents for the thematic and dialogic/performance analysis are available in Appendix C.

Relational Story #1 - Ruth’s transition into end of life – choosing to stop life-sustaining/acute treatments

Thematic analysis

A central element informing Ruth and Sarah’s current experience of end of life revolves around how Ruth has come to be in end of life. Midway through the first recorded interview, following a conversation about Ruth’s present-day experience of end of life, Sarah shifts the conversation to her Mum’s medical history, and references some of the choices that Ruth has made to not continue with certain medications and treatments. The relational story that unfolds within Ruth and Sarah’s first recorded interview is woven into two parts that are linked, across the broader interview. Part A of the first relational story provides us with a broader understanding of many different parts of Ruth’s choice. Specifically we are given the context of: what Ruth chose, why Ruth made this choice; how this choice is related to her medical history; how this choice links to Ruth’s present day experiences; and how Ruth’s husband has responded to this choice. Part B of this relational story moves to address the specifics of how Sarah responded to her mother’s choice, and how her response was different from other family members. Further this part of the relational story (i.e. Part B), addresses: why Sarah felt that her mother’s choice was hers to make, how Sarah and Ruth have talked about both Ruth’s choices and Sarah’s response; and finally and importantly, how this knowing lives within their relationship. My intent below is to speak to the primary themes that arise across both parts of this relational story, and how these themes help us understand the meaning of choice: for Ruth, for Sarah as Ruth’s daughter, and for Ruth and Sarah together, as they relationally experience end of life.

16 See Ruth (M) and Sarah (D) – Relational Continuum over time: Present Day dialogue on page 33 and 34
Part A -

The relational story that unfolds within this first part of the relational story centers around the meaning of choice, and how Ruth’s choice to not continue taking her medications and treatments, shifted her from a chronic stage of illness where she is receiving life-sustaining/acute treatments to prevent her illness from progressing, to an end of life/terminal stage. Strongly emphasized by Sarah initially, and further contextualized by Ruth, is how Ruth made this choice for herself, and how Ruth fully understands that she could have made the choice to continue with her medications. This is then followed by Sarah offering an overarching statement of where Ruth is in relation to the treatments:

D: …some of the, ah, choices that she made were choices that she made to, to not continue with certain medications –
M: I could have –
D: -- and to certain treatments. Because she’s done, she was just finished

Ruth then shifts to offer further context about the varying treatments and interventions she has had over the past number of years and how they seemed to have a limited impact. She notes how she didn’t want to prolong ‘it’, as in her life, particularly in light of her present day experiences. She ends this sequence with the central question of, “So what I’m doing here?”

M: -- I didn’t want to prolong it –
D: And she just sort of said, “You know what? I’m done here.” And that was –
M: I can’t talk, I talk, I can’t talk, but I can’t walk, I can’t read because I got a stroke in my left eye three years ago and I didn’t see with my left eye. So that’s why my eye sometimes is almost always closed. So what I’m doing here?

The final part of this section shifts to how Ruth’s husband has responded to Ruth’s choice to ‘leave it as it is’ and how he was upset with her for quite some time. This widening to other family members, and their responses to her choice, shifts the focus of choices that are individual, to an understanding that even choices that appear to be individual, are still relational and how the experience and outcome of individual choices are lived and experienced relationally.

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17 She’ reference within Sarah’s dialogue within this passage refers to Ruth
M: And my husband, for a long time he was upset with me, that I decided to leave it as it is, to go according to the line of I was well 'til 80 - 85 (I: OK). M: So for 35 years I suffered from depression I had a bout of depression. But I always came out very good, doctor in City C and he pulled me always through. But now I am a ruin so what am I doing here? Sleeping and eating? And I have no appetite whatsoever, (I: No, eh?) anyway.

Part B-

Part B of this relational story speaks much more directly to how Sarah has responded to her mother’s choice to not continue treatment, and how, “for some reason it was easier” for Sarah, than for her father and older sister. Ruth interjects with “to real-, to accept it”, which seems to imply that she was going to say something about “really” doing something, which could mean that there may have been some responses that appeared to be supporting, or were partially accepting, but were not actually fully, “accepting it”. Ruth’s husband and elder daughter (Sarah’s older sister) had serious concerns about Ruth’s ability and competence to make good and informed decisions for herself, at this time in her life. There were significant concerns that Ruth’s history of depression was informing her decision to not prolong her own life. Sarah had a very different response, as she felt that her mom was making this decision in a way that reflected who she was and how she made decisions, and that she had the right to make this decision.

D: And for some, for some reason it was easier for me than for my father or my sister (M: yes) to –
M: To real-, to accept it.
D: To accept that Mum’s decisions were hers to make (I: OK), and that they were likely the right decision (I: yeah) but right
D: And Mum knows that, that’s how I feel about it, that I do think that she was entitled to make her own decisions and that, um, that if she felt that the quality of her life would be so diminished that it wasn’t worth living –
M: -- that’s right –
D: -- then I wasn’t in any position to disagree with that because that is her decision to make.

In this story we see how decisions are made both individually and collectively between Ruth and Sarah, and how there is a link to both moral and individual rights, as Sarah relays she believes that her Mum is “entitled” to make these kinds of decisions for herself. Sarah, in our second
interview, which includes just Sarah and I\textsuperscript{18}, reflects on her ability to support her mother’s decision to end treatment, because she is able to fit this current decision within a framework that she has developed about who her mother is and how her mother made decisions in the past. Sarah notes that her mother was clear and lucid in her decision-making, and because this matched how she would have made decisions in the past, the issue could move away from concerns about her Mum’s mental health to a conversation of either accepting or not accepting her mother’s decision.

D: As a matter of fact, my sister and I were talking about that just earlier today, that she still doesn’t really – you know, she and I will never quite see eye to eye on, on our degree of acceptance or lack of acceptance of the decisions that Mum made. And the param-, and the conditions under which we feel she made those decisions. My sister is quite adamant that her mental illness affected the decisions that she was making. And I disagree. I think that they were quite clear and lucid, and a rational person with Mum’s personality would make those kinds of decisions. And my sister thinks that no, in some way, the, um, the depression had to have played a part. So it’s just, you know, we agree to disagree.

Importantly, Sarah also highlights how being able to accept the position and needs of her mother doesn’t make her experience of losing her mother any easier.

D: I still feel very much that she made the right decision for her. Not necessarily the same decision that the next person over would have made, but that she was entitled to make her decision and thus she made the right decision for herself. And I’m still very comfortable with that. Um, it doesn’t make me any happier about losing my mother. But it’s, it’s the way it is. It’s the way it is. And it was the right thing for her.

This reflects another important understanding of how Sarah, in her relationship with her mom, is able to reconcile what might appear to be two conflicting positions. While Sarah has come to a place of knowing and understanding the importance for her to support her mother’s decisions, she also knows that this support means that she will lose her mother earlier than she would have liked. Sarah’s support of her mother’s decision does not make her experience of losing her Mum any less difficult; she just believes that this is the ‘right thing’ for her. This particular understanding is an important one, as it not only speaks to individual differences in wants, needs,

\textsuperscript{18}At the time of the second interview with Ruth and Sarah, Ruth is too ill to participate, so this interview includes Sarah and I without Ruth.
and positions between mothers and daughters, and a relational awareness of each other’s needs, but it reflects the intersubjective context of relationships in end life. While mothers and daughters are in end of life together and their lives are intertwined together, there is an understanding that in this stage of life one person in the relationship will die and the other will continue to live.

In working to address the narrative thematic meanings and assumptions underneath this story, it is important to examine what the word choice means, and how the relational story builds on the idea and concept of choice for a number of important reasons. The word *choice* often implies some form of selection, or an act where someone chooses between positions. It is important for Ruth to acknowledge directly that she could have chosen to continue with her medical interventions, as a way of demonstrating her agency, and that she knows that she had the ability to choose to continue her treatments, as much as she had the ability to stop them. In thinking further about choices, there can also be a moral dimension with choices, as in an assessment or understanding that some choices are good choices, while others are bad choices. Who judges the moral evaluation of these choices, is often left a bit less clear. Ruth’s shift in the relational story, to the larger medical context of the length of time she had been actively taking these medication and treatments, and how these elements didn’t really help, is one way that she is able to show a rationale, or evidence of how she has come to this choice, and how this fits within a bigger context of her life. Ruth’s choice to not continue treatments is an interesting one conceptually as well, as it widens our focus to the choices that Ruth has been making in taking these medications and interventions over the last number of years, and it also positions her choice as one of *not doing* something, versus actively doing something. The subtle but important distinction between actively doing something, and not doing something, and the idea that in not doing something, or as Ruth says, “I decided to leave it as it is”, re-positions end of life as something that is part of her life trajectory versus something that is be avoided at all costs.

**Dialogic/Performance Analysis: Performance Genres**

In shifting to a dialogic/performance analysis, *Ruth’s transition into end of life – choosing to stop life-sustaining/acute treatments* is shifted from a relational story (Part A and B) to a performance wherein my focus shifts from *what* Ruth and Sarah are saying, to an examination of how the dialogue between Ruth, Sarah, and I, “is interactively (dialogically) produced and
performed as narrative” (Riessman, 2008, p. 105). In transcribing and working with the full relational story I separated the related text into five scenes, wherein each scene holds a particular ‘performance’ around Ruth’s choice. All five scenes draw on text and audio to fully capture the interactive and performance elements within these segments. Each scene has different performers, drawing on a range of voices and positions, and a variety of purposes, and my analysis works to examine and understand what is being performed to whom and why (Riessman, 2008). Please refer to Appendix C for the transcription legend and the full dialogic performance analysis.

Drawing on Riessman’s (2008) process of working with performance genres, I focused first on identifying and examining the direct speech within this performance. Within this performance there are two direct speech lines. The first direct speech line, is performed by Sarah, in her Mum’s voice, “…and she just sort of said, “You know what, I’m done here”. This direct speech line, directly and profoundly reflects the central purpose of this performance, which is Ruth’s experience of ‘being done’, and her need and desire to have others see and support the fact that she was ‘done’. The fact that this line is performed by Sarah, and not Ruth, that Sarah relays this direct speech on behalf of her Mum, further emphasizes the point of how important it is, that others see and acknowledge Ruth’s experience. The second direct speech line, performed by Ruth, in the form of a question ~ “You see?” speaks further to Ruth’s need to have others understand and support her choice. While this question is directed to me, I also believe that she is asking this question of a wider audience, to her family members, to others who may not have ever met her, whether they too ‘can see’, why she made the choices she made. Examining the relational story for repetition, the word know appears seven times, the word choices repeats three times, and the word done, decided, accept and everything are repeated twice. Further, Ruth asks two times “What am I doing here”. Ruth’s question offers another important part of this performance, which is often hidden from view. While there can be significant attention on the act of choosing to stop treatment, this ‘act’ alone\(^\text{19}\), does not always mean there is certainty

\(^{19}\) The notable difference here would be for patients who are living with life supports that are prolonging life, such as ventilators, which when removed can leave the person without vital organ function to sustain life. This said, even in these cases, there can still be uncertainty about how long someone will live after these supports are removed.
and/or predictability about when or how death will occur. The purpose underscoring this performance is to remind us that deciding to stop treatments is only the first part of this process, the second part is living with the unpredictability and uncertainty about what may unfold after this decision. Centrally highlighted within this performance is how Ruth was wrestling with the question of what she was still doing here. Ruth had made the decision to stop treatment, and this choice was made to allow her illness to progress and for her to die. This said, the actual experience of living (while dying), of further deterioration and loss, was very difficult for Ruth, and her repeated question of asking, “what am I still doing here” reflects how she is struggling to make sense about why it is taking so long for this to happen. For Ruth, the length of time between stopping treatment and dying was just less than three months. For others, this time-frame may be quite different, and as we will see when we meet Carrie and Elisabeth later in this chapter, a decision can be made to stop further treatment or interventions, and yet an illness may not progress the way it is anticipated.

The one performance genre ‘aside’ that is present in the transcript is utilized by Ruth, to provide some background about why one of her eyes is mostly closed and how she cannot see out of this eye, and how this is a result of a stroke she had a few years before. Also woven into the performance are expressive sounds and cues, which I have expanded to include noticeable shifts in pitch, quality and tenor of voice, that occur at different points within the performance. Examining expressive sounds and cues offers insights in examining how and when Ruth’s voice gets shaky, or shifts to higher pitches, and how these shifts are connected to particularly emotional and difficult parts of the dialogue. For Ruth, as she tries to recount her medical history and all of her treatments, her voice gets quite shaky, and the stability of her voice reflect how she is clearly shaken by the fact that she cannot recount all of the names of the treatments she has received over the years, and how they unfolded chronologically. Ruth’s need to have Sarah interpret and clarify the names of the treatments is quite difficult for Ruth, as there is a sense that Ruth feels that she should be able to recount this medical history. Further we can see and hear how Ruth’s voice shifts into a higher pitch in certain moments of the performance, particularly when she asks the question about “What am I still doing here?”, and further when she talks about how she is feeling now, in relation to how she felt when she was well. Ruth’s higher pitch reflects the magnitude of emotion and struggle that circulate for Ruth around her present day experiences, and her struggle in articulating this out loud. For Sarah, we see and
hear how her voice shifts to a lower pitch as she talks about her mum’s depression, and it’s difficult to know whether this shift in pitch, reflects Sarah’s process of trying to reconcile how her mother’s previous history with depression connects with her mother’s experience of her present day. Examining performance genres offer an important starting point in identifying who is performing “what to whom” within each performance, and importantly what the purpose is that informs each of these performances.

**Dialogic/Performance Analysis: Dialogic Voices & Multiple Layers of Context**

Building on what has been raised in the performance genres above; I shift to examine the relational voices that are being performed within this performance, both in what is being performed to whom, as well as the purpose that underscores these performances. Further as all of these relational voices are embedded in and across multiple layers of context, I also address: my own context as an interviewer; the context of the palliative care site or program; and how the broader social-cultural context informs the performance and production that unfolds (Riessman, 2008). Prior to this particular performance beginning, Ruth has been talking about her experiences of her present day 20, and as this performance begins, I invite the conversation to broaden to Ruth and Sarah, to try and have an understanding of how Ruth and Sarah are understanding where Ruth is, in relation to end of life. Sarah begins this scene with a strongly affirmative position of: D: *VERY much so [.], I mean, [.] you don’t know Mum’s medical history but some of the, ah, choices that she made were CHOICES that she made to, to not continue with certain medications*. Immediately Sarah presents three core purposes which are threaded through this performance: 1. How I as an interviewer, am an outsider and do not know about Sarah’s Mum’s medical history. 2. How Sarah’s Mum’s choices were/are choices that she herself had made, 3. How these choices were specifically about not continuing life-prolonging medications and treatments. Each of these purposes will be described below.

1. **My position as an interviewer - as an outsider and non-knower**

20 See previous dialogue represented on page 26 in this chapter under Section 4.2.1: Relational Continuum: “Present Day” experiences
How I am positioned within this performance is important not only for what it means about me and how I feel about this (which I will speak to below), but I would argue it is more important because of its bigger purpose, which is to strongly position Sarah, as Ruth’s daughter, within this performance. Relegating me to the outside, focuses my attention (and any general audience hearing this performance) on Sarah, as Ruth’s daughter, as an authorized knower and teller about who Sarah’s Mum is, and how Sarah’s Mum has come to be in end of life. This positioning of Sarah as ‘knower’, ‘narrator’ and ‘performer’ within this performance is important, as it enables Sarah to move within this performance between and across roles. As the performance unfolds, Sarah shifts between providing context and background (as a knower), to one where as a result of her knowing she can speak (as a narrator) to how and why her Mum made certain choices or how she was feeling in certain moments, and further as a result of her knowing and narrating, she can also speak (as a performer) on behalf of her Mum. Understanding all of these positions is important as it makes Sarah’s role and position clear, it legitimizes Sarah’s knowing and understanding, and it also draws on larger familial, social-cultural understandings of how family boundaries are constructed, how family narratives and experiences are shared (or not) outside of the family, and lastly, who owns and controls these stories (Langellier & Peterson, 2004). 

While as an interviewer I could see many of the positions that Sarah was moving within during this performance, and I could appreciate and interpret some of the purposes behind each of these positions, I was also aware of finding some of the boundaries that Sarah created between myself and Ruth and Sarah more difficult. While Sarah’s comment about me not knowing her mum’s history was absolutely accurate, as prior to the interview the only part of Ruth’s medical history that I knew was her primary diagnosis, I also felt that Sarah was demarcating a boundary with me for the rest of our conversation, as I interpreted her statement below, “the details aren’t that important”, as a way that she was communicating to me that Ruth’s medical history was off limits.

M: -I WAS for three [pause], three or four years, three years [pause], four years, [pause] first, they thought that they [pause], before they [pause], ah, heart, ah, oh, [voice shakey], when did they go for first – [Ruth’s voice is shaky and shifts to a higher pitch] …
D: She’s had x issues. The details aren’t that important. (I: sure). She’s had some, x issues (M: yes) so for some years, she was having y treatments, and then she needed to have z interventions (I: OK).

In the interview I found this boundary quite challenging as I have often found it quite helpful to hear how patients and families talk about and understand their medical history. In the interview I remember thinking that I needed to attend to further places in the interview around how I may be positioned as either in or outside of the medical history, context and story, and what the purposes of these boundaries might mean. While not reflected within this particular performance that is being examined within this dialogic/performance section, it was of interest to me that at the end of my interview with Ruth and Sarah, Sarah commented in a form of a performance genre ‘aside’ and said directly to me,

D: I’m actually surprised, in an interested kind of intellectual way that Mum is being as open as she is being, about her stories. Because I always thought that she was, although very open about it, that it was also sort of private. And that, you know, she wouldn’t necessarily talk to strangers, who, after all –
I: Strangers –
D: Although you’re a delightful person, [laughter] you’re a stranger to us.
I: A stranger, of course.
D: And so I’m interestingly surprised that mum is being as open as she is being, because I wouldn’t have expected that at all. And I’m much more private than what I’m seeing, what, you know, the way she’s interacting.

Sarah’s performance at the end of this passage helped to confirm my sense of some of the boundaries that I felt at different points in the interview with Sarah, and raised for me an awareness of how daughters may create a number of different boundaries with me, for a wide range of reasons.

In listening to the audio transcript multiple times, and in labelling and coding the expressive sounds and cues embedded within the performance, I have come to believe that Sarah’s comment ‘details aren’t that important’ was actually not something she was directing at

\[21\] As Ruth’s specific medical issue and the actual forms of treatments she received are not central to understanding Ruth and Sarah’s experience, I have removed the specific medical references, and have instead noted differences in treatments, interventions using ‘x’, or ‘y’.
me at all, but rather was something that she was communicating and performing to her Mum. In reviewing this performance, and really seeing and hearing Ruth’s confusion and distress in not only naming all of the varying treatments but outlining the chronological ordering of how each of these things unfolded, my understanding now is that Sarah used this statement as a way of calming and comforting her Mum’s distress. My sense now is that Sarah said, “the details aren’t that important” as a way to help her Mum re-connect with the main point of the conversation, and to help her Mum get back to more solid footing about what she did know about her experience. Ruth’s strongly emphasized “yes” as Sarah summarized her Mum’s experiences more generally, demonstrated for me, how Sarah’s interjection helped Ruth, as Ruth voice became stronger and clearer after Sarah’s comment. This realization pointed me to the subtlety of communication between mothers and daughters and how expressive sounds and cues can be one way to see relational patterns between mothers and daughters, which may be more difficult to see within the interview itself.

2. Sarah’s Mum’s choices were/are choices that she herself had made

The second purpose that is raised within this scene focuses on choice, and specifically who makes choices, what choices are made, and how choices are made. While there is a definite overlap between this section/purpose on Sarah’s Mum’s choices, and the following section/purpose on Not continuing life-sustaining treatments, I have purposely separated these choices into two different purpose sections as I believe that each section is addressing very different layers and performances of choice. Most strongly positioned within this performance, is Sarah’s performance around her Mum’s choices, and more secondary are Ruth’s accounts of her choices. Within Sarah’s account of her Mum’s choices, Sarah emphasizes how the choices that her Mum made were her CHOICES. CHOICES are within this performance, performed for not only the important purpose of narrating how Sarah’s Mum has made her own choices, but also how these choices reflect broader perspectives that circulate within palliative care sites and programs, as well as broader social and cultural contexts, about patient agency and autonomy. As Sarah is narrating how her Mum has come to a position of making choices about her treatment, it is important that Sarah’s Mum’s choice is firmly positioned as a choice that

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22 Ruth’s performance is much more apparent within the next section/purpose as the context of end of life is clearly outlined
comes from her Mum herself. Ruth, in fact further substantiates this position as she comments, “I COULD have” [continued to take her treatments]. This positioning ensures that I as the interviewer, and the more generic audience, hears that Sarah’s Mum’s choice came directly from her Mum. This position is important, as it ensures that the choices are located within Sarah’s Mum, and there are not assumptions being made (by me or anyone else) that these choices are connected to anyone else. This subtly touches on the broader social cultural context of how personal choices are examined or assessed with extra attention or care, with people who are considered vulnerable or at risk. As Ruth is in her late 80’s and is frail and is losing many of her physical abilities, there is the potential that either myself as the interviewer, or someone else hearing this performance, that we might have (or could have) a heightened attention and awareness in making sure that Ruth’s choices about treatment, are in fact Ruth’s choices, and not as a result of family members being coercive or overly directive. This positioning becomes even more important within this performance, as we find out that within Ruth and Sarah’s family Ruth’s husband and Sarah’s older sister do not agree with the choices that Ruth has made. Sarah’s emphasis on her Mum’s CHOICES are as a result contextualized as choices that are not only her own, but are also positioned as being in opposition to other positions within her family. The issue of choices also offers more context of what treatments Sarah’s mum has finished with. Performed by Ruth and Sarah, this scene speaks to Ruth’s process of choosing to do treatments over a number a years (with little impact), and how after all of this, she was done.

3. **How these choices were about not continuing life-prolonging medications and treatments**

As the performance shifts from Ruth’s choosing to do many years of treatment, and then her choice to not continue her life-prolonging medications and treatments, we shift into the broader context of the significance of these choices, and how these choices are connected to living or dying. In speaking to her present day experience, Ruth shares her experiences after she has chosen to stop treatments, and she intimately and courageously tells us about the significant losses in her abilities, and the many things that she cannot do. Notable is how this scene is the only scene across all five scenes where we hear only Ruth’s voice – powerfully reflecting that this scene is hers alone, and is something that only she can perform. Ruth then shifts to tell us about how her husband responded to her choice to stop treatment, and how upset he was that she had decided to leave things as they were, as in, to let her illness progress. Leaving things as they are, shifts the performance (and ultimate our focus), from a very detailed focus on Ruth’s
choices – choosing – having chosen’ trajectory, to a much expansive understanding of Ruth’s larger life course that has unfolded across eight decades. As part of this life course, Ruth shares her experience suffering from ‘bouts’ of depression over 35 years, and how during this time a doctor always pulled her through – but now - as she agonisingly says, “I am a ruin”. This is closely followed by Ruth’s repeated question of “what am I doing here”, and how her present experience involves sleeping and eating, and how even her appetite is also gone. This leaving us with an understanding that Ruth’s experience of her life is primarily one of sleeping (and not living). As this stanza ends, we are left in the uncomfortableness of seeing, hearing and feeling Ruth’s suffering, and ultimately her unanswerable question of, “What am I doing here”, ringing in our ears.

While earlier in this performance Sarah references Ruth’s experience with depression, it is within this scene and through Ruth’s performance above that we are introduced to the depth and extent of Ruth’s experience with depression. The reference to suffering with depression over three decades begins to unfold a larger understanding of how suffering has been part of Ruth’s life (and her families) for quite some time. Ruth’s choices to stop treatment and the fact that these choices would mean that her illness would progress and that she would die introduce into this performance a whole other layer of choice and decision-making as broader familial, medical and social-cultural concerns emerge about competence. While previously it was important to frame Ruth’s choices as one’s that were her decisions, and hers alone, this becomes more complicated if Ruth’s capacity to make these decisions is raised. How family members, medical care providers and our society define competence or capacity for individuals to make decisions for themselves opens up a much murkier context of choice and decision-making. We are presented with some of the layers of this complexity in how varying positions and perspectives are raised within this performance. This begins in Scene Four, as we begin to get a better sense of Sarah’s position in relation to her Mum’s choices. Prior to this scene, all of Sarah’s dialogue is either descriptive, in telling us about her mum experiences, or is dialogue which speaks on behalf of her mum. For Sarah, her response to her mum’s choices is importantly located within the larger family system, as she positions her response to her mum’s decision, as being ‘easier’ then it was for her father, or her older sister. This description of ‘easier’ is important, as is the context of Sarah not knowing why it has been easier for her. Threaded through Sarah’s performance is how the use of the word easier does not imply easy,
and in fact she makes a point of highlighting within this scene how difficult the process of accepting her mother’s decision has been. Not knowing how or why it has been easier for her also shifts the focus to one which underscores how every family member may have a different position or experience within this kind of situation. This emphasis on differing responses and positions also clearly outlines how important it is for Sarah to ensure that her response is not seen as the *right* or *good* response, but rather is hers alone, and is one that she can position and rationalize for herself. Sarah’s response to her mum’s decision, which is positioned as one that Ruth knows about, is one which focuses on Sarah’s belief that her Mum was entitled to make her own decisions and that only her Mum could feel and know whether the quality of her life wasn’t worth living, and as such that this decision was something that Sarah could not disagree with.

Threaded throughout the rest of this scene is the care and attention that Sarah takes in speaking to her specific position and response. Sarah deliberately uses ‘I’ statements throughout this scene, “how I feel about it…; I do think that…, I wasn’t in any position”, as she offers us her feelings, thoughts, and position, around her Mum’s choices and decisions. The focus within this performance is how Sarah’s response to her mum’s decision is not something that is experienced solely between Sarah and her mum, rather Sarah’s response lives in relation to the rest of her family, as her response is quite different from her father and her older sister’s response. This wider frame to the family is important – as it underscores how choices and decisions which may located within an individuals’ *personal choices*, are also situated within a variety of forms of relationships around the individual and the larger family. Most importantly, Sarah’s performance also locates and positions choices as dynamic which live within and across families, both at the time of the decision, *and* also afterwards. Ruth’s choice is performed as unfolding within a relational process of Sarah knowing and respecting her mother’s process of choice/choosing and having chosen, and how this knowing while difficult (for Sarah, for Ruth, for us as an audience) is also “right”. Ruth’s statement at the end of this stanza, “It’s PURPOSELESS” powerfully and poignantly captures Ruth’s present experience of her life. The last stanza which positions Ruth’s husband, and how he doesn’t understand how Ruth wants to die and he wants to live, positions these forms of choices within differences in mentality, and personality, and in terms of Ruth’s perspective, are differences perceived as “beyond us”.

In relation to how choices about stopping treatment are contextualized within broader social cultural contexts and end of life conversations, it is important to highlight how decisions
about the extent that a person can and should be able to make decisions about when and how they die, are central elements that inform some of the most highly politicized debates that circulate around end of life and end of life rights. These debates reflect challenging philosophical, moral, spiritual, medical and social concerns about who has the power to make these choices, in what contexts, when and how, and to what extent other people are involved in the decisions and acts. While these debates continue and euthanasia and physician-assisted suicide continue to be illegal in Canada (outside of more recent legislation in Quebec), medical health care providers have side-stepped some of these tensions, by differentiating between withdrawing life-sustaining care, and actively hastening or causing death to occur. Withdrawing life-sustaining or life-prolonging care, such as removing feeding tubes, or stopping life-sustaining equipment that is prolonging and enabling someone to continue to live, are in the context of patient goals of care, considered good forms of end of life care. Active care practices that actively hasten or cause death to occur, such as administering a lethal dose of opioids, or a physician giving a patient a specific prescription that would cause the person to die, are in many different contexts (although not all), considered poor forms of end of life care, and are seen as opposite to many of the principles which inform palliative and end of life care. This context is important in relation to Sarah and Ruth’s performance about Sarah’s choices, as Ruth’s decision to not continue with medical interventions, would very clearly fit within a practice of withdrawing life-sustaining care, and as such would be assessed and evaluated as ethical end of life care practices, particularly in how this choice would be considered in the interest of Ruth’s goals of care. As Ruth had already stopped her medication, treatments and interventions when she came onto the Palliative Care Unit for end of life care, Ruth’s decision to stop treatment would have been respected, and care practices would have been positioned around Ruth’s goals of care, and as such the care team would not have been focused on how Ruth made this decision, or her capacity or competence to make this decision. While this offers a very clear medical practice context, this does not address the differences that continue to exist within Ruth’s family about how Ruth has come to be in end of life, and what this means for Ruth, and Ruth’s family as Ruth gets progressively closer to the end of her life.

In summary, the thematic analysis on Ruth’s choice to not continue treatments, emphasizes individual choice, and how individual choices, particularly choices that are considered personal, or within the context or scope of personal rights, are both justified by the
person making the choice (i.e. Ruth situating her choice as one that follows a lengthy choice of doing treatments), as well as evaluated by other individuals around them, around whether someone has the ability or competence to make good decisions for themselves. This connects individual decision-making with individual competence and autonomy. The dialogic/performance analysis shifts the focus beyond the content of what is being said, to what is being performed to whom, and the purpose that underscores these performances. Within this focus, we gain greater clarity about Sarah’s position as a daughter, and the importance for Sarah to be understood and positioned as a knower, narrator and performer on behalf of her Mum. Further we see in this performance how I am positioned as an interviewer, and how I respond to this, and how relationships between interviewers and family members can also represent important boundaries about how outsiders are allowed into the family performance and production about what end of life means. As end of life experiences are firmly woven into palliative end of life care practise and contexts, we also see how broader understandings about patient autonomy, choice, competence and capacity also inform how patients and families experience end of life. Further we see how choices about end of life are not just personal choice, but rather are relational elements which weave between family members, and live on far beyond the actual choice to stop treatment. As family performances are also woven into the medical context of palliative care we also see how personal choices around withdrawing treatment are positioned in particular ways in end of life care practice, and while these positions may make things clear for medical care practice, they may not address some of the tensions that continue to exist within families about how decisions in the past have been made.

Relational Story #2 - Describing the indescribable

Thematic Analysis

The second relational story speaks to the parts of end of life that are difficult to articulate out loud, particularly to loved ones about concerns that people who are dying have about the experience of dying. Ruth notes in the interview that her daughter knows everything about her, and Sarah relays that within their family, things have always been shared directly and explicitly. Physically and emotionally Sarah is very involved in her mother’s care on the PCU. Sarah cuts up her mother’s food, lifts her in/out of bed, walks with her to/from the bathroom, helps her get dressed, and assists her in toileting and bathing. The level of intimacy between them and the
way that care shifts as Ruth’s needs change reflect a level of connection between them that is intimate and relational, as well as flexible.

Particularly relevant to Ruth’s experience of the Holocaust are a number of highly traumatic and stressful moments when she was in hiding, where she had very difficult somatic experiences: incontinence, starvation, vomiting, and severe breathlessness. Ruth is quite explicit and graphic as she shares these experiences, vehemently describing the terror and horror that these experiences held for her. It becomes clear, though, that while Ruth can share some of the terror from the past, it is much more difficult for her to share with Sarah what is terrifying in the present. Some of the somatic experiences that Ruth experienced when she was in hiding can also be common for people who are in the end stages of their life, and over the time of our meetings Ruth was struggling with many of the somatic experiences that she experienced in hiding, particularly around her increasing breathlessness. The links between Ruth’s experiences of the Holocaust and her present day experiences is a critical part of understanding not only what symptoms she is experiencing, but also how she is interpreting and understanding these experiences. Also of importance is how these experiences and symptoms are shared (or not shared) with family members and/or care team members.

As Ruth finishes talking about her specific experiences in hiding in an attic, where she had little air and where she and the others were quite ill and incontinent, I decide to ask her more directly about how whether her present day feelings of not being able to breathe (which she had referenced earlier) remained her of her feelings of when she was in hiding.

I: So that, that feeling reminds you of what it felt like then, (M: yes) your breathing right now.

M: That’s why it’s very hard for me, when I get really out of breath, I think I am dying. Yeah.

I: And you’ve told your care team about that, right?

D: Well, they’ve got her back on oxygen for (I: OK, good) when she needs it, yes. So that was a change. Um, I was here two weeks ago, I left – today is Friday. So I was here until last Tuesday, and then I left and came back yesterday, so that was Thursday. So in that ten-day period she had not needed oxygen before. And so now, when, things are slowly, her legs are a little bit more swollen, she’s a little less energetic. So things are changing and that’s, that’s a little hard.
I: Yeah, yeah, and really important to say that when you feel those things, to make sure that the care team knows that you’re feeling that (D: yes, yes) and that it has this meaning for you. Because then it’s figuring out how do we, how do we help (D: yeah, yeah) with that in terms of the breathing so it doesn’t, isn’t as intense or –

D: Yeah, no, the oxygen is --

My response to Ruth, which I can see in hindsight, is more of a directed statement/question, then a real question, reflects my increasing concern that the care team really needs to know how Ruth is experiencing her breathlessness and what it means for her. My concern about what has been told to the care team or not, is responded to by Sarah, and we can see in the exchange that Sarah shifts to talking about how her Mum is on oxygen now when she needs it, and how this reflects a change from the last time she was with her Mum. The shift in needing oxygen is perceived by Sarah as an indicator of her Mum’s illness progression, and this change reflects that her Mum’s end of life is getting closer. While I hear Sarah about her Mum being on oxygen and how this is difficult for her to see changes in her Mum, I also go back to relaying the importance of telling the care team about how Ruth is feeling and what the meaning of these feelings are for Ruth. Sarah in this dialogue continues to focus on the oxygen, and how her Mum has access to oxygen. The catch in this conversation is that I am seeing how for Sarah, her Mum’s breathlessness is resolved with having access to oxygen. While I do not have formalized medical expertise in breathlessness I have learned in my time in palliative care that how patients experience breathlessness, and the distress that breathlessness can cause, are critical elements in caring for these kinds of symptoms, that oxygen may not resolve. I’m aware that this is a critical place in my study where I am feeling very much pulled between dual roles, as well as the needs of Ruth and Sarah. The following excerpt is from my field journal.

Field Note – Day 3

Today I interviewed Mrs. X *and her daughter ______. It’s hard to know where to begin in starting to reflect on the absolute privilege it was to hear about their lives…. 

A few things were raised in this interview that I particularly want to be attentive to as my interviews continue. In getting a sense of how Ruth’s narrative shifted back and forth from her experience in the Holocaust, and her experiences in present day, I was aware that her experiences of dyspnea** and how it made her feel like she was dying, were interwoven with her experiences of being in hiding during the war. I decided to ask Ruth about this, and to see if the feelings she felt right now, were similar to the feelings she felt then. Immediately as I asked Ruth about this, I felt like Ruth was resonating with this link and that I was beginning to understand what her
breathlessness really meant to her. As I was making this connection though, all I could think about was how important it was for Ruth’s care team to know what Ruth was experiencing, and how her dyspnea is linked to her intense trauma during the war. As I was doing it, I could see myself launching into my ‘clinical hat’ voice with Ruth, damn – I know to be attentive to this in terms of my clinical background, versus my role as a researcher – but I was really concerned about whether Ruth’s care team knew and how every-time she has a hard time breathing Ruth might be reliving all of this trauma. I’m pretty sure I didn’t ask her just once about her care team, I asked twice, and Sarah responded both times to talk about how Ruth was now on oxygen. I was aware that Sarah was talking about what it meant for her to see Ruth’s change in her illness, and while I think I reflected back that I was hearing her, I’m pretty sure I went back again to stress the importance of telling the care team. Hmm – this is important as not only does this reflect a cross-over in my roles, it also feels like a place where I chose to focus on Ruth and her immediate needs, and not Ruth and Sarah together, and this is important – at minimum to recognize when and how I do this, and why I might be doing this….

* In my field note I referred to Ruth throughout my notes as Mrs. X, and I referred to her daughter by her first name. Later on in our connections she asked me to call her by her first name. In this field noted I have inserted the pseudonym for Mrs. X, and her daughter, for clarity sake.

** Dyspnea – is the medical term for breathlessness

Of interest in the interview, is how the dialogue with Ruth about her connections with being in hiding, and her present day experiences, shift her to talk about a recurring nightmare that she has been having, where they are swimming and swimming and she is going underwater and she can’t breathe. This is the first time that Sarah hears about these nightmares, and she immediately asks Ruth why she hasn’t told her about the nightmares.

M: I have those repeating, repeating dreams. They swim, swim and I am going under and I can’t breathe.

D: Oh, Mummy, I didn’t know that –

M: And that’s what frightens me.

D: You didn’t tell me.

M: What?

D: About these dreams.

M: Yeah, probably not –

D: You didn’t have a chance? Or didn’t think of it? (M: yes) No, I don’t know about this. That’s a little distressing. [Research note: It’s not clear which of these multiple questions Ruth is responding ‘yes’ to]
M: I am out of, I am dying because I can’t breathe –

D: Oh, it’s horrible. Do the dreams wake you up, Mama? (M: mmm?) Do the dreams wake you up? Do the dreams wake you up? Do you wake up, like, from a nightmare?

M: Yes, (D: oh, dear) sure. And then I have dreams of my father who, on the xth day of the invasion….

While Ruth is able to be very direct and explicit in her narratives about the Holocaust and the terror that she felt then, she does not tell her daughter or her care team about the nightmares. The nightmares are relegated to a personal part of her experience that she has, whether consciously or not, kept to herself. For Sarah, having her mother experience frightening nightmares is distressing, both because the experience is clearly terrifying and upsetting to her mother, but also because they are happening without her knowing about them. Sarah’s question about whether her Mom didn’t have a chance to share these nightmares with her daughter, and/or didn’t think to share these nightmares with her daughter, also speaks to how Sarah interprets her mothers’ silence. In Ruth’s response, and in her movement from this conversation to other frightening memories, Ruth seems to be suggesting that frightening memories and nightmares are a familiar part of her history, and that she knows that she hasn’t shared all of this with her daughter.

We could speculate that Ruth as a mother chose not to tell her daughter about her nightmares for certain reasons, such as a need or desire to protect her daughter, or protect herself and her daughter in some way. It’s difficult to know all of the elements that might have informed Ruth’s decision to not to tell her daughter about the nightmares. Underscoring this relational story are beliefs and understandings that operate both individually and collectively between Ruth and Sarah that while many things are shared relationally, some things are left outside of this relationship. The absence of connection around these elements builds a more complicated understanding of how and what is shared between Ruth and Sarah, and leaves questions around whether there are other parts of end of life that are not being shared between them.

