Adult Children’s Experiences of Caring for Elderly Chinese Immigrant Parents Managing Chronic Illness: A Qualitative Study

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
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Abstract

Research on Chinese families documents the importance of the family in providing informal health support and caregiving to elderly members. This research was guided by a phenomenological approach using in-depth interviews with individuals (N=23) to explore the experiences of adult Chinese-Canadian children who assist their elderly immigrant parents manage their chronic illnesses. The results from this study suggest that the experiences of caregivers who are Chinese are not necessarily different from those who are not Chinese; yet, Chinese identity was used by participants to frame their descriptions of their experiences. The Power Resonance Framework was developed to represent the dynamic nature of the relationships between patients, caregivers and healthcare providers. Finally, using vignettes developed from participant narratives, current conceptualizations of cultural competency among healthcare providers can be explored and critiqued. Many of the adult children in this study struggled with the dual roles of child and lay healthcare provider, referencing what they perceived as cultural norms to explain the conflict they experienced.
Dedication

This thesis is dedicated to my daddy and mommy, Mehdi and Fatima Mirza, to my aunt Bano (my other mom!), and to my sister, Sabina. On my first day at the University of Toronto, my dad and I came to campus together. We got off at the same subway station: he went to work at Toronto General Hospital and I went off to school. Not too long after, my dad was no longer able to come to work, but I continued to trek the same route my dad had for the previous 30 years. I learned about working hard from my dad. It was remembering my dad’s drive and determination, even when he was sick, that motivated me to keep going through much of this process. In all my days, there has never been a single time that I have heard my mother complain. I learned from my mom the importance of facing reality. My mother's message to me was always that reality is reality—whether I liked it or not—and that I should always be moving forward.

With my mother's steadfast support, I have learned to face my fears, to face my doubts, and to face the challenges. My aunt Bano taught me about gratitude. My aunt has been grateful for all of our family's accomplishments, for all of our little hopes, for all of our little moments, and for every little miracle. Thank you for your timely words of wisdom and for always reminding me that everything was going to be okay. My (not so little) sister has always been by my side, supporting me and encouraging me to never look back. It is because of my sister, who is my bestest friend (and safeguard), that I know what loyalty is. Having a sister like Sabina is one of the greatest blessings in my life, and I am grateful for having someone like her always there to listen to me, to challenge me to achieve and exceed the goals I set for myself, and to support me.

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This journey was full of ups and downs. I learned more than just the lessons of research and academia. I learned about the nature of enduring and lasting friendships, I learned about myself, I learned about letting go of the things that were not in my control, and I learned about holding on to those things that will always be important to me. I have a lot to be thankful for.

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Table of Contents

Abstract .................................................................................................................................................. ii
Dedication ................................................................................................................................................ iii
Acknowledgements .............................................................................................................................. iv
List of Tables ........................................................................................................................................... ix
List of Figures ......................................................................................................................................... x
List of Appendices ............................................................................................................................... xi

Chapter 1: Introduction ........................................................................................................................ 1
  1.1 Background .................................................................................................................................. 1
    1.1.1 Why Study Chinese-Canadians? ......................................................................................... 3
    1.1.2 The Role of Family Members in Chronic Illness Management ........................................ 4
    1.1.3 Caregivers in the Clinical Setting ..................................................................................... 5
    1.1.4 The Experiences of Caregivers ......................................................................................... 6
  1.2 Overall Purpose of the Study .................................................................................................... 9
  1.3 Overview of Thesis ..................................................................................................................... 10
  References .......................................................................................................................................... 12

Chapter 2: Methods ............................................................................................................................. 19
  2.1 Research Question .................................................................................................................... 19
  2.2 Objectives .................................................................................................................................. 19
  2.3 Research Methodology ........................................................................................................... 21
    2.3.1 Paradigm: Ontological and Epistemological Considerations ........................................ 21
  2.4 Methods: Phenomenology ....................................................................................................... 23
    2.4.1 Sample and Recruitment ................................................................................................. 24
    2.4.2 Recruitment Process ....................................................................................................... 25
    2.4.3 Data Collection ................................................................................................................ 26
    2.4.4 In-depth Interviews ......................................................................................................... 26
    2.4.5 Post-Interview Follow-up ............................................................................................... 27
    2.4.6 Member Checking ............................................................................................................ 30
    2.4.7 Data Analysis .................................................................................................................. 31
  2.5 Researcher 'Identity' and Positionality .................................................................................... 33
    2.5.1 Reflexivity ....................................................................................................................... 35
2.5.2 Quality and Rigor ........................................................................................................... 38

2.6 Ethical Issues .................................................................................................................. 38
   2.6.1 Informed Consent ...................................................................................................... 38
   2.6.2 Risks and Benefits .................................................................................................... 40
   2.6.3 Privacy, Confidentiality and Participant Withdrawal ................................................ 40
   2.6.4 Compensation .......................................................................................................... 41

2.7 Conclusion ....................................................................................................................... 41

References ............................................................................................................................ 42

Chapter 3: Results .................................................................................................................. 46

Using Impression Management to Understand Adult Chinese-Canadian Children’s 
Use of “Culture” to Explain their Experiences of Caring for Their Elderly Chronically-Ill Parents

Abstract .................................................................................................................................. 46

3.1 introduction ....................................................................................................................... 47

3.2 Background ...................................................................................................................... 48
   3.2.1 Self-Concept and Impression Management .............................................................. 48

3.3 Methods .......................................................................................................................... 50
   3.3.1 Data Analysis ........................................................................................................... 51

3.4 Findings ............................................................................................................................ 52
   3.4.1 Expectations of Care ................................................................................................. 53
   3.4.2 Experiences of Care .................................................................................................. 56

3.5 Discussion ........................................................................................................................ 60

3.6 Conclusion ........................................................................................................................ 64

References ............................................................................................................................ 65

Chapter 4: Results .................................................................................................................. 69

(Re)Framing the Patient, Caregiver and Healthcare Professional Relationship: The 
Power-Resonance Framework

Abstract .................................................................................................................................. 69

4.1 introduction ....................................................................................................................... 70
   4.1.1 The Role of Caregivers ............................................................................................ 70
   4.1.2 Power Dynamics within a Social Field ...................................................................... 73

4.2 Methods ............................................................................................................................ 75
Chapter 4: Findings

4.3 Findings .................................................................................................................. 76
  4.3.1 Alignment ........................................................................................................... 79
  4.3.2 Dispersion ......................................................................................................... 80
  4.3.3 Sway: The Various Alliances of Patients, Caregivers and Healthcare
  Professionals ............................................................................................................. 81
  4.3.4 The Changing Nature of Relationships ............................................................. 83

Chapter 4: Discussion

4.4 Discussion ................................................................................................................ 84
  4.4.1 Re-examining Patient Specific Chronic Care: Understanding Patient- Caregivers
  Healthcare Professional Relationships ........................................................................ 84

Chapter 5: Results

5.1 Introduction ............................................................................................................. 93

Chapter 5: Questioning the Utility of ‘Cultural Competency’ in Caring for Older Chinese Patients

Abstract .......................................................................................................................... 92

Chapter 5: Methods

5.2 Cultural Competency .............................................................................................. 94

Chapter 5: Findings

5.3 Methods .................................................................................................................. 97

Chapter 5: Discussion

5.4 Findings .................................................................................................................. 98

Chapter 5: Discussion

5.5 Discussion .............................................................................................................. 104

Chapter 6: Conclusion

5.6 Conclusion ............................................................................................................. 107

Chapter 5: References

5.6 Conclusion ............................................................................................................. 107

Chapter 6: Discussion and Conclusion

6.1 Overview of Key Findings ...................................................................................... 114

Chapter 6: Discussion and Conclusion

6.2 Re-conceptualizing the Patient-Caregiver-Healthcare Professional
  Interaction ..................................................................................................................... 115

Chapter 6: Discussion and Conclusion

6.3 Culture and the "Chinese Patient" .......................................................................... 118

Chapter 6: Discussion and Conclusion

6.4 Methodological Insights ......................................................................................... 120

Chapter 6: Discussion and Conclusion

6.5 Study Limitations ................................................................................................... 123

Chapter 6: Discussion and Conclusion

6.6 Strengths ................................................................................................................ 125

Chapter 6: Discussion and Conclusion

6.7 Directions for Future Research ............................................................................. 126

Chapter 6: Discussion and Conclusion

6.8 Conclusions .......................................................................................................... 128

Chapter 5: References

6.8 Conclusions .......................................................................................................... 128

Chapter 6: References

References ...................................................................................................................... 130
List of Tables

Table 1, Chapter 2: Data Collection Summary............................................................... 29

Table 1, Chapter 3: Key Demographic Information of Sample..................................... 52

Table 1, Chapter 4: Key Demographic Information of Sample..................................... 77

Table 2, Chapter 4: Caregivers as (powerful) Actors in a Social Field.......................... 77

Table 3, Chapter 4: Characterization of Interactions Between Patients, Caregivers and Healthcare Professionals,................................................................. 78

Table 1, Chapter 5: Key Demographic Information of Sample..................................... 99

Table 2, Chapter 5: An Overview of Cultural Competency Training in Canadian Medical Schools........................................................................................................... 113
List of Figures

Figure 1, Chapter 2: Overview of Research Methodology and Methods………………………… 20

Figure 1, Chapter 4: Health Council of Canada, Optimal Prescribing and Medication Use in Canada, Challenges and Opportunities………………………………………………… 72

Figure 1, Chapter 5: BASIC- Practical Ways Healthcare Providers Can Explore the Individual 'Life Contexts' of their Culturally Diverse Patients…………………………………… 112
List of Appendices

Appendix A: Study Participant Recruitment Records…………………………………… 133
Appendix B: Information Sheet and Consent Form………………………………………… 136
Appendix C: Interview Guide………………………………………………………………… 140
Appendix D: Follow-up Questions…………………………………………………………… 142
Appendix E: Member Check Questions……………………………………………………… 144
Appendix F: Translated Documents and Consent Forms…………………………………… 146
Appendix G: Procedure Map………………………………………………………………… 149
Appendix H: Study Poster……………………………………………………………………… 150
Appendix I: Interpreter Confidentiality Agreement…………………………………………… 151
Chapter 1
Introduction

This dissertation describes a qualitative study examining the experiences of adult children who identified themselves as caregivers, and were involved in the care for their chronically or terminally ill elderly Chinese parents. In this chapter, a brief review of the demographics of Chinese Canadians is presented to help explain the importance of studying the experiences of members of this immigrant group. This is followed by a short summary of the role of family members as caregivers for those with chronic illnesses. These topics are covered to provide background for the study and to justify why studying the experiences of adult children who act as caregivers for their elderly Chinese parents was chosen as the study focus. The chapter concludes with an overview of the thesis.

1.1 Background

Currently Chinese immigrants comprise the largest component of the immigrant population in Canada (Statistics Canada, 2006). After migrating to Canada, many older Chinese adults live with their children, continuing in their host country the tradition of the multigenerational family (Gee et al., 2003). In many families, the decline of a parent’s health or mental capacity requires adult children to play an increased role in the management of the parent’s chronic illness.

Within any family, Chinese or otherwise, chronic illnesses may be life threatening and are usually seen as life altering and intrusive to the daily routines of individuals within the entire family (Eloniemi-Sulkava, 2002; Poley, 2011). Further confounding the issue of chronic illness management within the context of the family is the fact that many elderly Chinese patients seeking care in Canada may not speak or comprehend English, may have poor health literacy, and may lack familiarity with Canadian or Western medical practices and health beliefs which may differ from their own personal sense of their health, illnesses and well-being (Ma, 1999; Lai & Surood, 2009; Lai & Surood, 2009). These factors may significantly affect how involved caregivers are in the management of the illness, and how information is exchanged amongst and between the patient, the caregiver and members of the healthcare team (Bevan & Pecchioni, 2008; Wolff et al., 2009).
The shift of care from the clinical setting to the home setting is an important aspect of chronic illness management, especially for immigrant Chinese families in Canada. Based on a widespread belief that social support leads to better health outcomes for chronically ill care recipients, there has been a push for greater involvement of caregivers in collaborative care with healthcare professionals, and a move towards more family-centered care options (Nolan et al., 2001; Nolan et al., 2003; Nolan et al., 2004).

This study focuses specifically on the experiences of the caregivers in an effort to enhance our understanding of the unintended consequences of the increased family involvement in care. This research was based on the following question: “How do adult children of elderly immigrant Chinese parents experience the management of their parents’ illnesses?” The research presented here focuses first on understanding their experiences as caregivers, and only secondarily exploring how (if at all) being Chinese shapes this experience.

The needs, values and potentially differing beliefs of caregivers are often ignored when considering the involvement and interactions of these individuals with healthcare professionals as part of the clinical encounter, as is often described in collaborative care models (Wagner et al., 2001; Callahan et al., 2006). The findings presented in this thesis challenge the assumption that including the caregiver in the healthcare professional-patient relationship can be understood as a simple additive process that leads to the expansion of the relationship, as Silliman (1989) suggests.

Current approaches to addressing issues of culture when providing care to patients of a range of ethnic backgrounds rely primarily on explanatory models that are based on the assumption that anyone who identifies as Chinese shares the same beliefs and values with regard to health and illness (Shih, 1996; Bowman & Hui, 2000; Dong et al., 2007). This thesis provides an opportunity to explore and critique our assumptions about the role of culture with regard to the experiences of caregivers and also as it relates to the provision of healthcare.
1.1.1 Why Study Chinese-Canadians?

Immigrants with Chinese origins grew from 14% to 31%, from 1980 to the mid 1990’s (Kinnon, 1999; Wang & Lo, 2005) in Canada. Among the large urban centers in Canada, 45% of Chinese immigrants chose to settle in Toronto, a city with a large Chinese population (Wang & Lo, 2004). Chinese immigrants report preferences for multigenerational habitation patterns (Boyd, 1991; Pacey, 2002; Lai, 2005), and the family remains the primary caregiving system and a source of social support (Chappell, 2003). Social support generally refers to a network of family, friends, neighbors, and community members that is available in times of need to give psychological, physical, and financial help (Malone-Beach & Zarit, 1995, p. 25-27). Within Chinese families, social support from family members may help to counter language issues and some of the negative effects of migration.

Housing data suggest that only 10% of all Chinese seniors in Canada live alone, with a higher proportion of Chinese older-adults (67%) living with extended families than Canadian-born elderly, and 20% living only with a spouse (Statistics Canada, National Population Health Survey, 1996; Pacey, 2002). Furthermore, for elderly Chinese immigrants, Chappell (2003) reported that children are the primary source of subsistence income and source of help in times of crisis and poor health. Coming from a home country where 'familialism' and the provision of care are embedded in tradition, the Chinese in Canada also appear to demonstrate a strong in-group orientation as highlighted by multigenerational habitation patterns and the continued immigration to Canada through the family and relative class (Kinnon, 1999; Guo & Devoretz, 2007).