Ruth and Sarah’s relational stories offer us a way to engage with who they are as mothers and daughters, and how their relationship has unfolded over time. The experience of trauma and loss built through Ruth’s lived experience of the Holocaust has been woven into the relationship between Ruth and Sarah, as Ruth became a living link to what happened to herself, her family,
and to Jewish people during the war. As Ruth and Sarah have developed their own relational understandings of what their shared history, culture, and faith meant to them individually and collectively, Ruth has continued to struggle with living with the memories of the Holocaust. As Ruth’s health continues to decline, she makes the decision to stop treatment, and in this way takes control of the looming threat, by making it a decision that she has come to in her own way. As Ruth’s family works to accept Ruth’s decision to stop treatment, Sarah connects strongly with her mother’s decision, and believes whole-heartedly that her mother has the right to decide when she feels her life is not worth living anymore. This active support of her mother’s decision also supports her mother’s sense of autonomy, and while Ruth is not able to control what the end of her life looks like specifically, it does allow her to stop prolonging her life with medical treatments. While Sarah fully supports her mother’s decision, and believes that this was the right decision for her mother, she is also able to articulate her sadness, and recognizes how supporting her mother’s decision also means that she is losing her mother earlier than she might have otherwise. While there is a deep level of connection and intimacy between Ruth and Sarah, there are also feelings, thoughts, and experiences which are kept outside of the relationship.

Understanding how patients and families navigate, interpret, and find meaning in the movement from active and life-sustaining treatments to palliative care and comfort measures is an area of end of life care where there is still much for us to understand. While holistic and person-centred models of care offer important understandings of the wide range of domains that are interwoven in who we are and how end of life involves all of these domains, there is still much to learn about the actual lived, relational experiences of how families understand, interpret, and make meaning out of these domains. Further still, understanding how patients and families navigate these shifts relationally, particularly when an individual decision about stopping treatment can be seen as the cause or reason for someone dying, is particularly complex and multi-layered, and requires a great deal of sensitivity and care to understand how families interpret how and why they are moving into end of life care.

4.2.2 Mary & Amelié

Mary, a soft-spoken, witty, French-Canadian Catholic woman is in her late 80s. Married for over 40 years, Mary and her husband had 5 children. Amelié is her youngest daughter, and second youngest child. Amelié is a gregarious, humorous, French-Canadian Catholic woman in
her late 40s. Most of Amelié’s upbringing was in a cabin, without water or electricity, on the outskirts of a village. About the cabin, Mary says, “I know I started to live as soon as I arrived there.” The family had a number of very large garden plots that they tended by hand, without herbicides or pesticides, and everyone, including the children, were very involved in helping in the garden, pumping water, and collecting wood. Amelié’s memories of growing up are filled with warm and loving relationships, where the family really worked together.

Throughout Mary and Amelié’s relationship, they have always been very close. Mary notes that Amelié was always very gentle, receptive, and open to helping others. Amelié notes that her mom was also very gentle, and that rather than telling her kids what love was, she showed them, just by being herself. Mary has been healthy for most of her life. Cancer, illness, and loss have woven closely through their immediate family, as Mary’s husband, (Amelié’s father) died when he was in his sixties, and more recently, Mary’s youngest son (Amelié’s younger brother) died of cancer when he was only 40 years old. As Mary had been feeling quite unwell for some time, neither Mary nor Amelié were surprised when Mary was diagnosed with metastatic head and neck cancer. As Mary went through varying treatments and her care needs became greater, she asked Amelié if she would be her primary caregiver. While Amelié was very glad that her mother asked her, and she knew that she would be a good match with her mother, she also found being her caregiver challenging, as she knew how much her mother valued her independence. Amelié is a very strong advocate for her mom and vehemently defends her mom’s rights to make her own decisions about what kind of care she wants, and how she wants this care to be delivered. Amelié has been an advocate and defender of her mom’s wishes with varying physicians and allied health care providers they have met across institutions, as well as with other family members. In the last year there has been some fairly significant tension in the family, due to a serious falling-out between Mary’s three older children and Amelié. This falling-out stems from a communication that was written on behalf of Mary and distributed by Amelié to her siblings, which asked her other children not to visit her while she was so ill. While some repair work has been done between Mary and her older children, there is still no communication between the older siblings and Amelié.

Mary has been on the PCU for just over a week when I meet them for the first time. We end up having our first recorded interview later that week. Our second recorded interview, with both of them participating, is a week later. Shortly after our second interview, Mary’s health declines even further and Mary is no longer conscious. While Mary is unconscious, she becomes very restless and is moaning and writhing in bed. Amelié and the care team decide to shift pain management and palliative sedation options, and afterwards Mary appears to be more settled. For the next number of days I visit Amelié often and we have a number of conversations. In our last conversation, Amelié and I sit on her cot in her mum’s room and we talk about her experience of participating in the study. Mary died late at night 2 days later, with Amelié at her bedside, 21 days after she was admitted.

My First Meeting

I meet Mary and Amelié approximately one month after I met Ruth and Sarah, and as it happens Mary is in the same room on the PCU that Ruth was in for most of the time she was on the PCU. Mary’s bed is on the far side of the room, close to a large north-eastern facing window where
there are a few plants soaking up the sunshine. In front of the window, beside Mary’s bed, there is a small cot with neatly folded bedding and a pillow. Since Mary was admitted, Amelié has been staying with her day and night. As I knock and enter the room, I am aware that the person in the first bed in the room is an elderly man who, given his withered frame, angular position in bed, and facial expression, appears to be unconscious and actively dying. Mary is in bed and Amelié is standing near the head of her mom’s bed. Mary is a petite woman, her face is pale, and her cheeks are somewhat shrunken, but her eyes are sharp and focused and when she smiles, her eyes twinkle and she lights up the room. Mary has short white hair that flows behind a wide striped headband that she wears around her forehead. Visible on the left-hand side of her forehead is a fairly large indentation, which I presume is a site of her cancer. Amelié has shoulder length auburn/brown hair, brown eyes, and a smile like her mother’s. As I begin to talk about the study, a nurse comes in and begins asking Mary a number of questions. The questions are brief and intimate, and they are listed off in quick succession, “How much have you eaten, Have you urinated? How much have you urinated? Have you had a bowel movement? Was it normal size?” As Mary is a very slow and soft speaker, the nurse shifts to ask these questions in French after not getting prompt replies. Amelié quickly interrupts, “Elle préfère parler Anglais” (She prefers to speak English). Not getting the replies she is looking for, the nurse begins answering her own questions, “So yes,” “Normal,” and directs the remaining questions to Amelié. As the nurse leaves, I look at Mary, and say softly, “I’m aware that you were not given the time to answer any of her questions.” Mary looks at me, and slowly says, “It’s...absolutely...humiliating.” While her voice is soft and she speaks slowly, there is a strength and determination that seems to emanate from within her as she talks.

First Interview

Our first interview is rescheduled because Mary has had a number of visitors over the week-end and is too fatigued for us to meet, so we arrange to meet the following day. When we meet for the interview, Mary is just back in her bed from a walk to the bathroom and it’s clear from her flushed cheeks that the walk has over-exerted her. As Mary and Amelié begin responding to my initial questions, the conversational style between them reflects a narrative that is interwoven and reciprocal, reflecting a high level of listening; Amelié ensures there is ample time for Mary to respond in her own time and manner. Amelié is particularly aware of not interrupting her mom, and while she is excited to share her own memories, it is clear she is consciously trying not to
take over in the interview. While Amelié has many stories to share about her relationship with her mom, Mary finds it more challenging to recall specific events. When Mary does remember experiences and events, she politely interrupts her daughter to share her thoughts while they are still immediately accessible to her. The stories that Mary shares range from light banter and teasing to heartfelt moments of loss and grief.

Mary (M) and Amelié (D) - Relational Continuum over time

*Mothering/Motherhood, Daughtering/Daughterhood*

Mary and her husband had five children, and Amelié is their second youngest. From the time Amelié was a toddler, Amelié and her family lived on the outskirts of a rural village in a house approximately forty minutes outside a medium sized city. Mary, in reflecting on their time in this home says

M: It was an old broken-down house [laughter] and we had to bring water from the well to the house. And the children loved everything they saw – butterflies and, huge butterflies I know I started to live as soon as I arrived there. Yeah, it was wonderful.

Their home, while not having running water or electricity, was surrounded by large gardens that everyone in the family tended to, and Mary and Amelié speak about this time of their lives with a lot of joy and tenderness. In speaking to Amelié’s childhood and adolescence, both Mary and Amelié reference in different ways, the limited economic means their family had during this time. Mary recounted how she learned how to make bread, and how she learned to supplement more expensive spices with things that she had growing in her own garden, and how she would prepare for months, in putting food away for Christmas holidays. Amelié talked about how at school her experience was very different from other kids, as she had never had sugary snacks that other kids had in their lunches, and how none of her toys were every new. Throughout all of the references to their economic situation at this time, each story was always followed by an emphasis on how plentiful the joy and love and connection they had with one another, and how particularly for Amelié, she didn’t ever feel like she had ever missed out on anything.

Woven across Mary and Amelié’s relationship is a very strong faith, and both are connected to the Roman Catholic faith and community. Mary shares that when she was young, religion and the church were forced on her, but that as she became an adult, she grew closer to God. Mary shares an early memory that she remembers having at Christmas of crawling into the
cradle that held Jesus when he was a baby. For Mary the cradle personified a feeling of being close to God, of being comforted and supported, and when Mary was feeling vulnerable, she longed to feel this closeness and protection. Amelié remembers nightly prayers with her Mom and asking God as a young child why people were mean to each other, and why they did not treat each other the way God intended. For both Mary and Amelié, there are very powerful relational beliefs and understandings about why things happen in the world, and the importance of trusting that God is always close by to hear and support them. These relational stories are shared and co-constructed between them and as Mary becomes ill, her illness and Amelié’s role in supporting her mom through living and then dying of cancer is contextualized and understood through this shared faith.

Amelié is married and has three children, and one of her children still lives at home. Many of the qualities that Amelié relays she learned from her mother about the importance of love, family and mothering are qualities that she has worked to weave into her own family with her husband and children.

*When Amelié was young*

In getting to know Mary and Amelié it is evident that they are very close to one another and that there is a great amount of love and care that is expressed between them in the form of laughter, and humour, and a gentle bantering/teasing moves between them. While Mary is very soft-spoken and speaks very slowly, her eyes are very expressive and in our conversation I learn to read her non-verbal cues about when she is about to say something. In particular I notice how her eyes twinkle and the edges of her mouth quiver, when she is about to tease Amelié. Amelié is also very attentive to her Mom’s nonverbal signs and while Amelié is excited to share in our interview, she also defers to her Mom, and on more than one occasion Mary interrupts Amelié to ask if she can share a memory, while it is still fresh in her mind. Recalling stories from Amelié’s childhood is a bit more difficult for Mary, and as Amelié is excited to share she begins with one of her favourite memories from when she was quite young.

D: Um, well, for me, ah, one memory in particular is, ah, when my siblings would be gone to school, and, because I wasn’t five yet, right? So, and back then, you didn’t go to pre-pre-kindergarten and, like, it was, you, you started at five, and that’s it. And, anyways, so, I had that time alone with Mom, at home. So every day, Mom would have a nap in the afternoon. We would have a nap, but I didn’t want to. [laughter]

M: the side near the wall, so I know she’d drop off [laughter] –
I: -- oh --

D: Or sometimes she’d drop me off. [laughter] But, ah, it’s, ah, during those, ah, naps, um, that I would, like, Mom would shut her eyes and she’d pretend she was sleeping. And then I’d, ah, I’d play with her hand. I’d just, like, grab her hand and make it fall down. And that would make me laugh, laugh, laugh. I didn’t know if she was sleeping or not. She told me later on that she wasn’t sleeping.

An experience of playfulness is experienced by Amelié in this story, and Mary’s ability to pretend and let Amelié play during her nap time, reflects for Amelié how she and her Mom enjoyed this special time alone together. Mary’s joke about positioning Amelié against the wall in order to know whether she had dropped off the bed, or as Amelié suggests, her Mom dropped her off the bed, reflects the free flowing banter that moved between them.

*When Amelié was an adolescent/young adult*

As Mary and Amelié talked about times when Amelié was growing up, Mary relayed stories of keeping a watchful eye on Amelié, and how it was important for her that all of her children learned to take care of themselves gradually. Amelié worked along with her siblings, in the garden and helped bring water in from the well, and logs in for the fire. Amelié shared how she was quite protective of her Mom when she was young, and how she would intervene with her father, if she felt that he was making her sad. Reflected across the stories from this time is how Mary attended to what Amelié was feeling and doing, and how Amelié was also attentive to what her Mom was feeling and doing. Reflecting on her youth Amelié relays that she was quite shy as a teenager, and that she had a difficult time standing up for herself or for those that she loved. This suggests that while Amelié was protective of her Mom at home, that standing up and protecting herself or those that she loved outside of her home, was much more difficult for her.

*Mary’s cancer diagnosis/treatment and shift to present day*

As Mary was diagnosed with cancer and moved through her treatments, Amelié was very involved in taking care of and advocating for her mom. In reflecting on this time, Amelié felt that God was preparing her for what was going to happen, and helping her become the person she is (and needs to be) today.

D: And, ah, it’s funny, because when I was younger, I was so scared of everything and I would never do that. I would never have, have been able to do that. I guess God, prepared me, slowly. He knew that this scenario would happen. And, ah, so, yeah, um, I
would have never been able to stand up for Mom or stand up for myself before. In high-
school, no.

D: Yeah, but now it’s like, after experiencing this, um, --

M: After what?

D: -- I’m stronger, after experiencing, ah, what we went through.

M: Oh yeah.

D: Together I’m, ah, stronger (M: yeah) and, ah, um, stronger, but in a, ah, good way.

*Present Day*

Mary is finding the decrease in her abilities a lot worse now and is finding that there are many
things that she cannot do, things that are now – impossible. Talking about her experiences shifts
her to make a statement that she is complaining, and Amélié is quick to respond that her Mom
isn’t complaining.

M: I find it worse now, with the, this, ah, cancer, I can’t do the same things. It’s
impossible. I can’t turn, anything, I cannot turn in the bed,

I: You need help, to get (M: yeah) someone to turn you. (M: yeah) Yeah.

M: But that’s complaining.

D: You’re not complaining, Mom (M: no)

Amélié’s youngest child spent a lot of time on the Palliative Care Unit with Amélié and Mary
and I end up having a few different connections with him throughout his visits. He moves
between his grandmother’s room and his Mom’s cot, to the family room down the hall where
there is a television where he can watch videos.

*Future*

The morning after Mary died; I came onto the PCU to find a note waiting for me at the nursing
station from Amélié. The note said:

Dear Pamela,
I had to drive my son (name) back home after he spent the week-end with me and mom. I was scared of leaving because I knew mom could pass away at any moment. So I asked God if he could ensure that Mom waited for me, because I had promised her that I’d be there until the end. Therefore I returned at her side at around 7:30 p.m. God gave me yet another gift, and to mom – he permitted her to pass away 3 hours later with me at her side praying and speaking to her. She drifted away slowly and calmly, not before opening her eyes wide as if looking at me and opening and closing her mouth as if saying goodbye. Thank you for your love.

I was honoured that Amelié left this letter for me to describe her last precious moments with her Mom. Clearly echoing throughout Amelié’s experience of her Mom’s death is a belief that God was with her and her Mom, a shared presence between them, and that he was providing many gifts to both of them as they walked this path together. While the end result of Amelié being able to be with her mom is interpreted as a gift, also present is the fear that Amelié felt in leaving her mom that night, and not knowing for sure whether her Mom might die when she was not there. The tension in needing to be present at the time of her Mom’s death, and not knowing whether she would actually be able to give this to her mom is a powerful experience for Amelié and speaks to the relational contracts and promises that have often been made either explicitly or implicitly between mothers and daughters about the time of death.

This relational story offers us profound insights into how someone’s faith informs their experience, interpretation, and sense of meaning that comes from journeying with someone who is dying. In order to fully hear how Mary and Amelié are experiencing end of life, it is critical that we understand what their beliefs are, and how these beliefs inform their relational experiences of end of life.

End of Life Relational Stories

The first end of life relational story speaks to roles and understandings that were developed between Mary and Amelié as a child, and then later as Amelié became an adult. Drawing on a strong emotional connection, their relationship reflected a strong level of relational awareness, and care and support moved reciprocally between them. Underscoring these stories is an important understanding of how Mary and Amelié connected to each other over time, and how this connection shifted and changed as Mary required more care. The second relational story speaks to protection, and how Amelié understood her role in protecting her mother’s identity and sense of self, and how this unfolded with formal care providers. Supporting documents for the thematic and dialogic/performance analysis are available in Appendix D.
Relational Story #1 - Shifting Roles and Relations within Caregiving/Care-Receiving Relationships

Thematic Analysis

As Mary talked about her experiences as her illness progressed, it was clear that she was frustrated. Mary, who had been strongly independent all of her life, found it incredibly challenging and frustrating to not be able to do things for herself. Given the level of connection and communication that existed between Mary and Amelié, there were a number of conversations between them about how Mary’s need for care was shifting things between them.

M: I find it worse now, with the, this, ah, cancer, I can’t do the same things. It’s impossible. I can’t turn, anything, I cannot turn in the bed by myself,

I: You need help, to get (M: yeah) someone to turn you. (M: yeah) Yeah.

M: But that’s complaining.

D: You’re not complaining, Mom (M: no)

[Later in the interview]

I: …in terms of needing help to do things, (M: yes) how is that feeling for you right now, to need help with that?

M: As long as it’s, um, someone who is compatible, aside from that, um, at first I didn’t, I didn’t like it, being helped. I felt losing, ah, myself. But, um, I’ve grown used, used to it so you can’t fight it.

M: That’s what I used to feel – Now I appreciate it. “Come, come, come”

D: “I want to go pee, please come!” [laughter]

This shift to needing and negotiating care is something that both Mary and Amelié talk about in many different ways throughout our conversations. Amelié notes how she and her Mom would talk about how her mom was feeling about needing more care, and how she would both support and validate her Mom’s feelings about it being hard to need and accept care, while also providing context for her Mom’s current situation. This ability to hold and support her Mom’s experience, while also contextualizing what her Mom needs, reflects how Amelié’s is trying to support her Mom’s sense of autonomy and control, while also fostering a sense of care that is mutual and reciprocal. Mary’s comment “but that’s complaining,” reflects Mary’s discomfort
and ‘dis-ease’ in being in a position where she needs care, and the challenge she has in articulating this out loud. Her statement addresses broader relational narratives which circulate about how care giving should be appreciated, and socially prescribed ways to name one’s experience and frustration that are not negative or as explicit. Amelié’s direct response to her Mom that she is not complaining is also focused on dispelling the notion that her Mom is not allowed or able to name directly what her physical needs are and how she feels about them.

As Amelié talks about how she and her Mom have navigated the shift in care between them, she initially situates her experience in the context of reversing roles between her and her Mom, as she is now able to care for her mom in the way she had been cared for as a child. Interestingly though, she moves this one step further when she share the difficulties she felt in holding what she felt were two contradictory roles: caregiving and protecting her Mom’s sense of self. Amelié shares her experience of realizing that protecting her Mom, what she believes in, and what she holds as integral to her identity also means that she needs to protect her Mom from her need for care, and ultimately protect her from her need for care from her daughter.

Recognizing the dissonance of knowing that she needs to provide care, while also sustaining her Mom’s identity as someone who is independent and does not want or needs these kinds of care, Amelié works to find a way to hold these contradictions:

D: …when I first started to help Mom out, ah, it was strange. Because, ah, it’s hard to explain, because, um, I was, like, my memories are from her helping me. And then having to, um, reverse that, I found it difficult not, not so much because I found it difficult, to do it, but I knew how Mom felt. And it goes back to, um, not wanting her to be sad, or, um, the protective? It was as if I felt I should protect her from, like, me. It’s, it’s, it’s hard to explain. Um, but at the same time I knew I had to, because she asked me to. So there was a turmoil. I don’t know if you can understand what I’m saying. Even though I knew, I knew I was the perfect match for her. But when she had asked me to be her caregiver back then, I said, “Yes.” But I didn’t know – even Mom says she, I didn’t know, both of us didn’t know what my “yes” meant –

D: -- back then.

D: And now I know. And, ah –

I: And what helped you with that turmoil? Like, what switched that in, to make that easier?

D: It’s God. Yeah. And He helped, um, with the people around me –with my husband and my co-workers and, ah, Mom also, ah, when she would say ‘thank you’ and we’d talk about how she felt, you know, and, ah, she felt like, you know, that she didn’t like it
(I: um hmmm) and I’d tell her, “I know, Mom, how you feel” you know. I’d just try to reassure her that I, I knew how she felt but that also I had to help her because she needed it.

**Dialogic/Performance Analysis: Performance Genres**

In shifting to examine this relational story as a performance, both Mary and Amelié are performing their experiences of how they navigated both individually and relationally to a position of needing and giving care. Please refer to Appendix D for the full dialogic performance analysis. The performance genres point our attention to the direct speech, the first two direct speeches reflect Mary’s position in how she shifted to accept and welcome care, “Come, come, come”, which Amelié playfully replies with, “I want to go pee, please come!”

The following direct speech passages, all performed by Amelié, focus on Amelié’s experience of her Mom asking her to be her caregiver, and how Amelié said, “yes”, and yet both of them (as in Mary and Amelié) “didn’t know” what Amelié was really saying ‘yes’ to, or what this would be like for them. This performance then shifts the focus from Amelié not knowing what she was saying “yes” to, towards a relational performance, where both Amelié AND her Mum, did not really know what this would mean for them. Further in this performance, Amelié speaks to the turmoil she felt in shifting to provide care and how one of the things that helped her navigate this turmoil, was her Mom saying “thank-you”, and how one of the things Amelié said to Mary was “I know, Mom, how you feel”. Within the direct speech that threads through this performance we see how asking for help and saying ‘yes’ is a conjoined process which unfolds between and across Mary and Amelié, and how even though Amelié said ‘yes’ there was uncertainty (for both of them), about what this would mean for them individually and collectively. Further we see how one of the things that helps Amelié is her Mom’s ability to see the care she provides by saying “Thank-you”, and one of the things that Amelié relays to her Mom to affirm her Mom’s experience, is to be able to tell her Mom, “I know how you feel”, but that she also had to help her because she needed it.

In examining the performance genre of repetition, we see a heavy emphasis on the word ‘help’ and ‘know’ as these words are used nine times within the performance. Further we see the word ‘felt’, as in how She/Mom felt (used four times), and I felt (used two times). This is followed by I knew, which is used five times throughout the performance. Amelié’s emphasis on what she knew her Mom felt, reflects a strong sense of connection and relational awareness, as
Amelié feels able to speak both on behalf of her Mom, and on behalf of her own knowing and feeling as a daughter, about who her Mom is, and what her Mom is feeling, and thinking about needing care. Lastly, the words need, come, and can’t/cannot appear four times in the performance, furthering the focus on Mary’s needs for someone to come, in the context of all that she cannot do for herself. In looking through this performance, there was not any evidence of performance genre ‘asides’, and in fact throughout both interviews with Mary and Amelié, ‘asides’ are not present at all. Finally, in examining the performance genre of expressive sounds we see, how both Mary and Amelié use higher and lower pitch to emphasize more difficult parts of their experience. With Mary we see this around how talks about not being able to turn in bed, and how this performance is a form of complaining. In Amelié’s performance, we see the challenges and difficulties that she experienced in sorting through and articulating her sense of protectiveness, and how she felt like she needed to protect her Mom from herself, and the challenge it was to put her feelings and thoughts into words, in a way that would make sense to me. Her questioning of whether I understood what she was saying, and the questions that this raised for her around her role and her relationship with her Mom were deeply woven into her sense of herself, and were significant questions for her to be thinking about, and for me to be witnessing.

**Dialogic/Performance Analysis: Voices in Dialogue & Multiple Layers of Context**

Moving further into the dialogic performance analysis, the first scene of this performance is performed by Mary, and speaks directly to what Mary ‘can’t’ do - how there are things that are now ‘impossible’ for her do, such as not being able turn in the bed by herself. This performance, directly and poignantly situates my focus (as the interviewer), as well as other listeners, (as a general audience) on what Mary can’t do, and how the things that Mary cannot do - NOT being able to turn in bed; NOT being able to shift to a comfortable position; NOT being able to roll over ~ are elements of living, that so many able bodied individuals rarely have to ever think about. For Mary this is her life, and for Amelié, this is also her life, as she and her Mum perform for us what mothering and daughtering practices look like at this time of their lives. Below I address: 1. My position as an interviewer within this performance as an active listener and witness; 2. Mary’s personal experience of loss, anguish and suffering are performed (and witnessed) and the limits of how this experience can be fully shared with others and 3. Amelié’s understanding and meaning making of her daughtering experiences over time and what this
means in relation to how care and mother and daughter relationships, are normally performed and produced.

1. **My position as an interviewer - an active listener and witness**

Within this performance with Mary and Amelié I position myself, and am positioned in the role of active listener and witness. I built rapport with Mary and Amelié quite quickly and I felt that both of them allowed me to really witness and be with them where they were.

2. **Mary’s personal experience of loss, anguish and suffering**

While there are many things that Mary could have pointed to that she cannot do, her focus on not being able to turn herself in bed – is profound – ensuring that I as the interviewer, and others hearing her, really and fully understand how much help she requires. It is important for Mary that we hear about what she cannot do, but she also knows that talking in this way can be perceived as complaining, which shifts the focus away from her experiences, to a broader performance about how much of one’s personal anguish can or should be brought into a public sphere. While there is a pause following Mary’s statement, which I believe is reflective of Amelié and I waiting to see if Mary was going to say anything else, Amelié then responds to her Mom that she is not complaining, which Mary and I both confirm. This performance explores how personal experiences of suffering are allowed (or not), to circulate more broadly, and how and/or whether people feel able to really speak to their experiences. There is in Mary’s performance a keen awareness that Mary, and Amelié and I know that there is nothing that can be done to change the situation that Mary is in. As a listener, it is impossible to shift the conversation with Mary towards some kind of problem-solving, or glossing over, or re-framing of her experience, rather her experience is what it is. Our position as a listener and audience to her performance is to listen. This said, while Mary takes up this space and shows us her experiences, there is also a shift out of this position, as she says, “But that’s complaining”. Immediately, Mary’s personal experiences of loss and suffering is shifted from a first-person description that is hers alone (that cannot be fixed or minimized), to a much larger social-cultural context where Mary’s narrative is now positioned as something that can be judged or assessed as to whether Mary is legitimately allowed to speak about her experience in this way, and whether she may be in fact over-extending or exaggerating, or worse-still self-focused and narcissistic.
This worry and concern about how others might hear a person’s experience of suffering, and judge it accordingly, are critical elements that constrain how and or whether people/patients may feel able to share how they are feeling. In a broader social-cultural context, there are often strong messages that personal sharing that may be difficult for others to hear, should be kept to a minimum, and that personal experiences of anguish, loss and suffering belong and should stay contained within the individual. This messaging, powerfully situates profoundly difficult emotions, such as death, dying and loss, within the individual domain of responsibility, and strongly isolates people at a time, when they need other people the most. As Eric Cassell (2004), “suffering exists, and often can only be understood, in the context of others” (Cassell, 2004, p. 34).

3. Amelié’s understanding and meaning making

Amelié’s performance of her turmoil offers important insights into how she as a daughter is wrestling with shifts and changes in her relationship with her Mom, and how her caregiving roles are in direct conflict with previously developed and reinforced roles of advocating and protecting her Mom. There are two important threads within Amelié’s performance that are important to highlight. The first speaks to the larger more all-encompassing narrative of mother and daughter relationships, and what a daughters’ role is in relation to her mother, and what this role means as a mother becomes ill. The second, which is interwoven with the first, is how daughters’ roles change over time, and what these changes mean for mothers and daughters in relation to the overall purpose, meaning, role and responsibilities of being a mother or a daughter. Strongly woven into North American values and beliefs about individualism, the primacy of the nuclear family, capitalism, and health and wellness, are critical messages about the role of daughters within families, the role of daughters economically, and most importantly the primary role for daughters in caring for their parents as they become ill. These messages have become normalized to such a degree that many adult daughters do not feel like they have a choice about whether they are a primary caregiver or not. Further, the emphasis on care as isolated and discrete care tasks which are performed from one person to another, do not acknowledge the reality of how care is experienced within relationships built over time between the care giver and the care receiver.
While a mother is well, such as we see with Mary and Amelié, Amelié’s role with her mother is one where she is very close to her Mom, she attends to what her Mom is thinking and feeling and she protects and advocates on behalf of her Mom. The challenge as we see reflected in Amelié’s performance around turmoil is how this relationship adjusts to care practices that may be quite opposite to the values and beliefs of the Mom when she was ill. The individual and relational turmoil Amelié speaks of underscores the importance of why socially prescribed understandings of care which focus on the present-day task-oriented elements of caregiving, miss the centrality of understanding how care unfolds within relationships that for mothers and daughters includes a life continuum of relational understandings and experiences. Further, the focus on normalizing care practices in a way where care is something that one does for or /to another, centrally misses how care practices are relationally performed and produced and can powerfully shift understandings of autonomy, power, dignity and self-hood in ways that are relationally quite complex. Being in a position of caring with and for one’s mother, lifting her, dressing her, helping her bathe, cutting up her food or helping her use the toilet are profoundly intimate acts that are deeply emotional, physical, relational and social. How mothers and daughters enter into these shifts within their relationship, and how they both experience and understand what these shifts mean has profound implications for how the practices of mothering and daughtering are experienced between mothers and daughters.

**Relational Story #2 - Protecting and Maintaining Who Mom is**

**Thematic Analysis**

As Amelié speaks more about her experiences protecting her mom, she begins to talk about how she sees herself protecting her Mom with care providers in varying care institutions. After probing to get a fuller sense of what protecting her Mom looks like, Amelié talks about ensuring that her Mom’s voice is heard and understood, as sometimes her mom has had a hard time articulating her needs with different care providers. She also refers to searching out and finding the care providers and getting them to tend to her mom, when her Mom needed care and it wasn’t being delivered. An important part of her role is also ensuring that her Mom is not forced into things, as sometimes she felt that doctors and social workers wanted to force her Mom into things that her Mom did not want. Amelié describes a particularly difficult moment she had with
a doctor about her Mom’s ability to make her own decisions and how she felt when he suggested that it was not just her Mom making the decisions.

D: And one doctor once, um, because she had been in the hospital many times and, ah, one doctor, he came and, ah, said, “Well, you have no choice but to accept.” He wasn’t nice in the way he was saying it. And, ah, I asked him exactly what he meant by that. And, um, I said, “It’s my mother who decides what she wants and what she doesn’t want.” And then he said, “Well, partially.” He was – I didn’t like him at all. And then, um, when I got upset, I raised my voice, you know, and I told him, “It’s not you who decides. It’s her.” And he started laughing --

I: Oh, my goodness --

D: Yes, it’s rare that I get angry. But I pointed my finger at him and I said, like, “Don’t you ever laugh at me again. It’s her that decides.” And then I walked out.

D: Um, I saw him after I had calmed down. But, um, she, she got the help later on, but when she was ready. And it was, like, a little bit at a time.

In Amelié’s narrative she then talked about how she feels that decisions within hospitals about care and how things unfold are based on normative beliefs and understandings of what all patients with varying stages of illness should receive, and how this process lacks the specific contextual elements that make each person a unique case, with specific needs, experiences and expectations.

D: It’s, it’s – you know, I know her. And they, they look at pieces of paper, you know, and “Oh, this person should receive this and that when, in this case and this scenario.” Yeah, well, that’s on paper. But a human being has decisions that they make for themselves and they want to live their sickness a certain way. And it’s different for Mom, it’s different for someone else. But it’s OK. It has to be respected. And sometimes I didn’t feel like they respected that.

Threaded throughout the interviews is a recurrent emphasis on the importance of people being able to live their sickness in their own way and how her role is to ensure that her mom is able to live her sickness in the way she wants. This response to the normative beliefs and understandings that exist around what all patients should do, and the implicit messages that family members can hear about what is ‘best’ for the patient, offer an important way of understanding how Amelié sees her role with her mom. The role of protecting her mom’s beliefs and thoughts was a priority for Amelié and she felt that one of the main reasons there was a big falling-out with her older siblings is because they did not respect her mom’s wishes for how she wanted to live her illness.
D: And my, my priority was always Mom. And it didn’t matter what I felt about it. It didn’t matter what they [other siblings] felt about it. It was what Mom felt about it, because I’ve always felt like it’s her sickness, it’s her body, it’s her life. And she’s always followed what God wanted. And I would too, and that’s all. And when it comes to Mom and her, protecting her beliefs and her thoughts and what she wants, that’s the priority and nothing else.

As I listened to Amelié talk about protecting her mom’s wishes, and the importance of her mom making her own decisions about how she lived her sickness, I found it difficult to tease out the elements of Mary’s experience of her illness that were Mary and Amelié’s together from the elements that were seen as Mary’s to hold, and Amelié’s to support. I decided to ask Amelié directly, “And what about you, (name), I’m hearing that it was important for the doctors to hear what your mom wanted, but what about you, what was important for you.” Amelié stops, and there is a pause and she says, “I don’t quite understand what I’m supposed to answer there.” I quickly move to say that there isn’t a correct answer, but that I’m trying to get a sense of what was important for her, as a daughter, as a person who is also very much a part of this experience. Amelié notes, “Oh, I felt better when they were able, when I saw that, um, the doctors and nurses responded to what I was saying [about what her mother wanted].” In this response, I took away a sense that Amelié’s role of knowing and protecting what her mom wanted was of the utmost priority, and that Mary’s thoughts and wishes were prioritized over any that Amelié might have on her own. This is further emphasized as Amelié talks about how she has a strong reaction, when messages are given that care and decisions about care should involve the family.

D: Standing up for what Mom wanted. Because it had nothing to do with, um, sharing. I, I don’t get that – they always say someone’s sickness is, has to be, like, you have to consult your family members, or, or, like, at the [name of local hospital], it’s um, it’s always in there, this sentence about you have to ask your [family] – no, you don’t. It has nothing to do with anybody else.

I: umm, in terms of decisions about care?

D: Yeah, like, how the person wants to (M: yes) live their sickness.

This reflects for me a place where understanding the relationship between patients and their families is absolutely critical. One interpretation of Amelié’s response is that she has lost her sense of self/identity and that she is enmeshed with her mother’s needs and wants. A second interpretation, and one that more accurately fits for Mary and Amelié, is that in her relationship with her mom, Amelié highly values her mom’s sense of self and what is important to her, and
from this place, she has decided that what is most important is for her to support her mom’s ability to make decisions for how she wants to live her sickness. This support of her mother’s decision-making is a shared belief and understanding and, in the context of their mother and daughter relationship, reflects a continuation of a strong mutual and reciprocal relationship. Amelié’s clear support for her mother’s decisions also ensures that Mary’s role and identity as a strong, independent woman and mother continues until she dies.

In summary, Mary and Amelié have developed a very strong reciprocal relationship between them, and have found important ways to navigate and bridge potentially conflicting roles of protecting from and caring for/and with each other as Mary’s illness has progressed. In examining Mary and Amelié’s performance, we can see how Mary’s ability to speak to her personal experiences are constrained by broader social norms about what parts of personal experience are shared more broadly. Further we see how Amelié’s turmoil in providing more care to her Mom, requires her to reconsider fundamental purposes, meanings and responsibilities of who she is in relationship to her mother. How Mary and Amelié navigate these changes offers tremendous insight for the strong level of communication, relational competence and awareness that is required for mothers and daughters to integrate these changes while still maintaining and prioritizing their identities, roles as experiences as mothers and daughters. Finally, Amelié’s prioritization of her mother’s needs, particularly in relationship to formal care providers, demonstrates how Amelié actively works to sustain and maintain not only her mother’s sense of self and identity, but also the mother and daughter relationship, as she ensures that care providers see her Mom as a person, and not just another piece of paper. It is essential as a result, that formal care providers take the time to build relationships with family members, so that they have a sense of the family history and family relationships that have been built over time. Understanding how family members, and particularly daughters, are understanding their roles and what is important to them to maintain for their mothers’ in end of life, offers critical insights about how relational care practices need to be respected and attended to throughout end of life care.
4.2.3 Marian & Pam

Marian & Pam

Marian, a warm, family-focused woman, is in her late 60s. Born shortly after the Second World War, Marian was the eldest in her family, followed by a sister who was nine years younger, and another sister 11 years younger. Marian says, “I was the older, floundering one.”

Marian and her husband have been married for 42 years. Marian has two daughters, her eldest from a previous marriage who is in her mid-40s, and Pam in her early 40s. Both of Marian’s daughters have kids; her eldest has three boys and Pam has a daughter that is 4 ½ years old. Marian is very close to her daughters and her grandchildren, and as they all live locally, they see one another regularly.

Marian has always been quite healthy, and as her parents lived until they were quite elderly, Marian thought that she too would live a long life. As Marian’s husband had varying difficulties with his heart, Marian thought that she would outlive her husband. In the fall of 2011, Marian found a lump on the side of her face near her ear, and was initially told that the lump was an infection from one of her earrings. Only after the lump didn’t go away did an ultrasound confirm that this was something more serious.

On December 16th, 2011, the family was told that Marian’s tumour was cancerous and required surgery. Due to the holidays and her surgeon’s vacation, Marian was not able to have surgery until January 21st, 2012. Marian notes that while she doesn’t blame the surgeon, the lump grew to 3 times the size during this time, and they do wonder whether she might have had a better outcome, if she would have had surgery earlier. After the surgery, the surgeon relayed that he was not able to get the entire tumour out without making things very uncomfortable for Marian to live with.

Since this time, Marian shares that she has been on a rollercoaster. She moves from good days to bad days, and feels like she never knows what is coming next. Pam and her sister are very involved in Marian’s care, and they pick up groceries, make meals, and have gone to all of Marian’s medical appointments.

Marian has been on the PCU for four days when I meet Marian and Pam. Marian was admitted on the PCU for acute palliative care as her pain and symptoms were very hard to control at home. I interview Marian and Pam shortly after we first meet. Marian is discharged home eight days after she is admitted to the PCU. As Marian is being discharged Pam says, “It was really good that we came here, we didn’t really know how to help my mom when things got bad at home and now we have a better sense of how to help her.”