There is a paucity of research on immigrants’ health help-seeking, and little research on how social support from adult children may assist in their parents’ negotiation of the healthcare system. What is known is that Chinese immigrants to Canada, over time, are more likely than the general immigrant population to report depression and at least one medical problem (Haley, 2003), and that their healthcare encompasses a broader range of medicinal products and healthcare providers to treat illnesses (Lai & Chappell, 2007).
1.1.2 The Role of Family Members in Chronic Illness Management

Chronic illnesses, considered to be any illness lasting more than three months (U.S. National Center for Health Statistics, 2009), may sometimes be life threatening and are almost always seen as life altering and intrusive to the daily routines of individuals. An important aspect of chronic illness management for the elderly is the potential impact of the illness on families. Although many qualitative studies, especially in nursing research, present the experience of chronic illness from the perspective of the ill person (Duggan & Dijkers, 1999; Keaton & Pierce 2000; Hwang et al., 2004), the insider’s view of managing the complexities of chronic illness also needs to include important others (such as adult children) who may actively assist the illness sufferer manage their chronic illness. Findings from studies on the experience of living with chronic illness suggest that the management of chronic illness creates prolonged demands, life adjustments and impingements on activities, not only for the older individual who is afflicted with the illness, but also for family members and caregivers (Von Korff et al., 1997; Bodenheimer et al., 2002; Brazil et al., 2003; Glajchen 2004).

In the same way that some individuals may treat acute and chronic illnesses differently, the nature of the long-term chronic illness may significantly affect how involved adult children are in the management of the illness, how information is exchanged amongst family members, and how the meaning of chronic illness may shape the experience and perceptions on how to deal with and treat the illness. Researchers have noted that positive social ties with children and spouses can influence the well-being of older adults, and effectively meet their informal healthcare needs (Ren et al. 1999; Seeman, 2000; Uchino, et al. 1996; Unger et al., 1999).

Close familial ties and social support have been conventionally seen as ‘health protective’ in Chinese society as well (Lan, 2002). Not surprisingly, Chinese immigrants to North America are very likely to discuss their health and illness issues with family members and to rely on them for support (Lai & Chappell, 2007; Dong et al., 2010). It is also well established in the healthcare decision-making literature that families are often relied upon for healthcare decision-making, healthcare and support (Candib, 2002; Kwak & Haley, 2005; McAdam et al., 2005). However, what appears to be missing from the discourse is an acknowledgement that family members can have their own interests that may not be reducible to the interests, values or preferences of other members of the same family. It is important to study the experiences of the adult children
caregivers as this may provide new insight into how and why these relationships are either supportive or conflictive and what can be done to help optimize the benefits of social supports so often described in the literature.

In some instances, conflict in families may be triggered by different levels of acculturation with the host society, differing endorsements of cultural values and attachment to ethnic identity (Costigan & Su, 2004). Elderly Chinese who are not fluent in English may be entirely reliant on their adult children or grandchildren (Mackinnon et al., 1996), individuals who may not share similar cultural, personal or health related values (Weng & Nguyen, 2011), to make healthcare decisions for them. Other types of conflict may arise in situations where there is an imbalance in social arrangements and dependency rather than interdependency between the generations (Kobayashi, 2000; Da & Garcia, 2010).

1.1.3 Caregivers in the Clinical Setting

It is not uncommon for older adults to be accompanied by their caregivers to medical visits. As Glasser et al., (2001) state, it is understood in geriatric practice that as patients get older, and are more dependent on caregivers, the patient-physician encounter has to expand to include the caregiver who may accompany an elderly patient. Physical and emotional support was the primary reason caregivers gave to explain why they were accompanying a family member to the medical setting (Prohaska & Glasser, 1996; Schilling et al., 2002), and those accompanied were usually found to be sicker than those who were not accompanied by a caregiver (Ellingson, 2002).

With ethnically and culturally diverse populations, caregivers may accompany family members to help translate (Tate, 2003), to facilitate or improve communication (Beisecker, 1989; Adelman et al., 1987), and to learn how to manage care for the patient (Coe et al., 1984). The presence of a caregiver within the medical encounter has been seen as both having positive and negative influences. On the one hand, including caregivers in the patient-practitioner interaction has been reported to have the potential to lower patient anxiety (Schofield et al., 2003) and improve communication between all individuals. Alternatively, it has also been reported that when caregivers are involved in illness management, they may be focused on their own “agendas”
rather related to the care of the patients which may or may not be aligned with the goals of the patient (Glasser et al., 2001). However, little inquiry has taken into consideration the experiences of being the “third person” of the triad (patient-practitioner-caregiver), from the perspective of caregivers.

Many studies of the involvement of the caregiver in the medical encounter appear to make the assumption that the patient and the caregiver share the same values, beliefs and orientations with regard to the management of the patient’s chronic illness (Sketris et al., 2007). The notion of protectiveness has been studied in the context of collusion between healthcare professionals and families (Low et al., 2009) trying to do what they believe is in the “best interest of the patient”. As Low et al., (2009) explain, families and attending healthcare professionals sometimes conceal life-threatening or serious illness from the patient in order to protect them and this is seen as the “default” practice in many Asian cultures. In contrast, seriously ill family members sometimes try to protect family members by colluding with healthcare professionals such that family members are not informed of their condition (Pang, 1999; Tse et al., 2003). These findings highlight how the assumption that caregivers, patients and healthcare practitioners share the same beliefs and values can be problematic. This study provided an opportunity to explore this assumption in depth from the viewpoint of the caregiver.

1.1.4 The Experiences of Caregivers

Studies of lay caregivers indicate that they are important partners for patients and healthcare professionals. Both quantitative and qualitative research methods have been employed to explore the experiences of caregivers. Topics such as caregiver burden and fatigue (Yokoyama, 1993), contributions to activities of daily living for the care recipient (Duncan et al., 2005), and self-reported health decline in caregivers (Caron & Bowers, 2003) have been explored previously. Qualitative research based on in-depth interviews and non-participant observation, has helped illuminate the complex experiences of being an adult caregiver. These studies consistently find that there is a strong emotional element to the caregiving experience and that decision-making with regard to the care of a loved one often leads to tensions in families (Owens, 2004; Lindhardt et al., 2006). Although the roles, responsibilities and experiences of caregivers for Chinese care recipients are likely to be similar in nature to those of the non-
Chinese (Janevic & Connell, 2001; Kung, 2003), cultural issues (i.e., stigmatized disease states, filial guilt) have been reported to add another dimension to the caregiving experience (Kung, 2003; Chang & Horrocks, 2006).

A number of studies have looked at the specific experiences of caregivers to Chinese patients, both in the Chinese context (Zhan & Montgomery, 2003; Chan & O’Connor, 2008; Liu et al., 2012) and in Western settings (Kung, 2003; Zhan, 2004; Lai, 2007; Shon & Adamek, 2010; Weng & Nguyen, 2011). The following factors have been identified as having the potential to impact the experiences of Chinese caregivers: cultural emphasis on managing care within the family (AARP, 2001), interpersonal harmony with family members (Gabrenya & Hwang, 1996), and expectations of treatment from care recipients (Hinton et al., 1999). The limited studies of Chinese caregiver experiences in Western countries suggest they are not dissimilar from their Western counterparts and include discussion of issues of stress (Kung, 2003), emotional strain (Kung, 2003), the adoption of various roles in illness management (Kung, 2003), and perceptions that caregivers needed to act in roles of protection and advocacy (Fulton et al., 2011).

However, there is some indication in the literature that caregivers in ethnically Chinese families may experience caregiving in some ways that are different from others. For example, Chinese caregivers, as reported in a study by the American Association of Retired Persons Multicultural Survey (AARP, 2001), showed participation in care practices that were more time consuming, and higher reported feelings of guilt than any other race surveyed. Stigma, perceived to be culturally-based, associated with some chronic illnesses (i.e., mental health issues) has been reported to create another dimension to the caregiving experience of Chinese caregivers (Dilworth-Anderson et al., 2002; Kung, 2003; Zhan, 2004). Attempts to “save face” for the family have been described to impact who caregivers discuss health-related issues with, as well as if and when they decide to access health services (Chang & Horrocks, 2006). For example, a qualitative study by Zhan (2004) on the experiences of Chinese-American family caregivers (N=4) to persons with Alzheimer’s disease reported that participants experienced stigmatization within the community due to the family member’s diagnosis with Alzheimer’s disease. This study identified a number of issues including a lack of what they described as the availability of culturally appropriate services (often times as a result of language issues), problematic
interactions with doctors and others involved in care practices, and personal feelings of not being prepared to provide care.

How caregivers of Chinese descent present their experiences is important, as it appears that they often emphasize the cultural element of their experiences. For example, culture was reported by Chan and O’Connor (2008) as influencing the caregiving experiences of Chinese caregivers for older, frail and/or chronically ill family members. The study found that by attending family support groups, Chinese caregivers were able to challenge long-held traditional values and beliefs often associated with Chinese culture (i.e., filial piety), and learned to speak up with regard to their own needs. Leung and McDonald (2007), who explored how Chinese ethnicity and culture influenced the care practices of caregivers and care recipients in Toronto, found that participants reported that culturally and linguistically appropriate services were lacking or unavailable. This perceived need for culturally and ethnically tailored support suggests that culture is an important element of the experience of caregiving that is very much embedded in the practices, beliefs and values of Chinese caregivers.

What is clear from the literature is the following: the management of chronic and terminal illness is increasingly shifting from the clinical, or formal setting, to the home, or informal setting (Dudgeon & Kristjanson, 1995; Dyck et al., 2005; Stajduhar et al., 2011). Also, that with Chinese families in Canada continuing to report a preference for multi-generational habitation patterns, adult children are often living with their elderly parents and providing care for them as a result of the onset of a chronic or terminal illness (Zhan & Montgomery, 2003). Furthermore, previous studies indicate that there is a perception amongst members of the Chinese community that there is a cultural expectation that adult children will provide care for their parents (Jones, 1995; Fung, 1998; Lai et al., 2007; Dong et al., 2010), and that culture plays a role in structuring the roles and responsibilities of adult children with regard to illness management (Chien & Chan, 2004; Hsiao et al., 2006).

What this suggests is that there remains a demonstrated, but unaddressed, need to understand the following: (1) what factors are perceived by caregivers to shape their experiences, as they are increasingly being relied upon to provide continuity of care from one setting of care to another;
(2) how the involvement of caregivers in chronic illness management with healthcare providers and their elderly parents has the potential to alter the dynamics of the doctor-patient relationship; and (3) how culture is (or is not) related to the experience of being a caregiver; and under what circumstances Chinese culture is referenced and prioritized by caregivers, when, and for what potential purpose. This qualitative study adds to our knowledge by filling these gaps in the literature.

Using a qualitative approach is particularly useful for understanding the unique lived experiences of adult children who act as caregivers for their chronically or terminally ill elderly parents. The findings from this study can be used by healthcare professionals to help them optimize the role of family caregivers when working with patients with chronic illnesses. The experiences of ethnically diverse caregivers remain under-represented in the literature, and with the changing demographics of Canadian society, warrant further exploration.

1.2 Overall Purpose of the Study

The purpose of this study is to better understand the experiences of adult children who take on caregiving roles for their elderly, ethnically-Chinese parents who have chronic or terminal illnesses.

The literature suggests that experiences of ethnically Chinese caregivers in the North American context are not dissimilar from those experiences of Caucasian caregivers. However, cultural and social pressures, along with migration and settlement issues, may add a layer of complexity to the experiences of ethnically Chinese caregivers that requires greater attention. It is not clear what, if any, role perceptions of Chinese culture have in defining and shaping the experiences of adult caregivers. Furthermore, it is not well understood when, why and how caregivers prioritize cultural issues when weaving the narrative of their experiences.
1.3 Overview of Thesis

This is a manuscript-based thesis formatted based on the Guidelines for the Format of Theses from the Graduate Department of Pharmaceutical Sciences. This first chapter provides a general introduction to the topic and the purpose of the study.

In the second chapter of this thesis, a detailed description of the methodology for the research is presented. This includes a discussion of the qualitative research design and phenomenological approach of the study, and an outline of the specific study objectives. Chapter 2 also includes a description of the procedures for sampling and recruitment of participants, and a description of the analysis of the qualitative data.

In Chapters 3, 4 and 5, the results are presented. Since this thesis uses the manuscript-based format, the results chapters are written as manuscripts and each includes an individual abstract, introduction, methods, results and discussion/conclusion section. Chapter 3 is a descriptive paper based on the lived experiences of being a caregiver to a chronically ill Chinese parent. The key finding from this chapter is that the experiences of caregivers who are Chinese are not necessarily different from those who are not Chinese. However, the caregivers in this study frame their caregiving experiences and struggles as largely being a result of being Chinese. This paper explores how and when caregivers evoke cultural issues when weaving the narrative of their experiences.

A reconsideration of the current conceptualization of the doctor-patient relationship, when a caregiver is involved in care processes and decision-making, was another important aspect of the research findings. The Power-Resonance Framework is introduced in Chapter 4 of the results. With this framework I aimed to question the current conceptualization of the patient/healthcare practitioner/caregiver relationship. The framework presented is based on the various interaction configurations (collaborative, contested or conflicted) that the healthcare professional-patient and caregivers took on, as described by participants in this study. The key finding from this chapter is that expanding the healthcare provider-patient relationship to include a caregiver is not a simple additive process.
Chapter 5 is composed of a manuscript that explores the issue of cultural competency. Our results are organized into 6 vignettes, which illustrate how “Chinese culture” is not a commonly understood or experienced phenomenon, but that the individual ways in which “culture” is interpreted by patients and healthcare providers do have the potential to impact care. The paper explores how cultural explanations are used to justify healthcare-related requests and decisions. The vignettes presented highlight that not all “Chinese patients” have the same “cultural” needs or sensitivities and underscore the need for good communication with patients and their family members to facilitate healthcare providers’ understanding of patients’ needs and values regardless of their ethnic background.

Finally, Chapter 6, provides a full discussion of key findings from the papers presented in chapters 3, 4 and 5. In this chapter, the findings are explored in relation to results from previous studies, as are the strengths and limitations of this study, and future research questions are identified as well. Chapter 6 closes with concluding remarks relating back to the original purpose and objectives of the study, and the research question: how do adult children of elderly immigrant Chinese parents experience the management of their parents’ illnesses?


Chapter 2
Methods

This section provides an overview of the research methodology and methods that were employed in order to conduct the research. The chapter begins with the research question, specific objectives and a description of the overall research design. This is followed by an explanation of the methodological approach including a justification for the choice of phenomenology as a guiding perspective. The chapter also includes a detailed description of how the study participants were selected, the recruitment process, data collection and analysis. Issues of researcher positionality and identity, as well as reflexivity, quality and rigor are also discussed. Finally, ethical issues are outlined in the last section of this chapter. An overview of the research methodology and methods is presented in Figure 1.

2.1 Research Question

The research question guiding this study was: how do adult children of elderly immigrant Chinese parents experience the management of their parents’ illnesses? The experiences of informal family members who provide care to chronically ill parents or relatives have been studied extensively (e.g., Penner, 2008; Cavazzi et al., 2010, Schumacher, 2010; Pereira & Bothelo, 2011). However, much of the caregiving literature continues to be based on the quality of life impact of caregiving especially with respect to caregiver burden. What remains largely unclear is how the role of a caregiver develops and how one experiences “becoming a caregiver”.