First Meeting/First interview

I interviewed Marian and her daughter on the same day that I met them. As I knock on Marian’s door and slowly enter Marian’s room, Marian and her daughter are sitting in club chairs just to
the right of the entrance. Marian is in a private room, and her bed is on the far side of the room near the window. In the 3 ½ months I have been meeting mothers and daughters for my study, all of the mothers I have met have been in bed. Dressed in slacks, a short sleeved shirt and shoes, and sitting beside her daughter in a chair, Marian does not convey the same aura of illness as other mothers I have interviewed. Her ‘street clothes’ and her separation from the hospital bed disrupt the usual illness ‘cues’ in the PCU. Marian is a petite woman with short grey hair; Pam is taller than her mom, has shoulder-length dark brown hair and looks a fair bit younger than the other daughters that I have met so far. Marian has a large microphone sitting in her lap that is connected to a hearing device in her ear. Marian relays that she needs the hearing device to hear anything, “Without it, I’m dead, I can’t hear anything.” Since being admitted to the PCU, Marian’s husband and her 2 daughters have been taking shifts, so that Marian has someone with her day and night. Marian’s husband has been staying overnight in the easy chair in the room, and Marian says that he is awake most of the night, sitting in the chair or wandering the halls. Pam shares that tonight; she and her sister are sending her dad home to sleep. As so many patients struggle with the cacophony of call bells that go off all day and night on the PCU, having constantly interrupted sleep is something that many patients and families talk about when they are on the PCU. In this instance Marian’s hearing is a small blessing, as she hears nothing when she takes the hearing device out of her ear.

Marian (M) and Pam (D): Relational Continuum over time

Mothering/Motherhood, Daughtering/Daughterhood

Marian has two daughters, her eldest daughter from a previous marriage, was quite young when Marian met and fell in love with her husband. Marian and her husband have been married over forty years, and Pam and her older sister are very close. Pam’s older sister is married and has three children, and Pam is married and has one child. Marian is very close to both of her daughters and her grandchildren, and shares, “Yeah, yeah, no, we have a good relationship, (D: yeah) even better as they’ve gotten older (D: yeah) and they’ve gotten their kids and (D: yeah)”.

While Marian’s husband has been ill throughout the years, Marian has always been quite healthy, and she and the rest of her family were quite shocked when she was diagnosed. Marian says that when she received her diagnosis, it was like a “bomb went off.” After she received the ultrasound results, she moved from surgery and then into various chemotherapy and radiation
treatments and she felt like “things have just rolled like a tumbleweed.” A big part of the context for how Marian and Pam are presently experiencing their time together, and specifically their time in palliative and end of life, is informed by the shock and confusion that this has happened to them in the first place. The experience of shock and disbelief weaves its way through Marian and Pam’s interview, and the interview is filled with a lot of emotion, tears and unfinished sentences. Both Marian and Pam are clearly struggling to integrate and digest the unthinkable, that Marian will die. For Pam, a critical part of her experience is how she hadn’t ever even seen her Mum sick before, so to see her so ill now, shifts everything she thought about her family and how she thought her Mum would always be there.

D: Yeah, I never thought, I’ve never seen my mum sick. [laughter]
I: Ever? Yeah.
D: She’s a, she’s –
M: No, I’ve never been sick, other than a cold –
D: Even if she has a cold, she’ll never show it. I mean, I don’t think I ever saw you, in forty years –
M: -- sick --
D: -- sick in bed.
I: Really?
D: Like, if she had a cold, she would just keep going. (M: yeah)
D: And never complain, ever – she just took care of everybody, and just kept going. And I just thought that, [laughter] I thought that it would be always –
M: That I would go on for a while, too – yeah, I did too.

When Pam was young

As Marian and Pam shared stories about when Pam was young, stories of Christmas time emerged, in picking ‘just the right tree’, and organizing presents, and Pam’s Dad capturing Pam and her older sister’s faces as they came down and saw the Christmas tree and their presents on Christmas morning. Marian shared a story about Pam when she was quite young, and how she had put a macramé bead up her nose, and how once Marian discovered this she and her husband had to rush Pam to the hospital to get it removed. They were able to remove the bead with a pair of tweezers and Pam was ultimately fine (as was Marian despite being very scared), and this ‘bead’ story was clearly part of the family lore and provided a lot of laughter for the family.
M: It’s one thing that I always remember, of, of you, a lot of [laughter] other little things, but the beads were, we laugh about that now, (I: yeah) when we [laughter] thought of it –

As Pam talked about her memories of her childhood, and her relationship with her Mum, she shared stories of special trips into the city, seeing certain tourist sites every year, and enjoying chocolate malt with her Mum and older sister, just like Marian used to do with her grandmother when she was young. Pam shifts from the fun memories to stories of how her Mum was always there for her and how when she was young she would pretend to be sick so that she had extra time with her Mum.

D: And just – well, those were the fun things, but I also remember she was always taking care of us. (I: mmm) Constantly. [laughter] (I: um hmm) And sometimes I would just pretend to be sick, because [laughter] (I: oh) I could stay home from school.

I: You wanted to be at home?

D: She’d always put us on the couch downstairs and put the TV on. And she’d just spoil us for the day. [laughter]

I: Oh, that's lovely, that's lovely. (M: yeah)

D: She was always –

M: My little girl –

D: -- there to take care of us. [laughter]

I: That’s a lovely memory —

D: She was good at that. (I: right) Yeah.

Woven through these stories is a warm, loving connection between Marian and Pam, and as they sift through these stories there are both humorous bits, and tender reminders of Marian “always taking care of” Pam, and Marian’s reference to Pam as “My little girl”.

*When Pam was an adolescent/young adult*

As Pam shares more of her early memories of her mom, she talks about how her mom was always there for her as a child and how she felt she could tell her mom anything, even if it meant keeping secrets from her Dad. Marian also notes how important it was that her kids knew that they could come and talk to her about anything.
M: Well I always wanted them to know that they could come to me and they could talk about anything. I don’t care if it’s sex, if it’s cigarettes, if it’s drugs – well, hopefully not drugs, [laughter] but if, relationships, anything like that, I wanted them to be able to feel free to be able to come to me and talk to me about it and, um, that’s what we, (D: yeah) I’ve tried to do with both of them.

This reflects strong relational beliefs and understandings between Marian and Pam, about how Pam could tell her anything, and how her mom would support her and be there for her. As Pam became an adult, this shifted into relational beliefs and understandings that were about shared communication between them, and how important it was for them to be open to one another. In addition to being open and available to her daughters, the other important message that Marian taught her daughters was the importance of being independent. It was critical for Marian that her daughters learned to “fly from the tree and look after themselves,” and that they were not dependent on her. Marian says how proud she is of her daughters and how they have done a wonderful job looking after themselves and their families.

M: I said I hope I’ve brought them up to be able to fly from the tree and look after themselves. That was my goal, (D: yeah) that they weren’t dependent on us and that they could live their lives. And that was important to me, that they know how to fly and look after their kids. And they’ve done a wonderful job. I’m so proud of them.

D: You did a good job. (M: eh?) You did a good job.

M: I tried. (D: mmm) Anyway, sorry.

Notable in the above passage is how Pam responds to her mom’s feedback by affirming how her mom did a great job parenting, which Pam needs to say twice for her mom to fully hear. Marian’s reply that she tried also seems to suggest that she tried to do a good job, but is not absolutely confident that she did a good job. Through this part of the narrative we see relational beliefs and understandings that emphasize both strong connection and independence, and how between Marian and Pam there is a strong bi-directional relationship, as they both seek to affirm each other about their roles.

Present Day/Future

A tension that arises for Marian revolves what she wants in the time she has left, and how this might conflict with some of the other messages that she has given to her daughters about being independent and taking care of themselves. In asking Marian what it is that she wants in her time left, Marian notes that she just wants to be with her family. This request though is quickly
followed by concerns that she does not want to put additional stress on her daughters, and that she has taught them to be independent and that they therefore need to take care of their responsibilities with their own families and careers.

I: …what is the most important thing for you right now?

M: To be together, yeah, yeah. I don’t care if anybody else comes. I just want my family around me.

M: I don’t want to pressure them, to feel that they have to come. You know, they’ve got families of their own. As I say, I taught you to fly from the tree, and I don’t, I know it’s difficult, but you have to, you have to have your job. You can’t lose your job. (D: yeah)

M: …because I worry about them taking, having to take so much time off and I don’t want them to lose their jobs or anything over me.

D: We’ve told her not to worry. [laughter]

Quickly following Marian’s statement about what she wants in the time ahead, is a concern that she is putting too much pressure on her daughters, or making them feel like they have to take care of her, and how this directly contradicts the messages she has given them about being independent and taking care of themselves. While this echoes the worries and concerns that many patients feel about being a burden on their family, it seems that as Marian links her concerns with her teachings about independence, that perhaps one of the motivating factors for Marian’s daughters to be independent and ‘fly from the tree’ is an underlying sense that she as the mother (the tree) may not always be there for her daughters. This indirect reference to the loss of a mother, and the importance of daughters being independent and able to take care of themselves, is one of the first places in this study, where there is an early reference to the importance of the mother and daughter relationship holding the fact that the loss of each other is part of the relationship. This said, this loss, however much Pam may be independent, is deeply difficult for Pam and Marian.

End of Life Relational Stories

In the end of life relational stories below, two different stories are shared that reference different forms of communication and action. In the first story, Marian shares a little more about her experience since her diagnosis, and she specifically shares a story from when she was last in hospital. Within this story, Marian shares how in an exchange about her illness with a hospital doctor, how the doctor told her (and her kids), that she had about three months to live. Hearing
this news absolutely stuns Marian, as no one has told her anything like this before. The story continues about how Marian’s family responds to this news, and further how her family physician responds when she relays what she has been told. The second relational story speaks to Marian and Pam’s experience participating in the Canadian Cancer Society’s Relay for Life, and how this event was an important even for both of them to ‘stand up’ and say something about cancer. Both of these stories speak to how an end of life prognosis ‘live’ within and across individual and relational and social contexts, and the importance of patients and families finding ways to communicate for themselves, what these experiences mean to them. Supporting documents for the thematic and dialogic/performance analysis are available in Appendix E.

**Relational Story #1 – Communicating Timelines**

**Thematic Analysis**

A few months prior to coming on the PCU, Marian spent twenty days as an in-patient at a local hospital. While she was in hospital, and while her family was with her in her room, she had a conversation with one of her doctors about her illness. This doctor told her that she had maybe three months to live. This hit Marian and her family very hard, as no one had told her/them anything like this before.

M: And it’s just been a nightmare ever since. Just a nightmare. It’s hard when they tell, like, when I was in the hospital the last time, and (the doctor)*23 came in and the kids were there. And I said something about my illness, or whatever, and (the doctor)* said, “Well, you have maybe three months.” I just about fell out of bed. Nobody had told me that.

M: And the kids were, (I: mmm) the poor nurses, they kept coming in and backing out, they didn’t know what to do, and everybody was crying and I said, “You’ve gotta be kidding,” And (the doctor)* said, “No,” (the doctor)* said, “I’m sorry, but that’s it.”

There are a number of things going on in this narrative that reflect how Marian and her family responded to the physician giving her this timeframe. In Marian’s reference to the conversation that she was having with the physician, it does not appear that she was in anyway asking the

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23 To maintain confidentiality of both doctors that were originally noted in the transcript using gender specific pronouns, these have been removed from this passage so all references are gender neutral as (the doctor).
doctor how long she had to live. While it is possible that Marian had made reference to future events that the physician felt needed to be corrected or contextualized, it does not seem like Marian had been looking for a timeframe, nor was she expecting this kind of response. Marian’s response of “You’ve gotta be kidding” reflects her shock at learning about the timeframe, and her inability to absorb what the doctor has said. For Marian, the other big part of this particular experience is how her kids were overhearing this conversation, and how they as family were emotionally responding to this news. Marian’s reference to the nurses coming in and then backing out of the room also speaks to how aware Marian was of the larger medical context, and how even the nurses did not know how to cope as her family responded to this news. Marian continues to talk about how her family physician responded, when she told (the doctor) what the physician in the hospital had said to her and her family.

M: And the doctor [family physician] was mad, because (the doctor)* said, “You can’t say that to anybody.” It’s him [motioning to heaven] that’s going to decide what’s going to happen, you know. (The doctor)* said things have taken a bad turn but that’s not to say we can’t get it under control, or (the doctor)* can’t fix it.

The doctor’s anger and response that no one (other than God) has a right to tell someone when they might die, and (the doctor’s) contradictory message that things were not going well but that they might be able to fix or get them under control, also reflect the contradictory messages that Marian and her family are receiving about palliative and end of life. All of these messages then swirl around the family, as they work to integrate not only Marian’s diagnosis of metastatic bone and lung cancer, but also what this means around how long Marian has to live.

**Dialogic/Performance Analysis: Performance Genres**

Please refer to Appendix E, for the full dialogic performance analysis.

The direct speech within Marian and Pam’s performance is extensive, and reflects how Marian’s style of narrating and performing is very interwoven around specific speech acts and meanings. Marian’s direct speech begins with her own voice, and how she tells her husband that she doesn’t want her husband to say anything about her diagnosis to her daughters. As the direct speech relays, the daughters know something was wrong, and a back and forth unfolds between the daughters’ asking to know what is wrong and Marian denying that there is anything wrong. This direct speech, emphasizes Marian’s position of ‘not ruining’ a family celebration. While Marian
is able to hold to this position, her husband is not, [perhaps something that she astutely thought might happen, and is foreshadowed in her first direct speech where she says to him “Don’t say anything”). Pam has her own remembrances of this account, and they are reflected in Scene 2A, to more fully capture how Pam experienced her Dad saying, “Your Mum has a tumour”, and how these words continue to echo deeply within Pam. This form of ‘not telling – but ultimately telling’, is juxtaposed with an entirely different form and style of communication, as a doctor tells Marian and her family that she has, “maybe three months” [left to live]. The doctor’s statement absolutely shocks Marian, as no one had ever told her this – in this way, or in relation to how her illness was progressing. This experience of ‘telling’ is then further complicated as Marian shares her family physician’s response to what the doctor in hospital has said, and how the doctor states, “You can’t say that to anybody”, and he further counters with, “Things have taken a bad turn but that’s not to say we can’t get it under control”. While the direct speech within this performance is plentiful – the performance is highly emotional and charged, as the direct speech appears to capture multiple-voices, as well as Marian’s, as she performs this piece.

In examining repetition, it is perhaps not a surprise that the most repeated word in the performance is said (relayed fifteen times), followed by something (said seven times), wrong (said five times), the words can’t, didn’t and always were said three times, followed by the words nothing and bomb which were both repeated twice. There are no performance genre ‘asides’ within this performance. Expressive sounds/cues reflect the emotional tenor and tone that are surrounding Marian and Pam as they continue to reel from the shock (bomb exploding), of Marian’s diagnosis. Both Marian and Pam struggle to communicate at different parts of this performance, and yet both remain steadfast in continuing and ensuring that I as the interviewer, and as person who works in palliative and end of life care, really hear their pain, sorrow and anguish as they try to put into words what their lives have been, since Marian was diagnosed.

**Dialogic/Performance Analysis: Voices in Dialogue and Multiple Layers of Context**

Within this performance, the primary thread of the performance is performed almost exclusively by Marian, and yet the performance is polyphonic as we hear Pam and her older sister’s voice and concern, Marian’s husband, and then in the hospital, the voice of the doctor, followed by the voice of the family physician. Within each scene we experience different levels and layers of protection – Marian’s with her husband, and then with her children, and how each person is
positioned in relation to the medical ‘knowing’ about Marian’s prognosis. Below I address 1. My position as an interviewer as an empathic observer. 2. How knowing is performed and operates within families, 3. How knowing and truth-telling is performed and operates within medical, end of life care practices.

1. My position as an interviewer - empathic observer

In reviewing the performance to examine how I positioned myself, and how I am positioned, my perception is that I am able to position myself as an empathic observer, and I feel within this performance that both Marian and Pam allow me to share and witness: their continued shock, and disbelief about Marian’s diagnosis; their emotional rawness and vulnerability in speaking to what is happening between them; and their tenderness and compassion in being with one another at this time of their lives.

2. How knowing is performed and operates within families

Marian’s daughters intuitively know and continue to ask what is going on, even amidst much denial. This offers us insights about how families protect, and how some experiences that are perceived as harmful or in tension with other family happenings are verbally tucked out of sight. This said, strongly performed within this performance is how knowing operates within families, and how families watch and interpret non-verbal cues to try and get underneath verbal denials, to get to the truth. Truth though within this performance is nebulous, as it’s unclear in the performance of the doctor, whether the doctor is positioned as speaking an ‘un-doctored’ truth, or whether the doctor is positioned as a care provider stating facts and figures that have no real certainty or truth in the matters of life and death. Both offer important insights about the broader medical context of how and in what ways physicians in particular, and yet I would argue this extends to all care providers, have knowledge and expertise that is shared with the patient and/or family, that may or may not meet their needs. The performance and positioning of the doctor saying, “No, I’m sorry, but that’s it” in response to Marian’s response of ‘You’ve gotta be kidding”, further widens the distance that exists between Marian’s experience of her life and this doctor’s prognosis. This performance of shocking communication is then widened to the wider background, as Marian draws our attention to the nurses coming in and out of room, and backing out when realizing that, “everybody was crying”. Marian’s performance seems to reflect two
different messages, one is the humour of nursing come in and backing out and not knowing quite what to do, which is quite opposite from how nurses and nursing behaviour may generally be perceived, the harder message that also seems to emerge, is how care providers can be perceived as coming and backing out, as the family crumbles inside the room.

3. How knowing and truth-telling is performed and operates within medical, end of life care practices

The hospital doctor’s performance followed by the family physician’s reaction of anger and incredulity, further questions who can give a prognosis, and what can or cannot be said to a patient about their life course. The family physicians’ last statement about recognizing that Marian has “taken a bad turn”, affirms that it is undeniable that Marian is not doing well, and that perhaps she may even be dying, but the doctor is positioned as focusing on how this bad turn does not mean to say, that “we can’t get it under control”. Of interest in examining the performance more closely is how there is a glimpse of Marian as ‘narrator’ in the very last part of the family physicians direct speech. Marian seems to end the family physicians direct speech with “we can’t get it under control”, and she follows this with, “or he can’t fix it”. The last part of this sentence, “or he can’t fix it”, seems in re-listening to the audio, positioned less as direct speech and more as a side reference to something the family physician may also have said, but which Marian herself may not actually believe.

The different positions of physicians within this performance points to the variability that exists in end of life care, and how there are considerable differences in how end of life conversations happen between and across medical specialities with patients. The polarizing of positions between the hospital doctor, who may or may not have been a palliative care doctor, and the family physician reflects some of the broader tensions that operate across medical care practice sites, around what patients and family members are told about their advanced diagnoses and what this means for their life expectancy. Many models of palliative and end of life care that are operating across Canada, place a considerable amount of emphasis on palliative care consultation services and programs working directly with family physicians, and building good relationships so that education and practice knowledge about palliative and end of life care can be interwoven into primary level care. This said, medicine’s broader emphasis on curing illness
and actively treating illness until there is absolutely nothing left to do, can mean that patients are not told directly when their illness is progressing, and when they may be getting closer to death.

**Relational Story #2 – Shining a Light Together: “Get up and Show Your Strength”**

**Thematic Analysis**

As Pam and Marian talk about their relationship over time, Pam talks about pretending to be sick as a child, so that she could have a special day with her mom. Her mom at these times would make up a bed in the living room, and pamper her all day, and she felt like her mom always knew that to do, and what to say to fix things. Since Marian’s diagnosis, Pam has felt quite helpless, and a number of times in the interview she talks about feeling helpless and just wanting to do something.

A few months before Marian was admitted to the PCU, the family decided to participate in the Canadian Cancer Society - Relay for Life. At this event, the whole family walked the survivor lap together, and this was an incredibly meaningful experience for both Marian and Pam. The day of the relay the weather was quite cold and it took a lot of effort and determination for Marian to participate. When I asked Marian why it was so important for her to participate in the survivor lap she said,

M: Yeah, I did that, and I managed – it was a horrible day. It was cold, it was raining, it was awful. But I said I want, I have to go to this. I want to be there. And so we did. And we walked as a family, the first round. I would have loved to have stayed, but I – it was so cold, and I just couldn’t stay. (D: yeah) I hadn’t been feeling good up to then, so – but it was something I really, really wanted to do. So we did that, and it was good. We got all the pictures and everything, it was really nice.

I: What made it so important for you to do that lap? (M: mmm?) What, what was it about that lap that was important for you to do?

M: Just to show that you can try and get through this. You know, that it doesn’t have to be the end and you can get up and show your strength, and try and, you know, even (Pam’s young daughter) came until eleven o’clock. [laughter] Little trooper. (D: yeah) Even my husband took a different perspective of it, once he was there. All the way out, he was ready to turn around and go back. He was worried, he said, “You’re going to get sick, it’s raining, it’s cold” and, you know. And I said to him, “(name), this is something that I have to do for me. I want to do it.”
Pam and her sister had created a team of eight friends who came together to raise money for the relay, and they raised over $1,400. When I asked Pam why it was important for her,

I: And what was it like for you to be in that relay?

D: It felt really good to do. And it was, I just, ah, I just feel like I have to do something. [daughter crying]

M: Yeah, they worked hard on it, and they hauled all these, they light up these, what they call luminaires, and you put from, who it’s from, and the kids all sign them.

M: ‘My grandma rocks,’ that was it –

D: It was a special day –

The Relay for Life created an opportunity for both Marian and Pam to do something to actively show their strength against cancer, and what cancer was doing to their family. The relay became something that they as a family could do together, to actively create a counter narrative to how much cancer had taken from them. Marian’s determination to participate, even though it was cold and she had been feeling quite poorly, superseded everything, and her participation, as well as her family’s participation with her, offered the family as a whole, a way to actively do something that was about living, and not just succumbing to the disease.

In summary, the relational stories that are apparent in Marian and Pam’s relationship speak to relational communication which is strong, open, and always accessible. This is closely followed by a very strong relational belief and understanding about independence and the importance that Marian placed on Pam and her sister to be independent and to take care of their responsibilities and their families. An important element which informs Marian and Pam’s present relationship is the shock that has come with Marian’s diagnosis. For both Marian and Pam, the diagnosis of metastatic cancer, and the more recent prognosis where Marian was told that she had about three months to live have been very challenging for the family to accept. Within this context they have also been given very different messages about palliative and end of life care, as Marian’s family physician still offers hope that things might change and he might be able to fix things.

Dialogic/Performance analysis shifts our attention to how knowing, protection and truth-telling operates within families, and how families navigate across these boundaries. Further, dialogic/performance analysis widens our focus to how knowing and truth-telling is performed and operates within medical, end of life care practices. Lastly, walking as a family in the Relay
for Life a few months earlier was a very important experience for the whole family, as it offered
Marian a way to show her strength and to show her family that it is possible to try and get
through this. It also offered Pam a way to raise money, and actively do something at a time when
she has otherwise felt very helpless.

4.2.4 Carrie & Elisabeth

Carrie – Elisabeth

Carrie is a sensitive, loving, family-focused woman in her late 70s. Carrie was married for 56
years, before her husband died, a little over a year ago. Carrie and her husband had three
children. Elisabeth, Carrie’s eldest child, is a warm, nurturing, compassionate woman in her late
50s. Carrie and Elisabeth have a very close connection and Carrie remembers from the moment
she first saw Elisabeth as a newborn, feeling an instant bond with her. Carrie remembers
Elisabeth being a very sweet child, and that even as a young child she was ‘motherly’ and
nurturing to her younger siblings.

Carrie first became ill when she was in her 40s, with a back injury which was followed by a
diagnosis of Polymyositis, a persistent inflammatory muscle disease. Elisabeth, who was an
early teenager at the time, remembers her role changing, and needing to take on more
responsibility in the home. At the time, Elisabeth didn’t feel like these responsibilities were
stressful, “You just, you know, somebody’s sick, you step up,” but she does remember having
questions about her mom’s illness and worrying about her. While Carrie and Elisabeth are very
close, they have also had moments when things have been more challenging between them.
These differences have resulted in both shorter and longer time periods where they haven’t been
in touch.

A number of years ago Carrie had a hip repair surgery, which was followed by a number of
different complications. Since this time, Carrie has been in and out of a number of different
acute and complex care institutions. During this time, Carrie’s husband and her children were a
strong support for her.

In the past two years there have been many compounding losses for Carrie. Shortly after Carrie
was finally well enough to move back home, Carrie’s husband was diagnosed with advanced
cancer. Not able to care for Carrie and himself, Carrie was moved by herself into a retirement
home. A little over a year ago, Carrie’s husband died at home. Carrie misses her husband
dearly, and she notes repeatedly in our conversations that she doesn’t want to live anymore
without him. Carrie’s health has also continued to deteriorate, and given her multiple infections,
she had her right leg amputated. The surgery though was not a success, and she regrets the
decision she made to have the surgery in the first place.

As Elisabeth is a nurse and a daughter, she has often felt like she has had to walk a fine line
between wanting to make sure that her mom receives the best care, while also knowing that she
isn’t the one providing the care. Overseeing her mom’s care, and helping her mom problem-
solve situations around poor care, is a big part of how she spends time with her mom. While
Elisabeth appreciates that part of her role is to take on these roles, what she most hopes for in the
time they have ahead is to find snippets of time where the two of them can connect meaningfully together, to both reminisce as well as to really connect together.

After Carrie’s last hospitalization which was a little over 7 months ago, Carrie was discharged back to her retirement home with the Home First program. Through Home First, Carrie was provided with 60 days of care for up to 8 hours of care each day. The care that Carrie received through Home First was seen as essential for Carrie’s physical, emotional, and social needs, as Carrie has been completely bed bound since she returned to the retirement home. The 60 day Home First support ended in March 2013. Since this time, Elisabeth has arranged through her mother’s estate to privately pay for her mom to receive the same level of care that was provided through Home First. Elisabeth did not feel like she could remove this level of care, as she felt that this would have been cruel and inhumane, given that this level of care provision was her mother’s whole world.

**First Meeting/First Interview**

After connecting with Elisabeth over the phone, we agree that she and I will meet in the lobby of her mother’s retirement home, and then head up to Carrie’s room together. I meet Elisabeth in the lobby and she and I sit down to have a brief conversation before we go up to Carrie’s room. Elisabeth has shoulder length blond hair, a fair complexion, and while her eyes are bright, they are also surrounded by a light pink hue, carrying possible signs of fatigue and stress. Elisabeth is just back from holidays, and while the holiday has been restorative, it has also provided enough time away for her to be feeling the weight of how much is on her plate. In the busyness of work, family, overseeing her mom’s care, and other family concerns, she had been able to push some of these feelings away, but taking a break seems to have invited some of these feelings to the surface. It is clear in our conversation that the loss of Elisabeth’s dad (Carrie’s husband) just over a year ago lingers close by and that grief and loss and other family tensions are tightly woven into the present day experiences of Carrie and Elisabeth’s relationship. As we go up the elevator to Carrie’s room I am struck by how fundamentally different the atmosphere is in the retirement home compared to the Palliative Care Unit. Some of the differences speak to physical lay-out, as the lobby feels like something between a condo and a hotel, as it has a large reception area where Elisabeth signs in. More specifically, though, I am struck by how many people in the lobby are actively moving around doing everyday tasks. People, both younger and older, some with wheelchairs/walkers/scooters and some without, are coming in and out of the building, and there are a number of people juggling, baskets of laundry, bags of groceries, leads with dogs etc. I am struck by how the everyday-ness of living, doing tasks such as these, are not apparent in the Palliative Care Unit, how these elements are stripped away, and in focus are people in bed, or
people being assisted in or out of the rooms, and not people doing things which are associated with independent living and being.

As we arrive on Carrie’s floor, we walk by a number of white doorways, all marked with the name of the person living within the room. We arrive at Carrie’s room and Elisabeth knocks and we enter. Carrie is in a hospital bed in the middle of the room. The head of her bed is raised, and her wavy short white hair rests against a soft light pink pillow case. The pink from Carrie’s bedding and her pajama top, which is pink and covered in small delicate flowers, offer a lovely dose of colour to her room, as the rest of the colours in the room are quite muted. As I comment on the loveliness of the pink surrounding her, Carrie smiles and says softly that she and Elisabeth have always liked pink. Beside Carrie’s bed is a white board that relays the schedule for the day, the times various support workers are arriving and leaving, and how things will unfold each day. This schedule, while not really needed by Carrie anymore as she knows her schedule and the names of all of her care providers, unfolds as a central part of both Carrie’s life as well as Elisabeth and Carrie’s relationship, as attending and keeping on top of this schedule is critical. As we begin our conversation, Carrie notes that we have 30 minutes, as then she has a support worker coming in, and she does not want to keep her waiting.

Carrie (M) and Elisabeth (D) – Relational Continuum over time

Mothering/Motherhood, Daughtering/Daughterhood

Carrie and her husband had three children and Elisabeth is their eldest. Elisabeth, married twice, has three children as well. For Carrie, her understanding of how she cares for her daughter is deeply woven into her role as a mother, and as someone who have lived “and battled” with illness for many years. For Elisabeth, her understanding of how she cares for her mother is deeply woven into her roles as a daughter and as a nurse. Between them they have had a very close relationship, and while they have had their ‘moments,’ they have over the years experienced a form of care that is bi-directional and reciprocal, as they both have provided, received, and shared care. As Carrie’s health has declined over the years, Elisabeth’s focus has been on doing her mother justice, and on ensuring that her mother receives the proper care and love. For Elisabeth, doing her mother justice involves a number of layers which examine and critique the level and extent of care she is able to give to her mother individually; the care her siblings and other family members are able to provide; and how other care providers provide
care. Teasing out some of the different layers of ‘doing justice’ is important here, as there are layers that speak to specific elements of mother and daughter connection between Elisabeth and Carrie, and there are layers that speak to wider familial and formal care relationships. This said there are challenges. Elisabeth struggles with prioritizing her own growing health needs over her mother’s needs, with weighing the costs and risks in intervening around care that does not meet expectations; and ultimately in seeing the parts of her mother’s suffering that she knows she cannot fix or take away. All of these challenges circle around as Carrie makes decisions to stop surgical interventions and amputations and Carrie and Elisabeth are left trying to resolve what doing justice looks like for both of them.

*When Elisabeth was young*

As Carrie shares stories about Elisabeth when she was young, she notes, “*she was a sweet little girl...who in relation to her younger siblings* was sort of motherly, *even at that point*”. Elisabeth resonates with her Mum’s description of her ‘maternal side’ and Elisabeth shares stories about how she and her siblings would mimic this in their play. While many of these memories are one’s which are warm, nurturing and humorous, Elisabeth also remembers finding it quite difficult when her younger sister went to kindergarten and Elisabeth was told that she need to be less protective of her younger sister, and how she had to let her be her own person.

D: But I also remember when my sister went to kindergarten. You know, how I wanted to be the big sister and, um, watch out for her. And I do remember the kindergarten teacher, um, I think, I think she was the one that discussed it with you [her Mum]. And then you [Mum] discussed it with me -- that I had to lay off and let her be her own person and, ah, stop trying to, ah, direct and guide. (M: yeah)

I: Right – well, it’s a hard thing to learn (M: yeah) when you’re young --

M: When you’re the oldest --

D: I remember something like that, and I was devastated. I just thought, how could they, you know, say that I had to do that, that I had to change, right? [laughter]

*When Elisabeth was an adolescent / When Carrie became ill*

Elisabeth has a deep respect for her mother, and over the years it has been quite important for her to have a sense that she is pleasing to her mother, and that she is doing enough as a daughter.
D: Yeah, I think, I think there’s always been a close-, like Mum describes it as a closeness in our bond, in our (M: um hmm) mother-daughter bond…I’ve always had a respect for my mom and what her thoughts were and …how she perceived me, you know? I always wanted to be able to please her as a daughter.

M: Um hmm, right, that’s true.

D: I always wanted to --

M: And she did –

D: -- to be pleasing to you, and so I don't know if you knew that.

M: Pardon?

D: I don't know if you knew that. Like, I wanted to have your approval, that I was, (M: yeah) that I was enough –

M: I guess so, yeah –

D: And that carried over to my own, um, (M: um hmm) looking at myself, not as a daughter but as a mother, too. Am I doing enough? Am I, I always had that kind of question –

Initially in this narrative we see Elisabeth talking about her respect for her mother, and how she remembers being interested in knowing what her mothers’ thoughts and perceptions of her were, and that it was important to know if she was pleasing to her mother. Carrie responds to this by saying, “…right, that’s true”, followed by, “And she did.” Elisabeth at this point moves the narrative from a conversation about herself and her needs to ask her mother a direct question about whether she knew about Elisabeth’s needs to be pleasing. In the shift between talking about herself to asking her mother a direct question there is some confusion, and Carrie asks for her daughter to repeat what she just said. Of interest here is that in repeating her questions, Elisabeth actually shifts her initial comment about being pleasing, and her mother’s perception of her, to something slightly deeper, as she adds, “That I was enough.” Carrie’s reply at this point is a little less committal, “I guess so, yeah-” and then Elisabeth moves into sharing how this question of “Am I doing enough” has followed her into her own family. Of interest within this narrative is that there is a shared understanding between Elisabeth and Carrie, that Elisabeth wanted to be pleasing and that she cared deeply about her mother’s perception of her. Where there is less of a shared understanding is when this deepens to a question of Elisabeth’s worry or concern of not just doing enough, but whether she is enough.
D: Um hmm. And yes, you know, if you were in hospital for something, of course I was right there, you know.

D: Part of it was wanting to make sure, wanting to make sure that everything was, was as good as it could be. (M: yeah). And then there were times where I felt I let you down. Sometimes I felt I let you down, (M: how?) you know, sometimes, just with your, ah, --

M: How, dear?

D: When you were in [name of other institution], you know, that I didn’t visit more there, and --

M: I never thought of that--

D: -- be there more for you, and --

M: No, I never thought of it that way at all.

D: Dad was there twice a day --

M: I know --

**Present Day**

In recounting previous health issues, Elisabeth is trying to take stock of her role as a daughter, and where she was able to support her mother, and the places where she felt she let her mother down. While Carrie is able to reply that she didn’t feel let down, Elisabeth’s ‘proof’ or evidence that she let her mother down comes from comparing herself to her father, who was able to visit her mother twice a day. Later in the interview, Elisabeth moves to name more directly how important it is to do her mother justice.

D: I just want to do you justice, because you deserve to --

M: You did, you have done me justice.

D: And I want to -- and you know how much I love you.

M: Well, I know that, definitely…

Following this conversation Elisabeth moves the conversation towards naming the emotional pain that she sees her mother experiencing as a result of a recent estrangement between Carrie and her two young children, Elisabeth’s younger siblings. This family estrangement seems to
have come about as a result of how Carrie and her husband’s estate has been divided up, and it seems Carrie’s two younger children (Elisabeth’s siblings) feel like Carrie has not been fair around how things have been divided. Of specific interest here is how Elisabeth highlights what she sees her mother feeling, and the limits around what Elisabeth feels she can and cannot do to help ameliorate this pain.

D: And I just want you to have everything that you deserve as far as, you know, the proper care and the proper love. And your emotional pain, like I said to you, I think this week, that that is something I wish I could take away from you.

M: Yeah, I wish I could give it away, too.

D: But it’s not mine to take away. (M: no) And if I could take it away from you --

M: You would, definitely.

D: I would take it away from you. (M: yeah) And that’s mother heartache that you’re feeling. That suffering bothers me.

M: I know, and it bothers me that you have to go through it all with me.

D: I don’t --

M: I really feel badly that my family have to see this happen.

I: Your family have to see

M: Me suffering and you feeling upset by it, and --

D: But I don’t – it doesn’t bother me. It bothers me that you have to go through it, but actually, you know, like, I feel like I can help you in ways that I am helping you. (M: yeah) And, but I can’t help with your heartache over the rest of the family issues.

M: Yeah, that’s tough.

D: And those are the ones that, those are the ones that really upset me.

Here we see Elisabeth articulate what she wishes that she could do to help her mother and the limits she feels around what she can and cannot do. Elisabeth is articulating what she would like to do and affirming the help she actually provides, but she is also articulating her limits around what she can do. This offers her a way to witness and support her mother’s pain, without having to do anything else with this.
In our second conversation, as the talk continues to circle around Elisabeth’s question of whether she is doing enough, I decide to take a bit of a risk and ask Carrie directly whether she feels Elisabeth is doing enough for her. In Carrie’s response she not only directly responds that Elisabeth is doing more than enough, she also notes how she sees that because Elisabeth is doing more than enough, that she is actually making herself ill.

I: Can I ask you a question about (Elisabeth)? (M: yes) So, one of the things, when we first started our interview the last time, (Elisabeth) talked about really wanting to please you. (M: um hmm) And that was really, really important…do you feel like she’s doing everything?

M: Oh, always, she’s pleased me, yes. Certainly. We’ve had our moments, where we’ve had little arguments and stuff, but it always got mended.

I: Yeah. And is she doing everything she needs to do to care for you right now?

M: Oh, my goodness, yes, more than enough. She’s making herself ill doing it.

I: Do you, do you hear that?

M: It’s true.

D: I’m fine. (M: mmm?) I’m fine.

M: You always say you’re fine, but I know when you’re not fine.

D: I know you know when I’m not fine, so I can’t, I can’t, [laughter] I can’t not --

I: There’s no hiding there --

D: -- not hide it. (I: yeah) Thank you, I cannot hide it. (M: yeah). She used to say, “I know if you just want a day off school or if you’re really sick, because [laughter] I can tell in your eyes.”