2.2 Objectives

The specific study objectives were to:

- **understand** the experiences of adult children in assisting their elderly Chinese immigrant parents’ management of chronic health condition(s);
- **explore** how the presence of a caregiver could affect the doctor-patient relationship;
- **explore** how and when cultural explanations are used by caregivers to support healthcare-related requests and decisions.
### Figure 1: Overview of Research Methodology and Methods

<table>
<thead>
<tr>
<th>Paradigmatic Stance:</th>
<th>Constructivism</th>
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<tbody>
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<td><strong>Research Question:</strong></td>
<td>How do adult children of elderly immigrant Chinese parents experience the management of their parents’ illnesses?</td>
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<tr>
<td><strong>Study Objectives:</strong></td>
<td>understand the experiences of adult children in assisting their elderly Chinese immigrant parents’ management of chronic health condition(s); explore how the presence of a caregiver could affect the doctor-patient relationship; to explore how and why cultural explanations are used by caregivers to justify healthcare-related requests and decisions.</td>
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<tr>
<td><strong>Why Phenomenology?</strong></td>
<td>to describe and make conscious the lived experiences of a life event or phenomenon illuminate the meaning of the phenomenon from the perspectives of those who have experienced the phenomenon</td>
</tr>
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<td><strong>Recruitment Strategies:</strong></td>
<td>Partnership with two agencies serving the needs of the Chinese community in Toronto: contact persons facilitated recruitment Word of mouth, Informational posters and advertisements in local newsgroups and Chinese community newspapers</td>
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<td><strong>Data Collection:</strong></td>
<td>In-depth Interviews: broad open-ended questions to allow participants to describe experiences to guide interview but not to structure within a rigid framework Field notes and reflexive diary of interactions and observations follow-up interviews with some participants for a period of 2-12 months; Interpreter assisted for 3 participants</td>
</tr>
<tr>
<td><strong>Data Analysis: Inductive Content Analysis</strong></td>
<td>transcribed verbatim data analysis concurrent with data collection: describe, compare, relate data organized around emergent themes Multiple reader coding for initial interviews generation of coding scheme and codebook Data management: N*Vivo 7 Software</td>
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<table>
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<tr>
<th><strong>Conductivist Perspective:</strong></th>
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<tr>
<td><strong>Ontology:</strong> No fixed objective reality; multiple realities possible</td>
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<td><strong>Epistemology:</strong> Multiple constructions and interpretations of the same phenomenon</td>
</tr>
<tr>
<td><strong>Axiology:</strong> True representation of participant experiences; separation and suspension of previous experience and knowledge from study of phenomenon</td>
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<td>adult children who self identified as ‘Chinese’;</td>
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<td>self-reported as having a parent who had a chronic or terminal illness</td>
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<td>participated in management of healthcare processes or chronic illness;</td>
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<td>mentally and cognitively competent;</td>
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<td>willing to complete in-depth interviews and follow-ups</td>
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<tr>
<td>Three research participants were given the opportunity to comment on and discuss interpretations</td>
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<tr>
<td>Goal: to ensure congruency of understanding and meaning between participant accounts and interpretations</td>
</tr>
<tr>
<td>not looking to generate new data</td>
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</tbody>
</table>
2.3 Research Methodology

A qualitative research design was selected for this study. As a research methodology, Tedlock (2000) suggests that qualitative methods place understandings and experiences into a “fuller more meaningful context”, and can produce “personally situated accounts, descriptions, interpretations, and representations of human lives” (Tedlock in ed. Denzin & Lincoln, 2000; p.455). Using a qualitative approach helped us understand how adult children who are helping their elderly immigrant parents manage chronic illnesses, express and reconcile their interests within the context of the family. For this research, initially approaching the research question from a broad qualitative approach provided multiple lenses with which to explore the phenomenon, and ultimately led to phenomenology as the method of choice. This approach helped me focus on the ‘lived experiences’ of research participants.

2.3.1 Paradigm: Ontological and Epistemological Considerations

In choosing a research methodology, researchers need to ensure congruency between their paradigmatic stance and the objectives of the study and the research question they wish to address. This is important in order to understand how worldview or beliefs may guide researcher actions, and has the potential to influence research outcomes. For example, ontology, relates to the philosophical question of “what is the nature of reality?” The constructivist ontological position taken for this study refutes the notion of a fixed objective reality. It was assumed that the reality related to managing chronic illness in families would not be a fixed, single, or measurable phenomenon. Rather that there would be multiple realities, that these realities would be shifting and emergent, and a product of the subjective experience of the individual children and parents interacting with their environments. This led to the understanding that if the design of this study was to, as DiCicco-Bloom and Crabtree (2006) suggest, strike a balance between depth of understanding and minimizing structure, semi-structured interviews with individuals would be suitable. Recognizing that “reality” for any given individual may be dynamic, it was important to design a study with initial interviews as well as follow-up interviews to explore how experiences of the phenomenon changed and evolved over time.
One’s epistemological stance is based on the answer to the philosophical question of “what can we know?” The constructivist perspective taken for the proposed research led to the assumption that within our sample of adult Chinese children who identified themselves as caregivers, multiple constructions and interpretations of the same phenomenon (i.e., when to consult a doctor or decisions about when to use medications) were possible. From this perspective, it was understood that giving research participants the opportunity to present their perceptions of their lived experiences as part of face-to-face interviews would be useful.

Other methods for data collection, such as focus groups, have been used as part of phenomenological research (Groenewald, 2004) and were considered for this research. However, due to the potentially sensitive nature of the information that participants could share, individual interviews were thought to be more suitable for this study. An important consideration was that the participant had to feel comfortable in order to speak about the issues associated with caring for an elderly parent honestly and in great depth, and participants may not have felt comfortable or confident in a focus group setting. Furthermore, I was trying to understand the point of view of the individual participants in their own words, and not necessarily as a result of their interactions with others which would have occurred in a focus group setting.

With regard to the collection and analysis of data, it was also important to consider the question of “what are my fundamental values?”, and to ensure that my own values were not impeding my ability to understand the experiences of the participants in my study. The challenge was to ensure that the voices of the respondents were represented as accurately as possible through the interview, and this meant that the prior knowledge, experience and views that I had gained through my own experiences had to be separated from the study of the phenomena at hand in order for me to remain as open as possible to understanding the experiences of my participants. The qualitative research methodology which provided the best fit with my ontological and epistemological positions as well as my primary research question was phenomenology.
2.4 Methods: Phenomenology

I employed a phenomenological approach, where the aim was to explore the experiences of caregivers, specifically adult children of elderly Chinese immigrants, who were involved in helping to manage their parents’ chronic illnesses. The purpose of phenomenology as Speziale and Carpenter (2007) suggest, is to describe and make conscious the lived experience of a particular experience, life event or phenomenon. The aim of phenomenological research then is to illuminate the meaning of the phenomenon from the perspectives of those who have experienced the phenomenon. The specific phenomenon this study aimed to understand and describe was the experience of being a caregiver who was caring for a parent(s) who immigrated from China to Canada and was now managing a chronic illness.

Research findings generated from phenomenological studies are dependent on the phenomenological approach that is used. There are two main frameworks used with the application of phenomenology within the health sciences: Edmund Husserl’s approach or Martin Heidegger’s approach (Heidigger, 1988). Although both approaches allow researchers to better understand the meanings individuals attach to lived experiences, descriptive or Husserlian phenomenological approaches (Zahavi, 2003a) are considered more appropriate for exploring phenomena about which little is known. As there is a paucity in the literature about the range of experiences of caregivers to Chinese elderly in a Canadian context, a Husserlian approach (Zahavi, 2003a) was employed with the aim of uncovering the essential meanings of these experiences from our research participant’s first-person accounts.

With the Husserlian approach (Zahavi, 2003a), it is thought to be important for the researcher to ‘bracket’ out previous knowledge and personal experiences related to the phenomena of study. The task at hand in carrying out the phenomenology is to be able describe the phenomena from the perspective of participants, rather than assuming a given reality for the phenomena (Giorgi, 2007). In order to suspend the influence of previous knowledge or experience, Munhall (1994) suggests that researchers need to assume a stance of “unknowing” in order for the various possibilities of the lived experiences of participants to be emergent, and for the researcher to focus on what the experience of the phenomena under study is like for each research participant (Thibodeau, 1993). In order to effectively bracket out previous knowledge (i.e., from completing the literature review and theoretical framework for this study) and personal experiences, a
reflexive diary was kept. Furthermore, two other steps were taken (discussed later in this section with respect to positionality and reflexivity) to consistently bracket out researcher subjectivity: 1) co-coding of initial interview transcripts with graduate supervisor to help ensure credibility and trustworthiness of the interpreted data; and 2) ongoing dialogue with regard to the links between data and analysis and the trustworthiness of the interpretations with my supervisor and committee members.

The methods, including the use of in-depth interviews and field notes were consistent with phenomenological studies that aimed to describe the lived experiences of individuals with respect to a particular phenomenon (Penner & McClement, 2008). Broad open-ended questions were used to allow participants the opportunity to describe their experiences in a manner that was guided by interview questions, but did not structure individual experiences within a preconceived or rigid framework.

2.4.1 Sample and Recruitment

The primary sample for this study was a convenience sample of 23 adult Chinese children. This was a similar sample size to those described in studies previously outlined in the literature review in the section on ‘The Experiences of Caregivers” (e.g., Owens, 2004; Mcilfatrick, 2005; Lindhart et al., 2006; Turner, 2007). Inclusion criteria for these participants were: adult children who self identified as ‘Chinese’; self-reported as having a parent who had been diagnosed with diabetes, hypertension, heart disease, arthritis, or other chronic or terminal illnesses; at least age 19 and older; mentally and cognitively competent, who described themselves as providing any sort of assistance to their parents’ medical processes or participated in any way in the management of their parents’ chronic illnesses, and healthcare decision-making; willing to complete in-depth interviews, be involved in follow-up consultations for this study, and participate in follow-up discussions. Adult children who identified themselves as healthcare professionals were excluded from this study as their health knowledge, abilities and attitudes concerning the care of their parents may have been based on their socialization as healthcare professionals and we wished to focus on the lay caregiver perspective.
A set sample size was not pre-determined prior to entering the field. Precedence in qualitative research, and samples from previous phenomenological studies of caregiver experiences, suggested that a sample size between N=8 and N=25 would be sufficient for in-depth findings and data saturation (Morse & Field, 1995; Creswell & Oaks, 1998; Endacott, 2005; Pickler, 2007). Data saturation has been defined by Glaser and Strauss (1967, p.61) as the point at which “no additional data are being found whereby the [researcher] can develop properties of the category.” Data saturation was reached at a sample size of 23 participants. This sample size was large enough that a range of experiences and perceptions were uncovered, no new themes were emerging, and recruitment stopped once data important to the analysis framework started to become repetitive (information redundancy), and as Glaser and Strauss (1967) state, data collected was no longer providing new insights.

Recruitment for this study occurred through word of mouth, informational posters placed in the community and information and contacts for this study were also advertised in local newsgroups and Chinese newspapers. This study was conducted in partnership with two community agencies serving the needs of Chinese communities and caregivers in the Greater Toronto Area, and recruitment was also facilitated by contact persons at the Yee Hong Centre for Geriatric Care and the CareFirst Seniors Association.

2.4.2 Recruitment Process

The recruitment process was initiated once a potential recruit responded to one of the ads, or was referred to this study by a contact person or by word of mouth. The recruitment process (see Appendix A: Study Participant Recruitment Records) involved three key steps.

1. The collection of basic information from the potential recruit and checking eligibility.

This initial step included the collection of general information such as the potential participant’s name, phone number, gender and age. General information with regard to the study was read to the potential participant and eligibility was checked. The eligibility check ensured that the potential participant met the age requirements; that they identified themselves as Chinese, and also whether the individual had a parent who was over 65 years of age, that this parent has been diagnosed with a chronic condition, and whether the adult child provided any sort of assistance
to the parent. The responses to the eligibility checklist helped determine whether an individual was eligible to participate or not, and to identity potential participants.

2. More in-depth study information provided to the potential recruit.

For those who were eligible, I provided a short introduction of who I was, and a verbatim reading of a short description of the measures that would be taken to ensure privacy and confidentiality (see Appendix A: Study Participant Recruitment Records). After this, I assessed whether the individual was still interested in learning more or interested in finding out if they were eligible. I also took the time to answer any initial questions that the individual may have had before moving forward.

3. Meeting information and confidentiality.

Once potential participants were identified, and eligibility had been confirmed (see Appendix A, Study Participant Recruitment Records), participants were given detailed information about the study and an initial meeting was arranged. At this meeting, participants were provided with an information sheet and consent form (see Appendix B: Information Sheet and Consent Form for Participants), and any questions or concerns were again clarified. Information sheets were reviewed with each participant, and it was requested of participants to make a commitment to address follow-up questions (during follow-up interviews) and to allow for field notes to be taken of those events or experiences that the adult child felt were important for managing the chronic illness of their parent over an extended period of time.

2.4.3 Data Collection

Data were derived primarily from in-depth in person interviews and follow-up consultations with a subset of participants. See Figure 2 for a summary.

2.4.4 In-Depth Interviews

In conducting semi-structured in-depth interviews I aimed to understand and capture: 1) the distinct and unique characteristics of each participant’s experiences; and 2) what was common to
individuals who had shared the same experiences, events or life circumstances. Prior to the commencement of the interview, I re-confirmed inclusion criteria and eligibility, reviewed the purpose of the study, and then proceeded to obtain consent from the participant. Of the 23 participants in this study, 3 individuals required a Cantonese/Mandarin interpreter. Although the participants seemed to be English fluent over the phone, once we met for the interview, it became clear to me that the participant would have a hard time engaging in conversation with me as they had difficulty understanding the consent form, my initial questions, and/or had a hard time answering questions. These interviews were rescheduled and were conducted with the assistance of a language interpreter.

In depth-interviews lasted approximately 60-140 minutes and were supplemented with extensive field notes and observations. An interview guide was used to facilitate discussion (please see Appendix C: Interview Guide), but participants were informed that the dialogue would seem more like a conversation and not an interview. Participants were also not discouraged from ‘going off track’ during interviews and informal discussions. The in-depth interviews allowed me to explore and elaborate on emergent themes with interviewees and to elicit information and feedback. No standardized probes or prompts were used, and prompt questions, when used, were used to gain a deeper understanding on a topic that participants discussed, and for purposes of elaboration and clarification. In-depth interviews were augmented with field notes taken about each encounter with participants. Interviews were conducted in the community setting, at partner sites, at the home of participants, or at the University of Toronto’s Leslie Dan Faculty of Pharmacy. All interviews were audio-recorded and transcribed verbatim. In situations where participants asked to have recording discontinued, extensive notes were taken with the permission of the participant.

2.4.5 Post Interview Follow-up

To document the changes over time that individuals and families experienced in managing chronic illness, I maintained contact with 12 of the participants in this study, and followed-up with these participants for a period of 2 to 12 months after an initial in-depth interview. Follow-up interviews were conducted in person, via email conversations or over the telephone, and
focused on issues raised by participants on which I needed clarification or elaboration, or on developments or decision-points in the parents’ care. Participants were encouraged to contact me to discuss emerging issues as they were identified during the follow-up period.

In following-up with participants, I attempted to contact each participant by telephone two weeks after his/her initial interview to review some of the key points/ issues that s/he had raised during their initial interview. Some participants declined to speak to me at this point, and asked to discontinue participation. Participants who wanted to remain engaged with the research study were given the option to contact me via telephone or email to discuss any new issues that arose with regard to the management of their family members’ chronic illnesses. Maintaining contact with a few of the participants for at least four follow-ups allowed me an opportunity to document the role and influences of the adult children over time as they helped manage their parents’ chronic illnesses and negotiated the informal and formal healthcare system. Questions from the follow-up interview guide were used to facilitate discussion (please see Appendix D: Follow-up Questions), as were important points derived from the analysis of transcript data from the first interviews.

Sample attrition meant that long term involvement was only possible with some of the participants. However, very in-depth information about the needs, experiences and concerns was collected from those participants that remained involved with this study long-term which justified doing this wherever possible. Interviews with participants who did remain involved with this study were often months apart in terms of timelines, and there were no set times (i.e., every week) that participants agreed to meet. As a result, multiple interviews and longer term involvement with participants allowed for data to be collected around changes in disease trajectory, clinical encounters, family discussions or other issues that participants felt were important in terms of the management of their parent’s chronic illness. The benefit to this flexible timeline was that sufficient time was available to analyze data, and that it was possible to remain responsive to the changes that were occurring (or not occurring) for participants.
Table 1: Data Collection Summary

<table>
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<tr>
<th>Participant</th>
<th>Age</th>
<th>Recruitment</th>
<th>Interaction 1</th>
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<th>Interaction 3</th>
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*Translator assisted; 'F' = female; 'M' = male; 'OTHER' = other, not recruited through partner agency; 'Yee Hong' = Yee Hong Centre, 'CareFirst' = CareFirst Seniors Association; 'IDI' = in-depth interview; 'TFUI' = telephone follow-up interview; 'EC' = email correspondence; 'MC' = participated in member-checking.
2.4.6 Member Checking

Having engaged in multiple interview interactions with a number of participants in this study, I had the opportunity to collect very rich and descriptive data. In order to ensure credibility and trustworthiness of the data, Lincoln and Guba (1985) suggest that qualitative researchers cross-check their work through the use of member checks. A member check or member-checking is a process through which research participants are able to comment on interpretations of data that the researcher has undertaken (Doyle, 2007). This process is meant to ensure that there is congruency between the accounts that participants had presented, how well these accounts were captured by the researcher, and whether the interpretation and analysis of those accounts by the researcher remained true to the experiences of the participants. It is not uncommon for researchers to request that participants review portions of transcripts, narratives or emerging theories to ensure that researchers remain on the right track (Merriam & Francisco, 1998; Curtin & Fossey, 2007).

As Creswell (2009) has suggested, member checking is best suited for the end of a study when data analysis has moved from general ideas to a more sophisticated level of emergent themes and patterns that participants can be asked to verify or elaborate on. For the purposes of this study, once data had been analyzed and the themes scrutinized by my thesis committee, three participants were purposively recruited for a one-time face-to-face member-checking interview. Participants were informed prior to our session that the goals would be to revisit their own personal narratives, and to review some of the major themes from project overall. The three participants were also informed that they would be requested to comment on the plausibility of emerging themes and the framework for understanding the triadic relationship between patients, providers and caregivers that had emerged from the data.

Participants were informed that I was not looking to generate new data, and were presented with three question sets that were meant to gain deeper insights into the narrative (Appendix E: Member-Check Questions). The first set of questions were related to a common recurring theme that had emerged from the data about the intersection of culture and experience; secondly, about the involvement of adult children in various positions of influence as part of a doctor-patient-caregiver triad (Power-Resonance Framework see Chapter 4 for more detail); and finally about a
common perception amongst participants that healthcare professionals needed to take Chinese culture into consideration when treating patients.

In a study by Koening et al., (2003), the researchers had chosen a theory that they wanted to discuss with research participants as part of their member check, and I followed this example in order to use participant insights to enhance or adjust the Power-Resonance Framework. As the informants who were participating in the member-checking had not necessarily articulated their own individual experiences in the way I had conceptualized the Power-resonance Framework, I was interested to know if it would still be relevant to their own experiences. The Power-Resonance Framework was meant to depict, capture and describe the general triadic relationships that could exist, as told by the narratives of all of the participants.

It is important to acknowledge that it has been argued by some (e.g., Sandelowski, 2002; Smythe et al., 2008) that member checking is not suitable for phenomenological research. The basis of the argument is that by conducting a member check the researcher assumes that there are fixed realities that members can "validate", that the experience of reality by various individuals can be neatly grouped and categorized, and that member checking is not consistent with the idea that an individual’s state of being within a certain context, time and place cannot be replicated. As individuals change, potentially through engagement in the research process with the researcher, so might their narratives and their views on that which is being checked. However, member checking has been part of numerous phenomenological studies (Doyle, 2007), and was deemed suitable for this study as member checking occurred beyond the stage where individual meaning was formulated, and themes and data could be addressed holistically. Member checking allowed for extended interaction with a number of participants, a deeper understanding on the part of the researcher, and an opportunity for participants to offer feedback on the collective narrative of participants.

2.4.7 Data Analysis

The data for this study consisted of in-depth interviews which were audio recorded and transcribed verbatim by a transcriber; as well as transcripts of email conversations, field notes and informal interview notes. Data analysis was concurrent with data collection. Text derived
from all data sources was subject to inductive content analysis (Berg & Heights, 1995; Morse & Field, 1995; Creswell & Oaks, 1998). This process of qualitative content analysis has been defined as: “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (Hsieh & Shannon, 2005, p.1278).

Interview transcripts, field notes, and data from other forms of correspondence were coded and analyzed using Bazeley’s (2009) data analysis method of “describe-compare-relate”. The initial focus for data analysis was addressing the question: “what are participants talking about?” This process involved an ‘immersion’ into the data through multiple readings of the transcripts and of field notes immediately after interviews were conducted, and as soon as interview transcripts were received (usually within a week after interviews were conducted). This led to the identification of themes, or important elements from the text data (Bazeley, 2009), by focusing first on words and phrases that participants in this study were using (Ryan & Bernard, 2003), and then focusing on the theme of the larger context related to the use of the word or phrase (Ryan and Bernard, 2003).

Transcript data and data from field notes were then organized around the major themes that emerged during the interviews: understanding of health, health related experiences, role in care practices, experiences related to parent’s use of medicines. Coding categories were derived directly and inductively from the raw data. This process also helped create a coding framework. This immersion and organization of data was undertaken as part of an ongoing process which helped generate a complete list of themes and issues reflecting experiences of adult Chinese children regarding the management of the health of their elderly immigrant parents. These themes and issues were then used to inform a general analysis of all text data (Endacott, 2005).

Field notes were also analyzed for emergent themes, and not only allowed for reflection on the experiences of participants and the research process, but also allowed me to focus my attention on issues needing further investigation in subsequent interviews (Burgess 1991). Interview transcripts of the first five interviews were reviewed by my supervisor and at least one other member of the research team, and patterns and themes were discussed collaboratively.
Once all data had been collected, subsequent readings of the text resulted in a more detailed coding scheme, including broad issues or themes, and application of codes and sub-codes related to the broader themes. Theoretical triangulation, which is the use of multiple theories and sensitizing concepts to address a research question, was also used to interpret data related to the theories outlined as part of the theoretical framework, and to increase confidence in the themes and codes that had been generated (Denzin, 1970). This allowed for different lenses from which to interpret the documented phenomenon (Thurmond, 2001), and as a means to compare and cross-check the themes that had been generated from the data with existing theoretical constructs and ideas.

Through the course of multiple meetings, team members coded data independently and then compared results for credibility as well as further discussed the themes and coding overall prior to proceeding. All qualitative text derived from in-depth interviews, fieldwork, personal memos and informal conversations was managed using N*Vivo 7 software (Richards & Richards, 2002).

2.5 Researcher 'Identity' and Positionality

Integral to the success of the research process in qualitative studies is the relationship between the researcher and the participant. Positionality, generally described as an individual’s position in relation to the study (Hopkins et al., 2007), may have implications for the way the study is carried out, and the way the results are interpreted. As a qualitative researcher, engaging in an inquiry process with my research subjects, I had to be conscious not only of my own positionality but also the positionality of my research participants.

As the process of inquiry was context dependent, I had to be aware that how I asked the questions, the location where I would be asking the questions, when I asked the questions, and with whom I was engaging with would affect the data I would collect, and also how I analyzed and interpreted my data. The participants in this study and I co-constructed the world as the participants had originally experienced it. Initially there were two very explicit considerations: first, I am a male researcher from a non-Chinese ethnic background, carrying out a study looking specifically at the experiences of adult Chinese children. Second, I am a graduate student from the University of Toronto, and I have been a caregiver for a sick (now elderly) father for the last
16 years. In this sense, I had a point of reference with the participants, as I also identify myself as a caregiver, and am heavily involved in the care practices of my chronically ill father, and at the same time, I had a point of divergence with participants as I was not Chinese.

My status as a PhD candidate at the University of Toronto, and the fact that I was not a healthcare professional was clearly stated in informed consent documents. My only role was that of a researcher. During the initial phases of recruitment for this research, after introducing myself and the study over the phone or in person, I became very conscious of the fact that the question of “why are you studying the experiences of Chinese adult children?” was important to those considering participation in the study. This served as a reminder that although some things were clear to participants as a result of my physical characteristics, for instance, that I was an ‘outsider’ to the Chinese community, that I needed to decide how, what and when my own personal experiences as a caregiver would be made evident to research participants.

The issue of being seen as an ‘outsider’ often affected my ability to gain access to research participants. Yet, my own ‘insider’ experiences as a caregiver offered me the opportunity to provide a rationale for the study that participants could relate to, and to present my research agenda around the need to present a detailed view of the experiences of Chinese caregivers. As part of the interview, I often used my own experiences to relate to the narratives of the participants, to build rapport and to gain credibility. I used my own experiences as a means to encourage interviewees to elaborate or clarify issues we had been discussing.

All of this presented a challenge for me to “bracket” my personal experiences and expectations as the literature indicates are important for phenomenological studies. Once I revealed to participants that I identified myself as a caregiver I had to be very cautious as to continue to separate my personal experiences from the interview and to present myself as naïve. My goal was to understand the experiences of the individuals in my study, and that if they saw me as an “insider” they may assume I already knew what they were talking about and provide superficial descriptions, rather than the richer, deeper accounts that I was looking to attain. One participant, while describing her frustrations in trying to manage multiple demands, stated “oh you know what I am talking about, you understand, you’re a caregiver too!” In response to that situation, I had to maintain that I was naïve to her experience, and encourage her to continue to give me more detail. This example highlights how I had to be conscious of my position; what and when I
revealed with regard to my personal life to participants; and how this may impact data collection. Although I maintained a conversational atmosphere in my semi-structured interviews, I also had to keep in mind that even when I thought I understood something a participant was saying to me because of my personal experiences, that I had to probe deeper to have the participant give me a fuller account to ensure I truly understood his/her experience, rather than assuming it was the same as my own.

What to include and what to exclude, with respect to the analysis of data, as Schiellerup (2007) suggests, may also reflect my positionality and therefore what ‘strikes’ me as important is based on my role not only as a researcher but also my viewpoint as a caregiver. From a constructivist/phenomenological perspective the goal of my analysis was to place emphasis on the individual meanings, perspectives and experiences of being a caregiver as presented by research participants. In order to bracket my own experiences out of the analysis, I initially organized my data around repetition in themes, the questions I had asked from my interview guide, as well as around the theoretical framework that I had developed. As such, I distanced myself from the analysis of the data on a personal level, and focused on the data.

2.5.1 Reflexivity

Awareness of one’s positionality, and reflecting on our practice of research is what May (2001) refers to as reflecting on ourselves. The idea that researchers have the ability to affect the research process, and that the research process has the ability to affect the researcher, is not new (Gilgun, 2010). Remaining aware of the fact that there are multiple factors that can shape and influence the researcher, the research subject and the research process as part of the individuals and events we are exposed to is the basis of reflexivity in qualitative research. This need for awareness, flexibility to adapt to the changing needs of the research project and self-critique are important considerations in order to acknowledge subjectivity, objectivity and biases in our research (Chun-Hsiung, 2008).
By taking a constructivist approach for this research, I was aware that the nature of the research process was ‘transactional’ and ‘subjective’ (Guba & Lincoln, 1994). From this perspective, there is no notion of ‘objectivity in truth’ that could stand the test of time and place, rather that an individual’s construction of the ‘truth’ is neither about being more or less true, but about a reality that the research subject is presenting as local and specific. As Guba and Lincoln (1994) explain, this means that the researcher and research participant are “interactionally linked” so that knowledge and findings are created as part of the research process. I maintained a reflexive diary throughout the research process as a strategy to continuously assess my assumptions, to document those factors which I felt shaped the research process (for instance, emotional responses leading me to turning off the recording of the interview) and as a means to ensure quality and rigor.

As I was recruiting through two agencies serving the needs of older adults and their families in Toronto’s Chinese community, I was often introduced to research participants at the centers. As part of the process of remaining reflexive, some of the other things I considered about my positionality were: 1) when people first met me in person, how did they react to me?; 2) how did I present myself to research participants?; and 3) did the individuals I recruited myself say or present things differently than those who were recruited through the agencies? My assumptions around these questions were that research participants recruited through the agencies might interact with me as someone who was an extension of the agency.

Much of the content of my reflexive diary, prior to entering the field, is about how to ensure that research participants don’t feel the potential social, economic or educational differences that might exist. I also considered how my gender, talk of religion, or dependency might reproduce relations of disempowerment within the context of the interview. I considered whether I should sit next to the person, or across from them while interviewing, or whether I should allow the participant to choose the seating arrangement. In interviews, I let participants choose, and in most interviews I sat next to the participants. Finally, in preparing for interviews, I had thought about how I would handle the emotional experiences of participants with regard to ethical options, for instance, the ability of the participant to ask to have the tape recording stopped and to take a break if necessary. What I realized after my first interview was that I had not thought about what to do if I felt the research participant was having an emotional breakdown, or if the disclosure of sensitive and tragic information meant that I could not continue with the interview.
because I could not handle what the person was telling me.

Many of these issues were raised in the first interview of the project. It was in the middle of a public library, one of a number of locations that this particular participant and I met over the course of our interactions. Although I had suggested I would meet the participant at her home, she wanted to meet at the library. The participant whom I was interviewing was female, and could not stop crying as she talked about her experiences. She requested that I continue recording and documenting what she was telling me. I immediately became aware of the public location of the interview, and the need to balance the needs of the research participant (to address her emotional distress) as well as the needs of the research (i.e. to continue to collect data. Other participants who became emotionally distraught during the interviews requested that I stop tape-recording. However, these participants would want to continue to engage with me in conversation and would want to continue to respond to questions. I had to maintain detailed notes as to not lose data, while constantly ensuring that the participant was ‘okay’ to continue talking or if they needed to take a break or discontinue the interview.

I also became aware of the fact that I could really relate to the emotional response of the participants, and how this ability to relate stirred an emotional response in me. After several interviews, my graduate supervisor suggested that we review emotionally difficult interviews together immediately after I completed them. I did not “tip-toe” around issues that exacted an emotional response, but after each instance, I became more aware of those topics that would cause this response. On a number of occasions it was very helpful not only to write in my reflexive diary, but to discuss the issues related to the interview with my supervisor.

Reflexivity as part of this research study was about awareness, remaining conscious of the often competing goals of the collecting data and understanding the needs of research participants, and about adapting. As Gilgun (2010) suggests, reflexivity enhances the quality of research work. It allowed me to adapt to and balance the needs of the participants in an ethical and moral manner, and also taught me how to remain accountable to my own personal and research needs while conducting difficult interviews.
2.5.2 Quality and Rigor

The issue of quality in qualitative health and health services research has received considerable attention. To ensure rigor and quality for this research proposal, the following characteristics were embedded within a systematic, self-conscious research design: member-checking at the end of data analysis, an awareness of reflexivity and positionality, multiple coders during data analysis, clear audit trail documenting data collection and analysis, member checking and the importance of triangulation. These have all been discussed earlier in this chapter with the exception of triangulation which will be addressed here.