The last section of this narrative is quite important as Carrie notes that she knows her daughter is getting sick because she is doing too much care for her, and she also knows that when she talks to Elisabeth about this, that Elisabeth will tell her mother that she is fine, when she is not. What is interesting about this is that Elisabeth does not deny this, that she acknowledges that her mother has a way of seeing through her hiding. The larger context behind all of this is that Elisabeth is not well and that she needs surgery to repair a pre-existing health issue, and that her doctor has just put her on medical stress leave. These things have not been communicated directly to Carrie, but it seems she knows anyway. This story above is important, as it offers important insights about how each mother and daughter have their own beliefs and
understandings about their roles as mother and daughters and how these roles, developed over time, may be powerfully interwoven with worries and concerns about not ‘doing enough’ for their loved ones. Understanding how these beliefs have been constructed, and understanding how mothers and daughters navigate what they believe they should do, and how they understand the limits of what they can do, offers important insights for how mothers and daughters communicate their needs, and how they can take care of themselves, while also staying in relationship. Situating these experiences in a broader social context of how daughters are socialized to be ‘good and pleasing,’ and how girls and women are inundated with messages to provide care selflessly and without limit, is vital if we are to understand the inner conflicts and turmoil that daughters (and their mothers) may be experiencing as they reach their own limits of what they can provide.

End of Life Relational Stories

The two end of life relational stories that are examined below address mothering and daughtering and roles and responsibilities. The first relational story speaks to the extensive roles and responsibilities that daughters and mothers may have in ensuring that good care is not only provided, but that good care is provided over time. The second relational story speaks to how mothers and daughters may have different, and competing, needs and wants in end of life. This second story reflects some of the profound and difficult differences that can arise relationally when a mother wants to die, and her daughter wants more time. Supporting documents for the thematic and dialogic/performance analysis are available in Appendix F.

Relational Story #1: Relationally Overseeing and Managing Care

Thematic Analysis

As Carrie and Elisabeth talk about their roles caring for each other, and how they understand these roles, it becomes clear that a significant amount of their individual and relational time is spent overseeing and managing all of the people involved in Carrie’s care. Elisabeth refers to this as her ‘business role’ and shares how she supports her mother by helping her mother oversee and manage her care.

D: we have to do the business part of it, [laughter] you know, we have to. Because that’s my role, is that I have to be Mum’s advocate, although she is very good at problem-
solving herself. But she needs some reassurance or just be pointed in the right direction, sometimes, to navigate, right, the right person. (M: um hmm) But you’re very good, you know, you remember the names of your care givers better than I do. But that, it just, um, so I don’t mind being there, you know, reviewing. What’s good, what’s not good, um, I don’t review too much what’s good, because it just goes unsaid [laughter] maybe what’s not meeting Mum’s expectations and then we try and problem-solve that. Because we’re just so grateful for everything that is good (M: yeah)

There is a strong emphasis within Elisabeth’s narrative on how her mother is capable and able to advocate for her own care. Elisabeth understands her role as one who listens to her mother’s concerns and offers reassurance and direction, so that her mother feels supported in navigating and negotiating her care. This emphasis on shared management of care is important, demonstrated by how Elisabeth moves from an indirect sharing/narrating voice describing things about her mom, “But she needs some reassurance,” to a direct conversation with her mother about this, “But you’re very good, you know, you remember your care givers better than I do.”

Also notable in the above passage is how often Carrie and Elisabeth are managing care which is not meeting expectations; as Elisabeth notes, they do not review care that is good, as “we’re just so grateful for everything that is good.” This emphasizes how most of what they are reviewing and talking about is how to problem solve care that is not at the level that they expect.

In our second interview, Elisabeth talks a little more about her experience of overseeing her mother’s care and the stress that she feels when she has to navigate conversations about care with other care providers.

D: it’s been a huge, um, undertaking on many levels. And maybe even more so, because of me being a nurse. I want to make sure that she’s receiving the utmost, best care. But at the same time, I’m not providing that care. And I don’t want to rock the boat when the care might not be what I see up to the quality that I would like. But it’s not a bad quality. But there’s a fine line you walk, because one, they’re from a different discipline than what I am. And then also they, um, I don’t want to create a conflict where they won’t be as receptive to giving good care to Mum. It’s a very fine line, that sometimes you don’t want her care to be compromised.

There are a few pieces in what Elisabeth is sharing that are important to highlight. The first piece is how Elisabeth being a daughter and a nurse makes her more attuned to the challenges in navigating care concerns with other care providers. The second piece speaks to the challenges which exist in talking about care that is not meeting expectations, but that is not of a ‘bad quality.’ This raises questions about whether there is a sense that it is quite appropriate and legitimate to raise concerns about ‘bad care,’ but that these mechanisms are not in place for
raising concerns when care is not as good as it could be. This carries a number of important beliefs and understandings and it helps us see that Elisabeth is trying to balance what her expectations are for what she feels her mother needs and deserves, with the knowledge that it is highly possible that her mother will not receive this level of care. Lastly, Elisabeth talks about the costs and risks associated with initiating any concerns that she might have about her mothers’ care, and how these could result in her mother receiving poor care.

In asking Carrie about her experiences in overseeing her care, she moves to talk more specifically about her overall assessment of the care, rather than talking about her experiences of overseeing her care. She notes that her care is “mostly good….pretty good” and how she likes things to be on time and organized, and how most of the time it is. She then moves to talk about a specific relationship she has with a care provider that is particularly ‘special’ and what makes this relationship different from the others.

M: -- By the way, (name of care provider) was asking for (about) you.
D: Oh, that’s nice.
M: They’re all nice, but she’s special. Yeah.
I: And the things that make her special…what are some of those things?
M: She’s caring and gentle. And she’ll stop and say, “Are you OK, are you OK?”
Well, some, most of them don’t do that.
I: They don’t.
M: I shouldn’t say most of them, but some don’t.
I: …so they don’t take the time to check in on how you’re --
M: No, they don’t, yeah --
I: -- how you’re doing.
M: Yeah, that’s right. On the whole, my care is good.

Carrie feels respected and well cared for by this care provider as she will stop and check-in with Carrie about how she is doing. This care provider is also connected to the mother and daughter relationship as well, as she asks Carrie about Elisabeth. While this care provider is clearly close and special, Carrie is hesitant to generalize to what most of her care providers do or do not do,
and even after noting how special this care provider is, she makes sure to end with the statement, “on the whole, my care is good.”

I was curious about Carrie’s experience and understanding of her role overseeing her care, as I was quite struck in our conversations about how Carrie attended to time, and how she responded when our conversations overlapped with her care schedule. This attention seemed to be about overseeing and knowing her own schedule, and it also seemed to be about navigating relationships with each of these providers. The risk that she could upset one of her care providers if she kept them waiting suggests that Carrie feels responsible to each of the care providers, and that she needs to attend to their needs, as well as her own needs for care.

M: I’m looking at the time and I don’t want (name) to get upset we’re keeping her waiting.

D: She won’t get upset –

M: It’s half an hour now.

D: Is it?

I: OK, I guess it is. (M: yeah) You’re more on the clock than I am, yeah.

M: I have to be.

D: But you’re so fine-tuned -

M: It’s a job, trying to remember everything, so --

While Carrie is noting the work that goes into remembering, overseeing, and managing her own care, she is also quite hesitant to say that this work is worrying or stressful for her. Elisabeth, on the other hand, feels quite differently, and believes that her mom is quite worried and stressed about overseeing her own care.

D: I do think Mum spends a lot of time stressing over your care, though. I do think you stress over it, because almost every day there’s a conversation, something about the care. And it’s, whether it’s just stressing over who’s coming to replace a person who’s normally scheduled for that time, or whether, she can fit in...the dressing changes (which are) not a regular basis, but every three days. So it was very difficult to get everything else in, on those days. And also, especially in the evening, Mum’s always, you’re always pretty stressed ’til you know who’s on here. For when you’re one-on-one here --
M: Well, I handle it better, though, with (Elisabeth)’s help. Because she’ll tell me, she’ll discuss with me, well, you can’t stress over and the good parts, about whether I’ve got the assistant that does such a good job, that’s here to help, that one that’s not always here. She’s filling in.

Here Carrie moves to focus on how she is handling the stress better, and how Elisabeth is able to help her discuss things, and see the good parts, like care provision from relief workers who do a good job. Between them we see that overseeing and managing care provision is a job that requires a great deal of energy and creates significant worry and stress. Notable across Carrie and Elisabeth’s narratives is how both of them are overseeing and managing the worry and stress of negotiating good care, and in addition how this lives between them, as they both try and find ways to be with each other relationally in these shared roles. For Elisabeth we see how much she values her mother’s autonomy and decision-making and how she walks multiple fine lines as a daughter, and as a nurse, to try and ensure that her mother receives the best possible care. We also see how important it is for Elisabeth that her mother’s decisions are upheld and respected. For Carrie, we see how much she tries to individually manage and control her own care, and how she works to ensure that she is fair in her assessment and evaluation of her overall care. We also see how Carrie values her daughter’s role and advice, and how she sees her daughter’s role as one that helps reduce her worry and stress, and helps her see the good things that also come as a result of shifts in her care. All of these nuances are important, as they move away from more traditional understandings of how care is experienced, which tend to focus more on the physical care ‘act’ (e.g. bathing, dressing changes), towards the larger context of how care is relationally delivered and to the people who provide care and how they relationally connect (or disconnect) with the people they are caring for. Larger still is the context of how this care is scheduled, how multiple care providers are administratively and logistically scheduled to provide a certain act of care at a certain time or date, as if care practices are interchangeable across care providers, and how patients and families are often left managing the impact and costs of these shifts and changes.

Dialogic/Performance Analysis: Performance Genres

Please refer to Appendix F, for the full dialogic performance analysis.

In examining the performance genres utilized within this performance it is notable, how little direct speech there is within this performance. The one direct speech that does appear, appears at
the very end of the performance, and is performed by Carrie, in Elisabeth’s voice relaying, “well, you can’t stress over” [care]. This direct speech line is profound in its positioning, as the rest of the performance is about the stressors of overseeing and managing care. In examining words used within this performance and repetition, the word care appears ten times, and the word good, nine times, further reflecting the strong emphasis within this performance on navigating good (and not so good) care. Further, Elisabeth relays four times ‘I don’t’ in varying forms of minding, or wanting to rock to boat or make things more difficult, while Carrie uses it once, to interject and end our interview as she says, “I don’t want [name of personal support worker] to get upset we’re keeping her waiting”. Other words that appear repeatedly throughout the performance, right (six times), stress (five times), appearing four times are: know, have, and always. Finally appearing three times are the words control and help. There are no performance genre ‘asides’ used within this performance. In relation to expressive gestures and cues, lower pitches and higher pitches in voice seem to correlate with the emotional tenor of the conversation for both Carrie and Elisabeth. Carrie’s performance, “I have to be [ G-Exp-higher pitch]” in relation to her need to oversee and attend to the time and when her varying caregivers arrive and leave, offers a particularly poignant performance of how Carrie understands her job in receiving care.

Dialogic/Performance Analysis: Voices in Dialogue and Multiple Layers of Context

Within this performance there are a number of different individual and relational voices being performed, which speak to how Carrie and Elisabeth are overseeing their own and each other’s care needs and responsibilities. Elisabeth’s voice strongly permeates this performance, and Elisabeth shifts between talking to me as a narrator/describer, to talking directly to her Mum. This seamless shift between talking about and then talking to, seems to capture Elisabeth’s need to have her Mum hear certain things, and for the interview to be an opening for Elisabeth and her Mum to talk more personally and intimately together. This broader objective for Elisabeth arises a few times within this performance, as Elisabeth talks about wanting to have more time to really ‘be’ with her Mum, and to not only have all of their time focused on the business of care. Below I speak to 1. My position as an interviewer, as both individual witness and relational navigator,
2. The hidden and powerful costs and demands of ensuring ‘good’ care, and 3. The powerful messages that circulate about ‘managing’ stress individually and relationally.

1. *My position as an interviewer - individual witness and relational navigator*

Within this performance with Carrie and Elisabeth, I was aware on multiple levels of how I was being positioned to see both Carrie and Elisabeth, as women who were closely connected, who each had their own performance and position to be witnessed. I was pulled within this performance to navigate between and across Carrie and Elisabeth and I found that there were a few moments within the performance, where I was compelled to see if I could support them in really hearing and seeing one another more clearly. This is perhaps most profoundly reflected in my performance, where after hearing Elisabeth speak at great lengths about whether she was doing enough for her Mum, and doing her justice, I asked Carrie directly, whether Elisabeth was “*doing enough*”. In hindsight as I reflected on this I was aware that my approach was a bit naïve, as of course Carrie and Elisabeth have been relationally connected across a life time of stories and experiences, and the layers of really hearing each other, require levels of hearing and being and opening, that are much more complex than what I was able to do within this performance. Of interest to me, is how I felt pulled and compelled into this role with Carrie and Elisabeth, how I felt woven tightly into our broader performance, and how I was compelled to try and navigate some of this with, and perhaps for them. This positioning is quite different from my experiences with the other mother and daughter dyads, and perhaps reflects my awareness of how Elisabeth is struggling and how the stress levels between Carrie and Elisabeth are quite palpable.

2. *The hidden and powerful costs and demands of ensuring ‘good’ care in a retirement residence*

As Carrie lives in a retirement residence that provides some basic care services, but other care services need to be privately arranged, there are additional costs and demands that are unique to their specific situation, that is different from the other mother and daughter dyads that participated. The extent and reach of these costs and demands are performed by both Carrie and Elisabeth, in a way where I as an interviewer can see, feel and hear how stress swirls around them. The large whiteboard in Carrie’s room is the first large visual of how there is a schedule, an infrastructure if you will, that provides the care that Carrie needs throughout her days and nights. Carrie is completely bed-bound and receives personal support care throughout the day, and then in the evening she has a call bell for anything that might arise during the night. While
this whiteboard reflects the background work of logistics in arranging who comes at what time, and what each care providers name is, what this whiteboard doesn’t reflects is the time, work and energy that is required to maintain and sustain this schedule. Maintaining and sustaining this schedule requires that Carrie and Elisabeth find ways to ‘problem-solve’ around care practices, that while not bad are also not at the standard and level that Carrie requires. Problem-solving discussions and the ensuing strategies that unfold wherein Carrie speaks to her care providers directly, or Elisabeth intervenes, strive to find delicate pathways to provide feedback, that while clear, are also not interpreted as a complaint or dissatisfaction that could have negative repercussions for Carrie’s care. Elisabeth finds that her dual role as a nurse, and as a daughter, makes this problem solving particularly difficult, and as an interviewer, I am left with the sense of how Elisabeth and Carrie are caught between defending their needs, rights and expectations, and the humbling and vulnerable position of needing and depending on ‘good’ care in order for Carrie to survive. Hidden within this performance are all the layers of how care practices can be abused, of how poor or bad care provision has enormous power and impact on the health and well-being a patient, and her family.

Also reflected within Carrie and Elisabeth’s performance is the time and energy that is taken in anticipating poor or bad care, and how each day Carrie wonders (and worries) who will be on call during the night, and whether it will be a care provider that she likes, or someone else. This constant focus on what might happen, and the way that this is performed within Carrie and Elisabeth’s relationships reflects how anticipating difficulties is also woven into their relationship as daily conversations occur about not only what has happened, but what might happen. The presence of these conversations further emphasizes how this is part of the work that Carrie sees as part of her responsibility in needing care. Good care practices are not expected, instead poor care practices are anticipated, and Carrie and Elisabeth’s work is in minimizing the costs of the poor care, as much as they can.

3. The powerful messages that circulate about ‘managing’ stress individually and relationally

Within this performance there are a few different perspectives and positions performed, about how Carrie and Elisabeth are handling the stress that comes from overseeing and managing care, and importantly how they feel they should be handling this stress. On one-hand Carrie positions herself as handling the stressors that arise, and how Elisabeth helps her find ways to see the
positive aspects of her care. On the other, Carrie powerfully shows us, in her concern and worry about upsetting her personal support worker, as our interview overlaps with the beginning of her personal support workers shift. Clearly woven into Carrie’s performance is how she feels personally responsible for making sure that she follows the routine, not only for herself, but because this is her job. Carrie appears within this performance to take personal responsibility for her stress, as if her stress comes for her own anxiety and worry, and not from the larger context of how her experiences of care have shown her that she needs to focus on sustaining, maintaining and anticipating the difficulties that will arise in her care. There is within this performance the explicit irony around how the presentation and messaging in how the retirement residence that Carrie is in advertises their residence as a place for people to move to leave their cares behind – and the reality of how all of Carrie’s concerns revolve around her care.

Relational Story #2 - Differing and Competing Needs and Wants in End of Life

Thematic Analysis

“M: Enough, I want to go”/ D: “Looking for snippets of time”

As the conversation continues, Elisabeth shifts to a broader statement about how aware her mother has been around her care, and how she has always been in control of knowing what feels right or does not feel right in her care. Here Elisabeth makes the link between her mother’s need for routine and control over her care, to the loss of control her mother has experienced as her illness has progressed, and how little control she has over her body. Elisabeth ends by emphasizing her mother’s cognitive ability, and her continued ability to know what she deserves. This moves Carrie to more directly name what she feels she deserves, and that is to die.

D: But Mum has been very aware of her care and has always been, like, in control of her, knowing if something is right or doesn’t feel right. And so, then, if it doesn’t fit for her, then I’ve encouraged you at times to problem-solve that (M: um hmm) with some help from me, but you to be the one (M: yeah) to initiate, um, a discussion (M: um hmm) with them. But they, things are very regimented. It’s very much a routine, right, Mum, (M: oh, yes) and you like it that way. (M: yeah) Because then you feel like you have control over, um, what’s happening (M: um hmm) to you. Whereas, you know, you’ve lost so much control over what has happened to your body, (M: yeah) unfortunately. So you definitely, you know, are sharp in the mind and you have, you know what you deserve to have, and --
M: Um hmm, I just wish it was all over.

Carrie’s clear and direct statement of wishing it was all over continues as she talks about her decision, following her leg amputation, to not have any more surgeries and how she had come to a place of saying “No, I had enough.” This decision, informed by her last surgery not being successful, as well as continuing concerns and worries about being a burden on her family, is also continuing to haunt her as she does not understand why she is still living, when she had decided that she had had enough. This conflict – of saying ‘enough’, becomes increasingly difficult as her body shows some sign of healing, despite her illness progressing.

M: I didn’t ever want to burden children with me being with them because that, they’re going to, you know, raising their children and relationships, and – but after my surgery, and then it wasn’t successful, and they wanted to do more, I said, “No.” I had had enough. Enough pain, enough surgery. But I’m still here and I don’t understand that.

I: You don’t understand why --

M: Being still here, yeah.

M: When I’d like to be with (her husband’s name). I mean, I’d like to have my children around too, but they are fine. They’re building their lives, and, and grandchildren, but --

D: It is hard to figure out, isn’t it? (M: it sure is) Because your body is healing --

M: And part of me says that’s good and a part of it says, “No, it’s not, because I want to go.”

I: You want to go. (M: yeah)

Underscoring this conflict for Carrie about wanting to die, and yet also acknowledging that there are parts of her that also want to be with her family, is also the fact that Elisabeth shares her own version of this conflict, as she sees her mother’s pain and exhaustion, and yet she is also pleased to continue having time with her.

D: And so I had that conflict too, you know, because I see Mum’s pain and I see her emotional exhaustion and yet I’m so pleased that she’s still here.

M: Well, I know, well, I know how they feel.

D: For our times that we have together (M: yeah) which are not as much as we’d like, (M: no) for either of us. (M: um hmm) A lot of it is for Mum’s, for conservation of her energy, and so we have snippets of, of times to visit, where there’s, where she’s not busy with care, receiving care or you’re not busy resting, right? (M: um hmm) We have snippets of time (M: yeah), but at least we have those snippets of time. (M: yeah)
M: That’s right.

... 

M: I’m ready, though.

Within this relational story we can see that Carrie and Elisabeth are trying to find a way to hold their positions together intersubjectively, while also not losing their own positions. Elisabeth is able to hear and acknowledge her Mum’s suffering and she is able to hear that her Mum wants to die, and she is also able to relay how in the time ahead she wants more ‘snippets’ of time to really be with her Mum. Carrie on the other-hand is able to hear and acknowledge that Elisabeth is wanting more time with her, and that Elisabeth would like more ‘snippets’, and Carrie responds that she too, would like to have these ‘snippets’ of time, Carrie is also clear on ending this discussion with a comment that she is ‘ready’, as in ready to die. Understanding how mothers and daughters hold differences and possible conflicts and tensions, particularly those that revolve around end of life, offers important insights about how relationships can and do hold tremendous anguish, pain, and exhaustion, while they also hold love, compassion, and connection.

In summary, Carrie and Elisabeth’s interviews reflect a number of shared beliefs and understandings of the type and level of care that Carrie should receive in her care, and how they individually and collectively work to ensure that this happens. Both Carrie and Elisabeth walk a fine line to ensure that Carrie receives the best care possible, while also prioritizing Carrie’s autonomy and control in knowing what she needs and deserves. Elisabeth’s performance about stress – is performed in relation to her perspectives of her Mum’s stress, and further, her own experiences of stress, as she tries to balance the ‘business’ part of things, with her need and want to have more meaningful ‘snippets’ of time with her Mum. These ‘snippets’ are hard to navigate for Carrie and Elisabeth, as their time to visit alone is quite constrained, and while Elisabeth wants to talk about the past and look at old family photos, Carrie finds this too difficult, as the pictures represent the loss of her husband, and the estrangement she has with her two other children. Lastly we see how Carrie and Elisabeth hold the inherent tensions and conflicts in doing each other justice, as they try to find a way to hold Carrie’s need and want to die with Elisabeth’s need for more time with her mother.
4.2.5  Diana & Susan

Diana (mother-in-law) – Susan (daughter-in-law)

Diana, a friendly, family-oriented wife, mother, grandmother, and hopeful great-grandmother is in her late 80s. Diana and her husband had one son, and while Diana notes that they would have liked to have more than one child, she feels very fortunate to have Susan as her daughter-in-law.

Diana’s son and Susan dated through high-school and university and were married in their mid-twenties. Susan is a registered nurse and has worked over the years in a variety of clinical and clinical management contexts. In fact, when Diana had her first heart attack and was brought into the hospital, Susan was a nurse at the same hospital in the Intensive Care Unit. Since this time, Susan has been the one that Diana and her husband have relied on to translate medical diagnoses and treatments into something that they both understand.

For much of their relationship, Diana and her husband and Susan and her husband have lived in different cities. While they didn’t see each other frequently, they would talk on the phone regularly. During this time, Susan and her husband had two children. Susan remarked that, when their daughter was born with health issues that required a tracheostomy, Diana and her husband learned how to change the tracheostomy tube and were actively involved in her care.

Fourteen years ago Diana and her husband sold everything and bought a mobile home and travelled like ‘vagabonds’ through the United States and Canada. Each weekend they would find a town or city to stay in, so that Diana could attend Mass. Over the years Diana has continued to have heart problems, as has her husband, and three or four years ago, Susan and her husband sat their parents down and encouraged them to live closer. Two years ago, Diana and her husband ended up buying a condo in the area, and have lived in the area ever since.

Over the past year Diana’s health has continued to get worse. Throughout this time, Susan took Diana to the Emergency Department a number of times, as Diana continued to decline. Diana’s legs became so swollen that she couldn’t walk due to severe edema, her heart and lung functioning were rapidly declining, and she was becoming increasingly dependent on oxygen.

Diana was on the PCU for just under a week when I met her and her husband for the first time. Shortly afterwards I met Diana and Susan for our interview. As they began talking about their lives, it became clear that when Diana was initially admitted to the PCU she was gravely ill, and it was uncertain how long she would live. Receiving comfort measures only, Diana was somehow able to rally and get stronger. After three weeks on the PCU, Diana was discharged home as part of the community regional health initiative, ‘Home First’. This initiative offers 60 days of 8 hours of personal care support, to assist patients in transitioning home from hospital based care.

Prior to First Meeting

It is important to acknowledge and reflect on how Diana and Susan, as mother-in-law and daughter-in-law, came to participate within this study on mothers and daughters. Prior to meeting Diana and Susan for the first time, I met regularly with the physicians on the PCU to
talk about patients and families who had recently been admitted and to see how might meet my inclusion criteria. When Diana was first admitted to the PCU the medical team thought that Diana’s health status was so precarious that she might die within a very short amount of time. During this time Susan and Diana’s husband were at Diana’s bedside, and the physicians and clinical care team members developed a close rapport with Susan. As the physicians and care team members learned about Diana and her family, they were quite struck by the relationship between Diana and Susan. As Diana’s health status shifted and it seemed that she was getting stronger, Diana and Susan’s relationship became more apparent and I began to have varying physicians and care team members ask me about whether I had heard about Diana and Susan. Each physician would begin telling me a bit about Diana and Susan’s history, of how Susan was the daughter that Diana wasn’t able to have, of how Susan started dating her husband as a teenager, and how Diana and Susan seemed to reflect a really interesting mother and daughter relationship. This early linking of Diana and Susan’s mother-in-law/daughter-in-law relationship to my study, pushed me to think about how and in what way biology and the nuclear family-structure was the primary construct informing mother and daughter relationships.

In my thesis proposal and in my ethics proposal I had already made a point of emphasizing the importance of including daughters that were not biologically related, as I wanted to ensure that daughters who were adopted (like myself), and/or step daughters would also fit within the scope of my study on mothers and daughters. As I thought about this more, it seemed that one of the most critical elements informing my study was a sense of how relationships build over time, and as such a critical component would be that each mother and daughter had a long connection with each other, to speak to this relational continuum. As Susan had started dating her husband in high-school, there was a lengthy relationship between Diana and Susan, and as such it felt like Diana and Susan would be able to speak to their relationship over time. As someone who has worked with Children Aid Societies about constructions of family, and older children as adoptees, the argument that a mother and daughter relationship requires a period of time when the daughter is ‘young’ to meet the criteria of ‘mother and daughter’ also fell short for me, as I would absolutely have included a mother and daughter relationship where the daughter was adopted at an older age, or in a blended family, where a step-daughter may have been woven into the family as an adolescent. Lastly, as Susan was a nurse, and Diana had been living with chronic heart disease for many years, it was also clear that
Susan had been actively involved in Diana’s medical experiences for quite some time. As I worked through all of these layers, I felt that my last ‘criteria’ was how Diana and Susan conceptualized their relationship, and as such I decided that I would talk to Diana and Susan about how they felt about participating in a mother and daughter study, and whether they felt that who they were in relationship would fit within the scope of this study.

**First Meeting**

I meet Diana and her husband for the first time in Diana’s room. Diana is in a private room, and as I enter the room, Diana is sitting in a wheelchair by the foot of her bed. Diana’s husband is behind her, as he is manoeuvring both Diana and the wheelchair to a spot near the foot of Diana’s bed. Diana and her husband have just come back to the PCU from an appointment, followed by lunch at Tim Horton’s. Diana, a petite woman with wavy short blond hair, is wearing a pair of dark slacks and a matching top. As I introduce myself and tell Diana about my study, her husband notes that their daughter-in-law Susan is not presently on the Palliative Care Unit. He explains that Susan is a nurse, and that when things were in a bad way the week before, she was there every day; now that Diana is better, Susan is off playing golf. Diana is very friendly and actively involved in our conversation and as we talk there are a number of staff that appear at the door to say hello, or to say good-bye. Diana knows all of the staff by their first names, and it is clear that she is well liked, and that she enjoys their company. We arrange to follow-up again, after I have connected with Susan.

**First Interview**

After connecting with Susan over the phone, I connect again with Diana, and between the three of us, we arrange to meet the following evening. The following evening I go up on the PCU and Diana is lying on top of her bed while Susan is sitting in a club chair beside Diana’s bed. Susan is tall, with wavy brown hair and she is dressed in a summer shift and sandals and has a coffee in hand, from the café downstairs. Susan introduces herself, and she and I pull up club chairs and sit on either side of Diana’s bed. While I have had separate conversations with them about my study being focused on mothers and daughters, I raise this again with both of them together, as it’s important to me that both Diana and Susan feel like this is a good fit for them. Both of them speak to the long time that they have been involved in one another’s life, and Diana comments on how she always wanted to have more children, so her sons’ choice in Susan, was a gift to all
of them. After we review the study specifics, and Diana notes that she is tired tonight as she did not sleep well last night. We agree to start the interview with the understanding that we can stop at any point, and that I will check-in with both of them regularly through our conversation to see how they are both doing. As we begin the interview it is clear that one of the immediate ties between Diana and Susan is their mutual love and respect for Diana’s son, Susan’s husband. As they begin to recount their relationship, it is also clear that Susan is woven tightly into the family, both because she had been part of the family since she was a teenager, but also because of her role as a nurse, as one of her primary roles in the family was to be a translator of medical information, so that Diana and her husband would really understand what was going on with them medically. This role, starting with Diana’s first heart attack 30 years ago, has been a role that Susan has played since then, and continues to play today.

Diana (M-In-Law) and Susan (D-In-Law) – Relational Continuum over time


Diana and her husband have one child, a son, who is married to Susan. Susan and her husband have two children. As Diana and Susan talked about their relationship over time, Susan mentions a few times how both sides of the family really respected each other. This respect was reflected in the awareness of a line between them, which meant that they did not step into each other’s business, but they supported and loved one another. As Susan is a daughter-in-law we might also speculate that Susan is perhaps even more mindful of a line between herself and Diana, as her role as daughter has been negotiated through her relationship with her husband and not directly through her role with Diana and her husband. As a nurse and as a daughter-in-law, Susan felt it was important that Diana and her husband problem-solve and make decisions for themselves as long as they were able, and that their decisions should be respected. However, leaving room for Diana and her husband to make their own decisions meant that Susan was often not aware of what appointments had been followed-up on, and which ones had not. As a nurse, Susan knew about the importance of initiating referrals and assessments, but on more than one occasion these referrals did not happen, and it was unclear where the breakdown in communication had been.

D: I respect them enough that I’m not going to go and bulldoze my way in there. You know, and saying things, (M: yeah) because that’s not what, that’s just not what we’ve
done, we’ve ever done, (M: um hmm) you know? We’ve always respected each other’s (M: yeah) space. You know?

One of the most challenging elements for Diana was that no one was overseeing the wide and growing range of drugs that she had been prescribed by the varying physicians that she was seeing. For months Susan had been trying to get Diana assessed by a geriatric assessment team, so that Diana’s medications could be reviewed. It was particularly devastating, as a result, when the family discovered that one of the primary reasons why Diana was gravely ill when she was admitted to the PCU was because she was essentially toxic with the wide range of drugs that varying physicians and specialists had provided.

This line between Diana and Susan had been shifting, though, and Diana notes that after so much of what has happened (referencing the fact that she almost died), she is not sure if the line that she thought was there between herself and Susan still exists. Diana suggest that after the personal level of care that she has been involved in, that perhaps this too has shifted their relationship to a new level.

M: I don't know if it is or not, Pam. It’s, I’ve kind of forgotten that it’s there. (I: yeah?) Yeah.

I: Yeah? Well, fair enough.

M: Well, after what I’ve been through and to think of what’s happened to me, you know, it – I really, ah, I don’t want to see the line any more.

D: Well, and, you know, I think that what happens too is that, you know, when somebody’s very ill and there’s so much personal care that you’re involved with (M: yeah) that it sort of then becomes at a different level. Like, you know, when you’re involved in that personal care. (M: yeah) You know, in the past, you know, up until when she was ill, you know, I wasn’t involved with giving her a shower, or helping her to the toilet, or, you know, trying to take care of those kind of personal needs. So it sort of changes the dynamics. (M: yeah) When you’re involved on that kind of level

This story offers important understandings of how mothers and daughters think about their relationship, and the ways that they may see their lives overlapping, and the places where there may have more definitive lines between them. These lines which may be constructed as important boundaries between them may be perceived differently between mothers and daughters, and may depend on whether the relationship between them is seen as unidirectional or reciprocal, or fixed or flexible. Understanding the history behind these lines and how mothers
and daughters have respected and responded to these lines offers important insights for understanding how differing needs and issues have been handled across their relationship.

When Susan was an adolescent/young adult

In speaking about their relationship over time, Diana and Susan talk about when Susan started dating her husband (to-be), (Diana’s son), and how her love for her husband (to-be) started in the penalty box, as he played hockey, with Susan’s brother

D: You know, (M: yeah) we, ah, (husband’s name) and I met, (husband’s name) and my brother played hockey together when they were twelve. (M: yeah) And (husband’s) dad was the coach of the team. So I used to go to the hockey games. And so, ah, (husband’s name), we always tease and say that, you know, he was in the penalty box and looked around and, you know, smiled at me and that was sort of, like, the beginning – [laughter] (M: yeah, yeah) and then that was, like, he was, so we started going out when we were in high school –

Susan talked about her memories of spending a lot of time at her husband’s home as an adolescent and how Diana and her husband were second parents to many of the kids in their neighbourhood as they were growing up. Susan then expands this to comment on how this was just the type of people Diana and her husband were/are, and how many of their childhood friends have remained in touch with them, even after all of this time.

D: Well, you know, when you think that, you know, (Diana) and (Diana’s husband) were, like, the second parents to so many of the kids, (M: yeah) like, our, (husband’s ‘name), their home was the place to hang out. (M: yeah) You know, there was a swimming pool in the back yard, (M: yeah) and, you know, they were always welcome there. (I: mmm) So (M: yeah) you know, that’s where people tended to come and to this day, you know, (M: yeah), they still think of them, (M: yeah) and visit them, (I: that's lovely) and -- yeah, you know, so it’s really nice. (M: yeah) It’s a testament to the people that they are, (I: um hmmm) as well. (I: um hmmm) You know, that, ah –

I: Yeah, sounds like quite a lovely, big, extended family, (M: yeah) community --

M: Yes, that’s about what it is, yeah. (I: yeah)

Previous history of illness

Illness has been part of Diana and Susan’s relationship for quite some time, as Diana had her first heart attack over thirty years ago, and as it happened, at the time Diana was admitted to the intensive care unit that used to be in the same building where the PCU is presently located.
During this time, Susan was working as a nurse in the same institution, and she remembers coming over and being involved in Diana’s care. Susan’s role as nurse has been a strong focus within their relationship, as Susan has helped Diana and her husband navigate through many different medical scenarios.

M: I swear, I don't know what I’d do if we didn’t have (Susan). Um, she, she’s taken over the, um, explanations and, of the, for the illness and what’s going on with my life and, ah, she just explains it all so that you understand and, ah, connects up, you know?

M: But, other than that, ah, I don't know what I would do. And my husband too, because he relies on her completely for that kind of stuff.

D: Um hmm. We had, you know, I guess if we think back to different illnesses and stuff, you know, you probably had your first heart attack (M: yeah) when you were --

M: -- [X years old] --

D: [x years old], yeah? And so, you know, thirty years ago, (I: wow) and so we navigated through that one. Actually, you were on, in this hospital (M: yeah) on the old wing.

M: That’s right –

D: And, ah, and I worked in the intensive care unit here –

I: OK (M: that’s right) Wow --

D: Way back, one time, when I first started off, yeah --

M: So she goes back a long way.

Diana’s last sentence is particularly important, as she references both the lengthy time that Susan has been a nurse, as well as how she goes back a long way as part of the family, and part of Diana’s history.

Present day/Future

Diana and Susan are navigating through a number of different shifts and changes, both in their relationship to each other around their involvement in each other’s lives, and in their experiences of illness/care and the future. Understanding how mothers [in-law] and daughters [in-law] individually and collectively experience and perceive change, both in terms of change that has
already happened as well as changes that are to come, is integral, if we are to find ways of fully supporting how they are experiencing end of life.

End of Life Relational Stories

The first end of life relational story between Diana and Susan looks at how Diana and Susan have different perspectives and perceptions of the care Diana needs. This story focuses on how Diana and Susan navigated changes around Diana’s care needs and how they have understood these changes. The second relational story speaks to the dissimilar thoughts that Diana and Susan have for the future and what the time ahead might include. This story strongly focuses on Susan’s concerns that her mother [in-law] receive the services and supports that she needs, as Susan understands as a nurse and as a daughter [in-law] that Diana will in the future need more care. Supporting documents for the thematic and dialogic/performance analysis are available in Appendix G.

Relational Story #1: Shifting Perspectives and Perceptions of Accepting Care

Thematic Analysis

“M: abdicating my responsibilities…I couldn’t work it out in my head”

The first end of life relational story between Diana and Susan looks at how they are navigating changes around care needs, and reinforces how important it is to take the time to understand how each mother/mother [in-law] and daughter/daughter [in-law] is interpreting these changes individually and collectively, and what these changes mean about who they each are as women in relationship. Further, underscoring this story is the importance in understanding how differences that may exist between mothers/mothers[in-law] and daughters/daughters[in-law] are navigated, and how these differences may inform how each of them are experiencing the needs and concerns about end of life.

An important role for Diana was to cook meals for her family. As Diana became more and more ill, she was determined to continue cooking meals for herself and her husband. As this became increasingly more and more difficult, Susan and varying case workers and social workers tried to suggest that Diana have other services come in and help them with food preparation. Diana was determined not to have a number of different people in her home, and
she was particularly determined that she did not lose her role as the one who prepared food for her family. In asking Diana to speak about why she did not want the support in her home, she said:

M: I, I didn’t like the idea of always different people – people were trying to help, but when you have, ah, say, um, five or six different people coming in to do different jobs, to me it was, ah, it was interfering. It was doing jobs that I should be doing myself. You know? And I, ah, couldn’t rid myself of that feeling, that I was, ah, abdicating my responsibilities. Yeah.

In the narrative above Diana is able to clearly articulate that she did not want a number of different people coming into her home and doing jobs that she felt were her jobs, and things that she felt she should be doing. Diana’s concern also speaks to the impact of not only having care providers come into her home to do jobs that she felt were hers, but the burden that comes from having many different people intruding in one’s home. Diana’s difficulty in accepting care in her home, speaks to how Diana’s sense of self and her identity are powerfully woven into gendered understandings of how she cares for her family, and how her illness is forcing her to reassess who she is, and who she is becoming in relation to her increasing needs.

Susan relays how adamant Diana was about not having supports in the home and how difficult it was to navigate this with Diana, as they could not seem to find a way to reach her, or shift how she was thinking about the situation.

D: I remember sitting at the table and you saying I don’t want people to come in and you were just, like, you were just beside yourself. (M: yeah) Beside yourself, because, but, you know, and it wasn’t, it wasn’t anything we could say to make you feel any different or better, because your brain just wasn’t taking in the common sense part of it, you know? It was just like, you got a thought in your head and that was the thought that stayed there. (M: I know) We couldn’t change it.

M: It was so frustrating for [name of husband], too. God.

I: Did he want something different?–

M: No, he always supported me. He kept saying it’s what you want. Whatever you want. But, but in that way, too, he was also leaving the decisions all up to me –

M: So I was in a catch-22 situation.