This study was designed on the basis of multiple triangulations, not as an ideal test of validity, but to ensure a more thorough understanding of the phenomenon (Marshall & Rossman, 1999). Data triangulation was achieved by using data from multiple individuals and time points, allowing for the comparison of the results from varying data sources has allow for patterns of convergence or divergence to develop and to corroborate interpretations (Marshall & Rossman 1999). The use of multiple theories (Sick role (Parsons, 1951), Collaborative Model (Bodenheimer et al., 2002), Family Systems (Bowen, 1974)) and sensitizing concepts (derived from Bourdieu’s (1990) notion of social fields and habitus (Endacott, 2005); and Foucault’s (1980) conceptualization of power/knowledge) proved fitting for theoretical triangulation (Thurmond, 2001). The use of qualitative data derived from in-depth interviews, follow-up discussions and field notes has allowed for methodological triangulation between the various strategies, facilitating a more comprehensive analysis of the data (Marshall & Rossman, 1999).

2.6 Ethical Issues

This study received ethics approval from the University of Toronto’s Office of Research Ethics, protocol reference #24298 and the Yee Hong Centre for Geriatric Care.

2.6.1 Informed Consent

Full informed consent procedures were followed. On a voluntary basis, individuals interested in the study were able to contact the researcher using the contact information provided. Participants were informed of the nature of the study, of risks and benefits and their eligibility to
participate. As part of the initial contact, participants were told that their involvement in the study was voluntary, and that their identity and the nature of their involvement in the study would be held in strict confidence. They were assured that anonymity would be maintained in research reports and that the content of all interviews would be held in strict confidence. These individuals were also given a signed copy of the consent document. Recruitment documents had been translated and were available in English as well as Cantonese and Mandarin (Appendix F: Translated Recruitment Documents and Consent Forms). Translation of the research documents to Cantonese and Mandarin was performed by an individual who is familiar with and fluent in both languages. These translated documents were available to ensure that research participants fully understood the consent and confidentiality process.

Prior to the interview, it was clarified that I was not a healthcare professional, and that a participant’s decision to participate or his/her choice to decline to participate in the research study would in no way affect his/her access to healthcare, or the healthcare services s/he received or was entitled to receive. In the interview portion, with the permission of participants, interviews were tape recorded, and participants were informed that they could request to have recording be stopped at any time, and that they could end their interviews, take a break from the interview, or indeed, withdraw from the study at any time. The consent form for participants is included (see Appendix F).

Furthermore, it was made clear in the information sheet/consent forms that an individuals’ decision to participate or not to participate in the study would not affect services that they were currently receiving at the agencies they may have been recruited from, or that they may receive in the future.

All participants were informed that the researcher had a legal obligation to report incidental information revealed by a participant to a researcher with regard to physical, psychological or social harm or abuse. Confidentiality was maintained to the limits of law. The information and consent forms (see Appendix B; Appendix F) included a statement which addressed this issue and clearly stated that a disclosure of confidential information as required by law, would not be considered to be a breach of any confidentiality agreement.
2.6.2 Risks and Benefits

Risks and benefits to participants in the study were discussed with prospective participants upon initial contact with study investigators, and were clearly outlined on the consent form. There were no direct benefits to participation in the study. As suggested, there was minimal risk to participants associated with participation in this study. Participants did occasionally experience heightened emotions and discomfort in discussing events related to the management of their parent’s health, but at the same time they stated that they truly valued the opportunity to discuss their experiences with others (Gibbs, 1997). Participants were free to decline to have their interviews tape recorded, to decline to discuss issues that they found uncomfortable, to request that components of their interviews not be tape recorded; or to stop participating in the study at any time.

Risks posed by this study were those that were associated with participants’ emotions becoming overwhelming when recalling various experiences; or the discomfort related to disclosing personal information about their experiences and being the subject of observation. However, participants being interviewed were able to control any possible discomfort, for example, by declining to answer specific questions, asking that audio-recording be stopped during an interview, or ending an interview at any time. Any risks associated with the observation during this research were mitigated by the right of the participants to ask the researcher to leave, to take a break or to discontinue participation in the study if they felt uncomfortable, or to refuse a request to the observations in the first place.

2.6.3 Privacy, Confidentiality and Participant Withdrawal

A master list of names of all participants in the study was stored in a separate location, but also in locked storage at the University of Toronto’s Leslie Dan Faculty of Pharmacy. While providing information with regard to the study and obtaining consent from participants, it was made clear to participants that they were under no obligation to participate or continue to participate in the study and that refusal or withdrawal would have no negative consequences. The information/consent form (see Appendix B, Appendix F) included a statement which explained that participation in this study was completely voluntary and that participants were free to
withdraw or discontinue their participation in the study at any time, or to take a break from or end the interview at any time, and to decide not to participate in this study.

Participants were informed that if they decided to withdraw from the study, I would use the data collected to that point, and would obtain their consent to do so. It was clearly stated in the information sheet/consent form (see Appendix B) that no further information would be collected after a study participant had withdrawn from the study, and that the information collected from the participant before they withdrew would be retained.

2.6.4 Compensation

A onetime honorarium of $20.00 was paid to each adult child participant at the end of the study. As a small honorarium was being offered to compensate participants for their time and for their contributions, participants were informed that if they started participating in the research but then withdraw, that they would still receive their compensation. The information/consent forms (please see Appendix B: Information Sheet and Consent Form) clearly stated: “I understand that if I choose to withdraw my participation before the end of the completion of the study, I will still be offered an honorarium of $20 as compensation from my time”. This statement also confirmed that the participant's consent was voluntary and not induced by a belief that the compensation was available only if they completed the research activity.

2.7 Conclusion

Using qualitative methods to explore the perspectives of diverse groups of caregivers with regards to their experiences is important for understanding their needs and may help improve collaboration with healthcare practitioners. Using a phenomenological approach to address my research question and guide the study methods, I aimed to develop an in-depth understanding of the complexity of the experiences of adult children who act as caregivers for their elderly Chinese parents in Canada. The following three chapters outline the findings from this study.
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Chapter 3
Results

This chapter has been prepared for submission to Qualitative Health Research. It will be submitted following the dissertation defence to allow an opportunity to incorporate any final comments from the dissertation examiners.

I, Raza M. Mirza, performed the entire work, that is, the conceptualisation of the study, the protocol design, the overall study management, the collection, analysis, and interpretation of the data, and the writing of the manuscript, under the guidance of Dr. H. Boon, Dr. Z. Austin, Dr. P.C. Hsiung and Dr. P. Ballantyne.

Using Impression Management to Understand Adult Chinese-Canadian Children’s Use of "Culture" to Explain their Experiences of Caring for Their Elderly Chronically-Ill Parents

Raza M. Mirza, MSc, Heather S. Boon, PhD, and Zubin Austin, PhD

Abstract
The purpose of this paper is to explore how and when culture is evoked by adult Chinese-Canadians when describing their experiences of helping their elderly parent(s) manage a chronic illness. In-depth interviews conducted in the phenomenological tradition with 23 participants were conducted, and follow-up interviews with 12 participants were ongoing for 2–12 months. The experiences related to the care of elderly parents described by our participants were complex and varied, and often times did not match what participants perceived to be expected of them. Culture was invoked to justify behavior and care-related decisions. Drawing on Goffman's theory of impression management, we speculate that participants in our study used cultural explanations to accentuate aspects of their caregiving experiences, to gain approval from those unfamiliar with their Chinese identity; and that the 'good' impression individuals tried to relay to others was often an ideal toward which the individual themselves aspired.

Acknowledgments: We thank our study participants and translators who made this research possible, as well as logistical support from our study partners at the Yee Hong Centre for Geriatric Care and CareFirst Seniors Association, Toronto, Ontario, Canada. Lori Hirschkorn provided research assistance. This study was unfunded.
3.1 Introduction

An increasing portion of care provision for the elderly within Canada is shifting to the home setting. Although the provision of home based healthcare for the elderly is a growing trend in Canada (Guerriere et al., 2007; Lilly et al., 2010), the expectation that care for elderly parents will be provided by adult children has historically been reported to be an aspect of the Chinese community (Sher, 1984; Ikels 1993; Zhan et al., 2006), which is currently the largest visible minority ethnic group (Statistics Canada, 1997; Statistics Canada, 2003) in Canada. In this article, we explore the experiences of caregivers who participate in the care for a chronically-ill or terminally-ill, elderly Chinese immigrant parent in the Canadian context.

A common thread in the caregiving literature is that there are both positive and negative dimensions attributed to the experience of being a caregiver. Studies have consistently found that the experiences of caregivers, regardless of cultural background, are replete with reports of overwhelming physical demands (Ho et al., 2009; Salter et al., 2010; Neri et al., 2011), emotional burden (Beesley et al., 2011; McCorkle & Given 2012) and the need for financial support (Kusano et al., 2011; Lilly et al., 2012). However, caregivers also often report positive outcomes related to their experiences. For example, providing care for a dying parent so that the parent may die at home with dignity has been described as giving the caregiver a sense of greater meaning in life (Koop & Strang, 2003), and providing an opportunity to achieve greater kinship with the parent (Jarrett, 1985). Although some previous research on caregivers who are Chinese report that their experiences are consistent with those caregivers who are not Chinese (Chappell & Kusch, 2007; Lai et al., 2007), inquiry into how and why Chinese culture is used to frame experiences (as we found in our data) is largely lacking. The literature remains sparse on how the experiences of Chinese caregivers are influenced by the intersection of illness and culture outside of China. To contribute, we are interested in understanding how the interpretation of, and identification with, Chinese culture may shape the experiences of caregivers of aging chronically ill immigrant parents in Canada.
3.2 Background
The management of chronic illness in the Canadian context increasingly involves patients and their families collaborating with healthcare professionals, who may or may not share the same cultural background. Broadly defined, culture refers to "the sum total of knowledge, attitudes and habitual behavior patterns shared and transmitted by the members of a particular society" (Linton, 1940, p. 37). Research into the health practices of immigrant Chinese individuals suggests that attitudes and beliefs about the provision of health and healthcare are often strongly tied to cultural values (Chen, 1994; Jung, 1998). These cultural values are reported to vary as a result of socialization in Eastern or Western culture (Chen, 1994; Jung, 1998). Adult children of Chinese descent are commonly thought to be a source of caregiving because they come from a country where familism and the expectation of care for the elderly by adult children are embedded in tradition (Chappell, 2003). It is also well established in the healthcare decision making literature that families are often relied upon to provide health-related care across a myriad of cultures (Candib, 2002; Kwak & Haley, 2005; McAdam, J. et al., 2005).

Previous research suggests that the provision of care for the elderly is based on the culturally normative belief that adult children have moral ‘responsibility’ for the care of their parents (Holroyd, 2003; Zhan & Montgomery, 2003; Leung & McDonald, 2007). However, providing care for older parents may be stressful and demanding for adult children (Aronson, 1994). It is also important to highlight that adult children who take on care responsibilities may perceive and interpret their ‘responsibilities’ and experiences within the context of their own individual socialization and experiences, cultural or otherwise. Again, it is not clear what, if any, role “Chinese culture” has in defining and shaping the experiences of adult children who act as caregivers for their parents in Canada. Furthermore, it is not well understood when and how caregivers prioritize cultural issues when weaving the narrative of their experiences. One way to explore these issues is to draw upon theories of self-concept and presentation of self.

3.2.1 Self-Concept and Impression Management
Fulfilling the caregiving role may not be an easy task, especially since many caregivers for older adults are thrust into the role under stressful circumstances where a parent has fallen ill. Although there are no instructions on how one is to provide care for an elderly parent, there still may be perceived parental or cultural expectations for care. Previous research suggests that that
much emphasis is placed on the provision of care to elderly parents by adult children within Chinese culture (Chappell & Kusch, 2007). It has also been suggested that these kind of expectations may influence an individual's self-concept, (Markus & Herzog, 1991) which is defined as "the accumulation of knowledge about the self, such as beliefs regarding personality traits, physical characteristics, abilities, values, goals, and roles" (Markus & Herzog, 1991, p. 110).

Cultural background is one of the many elements of self-identity that individuals may use to help frame their experiences, and justify their behaviors to others (Markus & Wurf, 1987). The presentation of self is thought to be an active process, performed for the purpose of potentially influencing another's opinion or for shaping the course of an interaction (Markus & Wurf, 1987). For example, individuals may strive to present themselves as 'good caregivers' or 'good children' based on what they perceive as Chinese cultural norms and expectations.

The presentation of self is described as dynamic and can be affected by the perceived and/or the stated opinions and judgments of important others; and may result in an individual making social comparisons that lead to the perception that one is similar and/or different from others (Markus & Wurf, 1987). It has been argued that a challenge to self-concept, caused for instance by differences in opinions related to whether or not an elderly parent should receive care in a nursing home, may lead to consciousness of differences from others even though individuals may not be conscious of their concept of self or identity with regard to their normal daily life or routines (Markus & Wurf, 1987).

The idea that individuals present themselves in a conscious, contextually oriented and dynamic manner first arose from Erving Goffman's (1959) interactionist approach to understanding impression management. The notion of impression management is concerned with the way that individuals present themselves, their behaviors and beliefs in order to influence the impressions that important others may have of them (Goffman, 1959, p. 203). For example, Yue and Ng (1999) found that providing care for aging parents was considered socially desirable. In this sense, social motives not only underpin behavior, but as Liu et al., (1999) suggest, allow one to maintain a positive sense of self and portray a positive impression to others who may pass judgment on adherence to cultural values.
Goffman's (1959) theory on the presentation of self suggests that when an individual is in the presence of others, his/her behaviour may be consciously performative. In this sense, the objective of the performative behavior is to use some element of one's identity to control and influence the conduct of others. Furthermore, Goffman (1959) argues that control is achieved largely by "influencing the definition of the situation which the others come to formulate, and he can influence this definition by expressing himself in such a way as to give them the kind of impression that will lead them to act voluntarily in accordance with his own plan" (Goffman, 1959, p. 327). This conscious performative aspect of self-concept may be important for understanding the health management experiences of caregivers who use "cultural guidelines" to explain their behavior to others.

The focus for this paper is on understanding how prioritizing culture as an important element of one's identity may function to benefit other's perceptions of the admirable qualities of the caregiver and the caregiver's agenda. This paper questions our previously accepted explanations regarding how culture influences adult Chinese children’s perceptions of expectations and their actual experiences and roles as caregivers for their elderly parents. We use our results to shift the focus to understanding the lived experiences of these individuals and explore how they evoke Chinese “culture” to explain their feelings and behavior as caregivers.

### 3.3 Methods

We employed a phenomenological approach, where the aim was to explore the experiences of adult Chinese children who were involved in helping to manage a parent’s chronic illness in Canada. Recruitment for this study occurred through various approaches: word of mouth, informational posters placed in the community, and advertising at centers that serve the Chinese community in the greater Toronto area. We recruited a convenience sample of 23 participants who self-identified as Chinese, were over the age of 19, and regularly (at least on a weekly basis) participated in the care processes of their elderly immigrant parents. Adult children who were healthcare professionals were excluded from participating in the study as their health knowledge, abilities and attitudes concerning the care of their parents may be significantly influenced by their socialization as healthcare professionals.
Data were derived primarily from in-depth in person interviews lasting approximately 60-140 minutes and supplemented with extensive field notes. The interview guide included a series of open-ended questions designed to probe the experiences of our participants related to assisting their elderly immigrant parents manage their chronic illnesses. To explore the changes that individuals and families went through in managing chronic illnesses over time, we conducted follow-up interviews with a sub-set of 12 participants intermittently for a period up to a year after an initial in-depth interview. The purpose of these follow-up interviews was to explore our adult child participants’ real-time experiences related to the trials and tribulations of managing their parents’ care. Follow-up interviews were conducted in person, via email conversations and over the telephone. These interviews ranged in length from a few minutes to more than an hour and tended to be triggered by developments or decision-points in their parents’ care. Participants were encouraged to contact the study team to discuss emerging issues as they were identified during the follow-up period.

All interviews and the majority of telephone conversations were audio recorded and transcribed verbatim. Detailed field notes related to all interactions with participants were maintained, including reflections from spontaneous telephone calls from the participants that could not be audio-taped. Transcripts of email conversations were retained for analysis.

3.3.1 Data Analysis

Text derived from interview transcripts was subject to inductive content analysis (Berg, 1995; Morse & Field, 1995; Creswell, 1998), with the focus initially on addressing the question: “how does this person perceive and present his/her experiences.” This process involved an ‘immersion’ in the data through multiple readings of the transcripts and field notes. This immersion and organization of data was undertaken as part of an ongoing process which helped generate a complete list of themes and issues reflecting experiences of adult Chinese children regarding the management of the health of their elderly immigrant parents (Endacott, 2005). Interview transcripts of the first five interviews were reviewed by three team members (RM, HB, and PB) and patterns and themes were discussed collaboratively. All qualitative text derived from in-
depth interviews, fieldwork, personal memos and informal conversations was managed using N*Vivo 7 software (Richards & Richards, 2002).

3.4 Findings

We first provide demographic information to describe our participants, and then we present the participants’ descriptions of, and feelings about, providing care for their parent(s) who are ill.

The 20 female and 3 male participants in this study ranged in age from 25 to 70 years of age. (See table 1). All of the participants were living in the community, with 21 of 23 living in the same home as their parent(s). Only 3 participants were born in Canada, and the other 20 migrated to Canada after spending their earlier years in China and/ or Hong Kong. Translation through a Mandarin interpreter was required for three of the participants; the rest spoke fluent English.

Table 1: Key Demographic Information of Sample

<table>
<thead>
<tr>
<th>Study Participants, N=23</th>
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<tbody>
<tr>
<td><strong>Participant Caregiver Age Range (years)</strong></td>
</tr>
<tr>
<td>Care Recipient Age Range (years)</td>
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<tr>
<td>Gender of Caregiver Participants</td>
</tr>
<tr>
<td>Marital Status of Caregiver Participants</td>
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<tr>
<td>Place of Birth of Caregiver Participant</td>
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<tr>
<td>Living Arrangements of caregiver participants and parent(s)</td>
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<tr>
<td>Chronic Illness of Parent</td>
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Two key themes related to the roles and experiences of managing care for a chronically ill parent will be explored in this paper: (1) perceptions that there was a “culturally-based” norm that children were expected to provide care for their parents; and (2) descriptions of how their “cultural expectations” differed from their experiences of providing care. In the first section of the findings, we document and describe participants’ perceptions of the expectation that they will provide care for their sick parents, and how participants explicitly portray this expectation as being derived from Chinese culture.

3.4.1 Expectations of Care

Participants described perceiving a strong expectation, which they defined as culturally-based, to care for their parents. Although they portrayed a strong internal motivation to provide care for a sick parent (“I saw this as my responsibility in the first place.”), they also described how it was simply “understood” that this is what one is to do when a parent or family member is ill. This behavior was explicitly described as being governed by social norms related to the care of family members in Chinese culture. One daughter stated:

*I think, um, the Chinese are more traditional...Okay, they, they always take care of their family members by themselves...*

These norms were not simply unspoken understandings. According to our participants they were explicitly discussed by parents with children throughout the life course. Participants did not perceive that there was much choice with regard to the expectations of caregiving. Many of the participants labeled the expectation that adult children would care for elderly parents as a “Chinese cultural expectation” that they had internalized. One participant described his perceptions of the expectations as follows:
For me, it’s just something that’s just been ingrained. You’ve been told from the very start, from the beginning: “I’ve taken care of you all of my life, now I’m going to get old. I hope somebody takes care of me...” So it’s just been ingrained and I guess being the eldest of four kids there’s that sort of added responsibility that I kind of grew up with. It’s like, okay, you’re the oldest, you look after your siblings. By the way, when you get older we hope that the oldest child will also look after their parents and it’s just a natural thing. Like, you’ve done it all your life for your siblings so when you get to be an adult, you transfer that over to your parents, because now they need some caring...I think it’s sort of being both Chinese and the oldest child.

Many participants in this study described the common features of what they called “Chinese” expectations of care. One of these features was that the oldest child would be the one to provide care for aging parents. Participants stated that the oldest child would be expected to make decisions in family matters, that the preference would be for parents to live with the oldest child, and that the oldest child would provide support to elderly parents. One participant explained:

...It’s just a common thing, I guess. I think by nature of being the oldest that I’ve been taught to take care of those that aren’t as healthy, as strong and are less fortunate. The parents expect that they have taken care of the kids all this time so now, as they get older, they expect their kids to take care of them... I think it’s a cultural thing...with Chinese families I find that the parents like keeping their kids at home....There’s this sort of understanding that once the kids are grown and raised that as the parents get older, the children in turn will now take care of the parents.

Many of the participants prefaced their responses about caregiving with the phrase “according to Chinese culture”, before explaining how expectations of care were structured. Participants stated that expectations of care were often structured and prioritized by hierarchies based on who was the oldest, and whether the caregiver was a son or daughter. As explained by two of our female participants:

I [a daughter] was the sole caregiver, but, my mom, like I told you, usually Chinese culture they are sexists, they like sons, ...My mom’s number one child is her son, ...I have an older brother and I have two younger brothers, so, she would want her sons to go to see her, and she’d say, why are you here? Where are your brothers? And I thought, what am I? A chopped liver! But, I understand. I understand where it comes from...And that hurt me sometimes, you know...Then I understand where it comes from and then I don’t really let it get to me. But it did, it was difficult.
In our Chinese custom or culture, the way we are brought up, you are supposed to love your parent. You’re supposed to, I don’t like to use the word, ‘we pay’, but I couldn’t find any English word. Like we have, not have to but we, it’s in us to look after your parents if they older, right. You know, it’s in us to make sure, to look after their welfare and that kind of thing. Usually it should fall on the sons’ responsibility. My experience [caring for my mother] was unfortunate. My mom didn’t like it because if I go there [to take care of her], she’s like, if you come then your brother won’t come.

Even if the oldest child was a daughter, many participants described a “culturally-based” expectation that the son in the family would provide care for aging and ill parents. Participants also identified an expectation that older parents would remain at home, with the adult child caregiver (preferably a son), and that 'outside' help would be frowned upon.

Giving care...it has to do with our culture....It’s pretty much the pattern...We grew up in China, so we saw... that the elders always lived at home...being looked after by family members...So that seems quite natural to us. For my generation at least....Things, I think, are changing now...But before that there was no nursing homes.

In reflecting on their perceptions about expectations around care for their parents, participants also stated that expectations were changing or would have to change as a result of the next generation of their family being socialized in Canada:

This is our eastern culture...We have to take care of our kids...As well as our parents... so probably we are the last generation thinking like that...Our next generation is educated here [in Canada]...They’ve got a different experience.

Participants expressed the belief that both they and their parents would be “happiest” if care was provided at home. There was also acknowledgment that doing anything contrary to what they described as cultural expectations could result in being ostracized within the Chinese community. One daughter explains:
If I did not take care of my parents, they would not be happy...and I would have to answer to questions like “why can’t you take care of your parents?” Your parents devoted all their life to you. I mean, if I were to put my parents in a nursing home I wouldn’t be happy. I would be like, “why can’t I care for my parents?” I think in a Caucasian society it would be like, “that’s normal. That’s fine.” But I think in an Asian community it would be like, “why can’t you take care of your parents?”

Finally, participants explained that they often felt a need to explain or justify their care-taking behavior to those who were not Chinese:

*Interviewer:* Okay, so it is an issue of being Chinese in a different culture that sometimes, it needs an explanation?

*F:* Yah I think the culture... it's something like a value. It's been carried on years and years. *The [Chinese] people, we, we have different, different values.*

These findings illustrate how participants framed and articulated what they perceived of as expectations that they would care for their parents in illness as being primarily culturally-derived and uniquely Chinese, and how they often felt the need to explain this to those who are not Chinese, for instance the interviewer. In our sample, these “Chinese cultural expectations” were described as a system of care that was structured around who was the oldest adult child, by gender, and based on an expectation that care should be provided at home without the help of others outside of the family.

3.4.2 Experiences of Care

In this section of the results, we document and describe how the “cultural” expectations outlined in the first section did not necessarily match the experiences of our participants. The key subthemes include: 1) experiences compared to expectations; and 2) using culture to explain care-related decisions.

Even though the expectation of many of the participants was that adhering to the cultural traditions would lead to a greater sense of satisfaction and happiness, taking on caregiving responsibilities left some participants dealing with uncertain emotions, isolation and anger:
...I’m becoming more and more insulated from the outside because my priorities...my sense of concentration is their care, what they need and then even though I don’t have to work a nine to five job, it was like a twenty-four hour job for me, and in terms of mental load it never stops, even, even at night when I’m sleeping I kept thinking, I was always in the high alert...”are thy okay? What have I missed today? What’s to do tomorrow or the day after and blah, blah, blah, blah.” ... I realized I almost have no social life...My social life just stopped...Isolated, ... then I noticed I have this tremendous anger towards the situation, or maybe towards them...

the experience is so stressful. The worst part was, at the beginning of the care, he would have a very bad temper, he doesn’t trust people, he doesn’t trust me...and at those time we have arguments all the time. Because sometimes his temper is so, um, excitable...He’ll be claiming you like, like an enemy, not a person that is good, so that’s really frustrating...And sometimes he will be emotional...So, it was so stressful ...I was mad at him and sometimes we have big fight and I will say all to myself, I will leave him alone, that’s it! I’m not going to do it again.

Participants in our study framed their experiences as resulting from cultural norms that were forced upon them:

I can certainly feel that there is pressure, there is invisible kind of force to force you to, to be certain things...I was fighting it...especially in Chinese culture you don’t feel empowered. You don’t have the power to fight it, but you, you question it

What was consistent across the accounts of all caregivers, was that for the most part, participants did not describe their caregiving experiences as positive.

Although there were male caregivers in our study (N=3), our sample was overwhelmingly female (N=20), and while our participants all agreed that the “Chinese cultural” norm was that the caregiving responsibility rested with the oldest son, this was not often the case in the experiences of our participants. The caregiving experiences of our participants appeared to depend greatly on contextual factors.

Within our sample, adult children who were unmarried, who had greater financial stability, and with whom parents had better interpersonal relations provided care. One unmarried daughter, who was the younger of the two siblings, and lived close to her parents, eventually moved in with them to provide care. This is how she explained taking on the caregiver role:
In our culture, usually the responsibility falls on the shoulder of older children. Since my older brother is number one, he should be looking after them [her parents] but because he had his family so I took over.

The idea that adult children were expected to take care of their parents without the assistance of 'outsiders' was often provided as another example of how reality did not match “cultural expectations”. Our study participants relied heavily on support from healthcare professionals, community social service agencies, and also on extended social support networks which included friends, other family members and complementary healthcare providers (e.g., traditional Chinese medicine practitioners or acupuncturists).

Participants described the need to be heavily involved in the care for their parent(s), but also to share decision-making responsibilities with others not part of the family. One participant explained that she was not only her father's primary caregiver, but also the family's representative. She was conscious of the fact that within the Western healthcare system, patient autonomy and confidentiality are priorities, and that within the Eastern healthcare system it was understood that patients (and their families) would be involved in the care of the older patient, and that collective decision-making was the norm. Within Canada, and the Canadian healthcare system, this participant perceived that the need for "involvement" on the part of the older patient's family may not be well understood or even accepted, and she felt she had to advocate for her family's right to understand the situation and have a collective say about treatment and care with the doctor. She explained these differences in terms of being "Chinese". She stated:

The doctor, the resident doctor, may be thinking of the confidential issue, like personal information,...For Chinese it’s a family matter...It’s a sharing, you know when the children get involved then they understand the situation better...They can communicate with the parent, with the patient and also with the doctor if they have any concerns...We take it as if it’s our own problem...Not just my parent’s problem. Or medical issue, it’s just we take it internally so that we know how to better care for them.

A daughter (who was a senior taking care of a senior) explained that there were many issues related to the care of her mother that were beyond her own abilities and that she was being encouraged by her healthcare providers to send her mother to institutionalized care not only by
her healthcare providers, but also by her family members. However, she explained that she would feel guilty that she was letting down her mother and not fulfilling what she described as her “culturally-defined” duty. This participant explained that she understood that her mother might be better cared for at the senior’s home, but that she could not come to terms with this decision.

Then all of a sudden she got a minor stroke and then we find out that she really have to depend on us...And because my mom doesn’t know any English here and not much friends here because she’s not working here before...Right, so she’s leading a kind of isolation life...And then I suggested, Mom, would you like to go to the old age home, so you can get some friends during the day time and then we take you back, after that, like the day care, right?...And then my mom started crying...She said, you guys want to desert me...Yah, you don’t want me anymore because I’m getting old...we never dare mention it again...

In our sample of participants, the adult children were reluctant to completely ‘hand off’ care or decision-making responsibilities to others outside of the family, or to institutionalize their parents. Participants often referred to culture and cultural expectations to explain these decisions. One daughter, although describing her experiences as overwhelming, explained that it was important for her to take care of her father and to maintain the Chinese tradition of providing care at home. To do otherwise would be shameful:

...because this is the culture that’s been carried on...it is shameful if we don’t look after our parents unless we just cannot do so. You know, people will be thinking, “why, it’s just not right.” Like, I got an aunt who is 93 years old, well recently entered a long term care facility...[my family member] felt couldn’t handle it, because she said, you know, she thought she was being kind of independent...but it’s not a natural thing for us to send the parents to a long term care. It’s only if we have no other choice

It was not uncommon for participants to describe their experiences as being driven by shame, fear or guilt. For one participant, the emotions he described feeling were linked to 'cultural judgments' -- this participant felt he was being judged by other family members as a result of not adhering to what he believed were cultural norms. What was ironic for this participant, was these same individuals who were casting cultural judgments on him, were perceived by him to not follow the cultural norms themselves. He felt that cultural norms were evoked to suit individual needs. He stated:
Participants described that the management of a parent’s chronic illness was emotionally challenging, and that it rarely provide them with a sense of satisfaction or happiness. Their experiences often diverged from what they described as the culturally-based expectations. Yet despite acknowledging this divergence in some areas (e.g., daughters providing care instead of sons), culture was often invoked to explain other care-related decisions such as caring for parents at home rather than seeking institutionalized care.

3.5 Discussion

Our findings suggest that many caregivers perceived their experiences of caring for their elderly parents to be influenced by cultural expectations. Caregivers described having internalized a sense of ‘responsibility’ for the care of their parents and our findings provide insight into how they strove to make sense of their caregiver roles/identities by using explanations drawn from Chinese culture. Here we discuss how participants may have positioned the personal narratives of their experiences as only being understandable in relation to Chinese identity and culture.

The Chinese caregivers in our study were instrumental in assisting their parent(s) with activities of daily living, managing and monitoring their parents' health at home, in interacting with healthcare professionals. These roles are similar to the caregiving roles described in a number of other studies of individuals who are from a range of ethnic groups and cultures. (Grant et al., 2004; Kazanowski, 2005; Guo et al., 2010; Dickerson et al., 2012). The caregiving experience, as explained by the participants in this study, does not appear to be unique to Chinese caregivers (Robley et al., 2010; Lulz et al., 2011; Turan et al., 2011). This leads one to ask why culture was so prominent in the perceptions and narrative recollections of participants?