For Diana, she relays that her husband was always very supportive, and he focused on supporting Diana in whatever she wanted. While Diana could see this as support, she also felt that he ended
up leaving the decisions up to her, and how this made things more difficult when she didn’t know what she needed. Not making a decision, or leaving a decision up to someone else is one way that family members may offer their support, and yet in moments of difficult decision-making, this can further exacerbate the sense of responsibility that a person may feel to make all of their decisions themselves. This then leaves other family members, such as Susan and her husband, to appear as if they are aligning against what Diana wants, as they are trying to reason with her to accept more care.

After Diana’s experience of coming on the Palliative Care Unit and almost dying, and experiencing a team of support that she could really count on, she is able to share how her perspective and need for care in the home has shifted, and how she feels now that she can see this more clearly.

M: Can you imagine how it feels to have someone say to you, if you need anything, call me? All I’ve got to do is press a button and somebody’s here. And they will do whatever they can to help me.

M: I tell you, (D: yeah) it’s really something.

I: Yeah. So, you’re in a different place now…. so I’m wondering how you feel now about receiving supports now.

M: Well, I feel a little ridiculous that I refused it, that I didn’t want it. Ah, I feel badly that I couldn’t work it out in my mind, you know? OK, you do this and I’ll do that sort of thing, you know? I couldn’t, ah, separate it like that.

This end of life relational story reflects the challenges that can exist in how mothers/mothers-in-law and their daughters/daughters-in-law navigate changes in their care needs, and how these changes need to be contextualized and understood in a way that fully appreciates how these changes may be perceived, and how these changes may be deeply interwoven with a persons’ core sense of who they are and who they are becoming. We also take away a profound understanding of the challenges that exist for mothers/mothers-in-law and their daughters/daughters-in-law in navigating these changes relationally. Woven within this end of life relational story is the importance of fully hearing and witnessing the places where the needs and wants of a mother (mother-in-law) may collide with the needs and wants of her daughter (daughter-in-law), and how these competing voices both need to be respected. Within this cacophony of competing voices, there were important roles and beliefs being expressed by both Diana and Susan, and of interest is how they were able to express their frustrations and
differences, while still respecting the line between them. Time also played a role in this end of life relational story, as Diana has shifted in both where she is, and in how she perceives her needs, and this time has allowed her to outline more clearly how challenging it was to shift her thinking.

**Dialogic/Performance Analysis: Performance Genres**

Please refer to Appendix G, for the full dialogic performance analysis.

The direct speech within this performance offers an important way of examining what was unfolding for Diana in her process of accepting care. The direct speech, begins with her saying, “I don’t want people to come in”, to her process of why she didn’t want people to come in and what having people come into her house meant about to her. Her shift to her amazement and wonder at the staff on the PCU telling her, “if you need anything, call me”, and that they would actually always come and do everything they could to help her, reflects the dramatic shift that had unfolded for Diana during this time. Diana’s performance, positioned for me as an interviewer, and a general audience, is focused on having us acknowledge and understand the depth and significance of this shift for Diana, and how this shift speaks deeply to who Diana is and what accepting and then relying on care means. In examining the words that are repeated throughout this performance the word feel is used six times, the word want is used five times, and the words, couldn’t, people and like were repeated four times. While there are not many expressive sounds/cues within this performance, the majority are Diana’s, and speak to the most difficult elements within this performance, and her higher pitch voice reflects this emotional intensity and difficulty within these parts of the performance.

**Dialogic/Performance Analysis: Voices in Dialogue & Multiple Layers of Context**

In examining the voices in dialogue and the multiple layers of context that arise within this performance, a number of elements emerge. Diana performs most of this performance, in her own voice, speaking to her difficulties in accepting and receiving care. As Diana’s process of accepting care unfolds across this performance we see the many different elements that inform how Diana positions herself towards her need for care. This performance captures the tension between how Diana feels about her needs, and what these needs mean about who she is as person, as a woman, a wife and as a mother. Susan’s performance while brief, speaks to her and
her husband’s experience of seeing and witnessing Diana’s distress, and yet not being able to change how Diana was feeling or thinking. Below I address 1. My position as an interviewer within this performance as an empathic listener and broader system ally/witness (protector) of a new understanding of care, 2. Diana’s performance of abdicating responsibility and 3. Pushing a button – and someone is always there

1. **My position as an interviewer – empathic listener and witness (protector) of a new understanding of care/ broader system ally**

During the interview and as I moved through my analysis I was aware of feeling positioned and pulled between two very different responses to how Diana and Susan were experiencing end of life. Diana’s performance and positioning as a woman who less than a week before had almost died, was deeply woven into Diana’s experience and wonder of being granted more time, and how amazed she was that in her current experiences of care, that the staff on the PCU told her to use the call bell if needed anything, and how they really wanted to help her. After Diana’s struggle in accepting care, her performance of how she can ring the bell, and people will come – reflects how she is absorbing how it feels to have a care team that is there to really help her. Susan’s experience, as a nurse who has worked extensively as a clinician and now as a nursing administrator, and as a daughter [in-law], is strongly situated in a broader realist understanding of the system, and all of the ways that the system has failed Diana throughout the last number of years of her care. While Susan’s focus is on the past, there are also strongly articulated concerns about the future, and Susan’s concerns about whether Diana would receive the care that she requires. These positions while focused on the same experience of end of life reflect some of the inherent differences between mothers/mothers [in-law] and daughters/daughters [in-law] in their individual and relational concerns. On one hand there is Diana talking about the absolute brilliance of being able to push a button and knowing (with certainty) that someone would arrive to come and help her in the best way they could. On the other there is Susan, focusing on the importance of Diana getting stronger and organizing logistics so that she would transition back home successfully. I am struck by the sense that as Diana talks about her experience of the call-bell, that Susan knows that there is no call button for Diana when she moves back home. There is within this performance the dissonance between Diana’s lived ‘present-moment’ experience, and Susan’s larger, more realistic understanding of how the medical care system works (or doesn’t), and Susan’s concerns about what may happen in the future. This tension reflects how
Susan is able to see the larger picture, and the possible pitfalls that will happen along the way, and how Diana is focused on the expansiveness/wonder of her present-day. These differences in focus, anxiety and tone reflect how Diana and Susan are in very different individual places, and yet collectively are experiencing end of life together.

2. Diana’s performance of abdicating responsibility

While this performance is primarily about Diana’s individual struggle in letting caregivers into her home and her process of receiving care, the performance begins with Susan, who performs initially as knower, narrator and performer of Diana’s distress. Susan then shifts to a dialogue with Diana, about how Diana was ‘beside herself’, and how Susan and her husband were not able to change how Diana was feeling or thinking about not wanting care in her home. While Susan’s performance focuses on how Diana was absolutely steadfast in her position, and unable to hear anything different, Diana names the frustration that was circulating for everyone (but herself), and makes clear her sense of responsibility for the frustration and distress that was circulating around them at this time of their lives. Centrally informing Diana’s position was the difficulty Diana had in working through what accepting care in her home meant on a larger scale about who she was, and her roles and responsibilities. Critical to Diana’s performance is her role within her family, of how she took care of her family, of how her role was centrally affixed to being in the kitchen and providing for her family, and how incomprehensible it was to her, to give up this role to a stranger ~ much less many different strangers. Diana’s use of the word abdicating is quite powerful, as this further positions Diana as someone not just giving up her role, but failing and not fulfilling significant responsibilities or duties in her life (Merriam-Webster, 2014). The weight of Diana’s sense of failure is palpable in this performance, and speaks to the depth and significance of the losses that she is experiencing. Further in the performance, Diana reflects on how even after all of these years of having this role [as provider, nurturer] that she still could not figure out a way of not being in this role. Diana’s performance suggests that even after having given so much of herself to/within this role, that she still could not find a way out of this role or identity. The extent and depth of Diana’s identity as a woman, wife and mother, and how providing for her family was (and is at this time of the interview) a fundamental part of her identity, reflects the tremendous difficulties women can have in knowing
and acknowledging who they are, when they are no longer able to sustain the same roles and care practices that they have held for many decades within their families.

3. Pushing a button – and someone is there

The way that the ‘call-bell’ (Diana refers to this as the button) was and is represented within this performance touches on a number of key elements related to communication and care-giving and care-receiving. The first is that the call-bell is a mechanism to ask for help, and that it communicates this need through a number of interrelated steps that are both individual and relational. The first step is that the patient (or a family member) rings the call-bell when there is a need recognized that needs support. The second step is that the care provider at the other end of the call-bell recognizes this bell/sound/light as a sign of need, and third that the care provider answers the bell and works to meet the recognized need. The underlying process of recognizing one’s needs, communicating these needs to others, and receiving support is a fundamental part of many care giving/care receiving practices. For Diana, the experience of pushing the button, and receiving support is one that fills her with wonder, as she says,

M: Can you imagine how it feels to have someone say to you, “if you need anything, call me” [G-Direct Speech] All I’ve got to do is press a button and somebody’s here. And they will do whatever they can to help me.

M: I tell you, (D: yeah) it’s really something.

Diana’s experience of the call-bell is one that reflects a strong interconnection between all of these steps, as she rings the bell and someone is always there. While the call-bell form of communication, of expressing needs and someone coming to meet these needs works well for Diana, there are many places along this communication process, where things can breakdown, or things can happen that get in the way of the person with the need getting their needs met. If we were to start with the first step of recognition of needs, while Diana reflects in the interview that on the PCU she is able to recognize her needs and push the button to get support, her previous

24 Notable here of course are care relationships where the patient or person in need is not able to communicate their needs, either verbally, or with signs and gestures, and then the step of recognizing needs is something that is interpreted by others on the person’s behalf.
relational story of being challenged to accept care in her home, reflects the challenges that can exist for patients in a) recognizing their needs, b) understanding that these needs, need or require support from someone else, and c) signalling to someone else that assistance or help is required. While Diana is able to push the call-bell at the time of the interview, there may have been times in the past, when she would not have been able to recognize her needs, or understand (and accept) that these needs required support from someone else, and/or that these needs required that she ask for assistance. While each of these steps can be difficult for many different people, as women, the ability to recognize that one has needs that are not able to be met independently, can often be quite difficult, given women’s socialization to recognize needs in others, and seamlessly meet these needs, while often ignoring their own needs. Some women as a result may not be able get to the stage of asking for assistance. Other women may use the call-bell with extreme caution, out of fear of being overly-needy to too-demanding to staff that are trying to manage a number of patients with limited resources. While still others, may wait until they are absolutely not able to deny their needs any longer, and then they ring the bell when they are in extreme agony or distress.

How a care provider responds to an individuals’ call, shifts the focus from an individual need to a relational context, as the care provider decides when and how to respond. The focus on timing of the response is important, as how quickly or immediately a care provider responds to a call bell is measured in a number of different ways. Some patients and family members may perceive the care providers’ response very prompt, while others may perceive the care providers response as too slow. Sometimes the sense of timing is measured in the urgency of the call, if someone is vomiting, seconds stretch forward into long minutes, while someone else who uses the call bell in advance of an urgent need, may feel like the response is very prompt. Further the tenor and tone of the care provider interaction is also important, as patients and family members may attend to whether the call is seen as an imposition, or whether the care provider appears to welcome the connection with the patient and family. As women, patients may be highly attentive to how their needs impact the needs of their care providers, and may look for non-verbal cues to attend to how a care provider is doing, or further, may shift the focus onto the care provider, as a way of attending to the care providers needs instead of their own.
Relational Story #2 - Differing Thoughts to the Tasks that Lie Ahead

Thematic Analysis

The second relational story looks at some of the inherent similarities and differences between Diana and Susan, around their hopes, beliefs and understandings about the time that Diana has left. These differing beliefs and understandings are informed not only by some of the relational ways in which they have respected differences between them over time, but also by an inherently different understanding of what the focus is, in the time ahead, between mothers and their daughters. As Diana and Susan talk about the fact that Diana is getting better and that it looks like she will be discharged home, I ask both of them what their hopes are for the future. Diana’s response focuses on how she has to accept what comes, and that she cannot really make demands on what is ahead because of the fact that she almost died. She then moves to wishes for her family, and how she wants to see her family settled and happy, which for Diana means a great-grandchild.

I: …so I’m wondering about what your thoughts are for what’s ahead.

M: I really haven’t had any. I, I have to, um, I have to accept whatever comes my way, I feel. After all that I’ve been through lately, ah, I really don’t feel that I can make any, ah, um, demands to further my life, or to change my life in any way. I don't know. I just feel like I want to drift alone, away, the way things are going to turn out.

I: Um hmm, yeah. Is there anything that feels important, that you want to have happen? Or you want –

M: I don’t think so. I think I want to see my family, ah, um, settled and happy.

D: She’s grilled the grandchildren. She figured that, you know, like, OK, I’m on my deathbed, I get to ask questions. When are you delivering? [laughter] Are you pregnant yet?

M: I keep after them, I’ve gotta have a great-grandchild. [laughter]

Diana’s response for what she hopes for the future is very different from Susan’s, as Susan is much more focused on how they as a family will handle the discharge home, and then the next time that Diana’s health becomes compromised. These differences in life-view, Diana in accepting what is to come, allowing things to progress as they will, and if possible having a great-grandchild, and Susan, in seeing all of the barriers to care provision, from the way that services can be accessed, to the limitations on how much care can be provided, offer two very
different understandings and beliefs about what end of life care is about. Somewhere in between these differences are the individual and shared experiences of end of life, as Diana tries to accept what is happening to her body, and Susan tries to accept/navigate what parts of care she will be able to count on, and what parts she won’t.

I am reminded of how Diana, in talking about her care on the PCU, talks about feeling (with most of the staff), her sense of security and safety, and how it feels for her that she can push a button and that someone will come and do their best to help her. Susan is looking for a similar sense of security and safety, a feeling that the community services being provided will be enough and will be flexible and adaptable enough, that she can trust that Diana will get the care that she needs. Susan’s experience as a nurse, and her experience in navigating varying care systems to date with and/or for Diana have built a strong distrust that the system will be able to meet these needs, and as such, she is not able to focus on what she hopes for Diana’s death, or what she hopes for her relationship with Diana and herself in the time that is left. She is too well aware of all of the things between now and then that could fall apart and leave Diana without the appropriate care she needs.

I: And what about for you, (daughters’ name), in terms of what’s ahead, anything that feels important for you?

D: Well, no, I think that just making sure that the supports are in place because it just, you know, it just, it pissed me off to no end that you have to end up in a hospital to be able to access services. Like, that is just the craziest (M: yeah) --

D: And so it’s like, you know, we’ve got this window of opportunity, right where they’re both going to be good for maybe a couple more months, you know. And we never know. Like, you know (M: no) something catastrophic could happen to you tomorrow. (I: mmm) Something catastrophic could happen to (name) --

D: And you get to the point where neither of you are going to be able to manage (M: yeah) you know, and yes, yes they say, you know, even with the Home First, it’s good for 90 days. (M: yeah) Up to eight hours of care a day for 90 days. Well, what happens after 90 days? Right? (M: that’s right) What happens?

D: You know, like, it’s great that you’re going to be able to go home. You’re going to get a couple of, you know, you’re going to get a couple of, hopefully, a couple, two, three, four more months of (M: yeah) good quality time. (M: yeah) But it’s not, it’s definitely, you know, we’re going to do this again some time. (M: yeah) And we know that. (M: yeah) And we’re not, and we’re just not going to do it with you, we’re going to do it with (husband’s name). (M: yeah)
Susan’s sense of responsibility, worry and concern about Diana’s needs being met in the future is a considerable source of stress for Susan, and these concerns reflect the real-life experiences of someone who understands that dying does not necessarily happen in governmentally funded and allotted Home First programs of 90 days of home-based services, or in governmentally regulated six-week compassionate leaves. Susan is looking for a sense that the care provision for Diana will be available and able to adapt to meet the wide range of things that may happen between now and her time of death.

Additionally, one of the strengths of the PCU that was pointed out, in comparison to services that might be available in the home, is the holistic understanding that end of life requires an interprofessional model of care that can hold the physical care needs as well as the emotional, mental, spiritual, and social needs for care. These elements, which are highly woven into palliative and end of life care on the PCU, are provided across an interprofessional care team that has regular clinical meetings about each patient and family on the unit. This depth of understanding about the specific needs and issues that are experienced in end of life, combined with a clinical care delivery model that offers an integrated, interprofessional team for patients and families receiving care at home, is a much more difficult model of care delivery for programs such as Home First to deliver on a larger community scale.

It is of considerable importance to note the level of connection and trust that exists between Diana and Susan, for Susan to articulate her concerns and worries so directly in front of Diana. This said, as Susan talked about these concerns in our interview, Diana too started to get heavily involved in all of the concerns about how care provision may unfold in her future, and it was clear that this conversation was distressing for Diana.

Diana notes,

M: And the mind is a good part of it too, because I can foresee that tonight I’m going to be a little anxious because of all we’ve discussed, and, ah, but they’ll give me a medication and it’ll help me over it, yeah --

M: But the thing is, here, I know there’s somebody around that will help, or at least try to help.

Understanding how mothers and daughters are thinking about the time that lies ahead of them offers important and critical insights about what each of them may be thinking about, hoping for,
and worrying about individually and collectively. Centrally underscoring the experience for mothers and daughters who are being discharged home, or who are receiving care at home, is the question of whether the care provided by varying care provision services can meet the needs that arise, and whether the care provision is able to be flexible enough, and adaptable enough, to really meet the needs of people who are dying.

4.3 Looking Across Mother and Daughter Dyads

As Catherine Riessman (1993, 2008) cautions, it is important in narrative analysis, both across thematic and dialogic/performance analytic approaches, to ensure that each narrative case remains carefully considered and examined as a whole, and that narratives are not immediately fragmented and isolated into seemingly context-less thematic components. This said, there are opportunities after having conducting a thorough review within each case, to step back and examine what appears to unfolding across all five mother and daughter dyads. Prior to addressing similarities and differences across the five mother and daughter dyads, I examine some of the specific elements which arose within Diana and Susan’s relationship as mother [in-law] and daughter [in-law].

Diana and Susan - mother [in-law] and daughter [in-law]

While Susan began dating her husband (to-be) when she was an adolescent, and has as a result known Diana for over forty years, most of the relational stories shared between Diana and Susan which really offer an understanding of who they are as mother [in-law] and daughter [in-law] begin when Susan was in her mid-twenties, and are focused around Diana’s first heart attack. Prior to this time, the relational stories shared provide an understanding of how Diana, Diana’s son (Susan’s husband), and Susan’s lives interconnect, but show us less about the specifics of Diana and Susan’s relationship. Diana and Susan’s relationship is strongly shaped by Susan’s role as a nurse. Since Diana’s first heart attack thirty years ago, Susan has been very involved in Diana’s medical care and she is seen within the family as a life-line for her ability to translate medical jargon, into a language that Diana and the rest of the family can understand. One of the unique elements that unfolded within the relational stories between Diana and Susan that was not found as explicitly stated within the other mother and daughter dyads, was the issue of respecting boundaries within and across the relationship. For Susan, as she talked about her relationship with Diana over the years, it was important for her to emphasize, how there was a strong sense of
respect between Diana and Susan. Respect was reflected in how they were able to attend to each other’s space, how there was a sense and awareness of a line between them, and how they didn’t ‘bulldoze’ into each other’s spaces. While there were elements within the other mother and daughter dyad’s that addressed similar forms of respect, such as respecting a mothers’ autonomy or a mother’s choices, the description of respect as a ‘line’ or boundary between mothers and daughters, seemed to be something that was quite unique to their mother [in-law], daughter [in-law] relationship. Notable however, is that as Diana’s health needs continued to progress, and as Susan moved into a position of providing more instrumental care around activities of living with Diana such as bathing and toileting, how both of them noted, how the line that existed between them over the years, had seemed to disappear.

Susan’s role as a nurse and a daughter [in-law] echo strongly with Elisabeth’s role as a nurse and as a daughter, and seem to suggest that the dual role of nursing and being a daughter or daughter [in-law] offer a critical blend of roles which powerfully shapes the relationships that unfold. Both Susan and Elisabeth offer a well-informed and structural critique about how the medical care system often fails in meeting the complex care needs of women as they age and require more care. While these critique are evident in some of the other mother and daughter dyads, there appears within Susan and Elisabeth’s narratives a much stronger structural critique, which are not softened or minimized as they appear to be in some of the other mother and daughter dyads. Both Susan and Elisabeth have concerns about how their mothers/mothers [in-law] care needs have been met in either the home, or within a retirement home, and both daughters/daughters [in-law] are extremely aware of the difficulties that exist in ensuring that their mothers/mothers [in-law] receive the care that they need now, as well as the care that they may need in the future. Important to differentiate though is how much the concerns and worries about the future are verbalized between mothers/mothers [in-law] and daughters/daughters [in-law], and at what point daughters/daughters [in-law] may not share all of their concerns with their mothers/mothers [in-law].

One area where there does appear to be some difference between Diana and Susan and the other dyads, relates to how much Susan shares her direct concerns and worries about the future with Diana. Part of the awareness is how much Susan shares her concerns about the future, and how these concerns are positioned in relation to the concerns and processes that Diana is experiencing and feeling about the time ahead. As I asked Diana what she wanted in
the time ahead, Diana had just been through a very close brush with death. Speaking from her position of having had this close call and yet feeling stronger and somewhat surprised to be alive, Diana’s thoughts on the future were about being with her family, and enjoying life, and maybe if she was lucky, seeing a great-grandchild. Susan on the other-hand was in a very different position. Susan was angry and frustrated at the lack of oversight over Diana’s medications, and how because of this oversight, Diana had almost died. Susan’s thoughts on the future were focused on Diana getting strong enough to go home, and on ensuring that adequate supports were in place to support Diana and her husband. As Susan walked through all of her varying concerns about things that could happen in the future, she emphasized how it was just a matter of time before they as a family would be back facing end of life care for both Diana and her husband. Throughout this discussion Diana became more and more agitated. Within this conversation, Susan was actively verbalizing her concerns about the future and as a nurse and as a nursing administrator, Susan’s concerns were well-founded as she knew first-hand how the medical care system and the home care system had serious flaws and limitations. This said Susan’s concerns were clearly distressing to Diana and it was quite evident that Diana struggled to hear Susan’s perspectives on the time ahead. As will be discussed in more detail in the discussion chapter, this was the only time within the interviews where a daughter/daughter [in-law] shared significant concerns and worries about the future, to the extent that the mother/mother [in-law] was quite agitated by the discussion.

Other differences between Diana and Susan and some of the other mother and daughter dyads, seem to be more related to the fact that Diana is about to transferred back home where there are inadequate care provisions, and many logistics to be sorted in arranging appropriate care, compared to other mothers who are either already living somewhere where they have access to full care, such as Carrie receiving care in a retirement home, or alternatively, are mothers such as Marian, who is being discharged home where there is extensive support available to provide full-time care.

Similarities and differences across mother and daughter dyads

Mothering/Daughtering, Mothering [in-law]/Daughtering [in-law], Motherhood/Daughterhood

Within and across the relational stories shared between the women who participated in this study, there were powerful and poignant reflections and representations of who each of these
women were, in the past, in the present, and who they were becoming as this time of their lives. Grounded within these stories was a strong understanding of how mothering and daughtering (mothering [in-law]/ daughtering [in-law]) practices, roles, relationships and understandings were lived and experienced individually, relationally and intersubjectively between them. Recognizing how their lives as women were situated within broader medical, social, cultural and historical contexts, mothers [in-law] and daughters [in-law] also reflected on how their experiences were further shaped and constrained by the institution of motherhood and daughterhood. Most profoundly reflected within these relational stories was a recognition of the power and strength of women in relationship, women who fiercely, protectively, compassionately and tenderly, focused on living (relationally) while dying.

Relational Continuum over time

Young Daughters

For the four mothers who had mothered their daughters from birth, mothers recounted what appeared to be well-worn family lore stories of important firsts: stories of how they felt the first time they saw their daughter; remembrances of their daughter’s first steps or first day of school; or the vivid recall of their daughter’s first accident or the first time they really worried about their daughter’s safety. These initial early stories were often followed by stories which demonstrated particular qualities and characteristics of each daughter – for one daughter it was her gentleness, for another her intelligence, for another it was how motherly the daughter was, even as a young girl. Within these stories, mothers were the primary narrators. While mothers shared these stories, daughters would actively listen and respond non-verbally in-kind – squeezing their mothers’ hands, or by pulling their mothers into a warm embrace. These relational stories, in their verbal and non-verbal manifestations, offered an important foundation for mothers and daughters to reflect on important memories and events, but also to relay how mothering, daughtering, and connection were woven into their relationships. Contained in these relational stories were powerful understandings of how mothers understood who they were as

25 Diana and Susan’s relationship began when Susan was an adolescent, and began dating Diana’s son. As a result the relational stories shared between Diana and Susan did not include stories from when Susan was young.
mothers in relation to their daughters, and the significance of their role in protecting, anticipating and encouraging their daughters at this time in their lives. Through these relational stories, mothers also demonstrated how daughters were taught about mothering, and more broadly about women’s caring, and how women’s care activities focus on identifying, meeting, and being responsible for the needs and development of others.

Adolescent/Young Adult Daughters

Relational stories that emerged as daughters were adolescents or early adults shifted to narratives that were co-constructed between mothers and daughters. Within these stories, mothers and daughters would share the narrator role, and the stories that unfolded were sometimes linear and other times more circular, as memories were shared of strong connection, difference, and disconnection. These stories offered important insights about how differences between mothers and daughters were navigated, and how these differences were held within their relationship. While many of the stories shared by mothers and daughters reflected strong messages and values about open and honest sharing between them, there was also evidence that sharing was sometimes limited, and that mothers and daughters made decisions about what to share and what not to share with each other. For mothers, this introduction of not sharing was framed primarily around protecting, in that mothers wanted to protect their daughters from getting hurt or from unnecessary harm. For daughters, not sharing seemed to be contextualized as a way of protecting parts of themselves, in keeping some parts of their experiences separate or private, and/or in worrying about parental reprimand or criticism. In some cases, daughters noted that they also wanted to protect their mothers from undue worry or concern. Of interest within these relational stories is not only that mothers and daughters had different understandings or experiences of events, but that for some mothers and daughters there were completely different remembrances of what each of them had said, or had not said to each other.

Illness/Present Day

Relational stories that unfolded about how mothers and daughters responded when illness first came into their lives varied across each mother and daughter dyad. Within these relational stories were important understandings of how care was integrated into the mother and daughter relationship. In two of the mother and mother [in-law] and daughter and daughter [in-law] dyads, mothers and mothers [in-law] had been living with chronic illness for many years.
Strongly present in these relational stories were understandings of how care and care practices are woven into the lives of mothers and mothers [in-law] and daughters and daughters [in-law]. Elisabeth was an early adolescent when her mother was initially diagnosed and Elisabeth was quite involved in her mother’s care. In reflecting on this time of her life/their lives, Elisabeth described caregiving as not particularly stressful or notable, but rather just what one does when someone is sick “You just, you know, somebody’s sick, you step up.” This response, of just stepping up and taking care of her mother’s need, was woven into Elisabeth’s beliefs and understandings about how one should respond when someone else is sick. What Elisabeth recounted as stressful about this time was not related to the care she provided, but rather to the isolation and fear that she felt as a result of her parents not telling her what her mother’s condition and prognosis meant for the future. Compounding this stress was also a strong relational understanding that while she knew she wanted and needed to know this information, she also believed that she could not ask directly for this information. Shifting into the present, Elisabeth continues to be very involved in her mother’s care, and Elisabeth and her mother (Carrie) spend a great deal of time overseeing and managing Carrie’s care. There continue to be many beliefs and understandings about what ‘one’ does when someone is ill, and these beliefs are woven into Elisabeth’s identity as a daughter, and as a nurse. These beliefs though are in tension with the reality that Elisabeth is overextended and has a result of varying stressors, gone on a medical leave. While Carrie is able to see how Elisabeth is overburdened and how her care provision to her mother is making her sick, Carrie and Elisabeth are not able to talk directly about these competing needs and tensions. All of these relational stories offer us important understandings about how Elisabeth and Carrie have negotiated (and continue to negotiate) care between them, of the activities of care that have moved and continue to move between them, of how sharing happens or does not happen, and how and or why some truths are shared relationally, and others are left unsaid.

In Diana and Susan’s mother [in-law] and daughter [in-law] relationship, Diana had her first heart attack thirty years prior and Susan was very involved in Diana’s care. As a daughter [in-law], and as a nurse, Susan worked to respect a line between herself and her mother [in-law] while also being very involved in interpreting and translating medical information into a form and format that Diana and her husband could understand. As Diana says, “I swear, I don't know what I’d do if we didn’t have (Susan). Um, she, she’s taken over the, um, explanations and, of
the, for the illness and what’s going on with my life and, ah, she just explains it all so that you understand and, ah, connects up, you know?” While Susan’s role as daughter (in-law) and nurse had worked quite well over the last three decades, more recently, Susan was struggling as she wasn’t able to help Diana navigate across the multiple (and competing) medical specialities that were involved in Diana’s care. As Diana’s symptoms continued to progress, Susan felt caught between recognizing and responding to Diana’s physical deterioration and need for medical oversight, while also respecting Diana’s autonomy and ability to make her own decisions about her care. After finding out that the multiple medications that Diana was taking were actually making her progressively more and more ill, Susan was angry and frustrated with the lack of medical oversight around Diana’s care. As Susan anticipated all of the varying care needs (and potential challenges) that would or could arise for Diana in both the short and longer term, Diana on the other-hand worked to try and digest in the immediate present; how it was that she was so close to death and yet didn’t die. The differences between Diana and Susan at the time of this interview reflect some of the inherent differences that can exist between patients and their families, as a result of their own individual positioning and entry in end of life. As Diana works to understand and integrate what it means to be given more time, Susan on the other-hand looks ahead to all of the other needs and issues that will arise in the future. Navigating very different beliefs, understandings and experiences, Diana and Susan have very different needs and concerns as they relationally experience end of life.

In the three other mother and daughter dyads, advanced illness and end of life were elements that had arisen more recently and these stories are woven into the end of life relational stories that are addressed below. While the relational stories that unfolded across all five mother and daughter dyads varied, each relational story offered a profound way to see how each mother and daughter had built (and were building) their own relational history/trajectory of how they had moved individually and relationally across and between connection and disconnection over time. Specifically relational stories allow us to examine and explore:

- how communication varied between mothers and daughters over time and how this informed mothers and daughters beliefs/knowledge/experience of connection/disconnection
• how empathy (mutual and anticipatory) was expressed within the relationship and how this informed mothers and daughters beliefs/knowledge/experience of connection/disconnection

• How support (individual and mutual) was experienced and how this informed mothers and daughters beliefs/knowledge/experience of connection/disconnection

• How difference and conflict was navigated between mothers and daughters, and how this informed mothers and daughters beliefs/knowledge/experience of connection/disconnection

In addressing how relational stories built over time between mothers and daughters inform experiences of end of life, I shift our focus to the end of life relational stories that were thematically and dialogically analyzed, and the implications these findings have for understanding how mothers and daughters experience end of life

*Thematic analysis similarities/differences*

In examining the specifics of two end of life relational stories for each mother and daughter dyad, there were specific elements that emerged within each mother and daughter relationship which strongly shaped how they were experiencing end of life in relationship to: *choices* – in making, accepting and honouring choices; *care* – in shifting, providing, receiving, and accepting care; *managing care* – in overseeing, anticipating, and problem-solving care; and finally *end of life needs and wants* - in communicating, hearing and reconciling differences in what mothers and daughters need and want in end of life. Tightly interwoven with each of these themes were broader reflections and understandings of how mothers and daughters responded navigated across tightly interwoven processes which were individual, relational and intersubjective.

*Dialogic/performance analysis similarities/differences*

Closely examining one end of life relational story/performance within each mother and daughter dyad offered further evidence of how these interwoven processes were not just lived between mothers and daughters, but how they were performed and reproduced within their relationship. Widening the focus to how these performances are performed with and in relation to others, offered the opportunity to see how relational, dyadic interviews offer a way to explore not only what women are sharing about their experiences, but how, when and why they are sharing their
experiences in particular ways and styles. Performance genres offered important insights about how direct speech in a relational story carries primary messages embedded within each story, and how repeated words offer a way to examine which activities or practices are most highly stressed within each relational story. While I believe that we need to use caution in how we interpret word frequency displays and I think it is critical that researchers think carefully about the scope and parameters that are drawn on within these queries, I believe that in this particular case, this visual display of ‘performance’ is important. Drawing specifically on the context of the repeated words used within each end of life relational story/performance, allows us to see the repeated words that are used across the relational stories in a spatial format. The larger format of the word ‘know’ reflects how across the repeated words utilized, that this word was used more often, and that words that appear spatially smaller, reflected repeated words that were used less often. Generalizations cannot be made about performance or narrative reflections outside of these end of life relational stories, as the word frequency only reflects these particular excerpts. See Figure 10, Word Frequency word cloud of repeated words used across relational stories examined with Dialogic/Performance analysis

Figure 10. Word frequency word cloud of repeated words used across relational stories examined with Dialogic/Performance analysis
In examining voices in dialogue and multiple layers of context across all five mother and daughter dyads there were similarities across the relational stories around the voices that were being performed, such as dialogue that was performed directly in a mother’s direct voice, or dialogue performed by daughters, on behalf of their mother’s voice. The interwoven nature of these voices and how mothers and daughters shifted across their own voices and the voices of others, and further how some of these voices were able to co-exist in tension, where with others, there was a need for consonance and harmony, reflects how performance is able to hold the polyphonic voices that thread through our relational stories. End of life practices and care sites emerged within these relational stories, through my own performances as a palliative care researcher, as a social worker and as a daughter, as well as in how prognosis elements were communicated, and in how end of life care activities and supports differed across practice sites and programs. Across all of the mother and daughter dyads there was a strong understanding of how mothers [in-law] and daughters [in-law] as women, and as women in relationship together, were navigating across a number of familial, medical, social, cultural and historical contexts and how as Ruth so eloquently and powerfully relayed, “It entwines, you know? One goes into the other. I can’t separate one from the other”.

In the following chapter I discuss further how the findings raised within this study support, challenge and add to the literature that already exists about how mothers and daughters experience end of life. Lastly I address how the findings of this study could be utilized to inform social work practice and social work practice education, and the implications this study has for further research in this area.
Chapter 5: Discussion

Within this chapter I begin by repositioning our focus on the overall design of this study, and how this work is informed and guided by a feminist epistemology. Specifically this study centers on what mothers and daughters know and experience in end of life, and how and why this knowing needs to be situated within the multiple contexts in which women live and die. Focusing on end of life relational stories, I explore how these stories were produced and performed between mothers and daughters, and how these stories reflect mothering/daughtering activities, practices and understandings which are deeply woven within individual, relational and intersubjective processes. In identifying and examining the central threads of each of these individual, relational, and intersubjective processes, and further how these processes are interwoven within mothers and daughters experiences of end of life, I address how my study findings support, challenge and add to the literature that already exists about how mothers and daughters experience of end of life. Lastly, and perhaps most importantly, I address what we learn in talking with people who are experiencing end of life and how this learning has implications for social work practice, social work education, and further social work research in this area.

Re-Centering our Focus on Women’s Knowing

In hearing, honouring and privileging the multiple forms of knowing which exist between mothers and daughters as mothers come to the end of their lives, this study examined how gender informs and influences what is considered, understood and valued as knowledge at end life. By situating mother and daughter knowing within larger practices and performances of motherhood and daughterhood, this study embeds women’s knowing within and across multiple and often competing relational, familial, medical, and social-cultural contexts. Recognizing the strong theoretical and conceptual links between feminist epistemology and narrative methodology, this study drew on stories and storytelling, and specifically focused on the stories that unfold between mothers and daughters within a joint/dyadic interview method.
Why I decided to do this study

After working on a number of research studies with women who were living with varying stages of illness, and hearing about the significance and importance of women and their relationships, I decided to focus specifically on how mothers and daughters experience end of life and end of life care. Recognizing and responding to the fact that most research in end of life does not focus on gender, or women’s roles, I was interested in privileging and prioritizing the specific knowledge and experience that lives between mothers and daughters as mothers receive end of life care. Drawing specifically on the relational stories co-constructed between mothers and daughters, was a way for me to access and further explore what I saw and continue to see in clinical practice, which is mothers and their adult daughters, individually, relationally and compassionately navigating across the complex layers of end of life and end of life care.

Stories, relationships and the unfolding of relational stories

Interested in understanding more about women’s “relational images” (Miller & Stiver, 1995), and what women believe and know about who they are as women, and as women in relationship in end of life, I explored how these images unfold within relational stories between mothers and daughters. Within this study I heard a wide range of stories about the lives and experiences of mothers/mothers [in-law] and daughters/daughters [in-law]. Some of the stories that I heard appeared to unfold seamlessly, narrated with an ease and a familial tone that suggested that these stories were well-worn stories, woven tightly into the relational fabric of who they were as mothers and daughters. Other stories that emerged were shared with less ease, they recounted particular moments and times when relationships were more difficult, narrated more cautiously and in some ways more individually reflecting stories of misunderstanding, hurt, and disconnection. From these stories, mothers and daughters would shift to relational stories of how they individually and collectively responded or resolved these differences, and how and in what ways these stories mattered or informed who they were. This is perhaps best demonstrated by Carrie as she said, “We’ve had our moments…but it always got mended.” The last type of story that emerged were the stories that hid in the shadows and were the most difficult to verbalize. These stories emerged to the surface in sentence fragments, words flowing and then stopping—caught in mid-flight, reflecting spaces and times where words could not be said out loud, where words were insufficient to express the deep and embodied experience of sorrow, grief, and loss.
Within all of these stories mothers and daughters actively and compassionately demonstrated who they were as women, as mothers, as daughters, as mothers [in-law] and daughters [in-law], and as mothers and daughters together. Woven into each of these stories was an understanding of how mothering and daughtering had been experienced over a relational continuum of time, and how across this continuum each relationship had shifted across social, historical, and relational contexts of motherhood and daughterhood. While one of the mothers and daughters dyads who participated in this study was a mother [in-law] and daughter [in-law], and there were some specific differences in relation to anticipatory caregiving which will be discussed below, I believe that there were more similarities with this dyad and the other mother and daughter dyads, than differences. My discussion below focuses on mothers and daughters, with a strong proviso that while in this case a mother [in-law] and daughter [in-law] are included within this sample as mothers and daughters, that further study is required to examine how mothers [in-law] and daughters [in-law] experience end of life with their own unique set of experiences and concerns.