Reference to Chinese culture or tradition was manifest throughout participants’ explanations of their perceived roles and responsibilities. Although the experiences of Chinese caregivers were not necessarily different from non-Chinese caregivers, what was different was that Chinese identity was used to frame the beliefs, practices and experiences of this sample of caregivers.
We speculate that the participants in our study repeatedly referred to their “Chineseness” as either a means to make sense of their experiences as caregivers to themselves, to healthcare providers or to the researchers. As has been reported in previous research on impression management, participants may have evoked cultural explanations and presented their Chinese identity as central to their caregiving experiences in surroundings where they perceived that a lack of understanding would threaten the image they were trying to portray of themselves, or felt the decisions they had made were being questioned. For instance, if a participant was trying to present his/herself as a "good Chinese child" by taking care of his/her parent at home, but was also describing feelings of being overwhelmed by caregiving responsibilities, the decision to not place a parent in a long-term care facility might be called into question. Maybe better care could be provided at a long-term care facility? When this situation arose during interviews, the participants commonly resorted to some variation of “it’s a Chinese thing, so I don’t really expect you to understand” which appeared to be a way to end a line of questioning from the non-Chinese interviewer.

Both newly immigrated older Chinese adults and Chinese-Canadians may be exposed to a world of Canadian healthcare practices and values that are very different from those which they may be used to. These differences may put patients and their caregivers in positions where they feel compelled to justify or rationalize their decisions which may be regarded as “unusual” or “different” from Canadian norms. Referring to Chinese cultural norms may be one way to attempt to explain their requests and decisions. For example, the role of the Chinese family in health-related decision making is well documented (Muller & Desmond, 1992; Pang et al., 2002), as is the reluctance to move older family members to nursing homes (Aroian et al., 2005; Mahoney et al., 2005). These themes were repeated numerous times by participants in the current study as well. Our findings indicate that, when a situation of conflict or difference of opinion with healthcare providers and our participant caregivers arose, participants described it as a dichotomy (i.e., the Western way vs. the Chinese way).

By framing disagreements not as individual differences, but rather as cultural differences, participants may have felt they were able to better explain their points of view; both in their own eyes, and in the minds of those with whom they were disagreeing. When healthcare practitioners, and other individuals in positions of influence are when faced with the argument
that things must be done a certain way because “that is the way we, the Chinese, do it” they may be less likely to argue or attempt to influence or interfere in decisions or resultant behavior.

The tenets of Goffman’s (1959) theory of impression management suggest that: (1) individuals will accentuate certain facts and attempt to conceal others; (2) individuals will try to ensure smooth interactions and attempt to gain favorable approval from those unfamiliar with their identity; and (3) that the impression individuals try to relay to others is often an ideal toward which the individual aspires. This theory provides a useful lens for trying to understand why certain facts related to Chinese culture were emphasized in our interviews. For instance, participants in our sample accentuated the emphasis on culture being the driver behind their decisions to care for their parents at home and played down the apparent mismatch between cultural norms and their experiences (e.g., daughters caring for parents instead of sons). In doing so, participants may have been trying to make a favorable impression of themselves as "good" sons and daughters in order to gain approval of the interviewer for their behavior. At the same time, this kind of justification may have been reaffirming to themselves that they had fulfilled their obligations of being a "good Chinese child".

Despite framing their actions as part of their “Chineseness”, our findings indicate that there was surprisingly little agreement regarding what the “Chinese” way of doing things was. Many caregivers talked about how their experiences in fact differed from what they perceived as the norm or ideal in Chinese culture. For example, despite being repeatedly told that in Chinese culture sons were supposed to take on the primary responsibility for the care of elderly parents, in our study much of the caregiving was in fact provided by daughters. Furthermore, marital status and other structural factors, such as proximity to care recipients’ residences seemed more important determinants with respect to who provided care than either birth order or gender, as our participants repeatedly told us Chinese tradition would predict.

In our cases, health related decision-making and care were often equally shared between sons and daughters, but for the most part female caregivers were responsible for caring and communicating with healthcare professionals and in health related decision-making. The few male participants in this study, with the exception of one, may have been involved in aspects of decision-making, but were much less involved with providing direct care. Thus, our findings
challenged the wide-spread and often-cited gendered nature of care in Chinese families, similar to the findings of Leung and MacDonald (2007), and Briggs (1998).

Another important aspect of chronic illness management for the elderly parent was the impact the illness had on the family and also on the caregiver. Our results pointed to important similarities with findings from previous studies indicating that the experience of chronic illness management is sometimes complicated by patient and family reluctance to complain, respect for others, and the desire to be a good son/daughter or caregiver (Lin et al., 2000; Chang et al., 2011). Reference to strong intergenerational ties between generations also suggests that ‘filial piety’ or moral obligation may underpin the care relationships experienced by adult children and their parents.

Research on the concept of ‘filial piety’ or ‘Xiao’, has found that many Chinese caregivers perceive and internalize the expectation that they are to take responsibility for their elderly parents (Zhan & Montgomery, 2003; Chang et al., 2011). As with previous studies, findings from our study indicated that participants who perceived that they were not doing enough for their parents, or living up to cultural or parental ideals, also stated that they experienced great anxiety, shame and guilt. Many of our interviewees also exhibited high levels of psychological distress and emotion when discussing their experiences.

We agree with the argument provided by Chang et al., (2010) that caregivers sometimes struggle in caring for their parent(s), and in confronting the challenges related to the management of chronic illness; yet continue to do so because they feel they want to fulfill the cultural need to solely and directly be responsible for their care. However, adhering to traditional cultural expectations was also a source of personal and familial conflict for our study participants. A number of participants suggested that their experiences and socialization in Canada had changed their perspectives on aging, independence, and also on issues related to end-of-life decisions and nursing home placement. This difference in perspective sometimes led to conflicts within families and amongst siblings, as perceived by caregivers, as care decisions for elderly parents were not always aligned with their perspectives.

A number of limitations of this study need to be acknowledged. The sample size (N=23) was appropriate to achieve a thick descriptive phenomenological analysis. However, the small sample size and non-random nature of the sample does not allow generalizations to be made about the
caring for chronically ill Chinese elders perceive, interpret and present their caregiving experiences, and thus to our limited understanding of how Chinese caregivers negotiate the management of chronic illness for their elderly parents. This study enhances our understanding of how culture may shape and inform perceived expectations about caregiving, as well as how caregivers evoke cultural references to frame and present their experiences.

The theory of impression management is helpful for our understanding of how Chinese caregivers may include culture as part of their self presentation. Of all the various personal and social dimensions of their identity that individuals can prioritize when presenting their experiences, that participants placed emphasis on their cultural identity is important. In this study, participants often used cultural explanations to stop or mitigate questions from the interviewer, to explain their behavior, in what could be interpreted to be attempts to lessen the impact of negative impressions, judgment and interference from others. Continued exploration of how and why people turn to cultural explanations for healthcare decisions, and how healthcare providers respond to this, is an area worthy of further study.

3.6 Conclusion

This study has contributed to our understanding of how caregivers for chronically ill Chinese elders perceive, interpret and present their caregiving experiences, and thus to our limited understanding of how Chinese caregivers negotiate the management of chronic illness for their elderly parents. This study enhances our understanding of how culture may shape and inform perceived expectations about caregiving, as well as how caregivers evoke cultural references to frame and present their experiences.
References


Chapter 4
Results

This chapter has been prepared for submission to Social Science and Medicine. It will be submitted following the dissertation defence to allow an opportunity to incorporate any final comments from the dissertation examiners.

I, Raza M. Mirza, performed the entire work, that is, the conceptualisation of the study, the protocol design, the overall study management, the collection, analysis, and interpretation of the data, and the writing of the manuscript, under the guidance of Dr. H. Boon, Dr. Z. Austin, Dr. P.C. Hsiung and Dr. P. Ballantyne.

(Re)Framing the Patient, Caregiver and Healthcare Professional Relationship: The Power-Resonance Framework

Raza M. Mirza, MSc, Heather S. Boon, PhD, and Zubin Austin PhD

Abstract
The presence of a family member within the clinical context is seen as commonplace, especially with regard to the care of chronically ill older patients. Often caregivers are adult children who are taking care of their elderly parents and need to interact with healthcare professionals around a health or illness related event. Few studies have explored the interactions between patients, their caregivers and healthcare professionals. Using Bourdieu’s ideas related to the social field and habitus, and Foucault’s conceptualization of power/knowledge, we analyzed interview data from adult caregivers to gain a better understanding of their perceptions of participating in chronic illness management as part of a triad that included their chronically ill parents and a doctor. We found that the doctor-patient-caregiver relationship was not a relationship where the patient and caregiver were necessarily aligned, as previously conceptualized in the literature. Rather, a complex and dynamic relationship which hinged on power relations between different actors in various care settings was revealed. The ability of one individual to influence the actions of another individual appeared to impact how care was managed. We identified specific factors which can shift and influence power dynamics within the healthcare professional-patient-caregiver triad. To capture the complexity of the interactions and relationships within our sample, we have developed the Power-Resonance Framework, which is aimed at helping us better understand how shifts in power can affect the course of action taken with regard to chronic illness management. We propose that training and support for patients, caregivers and healthcare professionals are needed to increase awareness of the complex dynamics involved when children take on caregiver roles for their chronically ill parents.

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4.1 Introduction

The patient-healthcare professional interaction has traditionally been studied in isolation from the social context of the patient’s life world, and continues to be conceptualized based on assumptions about the authority (and “technical expertise”) of the healthcare professional, as well as the passivity and deference of the patient (Parsons, 1951; Dahlberg et al., 2009). In contrast, new models of chronic illness management increasingly recognize the collaborative nature of care between the healthcare professional, the patient and often family members, with an assumption of greater responsibility for care within the family context and increased autonomy with respect to medical decision making for the patient (Bodenheimer et al., 2002). We argue that the current trend towards family-centered care is based on the following unquestioned assumptions: 1) family caregivers are allies that healthcare professionals and patients can be dependent on (Ikiagu & Ciaravino, 2007); 2) patient dependence on family caregivers improves the quality of care for chronically ill patients (Haas, 2006); and 3) patients and family caregivers share the same healthcare beliefs, values and orientations towards medicines and healthcare practices (Schumm et al., 2010).

4.1.1 The Role of Caregivers

Family caregivers are defined by the American College of Physicians (2009) as “including relatives, partners, friends and neighbors, who assist with activities of daily living and complex healthcare needs that were once the domain of trained hospital personnel” (American College of Physicians, 2009; page 1). The important roles that caregivers play have been previously noted to include administering and managing medications at home (Travis et al., 1999); learning and understanding complex care processes to assist the chronically ill person at home (Moorman & McDonald, 2012); as well as monitoring and presenting the patients symptoms, diagnoses and side effects to healthcare professionals (Gaugler, 2003). Studies find that up to 60% of older patients require a caregiver to accompany them to see their healthcare professionals (Rosland et al., 2011), and that increasing numbers of co-morbidities are positively correlated with the involvement of caregivers in primary care. As Glasser (2001) suggests, caregivers are part of a continuum of care and are seen as able to provide a bridge from the clinical setting to the ‘life world’ of the patient in various informal and formal care environments.
Collaboration between patients, caregivers and healthcare professionals has been shown to improve primary care outcomes, and much attention has been paid to the active involvement of caregivers in dementia, cancer and end of life care (Ory et al., 2000; Rhee et al., 2008; Northouse et al., 2011). Postoperative and post-chemotherapy outcomes have also been shown to improve when caregivers have been involved in the care processes from the onset of the illness (Haley, 2003). When physicians, patients and caregivers collaborate to address issues of diabetes and heart failure, patients have reported feeling more comfortable discussing “difficult topics” they may have avoided if alone with the doctor, and have suggested that the supportive environment created by the involvement of a caregiver allowed them to better “absorb” primary caregiver advice (Rosland et al., 2011). Increasingly collaborative healthcare models direct doctors to “create integrated and coherent plans for ongoing medical care in partnership with patients and their caregivers” (American College of Physicians, 2009; page 1).

The various roles caregivers play have been described previously in the literature as strengthening the alliance between doctor and patient; but, the healthcare professional-patient-caregiver relationship has also been described as one which is still “uneasy” (Glasser et al., 2001). Caregiver participation in the clinical encounter and in chronic care management has been reported as associated with positive physician experiences (Rosland et al., 2011), but has also been associated with reports of greater burden on the physician to include and educate the caregiver (Rosland et al., 2011); the physician feeling that the autonomy of the patient is being compromised (Rosland et al., 2011); and physician concerns over patient confidentiality being breached (Rosland et al., 2011). In contrast, patients almost always view the involvement of a caregiver in their care as positive (Dubenske, 2010). Within the clinical encounter, the role of the caregiver has been classified by Adelman, Greene and Charon (1987) as multidimensional, and which can be characterized as “advocate”, “participant”, and “antagonist”. Caregivers have also described their experiences as “having to be on guard” with healthcare professionals in order to protect the interests of the care recipient (Green & King, 2009).

The collaborative relationship between various actors involved in chronic illness management is built on the idea that care for the chronically ill patient requires the sharing of responsibilities between those involved in care (Bodenheimer et al., 2002). In this sense, ‘collaboration’ can be seen as problematic as it assumes that patients, healthcare professionals, and caregivers can
always be equal partners (Bodenheimer, 2002). Patients who are dependent on their caregivers or healthcare providers may have little autonomy and may be, in contrast to the goals of collaborative models, ill-informed and passive recipients of care and decision-making from both formal and informal caregivers.

This aim of this study is to critique the way the healthcare professional-patient-caregiver relationship is currently conceptualized in the literature (see Figure 1, below), where the assumption is that the patient’s values, beliefs and treatment goals are always aligned with the caregiver's (Sketris et al., 2007), and where the patient and caregiver are treated as a "unit of care" (Northouse et al., 2012) by healthcare providers, rather than as individuals.

**Figure 1: Health Council of Canada: Optimal prescribing and Medication Use in Canada, Challenges**

In re-framing the relationship between healthcare professionals, patients and caregivers, our aim is to emphasize how this relationship is complex and dynamic and hinges on power relations between different actors in various care settings. To capture the complexity of the relationships from our sample, we have developed the Power-Resonance Framework, which is aimed at helping us to better understand how health or illness related events may trigger shifts in power and can affect how chronic illness is managed in various settings. This new Framework, is based on the idea that individuals have *power* and thus have influence over their environment and the ability to control the behavior of others within the environment; and that the ability to wield power, or to be subjected to power and to resist power produces *shifts* or *oscillations* ("resonance") towards or away from consensus or collaboration between various actors.
The Power-Resonance Framework is also based on the understanding that in chronic illness management, the nature and balance of power is always changing in response to health or illness related events, for instance as a result of improvement of the patient’s condition, or a worsening of the patient’s symptoms. Our description of the Power-Resonance Framework acknowledges the intersection of sometimes differing personal and professional beliefs, values and goals of various actors, suggesting that an appreciation of power dynamics is required to understand the dynamics of collaborative care. The ability of one individual in the doctor-patient-caregiver triad to influence the actions of another individual may lead to clear influence with regard to treatment decisions, and decisional autonomy.

4.1.2 Power Dynamics within a Social Field

For caregivers, unlike healthcare professionals, assisting a patient manage his/her chronic illness is not bounded by interactions within the clinical encounter. Caregivers provide care in various settings, and the management of care within the ‘life world’ of the patient and caregiver may be complicated by the need to balance the recommendations, information and sometimes uncertain options presented by important others such as the patients themselves, physicians or family members within the realities of everyday life. A sociocultural and sociopolitical perspective, using the concept of ‘power’ by Michel Foucault and the conceptualization of the ‘social field’ by Pierre Bourdieu (1990), can provide a lens for examining the potential complexity of health decision-making and the dynamic nature of the interactions between the patient, caregiver and healthcare professional.