Coming back to the research questions guiding this study

1. What are the relational stories (beliefs/understandings) that inform mothers’ and daughters’ experiences in their relationship, and how do these relational stories inform their experiences of end of life.

2. How does the process of participating in a relational life review illuminate relational understandings of end of life, and how might this widen our understanding of shared loss and meaning at end of life?

The first question, explores the relational stories that inform mothers’ and daughters’ experiences in their relationship over time, and how these relational stories built over time, inform their experiences of end of life. The second question, which addresses the process and method of using relational life review interviews, will be addressed in the implications section below.

5.1 Mother and Daughter End of Life Processes: Individual, Relational, and Intersubjective

As mothers and daughters shared their relational stories of end of life, a number of mothering and daughtering activities, understandings, and end of life meanings were apparent, which reflected individual, relational and intersubjective processes. These processes were reflected in
not only what mothers and daughters talked about within the content of their relational stories, but how and why certain elements were performed and produced in some ways, and not others. While these processes are interwoven and difficult to untangle and separate, understanding how these processes work, and identifying the primary positioning of each process, can help illuminate the specific elements that mothers and daughters are navigating, and how we might better support mothers and daughters across and within these processes. For an Overview of Core Findings: Individual, Relational and Intersubjective Processes, please see Appendix H.

5.1.1 Individual Processes

Within the relational stories shared between mothers and daughters there were particular beliefs, understandings and activities which were constructed and performed as individual acts and processes. In focus are individual acts and understandings that are primarily situated and located within either mothers or daughters.

*Mother’s individual knowing and experience of end of life*

The individual process that is most apparent within the relational stories shared by mothers and daughters is the specific knowing and understanding that is aligned and situated with mothers’ experiences of end of life. Each mother’s knowing and understanding was framed from a position of knowing what it means to be a woman who has been told (directly or indirectly) that she is dying, and to live within a body that is struggling with illness and progressive decline. While mothers had shared much of their individual knowing and personal experience with their daughters prior to our conversations, it was also clear within the relational story content and how these stories were performed, that this form of knowing and experience was something that only mothers could give voice to within these stories. Strongly woven through each of the mother and daughter interviews was the tremendous respect and space that was given to mothers, to express in their own words, conversational style and narrative form, what it was like to be where they were, to be living (and dying), at this time in their lives. Each mother claimed this space, sharing in voices that varied from strong and determined, to slow and fatigued, what it was like for them to enter into end of life, what end of life meant to them, and what they needed and wanted others to hear about who they were as women and mothers in end of life. Each mother described directly and explicitly her present day experience, and we were strongly encouraged to really see the multiple challenges and difficulties, the growing list of activities that most of these
mothers could no longer do for themselves (i.e. eating, walking, getting in and out of bed, bathing) and most importantly, how mothers’ really experienced this time in their lives. Across a number of these stories were tensions and difficulties that mothers experienced in recognizing who they were in the present, and how this connected (or did not connect) with who they had been prior to their illness, or even who they were months or weeks earlier. This sense of irreconcilable differences, permeated many of the conversations as mothers shifted to talk about who they were; as a person, a woman, a mother, and a spouse. Reflected within each mother’s relational stories were core elements of Erik Erikson’s (1950) conceptualization of maturity, with a specific emphasis on ego integrity, as mothers reflected on who they were as women, both in relationship to who they were before illness and who they were now, but also who they were in relationship to their families, as they found themselves in end of life. While Erikson’s conceptualization around despair appears to focus on fears and concerns about running out of time to be or become who one might want to be, within mother’s relational stories these kinds of fears and concerns were not raised. Fears and worries which did emerge for mothers were focused on immediate concerns about dying, about suffering, and about suffering when they died.

**Daughter’s individual knowing and experience of end of life**

Daughter’s individual knowing and understanding of end of life was often positioned as secondary to their mother’s knowing and understanding. For most of the mothers and daughters, mothers would begin telling me about their experiences, and then daughters would fill in their own narratives and stories, often encircling and building on the stories their mothers shared. Woven within these stories were daughters’ descriptions of what it was like for them: to see their mother ill for this first time in their lives; to hear their mother’s suffering; to witness their mothers’ loneliness; to see their mum’s frailty and vulnerability. As the stories emerged, daughters shifted from narrating and describing stories, to sharing their own knowing and understanding, their feelings of hopelessness, their feelings of anguish and loss at not being able to fix things for their mother, or not being able to take away their mother’s pain. Many times, these feelings were half-expressed – sentences cut off, words followed by emotional sighs, voices trailing off in higher or lower tones. There was for me within these moments, a sense of the ‘boundedness’ of each relationship – of the flow of energy that lived between mothers and daughters that was below or underneath words – that just ‘was’ and ‘is’ between each mother and
daughter, that could not be communicated to someone outside of their relationship. As these stories emerged, daughters shifted from narrating and telling stories to me and their mothers, to direct conversation with their mothers, seamlessly weaving across and within multiple relations all at once. As daughters spoke about their feelings, and challenges, there seemed to be extra layers of attention to how their mothers’ might hear their concerns, and in attending to their mother’s verbal and non-verbal cues, daughters’ relational stories often threaded back to their mother’s relational stories, reasserting the primacy of their mother’s experiences of end of life. In examining the relational stories shared by daughters, there was less evidence of each daughter’s individual psychosocial stages or family life cycles. While each of the daughters had spouses as well as children who varied in age from pre-school to young adults, the needs and concerns of daughters’ as mothers themselves, and their immediate family members, were talked about less directly within daughter’s relational stories. Instead, daughters’ focused more explicitly and directly on their mothers’ individual psychosocial stages, and how they were actively involved in their mother’s family life cycle by ensuring that their mother’s needs in later life were being met. Each daughter’s emphasis on her mother needs, speaks further to the prioritization and positioning of each mother’s needs in end of life.

Core findings about mothers’ and daughters’ individual knowing and experience about end of life

1. Individual knowing and understanding of end of life is located (and clearly positioned by daughters), within the lives and experiences of women who are dying
2. Individual knowing and understanding of end of life by mothers AND daughters while located individually, lives relationally, and daughters are highly attentive to ensuring that their mothers’ voices and experiences are heard first, and then their own voices can be heard

Mother’s individual choices and daughters responses around treatment

Within the relational stories shared by Ruth and Sarah, and Carrie and Elisabeth, were the individual choices that Ruth, and Carrie, made to stop taking life-sustaining medications, treatments, or surgical interventions. Within each of these relational stories shared we were able to see how each mother assessed the possible impact or harm of continuing treatments versus
stopping treatments (primary appraisal), and we were able to see how each mother assessed and evaluated what could be done to change the impact or harm that would unfold in continuing or stopping treatments (secondary appraisal). As each mother and daughter shared their relational stories, mothers and daughters (on behalf of their mothers), shifted from a focus on the individual choice to stop taking medical interventions, towards identifying the broader elements that informed their decision-making. Within these broader elements were specific beliefs, values and goals, reflecting each mother’s **global meaning** (Park & Folkman, 1997), as well as specifics around how each mother’s global meaning connected with each woman’s specific **situational meaning** (Park & Folkman, 1997).

Situational meaning was constructed around:

- how each woman’s choice to not continue with treatments was/is connected to a larger medical/illness trajectory wherein choices were made to pursue medical interventions in the past (which were perceived as further damaging or not helpful), and further,
- how this choice was/is connected to each of the mothers’ larger life course trajectory.

Situational meaning reflects more implicit understandings and assumptions about how, individual beliefs and goals, which are woven into a broader understanding of **global meaning** (Park & Folkman, 1997), are also strongly woven and reproduced within larger social-cultural **meta-stories**26 about life, death and choice. These larger narratives speak to: the priority or sanctity of life (Singer, 1995); how as a society we deny and ignore the fact that death will happen (Clark, 2002); and lastly, that if a person is ill, that all options to live **should** be explored, until all possibilities are extinguished (Quill, 2000). To choose to stop taking treatments that could sustain (prolong) life, would as a result of these powerful narratives and conditions, **require** that patients be able to strongly position their choice in relation to these broader stories. Both Ruth and Carrie position their decision to stop treatments **after** having chosen to pursue

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26 Meta-stories would have some overlapping features with varying constructions of ‘meta-narratives’ or ‘grand narratives’ or ‘master narratives’ that are used to flag broader understandings which are interpreted as rules or regulations or norms in how actions, or experiences ‘should’ happen. (Irving & Klenke, 2004; Lyotard, 1984; Schwandt, 2007) In this context, my application is focused on the larger normative story, and how mothers and daughters speak to their perception or understanding of this larger story in relation to their own experiences.
medical treatments, and thereafter, lived with the costs and/or futility of the treatment, the excessive experience of burden, and a significantly diminished experience of quality of life. Within a further examination of situational meaning, we gather a sense of how Ruth and Carrie appraised the meaning of their illness, how at the beginning, they both actively sought treatment, and how they both worked to find a meaning for why they were ill and why it was significant that they both worked towards living as long as possible. As these meanings changed for them Ruth and Carrie needed to find other ways to reflect how and why their positions on continuing to take treatment had changed.

Both Ruth and Carrie also widen the context of their choice and decisions to their larger life course, as they both reference the varying struggles, challenges and transitions that they have been living with for many decades. Within this larger life course trajectory both Ruth and Carrie (and their daughters on their behalf) are able to communicate how they have struggled across their lives, and how both of them have experienced significant suffering. Within this larger life course trajectory we are also able to explore how stress and coping has been experienced across women’s lives, and how they have each developed their own resources and understandings of how they respond to stress. This reference to historical time and place, and how they have experienced pain and suffering throughout the course of their life, speaks to another meta-story which can circulate, which is that life is hard, and that life involves struggle and suffering and that life needs to be experienced and understood as an experience that is not easy or without pain. Some of this larger narrative can be traced back to a moral or religiously informed understanding about the value or growth that comes from individual pain and struggle. Experiences of illness and the burden of living with illness can be associated for some people with God’s will and can be seen as tests of an individual’s fortitude to continue onwards, in spite of great pain and suffering. Other elements may be traced to the birth of the protestant work ethic and early capitalism, as hard work (and suffering) were seen as part of contributing to a larger economic society (Baehr & Wells, 2002). The positioning of Ruth and Carrie’s larger life course, and the fact that suffering and pain have been woven through their life courses, further substantiates and supports that their decision to stop treatment comes after extensive work and costs in living with suffering for as long as possible. This further positions the choice to stop treatment as something that comes as a result of an individual coming to a place of reaching their personal and individual limits to tolerate pain and suffering, and as such shifts the focus back on individual experience.
and personal agency about what can and cannot be handled. Lastly, both Ruth and Carrie also acknowledge that they have reached their decision to stop treatment as a result of a ‘turning point’ (Elder & Shanahan, 2006) in their lives. For Ruth, her turning point is a particular point where the accumulation of her needs makes her realize that she does not feel like her life is worth living anymore. For Carrie, her turning point is linked to the loss of her husband, and since he died she has decided that she doesn’t want to live without him anymore.

While both Ruth and Carrie were clear that their decisions to stop taking their treatments were individual decisions, it is also very important to locate these individual decisions within the relationships, families and larger communities which surround Ruth and Carrie. While the focus of the relational stories between mothers and daughters was on how each of the mother and daughter dyads were responding to end of life, other family members’ opinions and perspectives were also raised within these relational stories. The presence of other family members within these relational stories, as shadows in the data27 reflects how each mother and daughter are part of a larger family system and broader community, that also informed how each mother and daughter experienced end of life. Below I will address how Sarah and Elisabeth responded to their mother’s choices, and then I will speak more broadly to the presence and role of other family members.

**Individual choices and responses living relationally – at the time of the choice – and afterwards**

Within Ruth and Sarah, and Carrie and Elisabeth’s relational stories, we see how Ruth’s choice to stop treatment, and Carrie’s choice to stop surgical interventions, have been made individually, drawing on their own appraisals and understanding of stress, how they can cope and respond, and the meaning that is associated with this choice. Further, we see how Sarah and Elisabeth, as daughters, also appraise the situation, and how they cope and respond and find their own meaning within their mother’s choices. While each mother and daughter is experiencing and responding to these choices individually, they are also living these choices relationally, as they work to talk about their experiences in end of life. Between Ruth and Sarah, we see forms

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27 Special thanks to Dr. Juanne Clarke who in an earlier version of this work raised the issue of ‘shadows in the data’ and what these shadows offer in terms of perspectives and understandings operating within each family and within each mother and daughter dyad.
of relationship-based coping that draw on *active engagement* (Coyne et al., 1990), as they share things between them and communicate collectively about how Ruth’s choices and problem-solving coping lives between them. There are also glimpses of *protective buffering* (Coyne et al., 1990) as Ruth does not communicate fully her distress about dying and she does not share her terrifying nightmares with her daughter. Similarly, with Carrie and Elisabeth, we see active engagement around how Carrie and Elisabeth are able to communicate collectively about Carrie’s decision to stop having surgeries, but we also see forms of protective buffering, as Elisabeth does not share with Carrie that she is on a medical leave and that she is experiencing a high level of stress overseeing her mother’s care.

Further we see how other family members are also present within these relational stories, as we see in Ruth in sharing about her decision to stop treatment, the conflict and hurt that exists between herself and her husband, as he doesn’t understand her decision. This difference and disconnection is very difficult for Ruth and her husband, and the distance and difference between them in their positions is characterized by Ruth as being “beyond us”. Further, Ruth’s eldest daughter also believes that Ruth’s decision to stop treatment was informed by Ruth’s history of depression, and she questions whether Ruth’s decision was made competently and clearly. While this speaks to different entries into assessing the stressors that Ruth is living with, and the different meanings that each family member is bringing to the situation, this also raises how families respond to stressors differently and how these differences can create strong forms of disconnection and difference between family members. Sarah positions her response to her mother’s decision within the larger context of her family, as Sarah’s response to her mother’s decision lives not only between herself and her mother, but it lives between Sarah and her father, and Sarah and her older sister. This broader context is important, as we see how Sarah has in her response to her mother, had to consider the impact of her decision on herself, on her relationship with her mother and how this means her mother will die earlier that she would have liked, and on her relationship with her other family members. The awareness of these multiple layers of relationships, and how individual decisions can cause conflict and tension between individual family members, can add further to the stress that each family member experiences as they respond to a loved one’s decision about their treatment.

Lastly, we see how decisions and responses to stressors have an impact not only when the decisions are made but also afterwards, as we see what happens after the stressors have
happened, within ‘meaning as outcome’ in situational meaning (Park & Folkman, 1997). This is apparent in how Sarah and her father and older sister, continue to hold different perspectives on how and why Ruth made the decisions she made. The presence of these differences while Ruth was receiving end of life care, reflects how the outcome of Ruth’s decision continues to live on within Ruth’s family. With Carrie and Elisabeth, the outcome of Carrie’s decision is even more directly apparent, as Carrie’s illness has not progressed, and therefore Carrie and Elisabeth are left wondering how to proceed knowing that Carrie wants to die, but that her body appears to show signs of healing and not further deterioration.

**Core findings about mothers’ and daughters’ individual choices around treatment in end of life**

1. Women’s decisions to pursue treatment or stop treatment need to be located within and across women’s larger life course trajectory which reflect a history of stress and coping resources that have been built over time.
2. Women’s beliefs and purposes (global meaning) about treatment and end of life are strongly woven and reproduced within larger social-cultural *meta-stories* about life, death and choice.
3. Each woman’s situational meaning around a specific choice or decision needs to be understood within a framework that recognizes the history, meaning, and outcome of how these decisions have lived and continue to live within their relationships.
4. Each mother’s decision and her daughter’s response to her mother’s decision are enacted individually, but lived relationally between them, as well as within and across the multiple relationships that they live and die within.

**Relevant theoretical and empirical literature**

*Supports*

Within the discussion above on individual processes in end of life, there is support for the centrality of a women’s life course trajectory, and how women’s knowing and understanding of end of life is strongly informed from the multiple transitions and turning points that she has experienced across her life course. This supports the centrality of life course theory in end of life, and re-affirms those researchers who have worked to broaden their focus on end of life, to a
wider framework of living with advanced illness into end of life, (such as Chunlestskul et al., 2008; Chunlestskul, Carlson, Koopmans, & Angen, 2008; Gotay, 1984; Tallman, Greenwald, Reidenouer, & Pantel, 2012), or further following patients and families from advanced illness into end of life and bereavement (such as Grbich et al., 2001; Stajduhar, 2003). Further, these findings challenge researchers to explore the life course beyond and outside the context of illness, as there may be important understandings from across women’s lives that can further our understanding of how women experience end of life.

These findings support individual psychosocial stages of mother’s experience of end of life, particularly in relation to maturity and ego integrity. These findings did not support the individual psychosocial stages of daughter’s experiences, as daughter’s focused more exclusively on the needs and concerns of their mothers. While there was evidence that family life-cycle theories were apparent in how daughters focused on supporting their mothers in transitioning in later life, there was less evidence within these findings of how the daughter’s family life-cycle in relation to her spouse and children were connected to the experiences of mothers and daughters in end of life. Given the focus and emphasis within this study and interviews on mothers and daughters it is important to acknowledge that these others forms of experience may have been obscured from view. Also strongly reflected within these findings is the relevance and applicability of stress and coping theories and how mothers (and their families) appraise the stress of advanced illness, continuing with treatment, and/or making the choice to stop treatment. Further, the widening of stress and coping theories to include global and situational meaning, encourages an understanding of how individual beliefs and goals interact with specific contexts and situations, and how all of these elements inform how mothers and daughters appraise and cope with the varying stressors that arise in end of life.

**Challenges**

The findings of this study strongly challenge researchers to identify or explore how gender and gendered roles and responsibilities inform how people experience end of life. While the issue of gender has been raised theoretically in relation to the experiences of caregivers (Mackinnon, 2009), and in relation to the experiences of women dying (Noppe, 2004), gender needs to be prioritized and examined within empirically based research studies in end of life. Not exploring how gender matters for women who are dying, or their daughters, silences and marginalizes
women’s experiences, and further strips women of who they are at a time in their lives when who they are means everything. In addition, these findings emphasize the importance of situating women within the relationships in which they live, and how research studies which examine patients and families together, may be able to access elements of end of life that are performed and lived relationally, that are not able to be seen through individual accounts.

*Adds to practices in end of life*

The findings of this study suggest that life review practices could be expanded beyond individuals to individuals in relationships. Widening the focus to individuals in relationship could support patients and their loved ones to review not only their individual lives, but their collective lives and experiences, and as such, could support families and loved ones in acknowledging the upcoming loss, and in saying goodbye to each other. Offering individuals who participate in the life review a hard-copy of the interview, builds on the practices used within dignity therapy (Chochinov, 2012; Chochinov et al., 2002; Hack et al., 2010) and life review and legacy programs (Ando et al., 2009; Ando et al., 2007; Keall et al., 2011), in providing participants a physical form of memoir which has been found helpful and supportive for family members as they move into bereavement. Further, by offering individuals an audio-file version of the interview as well, participants are able to listen to the interview again in the future, offering families in bereavement the opportunity to hear their loved ones voice, and to hear their own voice in relation to their loved one. While dignity therapy as a specific end of life therapeutic intervention draws conceptually on Erik Erikson’s psychosocial stage of *generativity*, this study points towards *ego integrity* (*Erikson, 1950*) as another core element that could be explored with people who are in end of life. Shifting from a sole focus on generating a legacy for the next generation to a broader examination of meaning and identity may offer important links for both patients and their families as they work to find meaning at this time in their lives. Importantly too, it seems that as much as possible, life review practices should include the people and/or persons that patients would like to have with them, as they do this reflection. Recognizing that women’s relationships span a wide range of relationships and contexts and that relationships may vary in intimacy, it is important that patients are supported to gather together the people of their choice, which in some contexts may be their daughters, and in others, may involve other family members or friends.
5.1.2 Relational Processes

Core findings within this study which reflected relational processes between mothers and daughters focused on how mothers and daughters navigate shifts within their care practices, both between them, and with other care providers. Understanding how care lives within relationships, and how care shifts and changes with advanced illness and end of life, is a core part of understanding how mothers and daughters relationally experience end of life. Critical to this discussion is an understanding of how care practices, are situated across women’s life course trajectories and relationships, and how care reflects and represents how connection and disconnection operate within and across relationships.

Care relationships over time between mothers and daughters

As mothers and daughters shared relational stories about their relationship over time, there were many different stories shared about how care between mothers and daughters shifted and changed between them. As mothers shared stories when their daughters were young, care was reflected in how mothers supervised and protected their daughters, and how mothers worked to anticipate the needs of their daughters. As daughters matured, mothering care practices focused on being available and accessible, and stressed the importance that daughters knew that they could come and talk to them if they had problems. Strongly woven through these relational stories was a sense of mutual empathy (Jordan, 2004), as mothers and daughters connected strongly to each other, and care and learning moved between them. As daughters matured they also learned both directly and indirectly about anticipatory empathy (Jordan, 2004) and the importance of thinking about how ones actions and thoughts might harm or impact someone else. Relational stories in adolescence and young adulthood, shifted to stories of disconnection, stories of mothers protecting their daughters from some of their concerns and worries, and further, stories of daughters protecting their mothers from certain parts of their lives. Through these stories were multiple examples of how mothers and daughters re-connected with one another during moments of conflict or disconnection. Reflected within these stories were examples of how strong positions or differences were shifted at varying points, and how mothers and daughters moved on from these moments and points in their relationship. Woven into these stories were examples of relational resilience (Jordan, 2004), as mothers and daughters both individually and collectively found ways to mutually support each other during these times.
As roles, identities and care practices shifted across the relational continuum, mothers and daughters needed to reconfigure an understanding of who they were as a woman, and as mother or daughter at each phase of the continuum. Mothers reflected this most explicitly as they talked about the shifts in their mothering practices when their daughters left home, and likewise daughters talked about shifts for themselves as they left home, and as they married and had their own children. Understanding how care practices as a mother and as a daughter are linked to a woman’s sense of identity and sense of self is critical in understanding how illness and particularly advanced illness impacts a woman’s life. As roles and identities shift between mothers and daughters in relation to end of life care, there can be similar tensions as daughters struggle between roles and identities that they might have had when their mothers were well, to roles and identities they take on as they provide more care. Underscoring these tensions are places where daughters may need to reconcile how in providing more hands-on care, that their present day care practices collide with previous roles they might have had of empowering and advocating for their mothers’ independence and autonomy. Across all five of the mother and daughter relationships there was a strong understanding that each mother’s identity and role was strongly and fiercely protected by both mothers and daughters, and that this remained as physical needs increased and more and more care daily living was required.

**Core findings about mothers’ and daughters’ relational care practices in end of life**

1. Mothers and daughters have a long relational continuum where care practices have shifted over time and this history of previous roles, meanings and purposes of care, need to be acknowledged as care practices shift in end of life
2. Care practices for women are often strongly woven into their sense of self, identity and role as a woman, and as a mother and daughter. Shifts in care practices need to be recognized for the depth and breadth of what these transitions mean for women, and women needed to be supported to modify or adapt care practices into new contexts and situations.
3. Mothers and daughters may need support to acknowledge the shifts and changes in roles and identities, as well as the losses and/or new elements that may arise with these changes.
Care relationships between mothers and daughters and care providers

In examining care relationships between mothers and daughters and care providers it is important to broaden our attention to the purpose of care and not just the actual tasks or acts of care-giving or care-receiving. Bowers (1987) seminal work on intergenerational caregiving is tremendously helpful in this regard, as she widens our focus of care from more traditional understandings of instrumental caregiving (Bowers, 1987), which refers to specific hands-on care acts (i.e. bathing, feeding), to the primary purposes informing care, and how and why the purposes of intergenerational caregiving need to be understood. Drawing primarily on a large sample of adult daughters, Bowers study found that protective caregiving was by far the most challenging and most important form of caregiving provided by daughters. Understanding the central purpose of protection, and how adult daughters are working to protect their ill parent’s identity and sense of self, as well as protect their relationship between themselves and their parent, offers critical context in understanding the work, and stress that can unfold between mothers and daughters and care providers. Elements of protective caregiving (Bowers, 1987) and anticipatory caregiving (Bowers, 1987), where daughters focus on anticipating a variety of possible outcomes that could happen “just in case” (Bowers, 1987, p. 25) were found across a number of relational stories shared by mothers and daughters within this study about their interactions with care providers. Also evident was a strong focus on the stress and burden that can arise for mothers and daughters in relation to other care providers, in overseeing and managing their care.

One notable difference found within the findings in relation to care practices and mothers and daughters is directly related to anticipatory caregiving. Of interest specifically is how, and or whether, adult children share their concerns or worries about the future with their parents who are in end of life. Within this study’s findings there was one dyad, Diana and Susan, wherein Susan relayed a number of concerns and worries that she had about Diana’s future end of life needs and issues. While Susan’s concerns and worries were well informed about the possible limitations that might arise in receiving appropriate supports, Diana found Susan’s concerns and worries quite anxiety provoking. Within Bowers (1987) intergenerational caregiving study, adult children were found to rarely talk about anticipatory caregiving with their parents, and further it was found that adult children intentionally did not talk openly about anticipatory caregiving with their parents. Reasons for adult children not talking openly about their concerns and fears with
their parents, were noted within Bowers study as related to fears of how these concerns could be interpreted as a lack of support, or further still adult children worrying that their concerns could be seen as implying that parents were not able to take care of themselves (Bowers, 1987, p. 26). There are important differences within this study’s findings and Bowers intergenerational caregiving study: the context of Bowers study is illness and not specifically end of life; it’s unclear whether any of the adult children were health care providers themselves; and lastly we can presume that Bowers study includes only family-of-origin children. Determining how and or why Susan was able to more directly and explicitly share her concerns and worries about the future with Diana, could be associated with any of the differences, and also could point to the fact that Susan is a daughter [in-law]. Further as there were some differences reflected in anticipatory caregiving between the daughters who participated, further research needs to establish whether there are notable differences in how anticipatory caregiving is expressed across different relationships.

**Core findings about mothers’ and daughters’ relational care practices (with care providers) in end of life**

1. Underscoring daughters’ relational care practices with care providers may be a strong connection and identification with protective caregiving, where daughters may be focused on protecting their mothers’ sense of self and identity and in ensuring the stability and security of the mother and daughter relationship.

2. Further within daughters’ relational care practices with care providers there may be a strong focus on anticipatory caregiving, and anticipating the multiple needs and concerns that may arise as their mother becomes more ill. Daughters can experience a tremendous sense of responsibility in both anticipating and meeting all of the variable needs that may arise for their loved one, and may feel that within the limits of the health care and home care system, that it is up to them, to ensure that their mother is protected and has their needs met.

3. Mothers and daughters in their relational care practices with care providers can experience a great deal of stress in overseeing and managing care and in ensuring that mothers receive ‘good care’. Managing care needs and responding to unmet needs involve weighing costs and risks as mothers and daughters worry about possible repercussions on future care.
Relevant theoretical and empirical literature

Supports

The findings of this study support the wide range of needs, tensions and challenges that can arise as patients (and their families) move across varying phases of illness into end of life. Rolland’s Family Illness Model (1987, 2005) helps us examine how varying psychosocial types of illness, such as the onset of illness, and course of illness, as well as the phase of illness, can strongly shape how patients and families relationally experience the developmental stages, tasks and challenges that arise in end of life. The findings from this study offer support for a number of the family developmental challenges that can arise within the terminal phases of illness, such as offering support and exploring family issues that can arise within mother and daughter experiences. Also apparent are the developmental challenges that may have arisen in earlier phases of illness, such as those around communication or meaning which may align with chronic or crisis phases of illness. Further the Family Illness Model helps us explore how family health beliefs and broader social cultural elements inform how families, and within this study mothers and daughters, experience end of life, and how these elements strongly inform how mother and daughters experience and make meaning of their experiences at this time of their lives.

In exploring more specifically how mothers and daughters experience end of life relationally, relational cultural theory (Jordan, 1997; Jordan et al., 2004) and Bowers (1987) intergenerational caregiving theories help us to explore more specifically how care lives between mothers and daughters, and how mothers and daughters navigate shifts in care in end of life. Integral to this study’s findings is how care and relational connection between mothers and daughters need to be situated more broadly across their relationship, and this supports research studies that have been conducted with mothers and their adult daughters about their relationship (Bojczyk, Lehan, McWey, Melson, & Kaufman, 2011); as mothers age (Aronson, 1991; Fingerman, 1995, 1996; Lewis & Meredith, 1988; McGraw & Walker, 2004; Pohl, Boyd, & Given, 1997; Walker & Allen, 1991), as well as studies with mothers and daughters as varying illnesses enters their lives (Hallé, Duhamel, & Le Dorze, 2011; Perry, 2004; Ward-Griffin et al., 2007). Each of these studies supports that mother and daughter relationships are unique, and that the relations that develop and unfold between mothers and daughters are quite different from other relationships that women experience in their lives.
Further these study findings support that women’s roles, as mothers and as daughters, can be tightly woven into their sense of self and their identity (O'Reilly, 2004; O'Reilly & Abbey, 2000; Rich, 1976), and that shifts in these roles require women to think critically about who they are as a result of advanced illness and increasing needs. This study also offers support for the importance of examining patterns of relating between mothers and daughters, as was noted in McGraw & Walker’s (2004) study, as the mothers and daughters in this study were emotionally and physically comfortable with one another, and used humour and laughter as a way of relating their care and trust in one another. Mothers and daughters in this study also reflected strong levels of relational competence (Jordan, 2004) and relational resilience (Jordan, 2004) as they were able to talk about shifts and changes in their identities and roles, and how these differences and losses lived within their relationship.

Bowers (1987) intergenerational caregiving theory offers important insights into the purposes informing caregiving between mothers and their adult daughters, and this study confirmed how daughter in end of life described and performed both protective caregiving and anticipatory caregiving. This is a strong addition to the understanding of mothers and daughters in end of life, as it demonstrates the importance of understanding what is informing care practices, and not just the activities of care-giving and care-receiving.

Challenges

While recognizing the significant benefits of studies such as that by Read & Wuest (2007) which examine and explore the experiences of daughters as they care for their parents while they are ill, this study challenges researchers to explore end of life experiences with mothers and daughters together, as a way of furthering our understanding of how women in relationship experience end of life care. While there are many important elements to consider in conducting research studies with mothers who are in end of life and their adult daughters, I think it is quite important that we do not shy away from research questions or studies that may involve sensitive conversations between family members.

Adds to practice in end of life care

It is absolutely paramount that social work practice in end of life responds and supports family members (as caregivers and as people in relation with someone who is dying), as they experience
the multiple needs and challenges that arise as their loved one moves into end of life. As patients
and family members oversee and manage care it is vital that they have access to the information
and psychosocial supports that they need to take care of themselves and each other. Findings
from this study suggest that a relational, narrative life review practice can support mothers and
daughters to reflect on who they are as women in relationship, and to explore how they are
experiencing end of life together. Further, offering a supportive environment for mothers and
daughters to share with one another their futures hopes and wishes for one another, opens a
conversation for mothers and daughters to speak more directly to end of life, and can support
mothers and daughters in relaying important messages to each other.

5.1.3 Intersubjective Processes

While the term intersubjective is used somewhat differently across disciplines (i.e. philosophy,
psychology, psychoanalysis), I am using the term here to reflect processes between mothers and
daughters where there is a “mutual knowing” (Arnd-Caddigan, 2011) of what each of them are
experiencing in relation to end of life. Specifically I am interested in what mothers and
daughters know and understand about where and how they are each positioned in relation to
dying and death in end of life. It is important to stress here, that mothers and daughters within
this study were given the space within our conversations to draw on their own language to speak
to end of life. While some mothers and daughters used the word death or dying directly, others
talked about an end, or what was coming without directly naming death and dying. As
conversations shifted to talk about end of life I purposely left these conversations open, as I
wanted mothers and daughters to speak to end of life in a way that felt comfortable to them. As
mothers began to describe what end of life was to them, and as daughters shared their own
thoughts and concerns, I purposely worked with their own language, so that these conversations
were situated in a context that was as informed as possible within their own meaning and
descriptors. Part of my rationale here is that I was interested in hearing how mothers and
daughters talked about end of life together and how and in what ways mothers and daughters
talked about their positions or thoughts in relation to death and dying. My interest stems from
some of my early experiences in data collection where it seemed that death and dying operated
on the palliative care unit in really explicit ways, while also operating more covertly, as if hiding
or pushed outside of direct view. Similar direct and indirect sightings were present within the
relational stories shared between mothers and daughters, and I was interested in exploring how these differences were recognized or supported between them.

*Mutual knowing in dying and death*

Within my conversations with mothers and daughters there were varying references, about, *being ready* or *being prepared* to die. These references seemed to arise at different points within the relational stories and seemed to be profound and poignant messages of how mothers were feeling in relationship to their proximity to death. While ‘readiness’ to die could in some way appear to be linked to the ‘acceptance’ stage with Elisabeth Kübler-Ross’s (1969) individual stages of dying, or further be part of the psychological and spiritual domains of Corr and Corr’s (1991-92; 2012) individual tasks of dying, questions remain about how these elements live intersubjectively between mothers and daughters.

For some of the mothers and daughters, there was a strong acknowledgement and respect that unfolded between mothers and daughters about how mothers were ready to die. For other mothers and daughters, mothers noted not only how they were ready to die, but that they wanted to die. Within these conversations, daughters worked to mutually know and support their mother’s desire to die, while also acknowledging either directly or indirectly their own position of wanting more time with their mothers. Critical to recognize within these conversations is the central paradox and tension that can exist between hearing and attending to the depth of loss and sorrow that informs a mothers’ desire to die, while also hearing and attending to a daughters’ need and desire to have more time with her mother. Reflected within this study’s findings was the tremendous care and attention that mothers and daughters intersubjectively held and attended to, as they navigated the cathexis of being in relationship while also living and dying. Lastly, mutual knowing about dying and death was also reflected within this study’s findings through experiences and understandings between mothers and daughters at the time of death.
Core findings about mothers’ and daughters’ intersubjective processes (mutual knowing) about dying and death.

1. Acknowledging, responding and attending to mutual knowing in dying and death requires an ability to hold different positions, wants and needs – while also acknowledging and articulating one’s own position and wants and needs
2. Mutual knowing of dying and death may also involve a recognition that some needs and concerns are left outside of the mother and daughter relationship and attended to by other relational supports
3. Experiences and understandings of mutual knowing between mothers and daughters while a mother is dying and at the time of a mother’s death can be powerful and poignant for daughters as they experience grief and loss

Relevant theoretical and empirical literature

Supports

The findings from this study support the understanding that the process of dying involves a number of tensions on multiple levels as patients and family members live in the liminal spaces between living and dying (McWilliam et al., 2008; Melin-Johansson, Henoch, Strang, & Browall, 2012; Syren, Saveman, & Benzein, 2006). Critical to these tensions is an awareness of how patients and families, and as was shown within this study with mothers and daughters, move across a wide range of experiences, feelings and thoughts as they shift between “living while dying and dying while living” (McWilliam et al., 2008). Finding ways to articulate these tensions and share this knowing and experience with loved ones can be tremendously challenging for patients and families, and yet as was reflected with a number of the mothers and daughters involved in this study, mutual knowing can provide significant connection at a very difficult time in women’s lives.
Challenges

Given that this area is just beginning to be explored in the literature, there are no immediate challenges from this study’s findings, aside from the importance that mothers and daughters be considered a particular patient and family member relationship that is worthy of further study.

Adds to practice in end of life care

While direct conversations about dying and death with patients and families requires a building of rapport, trust and understanding of how each family functions, I also believe that these conversations can invite patients and family members to initiate conversations that they may not know how to begin. Being mindful of the range of tensions that can exist for patients and families as they move between “living while dying and dying while living” (McWilliam et al., 2008) can also encourage social workers to explore how each family member is experiencing end of life in a particular moment in time. Further, individual and family centered counselling practices can explore a wider range of issues related to loss, grief and bereavement.

In addressing the specific needs of mothers who are dying and their adult daughters, social workers need to be mindful of the relational history that informs mothers and daughter relationships, and can invite mothers and daughters to speak to their lives overall in the context of how they are presently experiencing end of life. Further, adult daughters can be invited to think about attending support groups that are focused on daughters, or recently bereaved daughters, as there may be interest in attending bereavement groups for women who have lost a parent, or for women who have lost a mother. These groups may offer a strong connection around the role and identity of being a daughter, and the significance of what it means as a daughter, to live without one’s mother (Foote et al., 1996).

5.2 Study Limitations

As Elder and Shanahan (2006) note it is important, “to recognize is that there is not one optimum point of entry for studying human development across the life span… the multilevel nature of human development invites different points of entry (each with specific research questions) (p. 671). Each point of entry while having strengths, also carry limitations. While drawing on five mother and daughter dyads offered a strong context for closely examining each of these mother and daughter relationships, this also means that that there may be other elements of mothering
and daughtering which are important to explore, which were not reflected within this sample. As this study involved one mother and one daughter, it is quite possible that other forms of mothering and daughtering may have been operating within these same family units which were left outside the scope of this study. Further, as mothers and daughters were interviewed together, there may be important elements of mothering and daughtering that did not arise within the context of these relational interviews. In addition, other family members within each family unit, as a result of not being primarily in focus within this study, may have been further obscured, and these relationships may also be important in how mothers and daughters experience end of life. While there was some diversity within this sample in relation to culture, language, religion, and socio-economic status, further research needs to explore how the experience of mothering and daughtering may vary as a result of individual and familial identities and social-cultural locations related to race and ethno-cultural backgrounds, experiences of immigration, varying forms of ability and dis-ability and further variances in family structures, such as same-sex family units or blended families.

Most importantly, from this study, we learn important elements about how mothers and daughters experience end of life, and more broadly how families experience end of life and how these elements need to be woven into social work practice and social work education.

5.3 Implications for Social Work Practice and Education

There are a number of social work practice and education implications that arise from this study. Most central is an interest in encouraging and expanding social work practice in end of life care beyond patient-focused practices and interventions. Utilizing dyadic interviews as a research method invites us to consider integrating dyadic practices and interventions into end of life care. Drawing on dyadic practices and interventions can offer social workers a way of thinking holistically about patients and family members in end of life while also supporting an exploration of individual, relational and intersubjective processes that are often woven into experiences of end of life. Further this study stresses the importance of listening in our social work practice, as patients and families talk about their experiences in end of life. This listening needs to be particularly attentive to conversation and dialogue between family members, and needs to listen for possible tensions and negotiations that may be going on between patients and families around preferences for care, choices about treatment, where people want to die, and
what each family member may be concerned about in the time ahead. Further, attention to the individual, relational and intersubjective experiences of end of life need to be integrated more broadly into social work practice in end of life, so that there is a strong appreciation of how women’s lives are lived across their full life trajectory.

Most importantly, this study emphasizes how imperative it is that experiences of dying and end of life be re-connected as core and central elements of our experiences of living. The experience of end of life needs to be re-situated to the life that has been lived, to the history and identity of who the person is that is dying, and this understanding needs to encompass who this person was in the past, who they are now, and who they are becoming. As Ruth showed us so powerfully within her relational stories about the links between her history and her present day, “It entwines you know? One goes into the other. I can’t separate one from the other”. Further the identity and history of each person who is dying, needs to also be situated and located within the lives and histories of all of those people whose lives have interwoven with them, whether those relationships are a result of biology, marriage, family, chosen family, friendships, community or other connections and networks.

Social work education needs to include end of life care and supports, as regardless of what practice area or site a social worker works within, their practice will be touched by end of life, loss and bereavement. It is paramount as such that social work students have the required skills, knowledge and competency to work with end of life issues. There are a number of strong social work education courses, graduate and post graduate curriculums (Berzoff, Dane, & Cai, 2005; Christ & Blacker, 2008; Social Work Competencies on Palliative Education - SCOPE, 2014) available for social work educators to draw on as part of this teaching. Further end of life needs and issues needs to be woven tightly across individual, family and group curriculums, to ensure that end of life needs and concerns are addressed across all life stages and practice contexts and not only within specialized gerontology courses or contexts. In addition, social work students need to learn strong interviewing and clinical skills which expand beyond one-person practice contexts, to include skills and expertise in working with relationship dyads, such as mothers and daughters. Broadening our teaching of dyadic interviews and interventions from practices focused solely on couples, social work students need to learn how to work across many different forms of relational dyadic contexts. Further, ensuring that social work students are aware of the specific nuances of mother and daughter relationships, and how mother and
daughter relationships connect with relational care practices, aging, illness and end of life are paramount, given how many adult daughters are primary caregivers for their parents and their in-laws.

5.4 Implications for Research

While this study addresses and responds to a number of questions about relational understandings of end of life, there are still a number of questions that need to be answered. When I began this study I was as a feminist, social worker quite convinced that dying was and is relational. This knowledge came from my own experiences with loss, as well as my experience in supporting patients and family members. As I worked within this study, there were multiple challenges to my assumptions about relationality, and I am perhaps more convinced now (that I have ever been), that there are some elements or processes of dying that are individual, while there are others that are relational, and still others that are intersubjective. My understanding of these individual processes of end of life are less aligned with stages or tasks of dying, but rather are about individual knowing and experience. I believe that one of the places this knowing is located in within women’s personal experiences, in how women experience their bodies and illness and physical decline, in how women understand who they are as women, as mothers, daughters, and the many other roles and relations that women have with other people in their lives (Anderson, 2012). While I believe that there are elements of this knowing that are individual, I also believe that knowing exists across and within many different individual, relational and intersubjective processes. Critical is an understanding of how these processes weave together and how and in what ways we can better support patients and families and this time of their lives. Questions remain about what elements of end of life and death and dying can be shared with others, and whether it is possible to fully imagine, feel and experience what it is to be in end of life, if one is not there themselves.

While this study focused specifically on relational understandings of death and dying between mothers and daughters, questions remain about how relational understandings can be expanded to other family dyads, such as mothers and sons, fathers and sons, spouses, friends, siblings, or grandparent and grandchild. As there were some differences noted in the experiences of caregiving within a mother [in-law] and daughter [in-law] relationship, despite having a very long and close relational history, it is possible that there are other variations that may appear in
other mother and daughter, and mother [in-law] and daughter [in-law] relationships. Further as it was apparent within this study that other daughters within these same families had other experiences and perspectives, this seems to point to the fact that it may be less the specific role and relationship within the family, and more who mothers who are dying choose to do this life review work with, as they are in end of life. This leads into some of the questions that remain for me about what elements of each relational dyad are most important in determining who should be involved in this form of life review with a person who is facing the end of their life? Is it the relational history that the person has with the person who is dying, or is it involvement in their illness over time, or is it the comfort and relational intimacy that exists within a dyad that allows them to relationally explore who they are, and what end of life means? The more I have thought about this question the more I have come to believe that really what is most important is that the person who is dying can chose who they want to do this work with, and that the person who is chosen, also feels like this is an important experience for them. Future research also needs to explore how participating in a relational life review interview may inform daughters’ experience of bereavement and loss after the loss of their mother.

It is also important to consider how dyadic interviews may be used in contexts outside of end of life. While there is tremendous interest in relational understandings across a wide range of relationships and contexts, it is notable how often researchers chose methods which interview people in relationship separately. While there are elements of relationships which can be examined through individual interviews, I would argue that dyadic interviews offer a way to prioritize and privilege the relational elements that are being examined. Rather than being constrained by concerns that people in relationship will not be honest, dyadic interviews offer a way to see what does unfold within relationships, and offers ways to examine the active and co-constructed elements of relationships that are only visible within the relationship. This of course does not mean that one’s findings would not be different if one explored individual understandings of relationships, as of course they would, what it would mean though is that we would further our understanding of what actually lives between people in relationship, and how these processes inform who we are as people living within and across many different relationships and context.

While the findings from this study do not directly contradict existing literature, there is evidence that transferring existing theoretical constructs into a conceptual frame that has not
been used previously in end of life research, deepens and broadens an understanding of how these constructs operate within the context of mothers and daughters experiences of end life.

5.5 Conclusion

In light of the fact that we are all going to die, that the majority of Canadians will not die unexpectedly, and that most of us will die within an acute-care hospital setting, it is critical that we find ways to ensure that everyone who is dying hears, “You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die” (Saunders, 2005, p. 46). Strongly informed by a feminist epistemology, this study drew on a narrative methodology, which utilized dyadic interviews. Drawing on multiple conversations with five mothers receiving end of life care, and their adult daughter s (10 participants including one mother in-law and daughter in-law pairing), this study utilized a life review narrative approach, wherein mothers and daughters were asked to share relational stories over their relational continuum. Guided by Riessman’s (1993, 2008) narrative thematic and dialogic/performance analytic approaches, end of life relational stories were transcribed and examined to further our understanding of what mothers and daughters experience in end of life, and how and why mothers and daughters perform these experiences in particular ways as they speak to their experiences in end of life. Findings across the two analytic approaches reflect interwoven processes between mothers and daughters which are individual, relational and intersubjective. Individual processes address individual knowing and individual choices; relational processes reflect relational care practices between mothers and daughters, and mothers and daughters and care providers; and intersubjective processes address mutual knowing of dying and death. Implications of this study for social work practice and education strongly encourage social work practice to expand to dyadic interviews and interventions in end of life, with an emphasis on what we can learn if we listen carefully to what and how and why people say things in particular ways. This study also strongly argues for end of life practices and interventions to be re-connected with broader life course practices as a way of ensuring that the end of a life is connected to the life that has been lived. Implications for research in end of life encourage further questioning about how end of life is relational, and strongly encourage further research in other relational forms of end of life. Lastly, this study strongly urges researchers to explore relational dyadic interviews as a method to explore the dynamic elements of relations between people in relationship.


Canadian Institute for Health Information. (2013). End-of-life hospital care for cancer patients. Ottawa, ON: Canadian Institute for Health Information.

Canadian Institute for Health Information. (2007). *Health care use at the end of life in Western Canada*. Ottawa, ON: Canadian Institute for Health Information.

Canadian Institute for Health Information. (2011). Health care use at the end of life in Atlantic Canada. Ottawa, ON: Canadian Institute for Health Information.


Perry, J. (2004). Daughters giving care to mothers who have dementia: Mastering the 3 r's of (re)calling, (re)learning, and (re)adjusting. *Journal of Family Nursing, 10*(1), 50-69.


QSR International Pty Ltd. (2012). NVivo qualitative data analysis software. Doncaster, Victoria: QSR International Pty Ltd.


Appendix A:

Information Letter and Consent Form for Participants (Version 1 and Version 2)
Participant Information Sheet

Mothers and Daughters: Relational Experiences of Palliative and End of Life

Principal Investigators: Pamela Grassau 613-562-6262 Ext. 1638 and Dr. Tara Tucker 613-562-6262 Ext. 1067
Academic Supervisor: Dr. Izumi Sakamoto 416-978-8224

Background of Study - There has been a growing awareness about the unique needs and perspectives of mothers and their adult daughters in palliative and end of life care.

You are being asked to participate in a research study that looks at mothers and daughters and relational experiences of palliative and end of life. This study is focused on understanding how mothers and their daughters talk together about how their lives both individually and collectively have been touched by illness.

Pamela Grassau will carry out this research study as part of the requirements for completing her Doctor of Philosophy at the University of Toronto in the Factor Inwentash Faculty of Social Work.

Purpose and Design - This study has been designed to further our understanding of how families, and particularly mothers and daughters, experiences illness and end of life needs and issues when a mother is moved into a palliative care unit. This study involves eight (8) mother/daughter pairs who live in the Ottawa area.

Main Research Question:

How mothers and their daughters understand, talk about and interpret their experience(s) of illness as a mother is moved into palliative care.

Study Procedures – The study involves two (2) informal interviews with mothers and daughters together. Interviews will take between 45 minutes – 1 hour each and will happen in a private room on the Palliative Care Unit. With permission each interview will be digitally recorded for accuracy and then transcribed. If you are not comfortable with interviews being recorded then interviews will not be recorded and notes will be taken.

Interview 1 – involves an open-ended conversation about the mother-daughter relationship: who you are; your relationship over time; your current situation and your thoughts and concerns about the future. The interview will end with a brief introduction to collective legacy making and a box of art-supplies will be distributed.

Collective Legacy making – legacy making offers a creative arts-based component to capture experiences that may be better described in art-based forms such as photography, collage, scrapbooking, than in words or
conversation. The focus here is not on artistic quality, as all representations of experiences will be meaningful for participants. The study investigator will bring a blank scrapbook to each mother and daughter dyad, and you will be asked to fill the scrapbook with any photographs, images, poems, stories, which represent who you are, and your experiences with illness and end of life.

**Interview 2** – involves a review of the ‘legacy’ document that culminated from Interview #1. You will be asked to share your collective legacy and to describe what the legacy entails and what it means for you.

**Length of Study** – This study will recruit mothers and daughters on the palliative care unit between March 22nd 2013 – May 10th 2013. After the initial interview, mothers and daughters will have 4-6 days to create their collective legacy, and then the second interview will occur.

**Possible Side Effects and/or Risks** – One possible risk for mother and daughter participants is distress in discussing issues and experiences related to illness and palliative and end of life. Participants may speak directly to Pam Grassau to access support and/or referrals.

**Benefits of the Study** – While there is no direct benefit for participating in this study, you may benefit from having the opportunity to talk and reflect on your experiences and needs during the study.

**Withdrawal from the Study** – You may withdraw from the study at any time without any impact to your care. Your request to withdraw from the study will be respected and no further contact will be made to encourage further participation. Withdrawal will be possible until the submission of the full dissertation in September of 2013.

**Confidentiality** - All data will be kept confidential, unless release is required by law (e.g. child abuse, harm to self or others). Representatives of the University of Toronto Research Ethics Board, as well as the Bruyère Continuing Care Research Ethics Board, the Ottawa Hospital Research Institute and the Ottawa Hospital Research Ethics Board may review your original identifiable information under the supervision of Ms. Grassau or Dr. Tucker for audit purposes. You will not be identifiable in any publications or presentations resulting from this study. No identifying information will leave the Bruyère Research Institute (BRI). All information which leaves BRI will be coded with an independent study number.

The link between your name and the independent study number will only be accessible by Ms. Grassau/Dr. Tucker and/or their staff. The link and study files will be stored separately and securely. Both files will be kept for a period of 10 years after the study has been completed. All paper records will be stored in a locked file and/or office. All electronic records will be stored on the secure Bruyère Research Institute Servers and protected by a user password, again only accessible by Ms. Grassau and/or Dr. Tucker. At the end of the retention period, all paper records will be disposed of in confidential waste or shredded, and all electronic records will be deleted.

By agreeing to participate, you agree that information from your interview may be published in Ms. Grassau’s dissertation, as well as project reports and scientific journals. You will be asked to sign a separate release form to give permission for any photos from the co-created legacy to be used in Ms. Grassau’s dissertation, as well as project reports and scientific journals. You will not be identifiable in any publications or presentations resulting from this study.
Voluntary Participation – Participation in this study is completely voluntary. You are under no obligation to participate in the study, and you may choose to not participate or withdraw from the study up until the submission of the dissertation in September of 2013.

If you choose not to participate, or to withdraw your consent, your decision will not affect the care you receive at this Institution at this time, or in the future. You will not have any penalty or loss of benefits to which you are otherwise entitled to.

Questions about the Study

If at any time you have any questions or concerns about participating in the study, feel free to contact the Principal Investigators, Pam Grassau or Dr. Tara Tucker at the Bruyère Research Institute (613-562-6262 x 16138 or x1067).

If you have any questions about your rights as a research participant, you may contact Daniel Gyewu at the University of Toronto Ethics Office, d.gyewu@utoronto.ca, 416-946-5606, or Dorothy Kessler, Chair of the Bruyère Research Ethics Board, 613-562-6262 x 1420 or the Chair of the Ottawa Hospital Research Ethics Board at 613-798-5555, extension 14902.
Mothers and Daughters: Relational Experiences of Palliative and End of Life

Consent to Participate in Research

I understand that I am being asked to participate in a research study about mothers and daughters and their relational experiences of palliative and end of life. This study has been explained to me by P. Grassau.

I have read this 5 page Information Sheet and Consent Form (or have had this document read to me). All my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study. A copy of the signed Information Sheet and/or Consent Form will be provided to me.

Signatures

______________________________
Participant’s Name (Please Print)

______________________________  _________________
Participant’s Signature    Date

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study.

______________________________
Name of Investigator/Delegate (Please Print)

______________________________  __________________
Signature of Investigator/Delegate   Date

Please select your response :

246 Bloor Street West, Toronto, ON M5S 1A1 Canada  Version 4 14/03/2013
Tel: +1 416-978-6314 • Fax: +1 416 978-7072 • www.socialwork.utoronto.ca
At the completion of this study, I would be interested in receiving a report of the findings

- Yes   - No

Contact Information:

Address
Participant Information Sheet

Mothers and Daughters: Relational Experiences of Palliative and End of Life

Principal Investigators: Pamela Grassau 613-562-6262 Ext. 1638 and Dr. Tara Tucker 613-562-6262 Ext. 1067
Academic Supervisor: Dr. Izumi Sakamoto 416-978-8224

Background of Study - There has been a growing awareness about the unique needs and perspectives of mothers and their adult daughters in palliative and end of life care.

You are being asked to participate in a research study that looks at mothers and daughters and relational experiences of palliative and end of life. This study is focused on understanding how mothers and their daughters talk together about how their lives both individually and collectively have been touched by illness.

Pamela Grassau will carry out this research study as part of the requirements for completing her Doctor of Philosophy at the University of Toronto in the Factor Inwentash Faculty of Social Work.

Purpose and Design - This study has been designed to further our understanding of how families, and particularly mothers and daughters, experiences illness and end of life needs and issues when a mother is moved into a palliative care unit. This study involves eight (8) mother/daughter pairs who live in the Ottawa area.

Main Research Question:

How mothers and their daughters understand, talk about and interpret their experience(s) of illness as a mother is moved into palliative care.

Study Procedures – The study involves two (2) informal interviews with mothers and daughters together. Interviews will take between 45 minutes – 1 hour each and will happen in location agreed upon between the mothers and daughters and the researcher. (i.e. a private room on the Palliative Care Unit, in a patient’s home, in the researcher’s office). With permission each interview will be digitally recorded for accuracy and then transcribed. If you are not comfortable with interviews being recorded then interviews will not be recorded and notes will be taken.

Interview 1 – involves an open-ended conversation about the mother-daughter relationship: who you are; your relationship over time; your current situation and your thoughts and concerns about the future. The interview will end with a brief introduction to collective legacy making and a box of art-supplies will be distributed.
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Interview 2 – involves a review of the ‘legacy’ document that culminated from Interview #1. You will be asked to share your collective legacy and to describe what the legacy entails and what it means for you.

Length of Study – This study will recruit mothers and daughters through the palliative care unit, the Palliative Pain and Symptom Consult Service, and the Palliative Rehabilitation Service between March 22nd 2013 – July 31st 2013. After the initial interview, mothers and daughters will have 4-6 days to create their collective legacy, and then the second interview will occur.

Possible Side Effects and/or Risks – One possible risk for mother and daughter participants is distress in discussing issues and experiences related to illness and palliative and end of life. Participants may speak directly to Pam Grassau to access support and/or referrals.

Benefits of the Study – While there is no direct benefit for participating in this study, you may benefit from having the opportunity to talk and reflect on your experiences and needs during the study.

Withdrawal from the Study – You may withdraw from the study at any time without any impact to your care. Your request to withdraw from the study will be respected and no further contact will be made to encourage further participation. Withdrawal will be possible until the submission of the full dissertation in September of 2013.

Confidentiality - All data will be kept confidential, unless release is required by law (e.g. child abuse, harm to self or others). Representatives of the University of Toronto Research Ethics Board, as well as the Bruyère Continuing Care Research Ethics Board, the Ottawa Hospital Research Institute and the Ottawa Hospital Research Ethics Board may review your original identifiable information under the supervision of Ms. Grassau or Dr. Tucker for audit purposes. You will not be identifiable in any publications or presentations resulting from this study. No identifying information will leave the Bruyère Research Institute (BRI). All information which leaves BRI will be coded with an independent study number. The link between your name and the independent study number will only be accessible by Ms. Grassau/Dr. Tucker and/or their staff. The link and study files will be stored separately and securely. Both files will be kept for a period of 10 years after the study has been completed. All paper records will be stored in a locked file and/or office. All electronic records will be stored on the secure Bruyère Research Institute Servers and protected by a user password, again only accessible by Ms. Grassau and/or Dr. Tucker. At the end of the retention period, all paper records will be disposed of in confidential waste or shredded, and all electronic records will be deleted.

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well as project reports and scientific journals. You will not be identifiable in any publications or presentations resulting from this study.

**Voluntary Participation** – Participation in this study is completely voluntary. You are under no obligation to participate in the study, and you may choose to not participate or withdraw from the study up until the submission of the dissertation in September of 2013.

If you choose not to participate, or to withdraw your consent, your decision will not affect the care you receive at this institution at this time, or in the future. You will not have any penalty or loss of benefits to which you are otherwise entitled to.

**Questions about the Study**

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Mothers and Daughters: Relational Experiences of Palliative and End of Life

Consent to Participate in Research

I understand that I am being asked to participate in a research study about mothers and daughters and their relational experiences of palliative and end of life. This study has been explained to me by P. Grassau.

I have read this 5 page Information Sheet and Consent Form (or have had this document read to me). All my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study. A copy of the signed Information Sheet and/or Consent Form will be provided to me.

Signatures

________________________________________
Participant’s Name (Please Print)

________________________________________  _________________
Participant’s Signature    Date

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study.

________________________________________
Name of Investigator/Delegate (Please Print)

________________________________________  __________________
Signature of Investigator/Delegate   Date

Valid until March 14, 2014

Please select your response:

246 Bloor Street West, Toronto, ON M5S 1A1 Canada
Tel: +1 416-978-6314 • Fax: +1 416-978-7072 • www.socialwork.utoronto.ca

Version 5 03/07/2013
At the completion of this study, I would be interested in receiving a report of the findings

☐ Yes  ☐ No

Contact Information:

Address
Appendix B:

Interview Guide 1 & Interview Guide 2
Interview Guide for Mothers and Daughters – First interview

Demographics (collect at beginning or end, depending on interview)

Age Range of Mother -  35–44  45-54  55-64  65-74  75-84  85-94  95+
Age of Daughter –  25-34  35-44  45-54  55-64  65-74

# of days on the in-patient palliative care unit __________

# of consultation visits through PCCS __________

Let’s start getting with us getting to know both of you individually and then we will me move to talk about the two of you – in terms of your mother/daughter relationship.

Mom & Daughter – Rapport Building Questions

1. Can you tell me a little about why you both agreed to participate in this study?

   Probe:
   • What’s most important for me to know about you?
   • What’s something about who you are that the care providers here on the Palliative Care Unit may not know about you?
   • What are the things about you that the care providers here would know about you?

2. Is there a story or experience that you can think of, that reflects or demonstrates who you are as a family?

   Probe:
   • what does this story mean for each of you?

3. Tell me a little about the relationship between the two of you (skip if addressed in question #1)

4. If I were to ask you how you are like or unlike other mothers and daughters (your age/stage/similar experiences), What would you say?

   In thinking about your relationship, I would like to ask you about 3 or 4 different times in your relationship (Early Stories, Later Stories, Illness Stories/Palliative and End of Life Stories, and if you can tell me a story or experience about what was going on at each of these times.

Early stories

5. Relationships move a lot over time, and sometimes there are times when you might be very close and other times there may be times when there is more distance between both of you. Tell me a
story that demonstrates an early time or experience where the both of you were close with each other?

Probe:
- Describe the context/situation; Tell me about what happened, how did both of you respond – what did this story mean, and what does it mean now for both of you?

6. What about an early time or experience where you were less close or more distant with each other?

Probe:
- Describe the context/situation; Tell me about what happened, how did both of you respond – what did this story mean, and what does it mean now for both of you?

Later stories (Similar probes used within the following sections)

7. Tell me a story that demonstrates a later time or experience where the both of you were close with each other?

8. What about a later time or experience where you were less close or more distant with each other?

Entry of illness – tell me about when illness came into both of your lives

9. Tell me a story that demonstrates a time or experience related to your illness where the both of you were close to each other?

10. What about a story that demonstrates a time or experience where you were less close or more distant?

11. Thinking back to when illness first came into your lives, what did you think being ill might mean – as a person, how it might inform/impact your relationships?

   Probe:
- Were there expectations that you had for yourself as a patient? As a mother? As a daughter?
- Were there expectations that you felt from others about what you should or should not do?
  How did you respond to these expectations – why did you respond this way?
Present day

12. What did you imagine this time of your life might look like?
   Probe:
   • What do people around you think about this time of your life/lives?

13. How are you like other mothers and daughters who are in the same health position and how are you different?

Looking ahead

14. What are your hopes for each other?

15. What have you learned about life from each other, that you would like the other to know?

16. Are there important words you would like to offer each other?

End of Interview – Plan for 2nd interview
Interview Guide for Mothers and Daughters – 2nd Interview

1. First off, how are you both feeling since our last interview?

2. What pieces from our previous conversation have stayed with you?

   Probe
   • Surprises, Challenges

3. Is there anything you might like to add since our last conversation?

4. How are you feeling today?

   Probe
   any additional questions from the researcher based on Interview #1

5. What do you think you might do with this life review document now that it’s created?
Appendix C:
Ruth & Sarah Thematic and Dialogic/Performance Analysis
Ruth/Sarah – Ruth is in her late 80’s, and Sarah is in her late 50’s. At the time of the first interview, Ruth had been on the PCU for 38 days. Between the first and second interview I had multiple conversations with Ruth and a few brief connections with Sarah. Sarah lives in a different city (< 6 hrs drive), and as a result Sarah divides her time between being with her mom on the Palliative Care Unit (PCU) and staying overnight with her dad in his residence, and being at her home with her husband and children. At the time of the 2nd interview, Ruth’s 64th day on the PCU, Ruth has been moved to a private room and she is moving in and out of consciousness. The second interview includes Sarah and I together, and not Ruth. Ruth died on the PCU 6 days later.

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<td>BEING PRESENT/ AFFIRMING PRESENCE Ruth (M) – Being (continually) available/ present / Sarah (D) – Acknowledging/Affirming mother’s availability/presence</td>
<td>TRUTH-TELLING/ HONOURING PAST TRAUMA Ruth (M)-Educating and Sharing Harsh Knowing/ Experiences -Truth-telling / Sarah (D)- Affirming parents traumatic experience – and Amazement at parents Survival/Normalcy/ Resilience ENCOURAGING AND NOT HINDERING SEPARATION (HIDING SUFFERING)/ CHOOSING SEPARATION Sarah (D) - leaving home at a young age/Ruth (M) hiding suffering THREAT &amp; RISK OF CONFLICT /RECONCILIATION Sarah (D) falling in love and wanting to marry someone not Jewish – Ruth’s (M) decision to support her daughter.</td>
<td>SUFFERING &amp; STRUGGLING/ COPING &amp; CARRYING ON Ruth (M) -Suffering and Being Pulled Through/ Sarah (D) ‘You just cope’ – Coping and Being with Mother’s Illness CARE/NEEDS – CONFLICTING –BEING ANNOYED &amp; NOT FEELING GOOD Sarah (D) –being annoyed about Ruth’s (M)’s needs - and not feeling good about being annoyed CAREGIVING FROM AFAR WITH FULL PRESENCE Daughter’s caregiving experience from afar but with full 24 hr/7 day presence when she is with them.</td>
<td>BEING AN OUTSIDER /TRAVELLING BTW FAMILY Ruth (M)- not recognizing herself &amp; Sarah (D)– travelling back and forth TRANSITION – CHOOSING TO STOP TREATMENT (Tx)/ SUPPORTING DECISION Ruth (M) stopping Tx &amp; Sarah (D) supporting her decision</td>
<td>RE-MEMBERING &amp; WANTING TO FORGET/ WISHING FOR LESS PAIN Ruth (M) – Living in the past - wanting to forget/ Sarah (D) wishing it was less painful for her mother NOT SUFFERING/ TIME TO BE SHORT Ruth (M) Not wanting to suffer/Sarah (D) Time for her mom to be short because that’s what she wants.</td>
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<td>DAUGHTERING</td>
<td>CARE MEMORY – MOTHER PROVIDING EASE FOR DAUGHTER Sarah (D) – reflecting on how her mother always provided ease in her suffering/ Ruth (M) remembering experience ACTIVE PARTICIPATION IN EDUCATION/ FONDLY REMEMBERING Ruth (M) -Facilitating/ Promoting/ Participating in daughter’s education, Sarah (D) fondly remembering her mother participating, supporting her.</td>
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Ruth – Mother; Sarah – Daughter. Relational Story: Thematic & Dialogic Analysis; Relational Story examined with Thematic analysis only
**Transcription legend** – modified from (Ochs & Capps, 2001)

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- [G- Direct Speech] Represents the performance genre of direct speech, and involves highlighting direct speech lines performed within the passage
- **choices** Represents the performance genre of repetition in *words (phrases)* that are used repeatedly within the passage
- [G-Aside] Represents the performance genre of asides, where information is shared within the performance that provides background that is outside of the main story or performance
- [higher/lower pitch] Represents the performance genre of expressive sounds within the dialogue which in this study includes how voices move higher or lower in pitch/tone in relation to speech
Ruth & Sarah – Dialogic/Performance Analysis

Condensed Legend of Transcription Conventions 1
I= Interviewer
M= Mother
D= Daughter

Prelude: Prior to this scene unfolding, Ruth has been talking about her experience of her present day. (See Ruth (M) and Sarah (D) – Relational Continuum over time: Present Day dialogue on page 27 in this chapter for the dialogue that unfolded right before this scene begins)

Scene 1

I: And how about for the two of you around that, in terms of (D: um) knowing where she is?

D: VERY much so [,], I mean, [,] you don’t know Mum’s medical history but some of the, ah, choices that she made were CHOICES that she made to, to not continue with certain medications –

M: I COULD have – [G-Exp - higher pitch]

D: -- and to certain treatments. Because she’s done, she was just finished

Scene 2

M: -I WAS for three [pause], three or four years, three years [pause], four years, [pause] first, they thought that they [pause], before they [pause], ah, heart, ah, oh, [G-Exp - voice shakey], when did they go for first – [G-Exp - Ruth’s voice is shaky and shifts to a higher pitch]

... 

D: She’s had x² issues. The details aren’t that important. (I: sure). She’s had some, x issues (M: yes) so for some years, she was having y treatments, and then she needed to have z interventions (I: OK).

M: -- and they didn’t help much –

D: And she decided, and she also suffered from depression –

M: -- I didn’t want [pause] to prolong it –

D: And she just sort of said, “You know what, I’m done here.” [G -Direct Speech]

And that was –

1 Please see preceding page in Appendix for a full overview of the transcription conventions used within this excerpt.

2 As Ruth’s specific medical issue and the actual forms of treatments she received are not central to understanding Ruth and Sarah’s experience, I have removed the specific medical references, and have instead noted differences in treatments, interventions using ‘x’, or ‘y’.
Scene 3

M: I can’t talk, I can’t [ ], I can talk [G: Exp chuckle], but I can’t walk, I can’t read [,] because I got a [ ] stroke in my left eye a few years ago and I didn’t see with my left eye. (I: no, eh?) So that’s why my eye some-, is almost always closed. [G-Aside] (I: right). So [higher pitch] what I’m doing here? [pause] (I: mmm) [pause] (I: yeah)

D: So some of the –

M: And my husband, [,] for a long time he was upset with me, that I decided [,] to leave it as it is, to go according to the line of I was well ’til 80 [,] 85 [,] (I: OK).

M: So [,] for 35[,] years I suffered from depression [G-Exp - lower pitch]. I had a bout of depression [G-Exp - lower pitch]. But [,] I always came out very good, Dr. in City C and he pulled me always through. [pause] But now [G-Exp high pitch] I am a ruin so [,] what am I doing here? Sleeping and eating? And I have no appetite [G-Exp slower speed] [pause] whatsoever, (I: No, eh?) anyway.

Scene 4

I: So I’m wondering about [,] in terms of recognizing some of the choices you’ve made not to have further treatments, or not to have further things –

M: And no [,] no surgical intervention.

I: OK, so none [,] none of that. So I wonder, then, around where both of you are then, in terms of what that means around end of life (M: yes) and whether there are things that you have shared with one another that are really important things that you want to, um, make sure that you hear?

M: She knows everything about me –

I: She knows everything.

D: And for some [,] for some reason it was easier for me than [,] for my father or my sister (M: yes) to –

M: To real-, [,] to accept it.

D: To accept that Mum’s decisions were hers to make (I: OK), and that they were likely the right decision [G-Exp- lower pitch] [,] DIFFICULT, (I: yeah) but right!

D: And [,] Mum knows that, that’s how I feel about it, that I do think that she was entitled to make her own decisions and that, um, [,] that if she felt that the quality of her life would be so diminished that it wasn’t worth living –

M: -- that’s right – [G-Exp- higher pitch]

D: -- then I wasn’t in any position to disagree with that because [,] that is her decision to make [higher pitch] [pause] [strong non-verbal cues of emotional intensity]

I: Sure, [pause] and [,] very difficult, too.

I: [,], Yeah, [pause], yeah -

M: It’s [slower speech], PURPOSELESS. [pause]
Scene 5

D: It’s very much a personality [..], every individual will make that decision (M: yes) differently.

M: Yes[..], My husband wants to live and he, [..] he is X3 [..] And I don’t. It’s our [pause], where we collide.

D: He’s having a hard time with it –


I: Right, [..] and these are very [..] complicated [..] things (M: yeah) to, to navigate –

M: It is beyond us [..], really.

Performance Genres

Direct Speech - You know what, I’m done here

You see?

Repetition- Know (7), Choices (3), What am I (I’m) doing here (2), Done (2), decided (2), accept (2), everything (2)

Aside- M: …So that’s why my eye some-., is almost always closed.

Expressive sounds/cues M: I COULD have – [higher pitch]

i.e. Pitch/Speed/Quality/ Emotion M: So [higher pitch] what I’m doing here?

M: So [..] for 35[..] years I suffered from depression [lower pitch]

M: …first, they thought that they [pause], before they [pause], ah, heart, ah, oh, [voice is shaky],

M: ..when did they go for first – [voice is shaky] [higher pitch]

M: I can talk [chuckle]

M: I had a bout of depression [lower pitch]

M: But now [high pitch]

M: And I have no appetite [slower speed]

D: …and that they were likely the right decision [lower pitch]

3 Removed re potentially identifying information
M: -- that’s right – [higher pitch]
D: …that is her decision to make [higher pitch] [strong non-verbal cues of emotional intensity]
M: He doesn’t understand my mentality [slower speed],
M: that I want to die [lower pitch].
M: He wants to live [higher pitch]
M: Person-alities. [higher pitch]
Overview Direct Quotes and Repeated Words

Direct Quotes – Ruth & Sarah

You know what, I’m done here

You see?

Repeated Words

Know (7), Choices (3), What am I (I’m) doing here (2), Done (2), decided (2), accept (2), everything (2)

The word frequency image below has been created in NVivo 10 drawing on the repeated words that were generated within the specific end of life relational story analysed for Ruth and Sarah. While I believe that we need to use caution in how we interpret word frequency displays and I think it is critical that researchers think carefully about the scope and parameters that are drawn on within these queries, I believe that in this particular case, this visual display of ‘performance’ is important. Drawing specifically on the context of the repeated words used within this end of life relational story/performance, allows us to see the repeated words that are used within this specific relational story in a spatial format. The larger format of the word ‘know’ reflects how across the repeated words utilized, that this word was used more often, and that words that appear spatially smaller, reflected repeated words that were used less often. Generalizations cannot be made about Ruth and Sarah’s performance or narrative reflections outside of this end of life relational story, as the word frequency only reflects this excerpt.
Appendix D:
Mary & Amélié Thematic and Dialogic/Performance Analysis
Mary/Amélié - Mary is in her late’s 80’s, and Amélié is in her mid 50’s. At the time of the first interview, Mary had been on the PCU for 9 days. Between the first and second interview I had multiple conversations with Mary and Amélié as Amélié slept on a cot beside Mary’s bed. At the time of the 2nd interview, Mary was on her 16th day on the PCU. Mary died on her 21st day on the PCU. Prior to coming into the PCU, Mary and Amélié and Amélié’s husband and children lived together in Mary’s home.

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<td>Central to Mary’s life are her children. Mary and her husband had five children. Amélié is the 2nd youngest. Mary and Amélié have a very close relationship. Memories are woven tightly within rural living and being poor financially, but never lacking in love and family. Mary and Amélié have a very strong faith and believe God intervenes on multiple levels.</td>
<td><strong>SPECIAL ALONE TIME-ME AND MOM</strong></td>
<td><strong>MOTHERING – BEING NOT TELLING</strong></td>
<td><strong>KNOWING – BEFORE THE DIAGNOSIS / NEED TO KNOW MORE BEFORE RELAYING INFORMATION</strong></td>
<td><strong>D-CAREGIVING SHIFTING ROLES – INNER CONFLICT</strong></td>
<td><strong>MAKE PEOPLE UNDERSTAND WHAT IS MOST IMPORTANT</strong></td>
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<td><strong>CHILDREN LEARNING INDEPENDENCE</strong></td>
<td>Amelié’s (D) - story of special alone time with her mother before she started Kindergarten</td>
<td>Amelié (D) - sharing – teaching/love which was reflected/ represented in who and how mother lived and</td>
<td>Amelié (D) sharing about mothers’ diagnosis and about coming home and needing to find out more information before relaying diagnosis with her mother</td>
<td>Turmoil for Amelie (D) in shifting past/previous roles between support of her mother’s autonomy and providing care</td>
<td>Mary (M) – “My children have been the most important part of my life”</td>
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<td><strong>OTHER FAMILY RELATIONSHIPS – SIBLING CONFLICT/ PAST-PRESENT – LOSS</strong></td>
<td>Mary (M) - story of Christmas preparation/ economics/ provision/ children learning independence</td>
<td>Amelié (D) feeling a sense of protection of her mother even when she was young. Intervening with her father. Amélié’s strong connection with her mother’s feelings of sadness</td>
<td>BAD MOMENTS – ESTRANGEMENT/ CONFLICT/ PRIORITIZING MOM’S NEEDS OVER EVERYTHING AND EVERYONE</td>
<td><strong>IT’S IMPOSSIBLE – BUT THAT’S COMPLAINING</strong></td>
<td>Mary’s (M)-Experience of limited abilities/ needing help to do everything</td>
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<td><strong>DIFFICULTY ADVOCATING FOR MOM OR SELF WHILE IN HIGHSCHOOL</strong></td>
<td>Amelié (D) getting angry at her younger brother. Amélié (D) –stories of closeness with younger brother who died of cancer.</td>
<td>Amelié (D) sharing how she was quite scared to stand up for things – illness has “I’m stronger – Together, I’m stronger”</td>
<td>Mary (M) – talked about the estrangement with her other children over an misunderstanding that Amelie (E) was blamed for. Amelie (D) shares how her mother’s needs are prioritized over her own needs and her siblings needs.</td>
<td><strong>PROTECTING &amp; MAINTAINING WHO MOM ‘IS’ WITH FORMAL CARE PROVIDERS</strong></td>
<td><strong>Daughter caring for her mom on the PCU and being with her when she died</strong></td>
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| Amelié (D) – speaks to how she mothers in a similar way. | | | | | Amelie (D) promised to be with her mother when she died. She was able to spend the last few hours with her and experienced her mother saying ‘good-bye’.

Mary – Mother; Amélié – Daughter. **Relational Story: Thematic & Dialogic Analysis; Relational Story examined with Thematic analysis only**
Transcription legend – modified from (Ochs & Capps, 2001)

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Mary and Amelié- Dialogic/Performance Analysis
Condensed Legend of Transcription Conventions
I= Interviewer
M= Mother
D= Daughter

Prelude: Prior to the excerpt below, Mary is talking about a time when she hurt her back when the children were young and she needed to stay in bed and allow her back to heal. This injury while difficult was an acute injury and she shifts from talking about how she needed to stay in bed and she couldn’t do very much, to her experiences in present day.

Scene 1
M: Ah [...] I find it worse now, with the, this, [...] ah, cancer, [...] I can’t do the same things. It’s [pause] impossible. I can’t turn, anything, I cannot turn in the bed by myself [G-Exp soft, slow speed], [pause] [pause]
I: You need help, to get (M: yeah) someone to turn you. (M: yeah) Yeah. [pause] [pause]
M: But that’s complaining [G- Exp –lower pitch] [pause] [pause] [pause]
D: You’re not complaining, Mom (M: no) (I: no)

Scene 2
I: …in terms of needing help to do things, (M: yes) how is that feeling for you to need help with that?
M: As long as it’s, um [...], someone who is[...] compatible, aside from that,[pause] um [pause], at first [pause] I didn’t [...], I didn’t like it,[...] being helped. I felt losing, ah, myself. But, um,[...] I’ve grown used, used to it [pause] so [...] you can’t fight it.
I: Right. And do you still feel like you’re losing yourself?
M: If I feel someone, is – ?
I: If you lose, ah, so you said when people help you, you lose part of yourself? How does that feel, now?
M: That’s what I USED to feel – Now I appreciate it. “Come, come, come” [G- Direct Speech] [G-Exp laughter] [pause] [pause]
D: “I want to go pee, please come!” [G-Direct Speech] [G-Exp high teasing pitch] [G-Exp -laughter]
Scene 3

D: ...there’s something I want to say. When I first started to help Mom out, ah, [...] it was strange. Because, ah, [...] it’s hard to explain, because, um, [G-Exp sigh] [pause] I was, like, my memories are from her helping me. And then having to, um, reverse that, I found it difficult NOT, [G-Exp sigh] not so much because I found it difficult to do it, [...] but I knew how MOM felt. And it goes back to, um, [...] not wanting her to be sad, or, um, the protective? [G-Exp –questioning voice] It’s weird, it was as if [...]as if I felt, I felt I should protect her from, like, ME [G-Exp higher pitch]. It’s, it’s,[...] it’s hard to explain. [pause] Um, but at the same time I knew I had to, because she asked me to. So there was a turmoil.[G-Exp lower pitch]. [...] I don't know if you can understand what I’m saying? [G-Exp –questioning voice].] Even though I knew, I knew I was the perfect match for her. But when she had asked me to be her caregiver back then, I said, “YES.” [G-Direct Speech] But I didn’t know – even Mom says she, “didn’t know” [G-Direct Speech], both of us didn’t know what my “yes” [G-Direct Speech] meant –

D: -- back then.

D: And NOW I know. And, ah [pause] [pause]

Scene 4

I: And what helped you with that turmoil? Like, what switched that in, to make that easier?

D: It’s God. Yeah. And He helped, um, with the people around me [...] with my husband [G-Exp lower pitch] and my co-workers [G-Exp lower pitch] and, ah, [pause]Mom also, ah, when she would say ‘thank you’ [G-Direct Speech] and we’d talk about how she felt, you know, and, ah, she felt like [...], you know, that she didn’t like it (I: um hmmm) and I’d tell her, “I know, Mom, how you feel” [G-Direct Speech] you know. I’d just try to reassure her that I, I knew how she felt but that I also HAD to help her because she needed it.

Performance Genres

Direct Speech -

Come, come, come

I want to go pee, please come!”

Yes

I didn’t know

Yes

thank you

I know, Mom, how you feel

Repetition-

help (9), know (9), felt (6) [e.g. She/Mom felt (4), I felt (2)],

I knew (5), need (4), come (4), can’t/cannot (4)
Aside- None

Expressive sounds/cues
M: I cannot turn in the bed by myself [G-Exp soft, slow speed],
i.e. Pitch/Speed/Quality/ M: But that’s complaining [G- Exp –lower pitch]
Emotion M: “Come, come, come” [G-Exp laughter]
D: “I want to go pee, please come!” [G-Exp high teasing pitch] [G-Exp -laughter]
D: And it goes back to, um, [.] not wanting her to be sad, or, um, the protective? [G-Exp –questioning voice]
D: It’s weird, it was as if [.] as if I felt, I felt I should protect her from, like, ME [G-Exp higher pitch]
D: So there was a turmoil.[G-Exp lower pitch]
D: I don't know if you can understand what I’m saying? [G-Exp –questioning voice]
D: with my husband [G-Exp lower pitch]
D: and my co-workers [G-Exp lower pitch]
Overview of Direct Quotes and Repeated Word

Direct Quotes – Mary and Amelié

Come, come, come
I want to go pee, please come!”
Yes
I didn’t know
Yes
Thank you
I know, Mom, how you feel

Repeated Words

help (9), know (9), felt (6) [e.g. She/Mom felt (4), I felt (2)], I knew (5), need (4), come (4), can’t/cannot (4)

The word frequency image below has been created in NVivo 10 drawing on the repeated words that were generated within the specific end of life relational story analysed for Mary and Amelié.
Appendix E:
Marian & Pam Thematic and Dialogic/Performance Analysis
Marian/Pam is in her late 60's, and Pam is in her early 40's. At the time of the first interview, Marian had been on the PCU for 3 days. Marian was discharged home from the PCU on her 8th day on the PCU. Following discharge I had a brief telephone follow-up conversation with Marian at her home while Pam was making her dinner. Marian passed away at home two months later. Prior to coming into the PCU, Marian lived locally with her husband, and Pam lived with her husband and young child in the same city. Pam's older sister also lived in the same city with her spouse and 3 children. Marian died at home three months after being discharged from the PCU.

<table>
<thead>
<tr>
<th>M/D RELATIONSHIP</th>
<th>WHEN THE DAUGHTER WAS YOUNG</th>
<th>WHEN THE DAUGHTER WAS AN ADOLESCENT/YOUNG ADULT</th>
<th>WHEN ILLNESS ARRIVED</th>
<th>PRESENT DAY</th>
<th>FUTURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>MOTHERING</td>
<td>PRESENCE AND BEING TOGETHER AS A FAMILY/AFFIRMING FAMILY PRESENCE</td>
<td>ACCESSIBILITY/OPENNESS OF MOTHER – “COULD TELL HER ANYTHING AND SHE WOULD FIX IT AND KNOW WHAT TO SAY”</td>
<td>DIAGNOSIS/SHOCK ‘LIKE A BOMB’ WENT OFF</td>
<td>ROLLEROASTER – HAVE TO TAKE EACH DAY AT A TIME</td>
<td>MANAGING/SHARING CARE</td>
</tr>
<tr>
<td></td>
<td>Marian (M) – The importance of being together as a family, special holidays, time. Pam (D) – Affirming meaning (meaning/legacy/generativity)</td>
<td>Pam (D) – Mom was always available (unconditional support/strong problem-solving) – contrast with present day experience of daughter feeling helpless</td>
<td>Marian (M) – diagnosis a complete shock, thought I would live into old age (generational health beliefs)</td>
<td>Marian (M) – difficulty in taking one day at a time – (shift in identity/roles)</td>
<td>Pam (D) relaying how she and her sister rotate days and her dad stays overnight so Marian (M) is never alone (connection)</td>
</tr>
<tr>
<td></td>
<td>FAMILY STORIES – REPEATING GENERATIONAL SUMMER TREATS</td>
<td>DAUGHTERS KNOWING SOMETHING WAS WRONG – BUT MOM DELAYING SHARING THIS NEWS AT FAMILY EVENT</td>
<td>Pam (D) – have never seen my Mom sick – shock (too difficult to put into words what is happening)</td>
<td>Marian (M) – g a day out with family – a good day amidst bad (normalcy/living while dying)</td>
<td>TO BE TOGETHER – I JUST WANT MY FAMILY AROUND – BUT I DON’T WANT TO PRESSURE / WE TELL HER NOT TO WORRY</td>
</tr>
<tr>
<td></td>
<td>Pam (D) and Marian (M) share special family stories of summer treats/traditions running across the generations (family lore)</td>
<td>Marian (M) going to a family event the night of her diagnosis and denying there was anything wrong (anticipatory empathy)</td>
<td>Marian’s (M) experience of receiving a 3 month prognosis – shock/denial/uncertainty</td>
<td>Marian (M) wanting her family to be around her, but doesn’t want to burden them (self-burden, anticipatory caregiving)/ Pam (D) family tells mother not to worry (protectiveness)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PRETENDING TO BE SICK TO HAVE SPECIAL TIME WITH MOM</td>
<td>DAUGHTERS CAREGIVING – ALWAYS THERE FOR US / YOU DID A GOOD JOB MOM</td>
<td>Pam (D) – teaching autonomy/independence ‘just in case’ – anticipatory caregiving)</td>
<td>Marian (M) – teaching how much support her daughters are giving her and her husband (availability/presence/recognition of support). Pam (D) – affirming mother (role/identity/meaning)</td>
<td>SHINING A LIGHT TOGETHER “GET UP AND SHOW YOUR STRENGTH” Marian (M) – participating in the survivor lap of Relay of Life – “show” you can do something / Pam (D) – collecting pledges – have to do something</td>
</tr>
<tr>
<td></td>
<td>Pam (D) sharing how she would pretend to be sick to stay home and be ‘spoiled’ by her mom (care, illness, roles)</td>
<td>Marian (M) – always taught my daughters to take care of themselves and be independent (mothering/daughtering – teaching autonomy/independence ‘just in case’ – anticipatory caregiving)</td>
<td>Marian (M) – sharing how much support her daughters are giving her and her husband (availability/presence/recognition of support). Pam (D) – collecting pledges – have to do something</td>
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</table>

Marian– Mother; Pam – Daughter. Relational Story: Thematic & Dialogic Analysis; Relational Story examined with Thematic analysis only
Transcription legend – modified from (Ochs & Capps, 2001)

<table>
<thead>
<tr>
<th>Symbol</th>
<th>Description</th>
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<tbody>
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<td>Mother</td>
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<tr>
<td>D</td>
<td>Daughter</td>
</tr>
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<tr>
<td>word</td>
<td>reflect an emphasis on this word in the speech turn that is different from other words used in the same speech turn</td>
</tr>
<tr>
<td>WORD</td>
<td>reflects a very strong emphasis on this word within the speech turn</td>
</tr>
<tr>
<td>[motion X]</td>
<td>reflects non verbal signs/cues/motions</td>
</tr>
<tr>
<td>(.)</td>
<td>brief pause,</td>
</tr>
<tr>
<td>(pause)</td>
<td>reflects lengthier pause where this is a noticeable silence of more than two seconds.</td>
</tr>
</tbody>
</table>

Performance Genres (Riessman, 2008)

- [G- Direct Speech] Represents the performance genre of direct speech, and involves highlighting direct speech lines performed within the passage
- choices Represents the performance genre of repetition in words (phrases) that are used repeatedly within the passage
- [G-Aside] Represents the performance genre of asides, where information is shared within the performance that provides background that is outside of the main story or performance
- [higher/lower pitch] Represents the performance genre of expressive sounds within the dialogue which in this study includes how voices move higher or lower in pitch/tone in relation to speech
Marian and Pam- Dialogic/Performance Analysis
Condensed Legend of Transcription Conventions 1
I= Interviewer
M= Mother
D= Daughter

Prelude: Prior to the excerpt below, Marian and Pam have been talking about their relationship over time. Right before Marian responds, I have just shifted the conversation about Marian’s illness (in general terms) and I ask if they can tell me about when Marian became ill and how they both responded to this.

Scene 1
M: For me, it’s been like a BOMB exploded [G-Exp higher voice, voice catching, starting to cry]. (I: yeah) [pause] I always thought I’d live[G-Exp – voice catches] to be 90. My mum and my grandmother, they all lived [.].I think we always thought Dad would go first, (I: mmm) because of all his problems. It was just like a [. ] bomb [G-Exp – voice catching] going off [G-Exp – sigh].

Scene 2 (see Scene 2A on following page for Daughters’ remembrance of this story)
M: We were going to (older daughter’s name) for (name of grandchild)’s birthday (D: yeah) and I said to Dad, “Don’t say anything,” [G-Direct Speech] because we had just found out. (I: mmm) And we walked in and both of them said to me, “What’s wrong?” [G-Direct Speech] (I: yeah) I didn’t want to upset (name of grandchild)’s birthday. (I: yeah)

Scene 3
M: And it’s just been a nightmare ever since. [G-Exp – crying – daughter]. Just a nightmare [G-Exp – lower pitch] [pause] [G-Exp – crying – daughter/mother]. It’s hard when they tell, like, when I was in the hospital the last time, and the doctor came in [.].and the kids were there. [ ] And I said something about my illness, or whatever, and the doctor said, “Well, you have maybe three months.” [G-Direct Speech] I just about fell out of bed. Nobody had told me [G-Exp – higher pitch] that [G-Exp –crying – daughter/mother].

1 Please see preceding page in Appendix for a full overview of the transcription conventions used within this excerpt.
M: And the kids were, [G-Exp – chuckle] the poor nurses, they kept coming in and backing out, they didn’t know what to do, and everybody was crying and I said, "You’ve gotta be kidding," [G-Direct Speech] And the doctor said, “No,” the doctor said, [G-Exp lower pitch], “I’m sorry, but that’s it.” [G-Direct Speech]

... 

Scene 4

M: And the doctor [family physician] was mad [G-Exp – lower pitch], because he said, “You CAN’T say that to anybody.” [G-Direct Speech] “It’s him [motioning to heaven] that’s going to decide what’s going to happen”, you know. He said, “things have taken a bad turn but that’s not to say we can’t get it under control”, [G-Direct Speech] [pause] or he can’t fix it [G-Exp – crying – daughter/mother]

Scene 2 A – Daughter’s remembrance of being told about her Mom’s

I: …So, I’m interested for you, (name). (D: yeah) So that time where you, when you both came in and you knew (D: yeah) there was something wrong, to hearing, (D: yeah) what was going on for you?

D: Um, I was [.] SCARED [G-Exp – voice catch, higher pitch]. (I: yeah) And, ah, [.] I never forget it, because I, Dad was in the kitchen and I had (name of child) in my hands, and I, he was saying something to (name of sister) and I had missed the first part. (I: mmm) And I could tell something was wrong, and then he had said, “Your mother has a tumour” [G-Exp –voice catch, higher pitch] [G-Direct Speech] And I think I just dropped (name of child) [G-Exp- voice catch, higher pitch, quick inhale (laugh/cry)] (I:Oh) I just, ah [.], just kind of fell apart, [G-Exp –voice breaking](I: yeah) because – I’ve always remembered those words. [G-Exp – voice catch, higher pitch, crying] And I –[G: Exp-voice breaking – crying]

Performance Genres

Direct Speech - Don’t say anything

What’s wrong?”

Nothing’s wrong, no, nothing’s wrong

Was Dad upset about coming here, or was he –

No, he’s fine, everything’s fine

There’s something going on between Mum and Dad. I don't know what it is
I told the girls

Your mother has a tumour

You didn’t, not at (name)’s birthday

Well, you have maybe three months

You’ve gotta be kidding

No, I’m sorry, but that’s it

You can’t say that to anybody.

Things have taken a bad turn but that’s not to say we can’t get it under control

Repetition-
said (15), something (7), wrong (5), can’t (3), didn’t (3), always (3), nothing (2), bomb (2)

Aside-
None

Expressive sounds/cues
i.e. Pitch/Speed/Quality/ Emotion
M: For me, it’s been like a **BOMB** exploded [G-Exp higher voice, voice catching, starting to cry].
M: I **always** thought I’d live [G-Exp – voice catches]
M: It was just like a [.] **bomb** [G-Exp – voice catching] going off [G-Exp –sigh].
M: And it’s just been a nightmare ever since. [G-Exp – crying – daughter].
M: And the kids were, [G-Exp – chuckle]
M: “No,” the doctor **said**, [G-Exp lower pitch],
M: And the doctor [family physician] was **mad** [G-Exp – lower pitch]
M: or he can’t fix it [G-Exp – crying – daughter/mother]

D: Um, I was [.] **SCARED** [G-Exp – voice catch, higher pitch].
D: “Your mother has a tumour” [G-Exp –voice catch, higher pitch]
D: And I think I just dropped (name of child) [G-Exp- voice catch, higher pitch, quick inhale (laugh/cry)]
D: just kind of fell apart, [G-Exp –voice breaking]
D: I’ve **always** remembered those words. [G-Exp – voice catch, higher pitch, crying]
D: And I –[G: Exp-voice breaking – crying]
Overview of Direct Quotes and Repeated Words

Direct Quotes – Marian and Pam

Don’t say anything
What’s wrong?”
Nothing’s wrong, no, nothing’s wrong
Was Dad upset about coming here, or was he –
No, he’s fine, everything’s fine
There’s something going on between Mum and Dad. I don't know what it is
I told the girls
Your mother has a tumour
You didn’t, not at (name)’s birthday
Well, you have maybe three months
You’ve gotta be kidding
No, I’m sorry, but that’s it
You can’t say that to anybody.
Things have taken a bad turn but that’s not to say we can’t get it under control

Repeated Words

said (15), something (7), wrong (5), can’t (3), didn’t (3), always (3), nothing (2), bomb (2)

The word frequency image below has been created in NVivo 10 drawing on the repeated words that were generated within the specific end of life relational story analysed for Marian and Pam
Appendix F:
Carrie & Elisabeth Thematic and Dialogic/Performance Analysis
Carrie/Elisabeth - Carrie is in her early 80’s, and Elisabeth is in her late 50’s. Carrie lives in the community and has been living in her current residence for the past two years. Carrie began receiving Palliative Care Consultation Services at the end January of 2013 and received five consultation visits across a seven month time-frame. Elisabeth lives in the same city with her husband and children. Carrie’s husband (Elisabeth’s father) died the year before I met Carrie/Elisabeth. While Carrie decided to stop surgical interventions, her illness did not progress the way it was anticipated. A year after our interview, Carrie continues to live in her retirement residence.

<table>
<thead>
<tr>
<th>M/D RELATIONSHIP</th>
<th>WHEN THE DAUGHTER WAS YOUNG</th>
<th>WHEN THE DAUGHTER WAS AN ADOLESCENT/ YOUNG ADULT WHEN ILLNESS ARRIVED</th>
<th>PRESENT DAY</th>
<th>FUTURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>MOTHERING</td>
<td>‘ALWAYS FELT THAT WAY ‘SHE’S MINE’ Carrie (M) about her connection/bond with Elisabeth (familial, biological connection)</td>
<td>COMMUNICATION – PRESENCE – BEING TOGETHER - DAUGHTER TAKING ON MORE ROLES AT HOME – WORRYING ABOUT WHAT IS NOT BEING SAID Elisabeth (D) – shares her experience caregiving as an adolescent – “you just step up and help” (gendered roles about naturalness/normalcy of care and caregiving)</td>
<td>RELATIONALLY OVERSEEING AND MANAGING CARE / Elisabeth (M) shares the stress/burden of ‘overseeing/managing care’. Problem-solving not bad care, but not good care either. (anticipatory and protective caregiving; social context of risk of complaining and this impacting care)</td>
<td>NOT WANTING TO BE A BURDEN – I’VE HAD ENOUGH Carrie (M) – not ever wanting to be a burden on her children, as they are living their own lives (family roles, family life cycle, stress/coping about burden)</td>
</tr>
<tr>
<td>DAUGHTERING</td>
<td>SHE WAS MOTHERLY EVEN AS A YOUNG GIRL – Carrie shares how Elisabeth was ‘motherly’ as young girl (gendered roles about care and care roles/practices with older/younger siblings)</td>
<td>HOMESICK/NOT SHARING LOSS &amp; OVERSEEING WHEN DAUGHTER LEFT HOME Elisabeth (D) shares her experiences of going away to nursing school and being terribly homesick. Carrie (M) shares with Elisabeth that she too really suffered during this time – but didn’t share this with Elisabeth Carrie (M) - “I had to think of your feelings” (anticipatory caregiving) (connection/disconnection; protective buffering; protection)</td>
<td></td>
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<tr>
<td>EXPERIENCE OF BEING TOLD TO BACK-OFF FROM OVER-PROTECTION OF YOUNGER SISTER AT SCHOOL Elisabeth (D) shares a story of how when her sister started school, the teachers felt she was too overprotective of her and they asked her to give her sister more room to be her own self. (protectiveness, anticipatory and preventive caregiving)</td>
<td>DAUGHTER MOVING BACK TO PARENTS HOME WITH YOUNG CHILDREN Elisabeth (M) shares how she moved in with her parents with your young children as result of a marital separation, and needing caregiving support during shift work (family roles, autonomy, difference / disconnection / relational resilience, dexterity/imbalance – mothering &amp; work)</td>
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Carrie– Mother; Elisabeth – Daughter. Relational Story: Thematic & Dialogic Analysis; Relational Story examined with Thematic analysis only
**Transcription legend** – modified from (Ochs & Capps, 2001)

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<td>reflect an emphasis on this word in the speech turn that is different from other words used in the same speech turn</td>
</tr>
<tr>
<td>WORD</td>
<td>reflects a <strong>very strong</strong> emphasis on this word within the speech turn</td>
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**Performance Genres (Riessman, 2008)**

- **[G- Direct Speech]** Represents the performance genre of direct speech, and involves highlighting direct speech lines performed within the passage
- **choices** Represents the performance genre of repetition in **words (phrases)** that are used repeatedly within the passage
- **[G-Aside]** Represents the performance genre of asides, where information is shared within the performance that provides background that is outside of the main story or performance
- **[higher/lower pitch]** Represents the performance genre of expressive sounds within the dialogue which in this study includes how voices move higher or lower in pitch/tone in relation to speech
Carrie and Elisabeth - Dialogic/Performance Analysis

Condensed Legend of Transcription Conventions

I= Interviewer
M= Mother
D= Daughter

Prelude: Prior to the excerpt below, I have just asked Carrie and Elisabeth what their hopes are in the time ahead and what is most important to them.

Scene 1

D: we have to do the business part of it, [G-Exp-laughter] you know, we have to. Because that’s MY ROLE, is that I have to be Mum’s advocate, although she is very good at problem-solving herself. But she needs some reassurance or just be pointed in the right direction, sometimes, to navigate, right, the right person. (M: um hmm) But you’re very good, you know, you remember the names of your care givers better than I do. But that, it just, um, so I don’t mind being there, you know, reviewing. What’s good, what’s not good, um, I don’t mind reviewing too much what’s good, because it just goes [G-Exp – higher pitch] unsaid [G-Exp laughter] maybe what’s not meeting Mum’s expectations and then we try and problem-solve that. Because we’re just so grateful for everything that is good (M: yeah)

Scene 2

M: I’m looking at the time and I don’t want (name of care provider) [G-Exp lower pitch] to get upset we’re keeping her waiting.

D: She won’t get upset –

M: It’s half an hour now [G-Exp lower pitch, concerned]

D: Is it?

I: OK, I guess it is. (M: yeah) You’re more on the clock than I am, yeah.

M: I HAVE to be [ G-Exp-higher pitch]

... 

D: But you’re so fine-tuned -

M: It’s a job, trying to remember everything, so –

...

Scene 3

D: it’s been a huge, um, [pause] undertaking on many levels. And maybe even more so, because of me being a nurse. I want to make sure that she’s receiving the utmost, best care. But at the same time, [...] I’m not providing that care. And I don’t want to rock the boat when the care might

---

1 Please see preceding page in Appendix for a full overview of the transcription conventions used within this excerpt.
not be what I see up to the quality that I would like [G-Exp higher pitch]. But it’s not a bad quality. But there’s a fine line you walk, because one, they’re from a different discipline than what I am. And then also they, um, I don’t want to create a conflict where they won’t be as receptive to giving good care to Mum. It’s a very fine line, that sometimes you don’t want her care to be compromised.

... 

Scene 4

D: I do think Mum spends a lot of time stressing over your care, though. I do think YOU stress over it, because almost every day there’s a conversation, something about the care. And it’s, whether it’s just stressing over who’s coming to replace a person who’s normally scheduled for that time, or whether, she can fit in...the dressing changes (which are) not a regular basis, but every three days. So it was very difficult to get everything else in, on those days. And also, especially in the evening, Mum’s always, you’re always pretty stressed ’til you know who’s on here. For when you’re one-on-one here --

M: Well, I HANDLE it [G-Exp – higher pitch] better, though, with (Elisabeth)’s help. Because she’ll tell me, she’ll discuss with me, “well, you can’t stress over” and the good parts, about whether I’ve got the assistant that does such a good job, that’s here to help, that one that’s not always here. She’s filling in.

Scene 5

D: But Mum has been very aware of her care and has always been, like, in control of her, knowing if something is right or doesn’t feel right. And so, then, if it doesn’t fit for her, then I’ve encouraged you at times to problem-solve that (M: um hmm) with some help from me, but you to be the one (M: yeah) to initiate, um, a discussion (M: um hmm) with them. But they, things are very regimented. It’s very much a routine, right, Mum, (M: oh, yes) and you like it that way. (M: yeah) Because then you feel like you have control over, um, what’s happening (M: um hmm) to you. Whereas [G-Exp higher pitch], you know, you’ve lost so much control (I: mmm) over what has happened to your body, (M: yeah) unfortunately. So you definitely, you know, are sharp in the mind and you have, you know what you deserve to have, and --

M: Um hmm, I [G-Exp-higher pitch] just WISH it was all over.

Performance Genres

Direct Speech - well, you can’t stress over

Repetition - care (10), good (9), don’t (6) [D-I don’t (4), M-I don’t (1), D-You don’t (1)], right (6), stress (5), know (4), have (4) [We have (2), I have (2)], always (4), control (3), help (3)
**Aside-**

**Expressive sounds/cues**

i.e. Pitch/Speed/Quality/Emotion

None

D: **we have** to do the business part of it, [G-Exp-laughter]
D: **I don’t** review too much what’s **good**, because it just goes [G-Exp – higher pitch] **unsaid** [G-Exp laughter]
M: **I don’t** want (name of care provider) [G-Exp lower pitch]
M: It’s half an hour now [G-Exp lower pitch, concerned]
M: **I HAVE** to be [G-Exp-higher pitch]
D: that I would like [G-Exp higher pitch].
M: M: Well, I **HANDLE** it [G-Exp – higher pitch]
D: Whereas [G-Exp higher pitch],
M: Um hmm, I [G-Exp-higher pitch] just **WISH** it was all over
Overview of Direct Quotes and Repeated Words

Direct Quotes – Carrie and Elisabeth

well, you can’t stress over

Repeated Words

care (10), good (9), don’t (6) [D-I don’t (4), M-I don’t (1), D-You don’t (1)], right (6), stress (5), know (4), have (4) [We have (2), I have (2)], always (4), control (3), help (3)

The word frequency image below has been created in NVivo 10 drawing on the repeated words that were generated within the specific end of life relational story analysed for Carrie and Elisabeth.
Appendix G:
Diana & Susan Thematic and Dialogic/Performance Analysis
<table>
<thead>
<tr>
<th>MOTHER-IN-LAW/DAUGHTER-IN-LAW RELATIONSHIP</th>
<th>WHEN THE DAUGHTER-IN-LAW WAS AN ADOLESCENT/YOUNG ADULT</th>
<th>WHEN ILLNESS ARRIVED</th>
<th>PRESENT DAY</th>
<th>FUTURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>MOTHER-IN-LAW (MOTHERING)</td>
<td>OPENNESS/PRESENCE</td>
<td>DAUGHTER-IN-LAW LAW AS TRANSLATOR/EXPLANATIONS</td>
<td>SHIFTING PERSPECTIVES AND PERCEPTIONS OF ACCEPTING CARE</td>
<td>CONCERNS ABOUT FUTURE NEEDS AND OVERSEEING/MANAGING CARE IN SHORT TERM AND WHEN ILLNESS NEEDS PROGRESS</td>
</tr>
<tr>
<td>Diana and her husband only had one son, and while they wanted to have a second child this didn’t happen.</td>
<td>Susan (D-IN) shares how as an adolescent many of the youth that they went to school with spent time at Diana and her husband’s home. Susan notes how they were ‘second parents’ to many of their friends, and how many of these people are still in contact with them.</td>
<td>Diana (M-IN) stresses how important Susan has been as a nurse and as a daughter-in-law in translating medical information and supporting them in their varying illnesses) (medical context translator/navigators, affirming Susan’s role in relationship/family, challenging dominance of biology as primary connector)</td>
<td>Diana (M-IN) difficulties in accepting care in her home despite significant physical needs/burden (gendered roles/identity, sense of self, autonomy)</td>
<td>Susan (D-IN) expressed significant concerns about the future for Diana and for Diana’s husband. (medical context of limitations in the health care system and daughters/daughters-in-law feeling responsible for ensuring consistency of care across the longer term)</td>
</tr>
<tr>
<td>DAUGHTER-IN-LAW (DAUGHTERING)</td>
<td>Much of the relationship between Diana and Susan was across some distance as they lived in different cities. In the past few years though, Diana and her husband moved to be closer to Susan and her husband.</td>
<td>ADVANCED DIRECTIVES</td>
<td>EXPERIENCES OF CARE ON THE PCU – RELYING ON CARE</td>
<td></td>
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<tr>
<td>Susan began dating her husband (to-be) when they were both in high school and married after they finished university.</td>
<td>Susan (D-IN), relays how Diana and her husband had completed their advanced directives a number of years prior to her latest admission, and how this helped family in decisions around comfort-measures (patient goals of care, substitute decision-making, end of life)</td>
<td>Diana (M-IN) relying on the care, and the fact that they really will come and want to help her (accepting/relying on care; shifting expectations of care and need)</td>
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<tr>
<td>DAUGHTER-IN-LAW AS MOTHER</td>
<td>RESPECTING INDEPENDENCE/AUTONOMY/DISAPPEARING LINE BETWEEN THEM</td>
<td>Differing Thoughts to the Tasks that lie ahead</td>
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<tr>
<td>Susan and her husband have two children.</td>
<td>Susan (D-IN) notes how she respects Diana and how across their relationship they have maintained a supportive line/space of respect between them. As Diana (M-IN) needs increase and she needs more care, both Diana and Susan note how this line seems to have disappeared.</td>
<td>Diana (M-IN) have to accept what comes – would like to spend time with family and enjoy the time left/Susan (D-IN) significant concerns and worries about future care needs and overseeing/managing logistics (tasks of dying, stages of dying, anticipatory and preventive caregiving)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Transcription legend** – modified from (Ochs & Capps, 2001)

<table>
<thead>
<tr>
<th>Symbol</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Interviewer</td>
</tr>
<tr>
<td>M</td>
<td>Mother</td>
</tr>
<tr>
<td>D</td>
<td>Daughter</td>
</tr>
<tr>
<td>-</td>
<td>shows an overlap or interruption in the speech turn</td>
</tr>
<tr>
<td>word</td>
<td>reflect an emphasis on this word in the speech turn that is different from other words used in the same speech turn</td>
</tr>
<tr>
<td>WORD</td>
<td>reflects a very strong emphasis on this word within the speech turn</td>
</tr>
<tr>
<td>[motion X]</td>
<td>reflects non verbal signs/cues/motions</td>
</tr>
<tr>
<td>(.)</td>
<td>brief pause,</td>
</tr>
<tr>
<td>(pause)</td>
<td>reflects lengthier pause where this is a noticeable silence of more than two seconds.</td>
</tr>
</tbody>
</table>

**Performance Genres (Riessman, 2008)**

- **[G- Direct Speech]** Represents the performance genre of direct speech, and involves highlighting direct speech lines performed within the passage
- **choices** Represents the performance genre of repetition in **words (phrases)** that are used repeatedly within the passage
- **[G-Aside]** Represents the performance genre of asides, where information is shared within the performance that provides background that is outside of the main story or performance
- **[higher/lower pitch]** Represents the performance genre of expressive sounds within the dialogue which in this study includes how voices move higher or lower in pitch/tone in relation to speech
Diana & Susan – Dialogic/Performance Analysis

Condensed Legend of Transcription Conventions 1
I= Interviewer
M= Mother
D= Daughter

Prelude: Prior to this scene unfolding, Diana and Susan are talking about Diana’s difficulty in allowing people to help her, and yet how her health limitations were such that she didn’t have the energy to push a button on a microwave, much less make a meal or clean the house.

Scene 1

D: I remember sitting at the table and you saying, “I don’t want people to come in” [G-Direct Speech] and you were just, like, you were just BESIDE yourself. (M: yeah) BESIDE yourself, because, but, you know, and it wasn’t, it wasn’t anything we could say to make you feel any different or better [G-Exp higher pitch] because your brain just wasn’t taking in the common sense part of it, you know? It was just like, you got a thought in your head and that was the thought that stayed there. (M: I know) We couldn’t change it.

M: It was so frustrating for [name of husband], too. God. [G-Exp - lower pitch]

I: Did he want something different?

M: No, he always supported ME. He kept saying, “it’s what YOU want, whatever you want.” [G-Direct Speech] But, but in that way, too, he was also leaving the decisions all up to me –

M: So [G-Exp high pitch] I was in a catch-22 situation [G-Exp lower pitch].

...

Scene 2

M: I, I didn’t like the idea of always different people [.] people were trying to HELP, but when you have, ah, say, um, five or six different people coming in to do different jobs, to me it was, ah, it was [G-Exp sigh] interfering. It was doing jobs that I should be doing myself. “You know?” [G-Direct Speech] And I, ah, couldn’t rid myself of that feeling, that I was, ah, abdicating my responsibilities [G-Exp higher pitch]. Yeah.

...

Scene 3

------------------
1 Please see preceding page in Appendix for a full overview of the transcription conventions used within this excerpt.
M: Can you imagine how it feels to have someone say to you, “if you need anything, call me” [G-Direct Speech] All I’ve got to do is press a button and somebody’s here. And they will do whatever they can to help me.

M: I tell you, (D: yeah) it’s really something.

I: Yeah. So, you’re in a different place now…. so I’m wondering how you feel now about receiving supports now.

M: Well, I feel a little ridiculous that I refused it, that [pause] I didn’t want it. Ah, I feel badly that I couldn’t work it out in my mind, you know? [G-Exp higher pitch] OK, you do this and I’ll do that sort of thing, you know? I couldn’t, ah, separate it like that.

**Performance Genres**

**Direct Speech**
- I don’t want people to come in
  - You know?
  - it’s what you want, whatever you want
  - if you need anything, call me

**Repetition**
- feel (6), want (5), couldn’t (4), people (4), like (4),

**Aside**
- None

**Expressive sounds/cues**
- D: to make you feel any different or better [G-Exp higher pitch]
  - M: It was so frustrating for [name of husband], too. God. [G-Exp lower pitch]
  - M: So [G-Exp high pitch] I was in a catch-22 situation [G-Exp lower pitch]
  - M: that I was, ah, abdicating my responsibilities [G-Exp higher pitch].
  - M: I couldn’t work it out in my mind, you know? [G-Exp higher pitch]
Overview of Direct Quotes and Repeated Words

Direct Quotes – Diana and Susan
I don’t want people to come in
You know?
it’s what you want, whatever you want
if you need anything, call me

Repeated Words
feel (6), want (5), couldn’t (4), people (4), like (4),

The word frequency image below has been created in NVivo 10 drawing on the repeated words that were generated within the specific end of life relational story analysed for Diana and Susan.
Appendix H:

Overview of Core Findings: Individual, Relational and Intersubjective Processes
Overview of Core Findings: Individual, Relational and Intersubjective Processes

<table>
<thead>
<tr>
<th>Individual Processes</th>
<th>Relational Processes</th>
<th>Intersubjective Processes</th>
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<tbody>
<tr>
<td><strong>Individual knowing and experience about end of life</strong></td>
<td><strong>Relational care practices between mothers and daughters in end of life</strong></td>
<td><strong>Intersubjective (mutual knowing) between mothers and daughters in death and dying</strong></td>
</tr>
<tr>
<td>1. Individual knowing and understanding of end of life is located (and clearly positioned by daughters), within the lives and experiences of women who are dying.</td>
<td>1. Mothers and daughters have a long relational continuum where care practices have shifted over time with different roles, understandings and identities.</td>
<td>1. Acknowledging, responding and attending to mutual knowing in dying and death requires an ability to hold different positions, wants and needs – while also acknowledging and articulating one’s own position and wants and needs</td>
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<tr>
<td>2. Individual knowing and understanding of end of life by mothers AND daughters while located individually, lives relationally, and daughters are highly attentive to ensuring that their mothers’ voices and experiences are heard first, and then their own voices can be heard.</td>
<td>2. Care practices for women are often strongly woven into their sense of self, identity and role as a woman, and as a mother and daughter. Shifts in care practices need to be recognized for the depth and breadth of what these transitions mean for women, and women needed to be supported to modify or adapt care practices into new contexts and situations.</td>
<td>2. Mutual knowing of dying and death may also involve a recognition that some needs and concerns are left outside of the mother and daughter relationship and attended to by other relational supports</td>
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<td><strong>Individual choices about treatment in end of life</strong></td>
<td>3. Mothers and daughters may need support to acknowledge the shifts and changes in roles and identities, as well as the losses and/or new elements that may arise with these changes.</td>
<td>3. Experiences and understandings of mutual knowing between mothers and daughters while a mother is dying and at the time of a mother’s death can be powerful and poignant for daughters as they experience grief and loss</td>
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<td>3. Women’s decisions to pursue treatment or stop treatment need to be located within and across women’s larger life course trajectory which reflect a history of stress and coping resources that have been built over time.</td>
<td><strong>Relational care practices between mothers and daughters and care providers in end of life</strong></td>
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<tr>
<td>4. Women’s beliefs and purposes (global meaning) about treatment and end of life are strongly woven and reproduced within larger social-cultural meta-stories about life, death and choice.</td>
<td>4. Underscoring daughters’ relational care practices with care providers may be a strong connection and identification with protective caregiving, where daughters may be focused on protecting their mothers’ sense of self and identity and in ensuring the stability and security of the mother and daughter relationship.</td>
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<td>5. Each woman’s situational meaning around a specific choice or decision needs to be understood within a framework that recognizes the history, meaning, and outcome of how these decisions have lived and continue to live within their relationships.</td>
<td>5. Within daughters’ relational care practices with care providers there may be a strong focus on anticipatory caregiving, and anticipating the multiple needs and concerns that may arise as their mother becomes more ill. Daughters can experience a tremendous</td>
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### Overview of Core Findings: Individual, Relational and Intersubjective Processes

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<td>sense of responsibility in both anticipating and meeting all of the variable needs that may arise for their loved one, and may feel that within the limits of the health care and home care system, that it is up to them, to ensure that their mother is protected and has their needs met.</td>
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<tr>
<td>6.</td>
<td>Mothers and daughters in their relational care practices with care providers can experience a great deal of stress in overseeing and managing care and in ensuring that mothers receive ‘good care’. Managing care needs and responding to unmet needs involve weighing costs and risks as mothers and daughters worry about possible repercussions on future care.</td>
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</tbody>
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Figure 3, The Role of Hospice Palliative Care During Illness from A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002. Page 18, Figure 8 is reproduced with permission from the Canadian Hospice Palliative Care Association (CHPCA) as the copyright holder.