Foucault’s (1972, 1973, & 1977) explanation of power may be extended to examine the complex relations of power operating within the context of managing chronic illness. Although Foucault (1980) does not explicitly define power, he equates power to the regulation and governance of the actions of individuals by others. An examination of differences in power and knowledge held by members of the physician-patient-caregiver triad may help illuminate our understanding of how various positions are established by the actors involved in chronic illness management. More specifically, we are interested in how attitudes and intentions to act around an elder’s chronic health problem may be controlled by those with power and knowledge (for instance,
caregivers who act as language translators, and healthcare professionals who are seen as health experts).

Bourdieu’s (1992) conceptualization of the social field is applied in this study to address the need to explore the patient, healthcare professional and caregiver as occupants of a social field (or ‘space’) constantly negotiating and expressing forms of power over defining, and acting upon, situations of ill-health. For Bourdieu (1992), a social field is a dynamic space, characterized by a set of “objective, historical relations between positions”, and habitus is defined as “a set of practices shared by a group of individuals acting in the field” (Bourdieu & Wacquant, 1992). Bourdieu's (1992) concept of the social field is important as it suggests there is a dispersed allocation of power, and that power is not always held by any one individual or situated within any specific setting. As such, health behavior may be the result of the interaction of various players in the field of healthcare in response to a health or illness related event. From this perspective, the interactions that produce the collective habitus may be influenced by the authority and expertise of the healthcare professional in one setting, and the management of health, practice and surveillance which takes place at home (and includes the influence of caregivers). The resultant health behaviors emerge as a result of the complex interactions of these various players in the healthcare field.

How individuals are positioned in the field, and relate to one another, is a function of interpersonal relationships, commonalities and points of conflict (Bourdieu & Wacquant, 1992) Normative role expectations for caregivers suggest that they should act in the best of interest of the patient, but caregivers may also be acting in their own best interest. For example, in the informal setting, within the same social field of healthcare, the habitus of the patient and caregiver may be influenced by social and cultural norms and expectations that may result in familial and caregiver role conflicts (Sun et al., 2012).

These theories provide a lens by which to view chronic illness management as part of a field, and also a means to highlight the structural factors, such as power, that may come into play when the various actors interact. Although the introduction of the caregiver into the doctor-patient relationship, especially for elderly patients, may be an effective means of improving communication (Maguire, 1999) or ensuring continuity of care from one setting to another
(Coleman et al., 2004), the process should not be presumed to be one where consensus and collaboration are easily achieved or one that necessarily benefits the patient in all cases.

4.2 Methods

We employed a qualitative approach, where the aim was to explore the experiences of caregivers, specifically adult children of elderly Chinese immigrants, who were involved (at least on a weekly basis) in helping to manage their parents’ chronic illnesses. Recruitment for this study occurred through word of mouth, through informational posters placed in the community, and by advertising through two centers that serve the Chinese community in greater Toronto. We recruited a convenience sample of 23 participants (those who identified themselves as regulated healthcare professionals were excluded), of which 20 of the respondents were female and 3 of the respondents were male.

Data were derived primarily from in-depth in-person interviews lasting approximately 60-140 minutes and supplemented with extensive field notes and observations. (See interview guide in Appendix C). To explore the changes that individuals and families went through in managing chronic illnesses over time, we conducted follow-up interviews with a sub-set of 12 participants intermittently for a period up to 12 months after the initial in-depth interviews. The purpose of these follow-up interviews and interactions was to develop an ongoing dialogue with the adult children participants about the real-time experiences related to the trials and tribulations of managing their parents’ situations. Follow-up interviews were conducted in person, via email conversations and over the telephone, ranging in length from a few minutes to more than an hour and tended to be triggered by developments or decision-points in the parents’ care. Participants were encouraged to contact the study team to discuss emerging issues as they were identified during the follow-up period.

Primary analysis of the data (including verbatim transcripts of formal interviews, email conversations, and field notes) started with a process of ‘immersion’ into the data, in which the data were read and interpreted to reflect initial ideas about the data (Bazeley, 2009). This led to the generation of an initial list of themes and issues reflecting questions that had been asked from the interview guide, and general content from interviews (Endacott, 2005). Subsequent readings of the text resulted in a more detailed coding scheme, focusing on around broad issues or themes.
related to participants’ experiences, their understanding of health and chronic illness management, and interactions with healthcare providers and their parent.

Interview transcripts of the first five interviews were coded individually by three team members (RM, HB, and PB) and patterns and themes were discussed at several coding meetings. Through the course of multiple meetings, team members (RM and HB) further discussed the themes and coding, coded data independently and then compared results. Data collection and analysis continued simultaneously until codes become saturated or repetitious, and there was redundancy in information being shared by participants (Lincoln & Guba, 1985). All qualitative text were managed using N*Vivo 7 software (Richards & Richards, 2002).

4.3 Findings

In this section, we first describe our sample, and then we focus on how participants describe the negotiation of care between themselves, their parents and healthcare professionals. We have created the Power-Resonance Framework to explain our findings in a way that acknowledges the important and influential role caregivers play, and how their positions in the social field are often distinct from that of patients.

The 20 female and 3 male participants in this study ranged in age from 25 to 70 years of age (please see Table 1). All of the participants were living in the community, with 21 of 23 participants living in the same home as their parent(s). Only 3 participants were born in Canada and the other 20 migrated to Canada after spending their earlier years in China and/or Hong Kong. Translation through a Mandarin interpreter was required for three of the participants; the rest spoke fluent English.

Table 2 presents information on the caregivers’ descriptions of the various roles they played in support of the management of their parents’ health. As reported elsewhere by Mirza et al., (2012) these caregivers presented themselves as acting as ‘health mediators’, which meant that sometimes their responsibilities were to negotiate and reconcile various approaches to managing care between individuals involved in the care of their parents.
Table 1: Key Demographic Information of Sample

<table>
<thead>
<tr>
<th>Study Participants, N=23</th>
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<tbody>
<tr>
<td><strong>Participant Caregiver Age Range (years)</strong></td>
</tr>
<tr>
<td>Age Range (25-70)</td>
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<tr>
<td><strong>Care Recipient/ Patient Age Range (years)</strong></td>
</tr>
<tr>
<td>Age Range (64-99)</td>
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<tr>
<td><strong>Gender of Caregiver Participants</strong></td>
</tr>
<tr>
<td>Male N=3 (13%)</td>
</tr>
<tr>
<td>Female N=20 (87%)</td>
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<tr>
<td><strong>Marital Status of Caregiver Participants</strong></td>
</tr>
<tr>
<td>Single N=15 (65%)</td>
</tr>
<tr>
<td>Married N=7 (31%)</td>
</tr>
<tr>
<td>Divorced N=1 (4%)</td>
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<tr>
<td><strong>Place of Birth of Caregiver Participant</strong></td>
</tr>
<tr>
<td>Canada N=3 (13%)</td>
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<tr>
<td>China N=17 (74%)</td>
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<tr>
<td>Hong Kong N=3 (13%)</td>
</tr>
<tr>
<td><strong>Living Arrangements of caregiver participants and parent(s)</strong></td>
</tr>
<tr>
<td>Lives with parents N=12 (52%)</td>
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<tr>
<td>Lives with mother, father deceased N=9 (39%)</td>
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<tr>
<td>Lives with mother, father in nursing home N=1 (4%)</td>
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<tr>
<td>Parents live alone N=1 (4%)</td>
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<tr>
<td><strong>Chronic Illness of Parent</strong></td>
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<tr>
<td>Osteoporosis, heart disease, stroke, angina, obesity, kidney disease, high blood pressure, high cholesterol, cancer, dementia, joint disorder</td>
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Table 2: Caregivers as (powerful) Actors in a Social Field

**Various Roles Caregivers Took On In Managing Care for their Parents**

- Assist with activities of daily living
- Accompany parent to medical visits
- Administer and monitor medications and assess side effects
- Make medical decisions on behalf of parent/ with parent in clinical and non-clinical settings
- Provide and interpret medical information to parent
- Translate in clinical setting
- Provide assessments of parents’ health status for healthcare professionals

We have categorized the data for this paper related to caregiver involvement with the patient (parent) and healthcare professional under the main themes (see Table 3) of: 1) ‘alignment,’ a type of interaction where the caregiver, the patient and the healthcare professional are in agreement with regard to how to proceed with the care of the patient; 2) ‘dispersion’, a type of
interaction where the caregiver, the patient and the healthcare professional are at odds with regard to how to proceed with the care of the patient; and 3) ‘sway’ which is defined as occurring when different types of alliances between the caregiver, the patient and the healthcare professional develop.

Table 3: Characterization of Interactions between Patients, Caregivers and Healthcare Professionals

<table>
<thead>
<tr>
<th>Characterization of Interaction</th>
<th>Alignment</th>
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<tbody>
<tr>
<td></td>
<td>All parties involved have similar views, values, beliefs, goals regarding how to proceed with treatment or management of chronic illness; equal power sharing amongst actors</td>
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<table>
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<tr>
<th>Dispersion</th>
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<tr>
<td>All parties involved have different values, beliefs, goals regarding how to proceed with treatment options or management of chronic illness; power dispersed amongst actors</td>
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<table>
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<tr>
<th>Sway</th>
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<tbody>
<tr>
<td>Two of the three parties involved have similar values, beliefs, goals with regard to how to proceed with treatment or management of chronic illness, but these differ from the third party; unequal power sharing amongst actors</td>
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4.3.1 Alignment

Alignment, when all parties shared basic values, perspectives and opinions, was commonly described by our participants. Although not the most common type of interaction, participants described alignment as highly desirable as it made decision-making easier and participants reported feeling most supported in their caregiving roles when decisions were made in situations of alignment.

In this “ideal” situation, power was seen as shared and decisions were described as collaborative:

…when my father was diagnosed with cancer and I told my brother and sister what the doctor suggests and stuff and they all agreed. We’re all in agreement in terms of what my dad should be doing. So there were no disagreements or conflict in terms of what should be done, in terms of his health, the taking care of his health [between the patient and all those involved in his care].

An example of a perceived facilitator of alignment was when healthcare providers, caregivers and patients were all of the same ethnic and cultural background (in our case Chinese). One daughter explained how when a doctor understood ‘unspoken’ cultural nuances, it made it easier to make decisions:

“With a Chinese doctor, at least she can put the picture, the puzzle together… like she [the doctor] knows what the family is making the decision on, makes sense…You feel like, you know, the doctor is more sensitive towards cultural issues”

Alignment also resulted when the caregiver and the patient agreed to defer decision-making to the “expert” healthcare professional:

"It’s really straight forward what I have been told, like what I can understand and my dad agreed and there’s really not much of an argument or debate going on for what he’s going to get because he has no choice…Like to me it’s a necessity…Especially when I’m not a medical professional. I kind of count on, you know, what the doctors told us, if it makes sense. Like if it makes logical sense to us”

In contrast to the literature which suggest that the interactions that we have classified as alignment are the most common (or are assumed to be the only) type of health-related interaction involving patients care-givers and healthcare providers, our participants described a wide range of relationships that resulted from values, beliefs, orientations and information sources not being
shared or equal between the actors in the interaction. We categorized these into two main types of interactions: dispersion and sway.

4.3.2 Dispersion

We have categorized the second grouping of interaction experiences that emerged from our data as “dispersion”, in which the healthcare provider, the patient and the caregiver have conflicting underlying values, beliefs, perspectives and which leads to differing opinions regarding health-related decisions and what is “best” for the patient. For example, one participant described an interaction categorized as in dispersion:

"There was a lot of disagreement and argument and I think we’ve all learned from that… …Personal reasons got all mixed up in this [the decision making process] …it’s really something very personal and, and it goes that long way to how we have related in the past and there were differences, but sort like we brush it aside [In order to make decisions for the parent]…"

Healthcare decisions were described as the most contested and difficult when the relationship became structured as dispersion. In the following excerpt, a self professed “pill popper” explains that her views were different from her parent’s doctors with regard to medication use, and also from her parent’s own aversion to medications, yet she tries not influence the decision-making unless necessary. She states:

"They don’t like to take medications, even if it’s an over the counter, like Advil and sinus, they refuse to take it … They want to tough it out. They hate the idea that they have to take these pills for life for their high blood pressure, for cholesterol and this and that and everything else. They do it because they have to, because the doctor told them, but if they get the flu or if they are sick or they have a headache, they won’t take an Advil, they won’t take Tylenol, they won’t take anything…If it gets to the point where they can’t function in everyday life, that’s probably where I would come in and be more involved in taking care of them and their needs and what needs to get done"

A dispersion configuration generally suggested that the individuals involved in care processes held different ideas and beliefs about what to do with regard to managing chronic illness. As a result, it was often perceived to be difficult to achieve consensus in decision-making and to collaborate.
4.3.3 Sway: The Various Alliances of Patients, Caregiver and Healthcare Professionals

We have characterized the various alliances that can develop between the patient, the caregiver and the healthcare professional in response to a health or illness related event as ‘sway’. We use the ‘sway' grouping to capture the idea that the response to the health or illness related event may be swayed by an alliance of two of the three (or more) parties involved. From our results, it was apparent that alliances between the various actors could develop in a variety of ways. For example, caregivers reported that the patient was sometimes virtually excluded from the decision-making. In some instances, caregivers reported that there was less reliance on the healthcare provider, and there was an alliance of the patient and caregiver with regard to how to proceed in managing the chronic illness. Some caregivers reported that the healthcare decision-making was clearly dictated by the relationship between the doctor and the patient, and that they felt excluded.

In the sway configuration in which the patient is excluded, the "gate keeping" role for caregivers was often very clearly described. Participants stated that part of this meant that they “edited out information” they personally felt was not important for their parents to know:

"Okay, when she was in the hospital, all the staff spoke English, so I had to translate everything to her. But whatever I thought wasn’t necessary, like she really didn’t need to know, then I just would omit it."

Within this type of interaction, where the caregiver and physician were allied, caregivers often explained that they concurrently exercised their knowledge with regard to what they believed was best for their parents and their family, alongside what the doctor felt was best for the patient.

One daughter explained that she and her father felt that her mother needed to see a psychologist, and so they relied on the family doctor to encourage the mother to see one. Knowing that if her father or herself suggested that the mother see a psychologist, that her mother wouldn’t go, the daughter and father went ‘behind the mother’s back’ and met with the physician, who at the mother’s next doctor’s appointment suggested she see a psychologist. The daughter described the situation as follows:
"But my dad said, ‘how do we make your mom go to see a psychologist? How?’ And then I’m thinking. We need to use our family doctor. I tell my dad, ‘can you talk to the family doctor and let the family doctor tell mom that she needs to go to see a psychologist? And then refer her, but never, never mention me, and my dad?’ …And then, okay, my dad does talk to the family doctor, because he knows when my mom need to see a family doctor… and then, of course, underground, we then talk to the family doctor and family doctor agrees and then, okay. He talks to my mom and then asks her, suggests ,’maybe you need to see a psychologist”

Alliances of the caregiver and patient (often against the doctor) were also commonly described by our participants. One daughter explained that she and her mother felt that the ‘curve’ that was developing in her mother’s spine was a normal part of aging and that they did not agree with the doctor’s suggestion that the mother have surgery. The daughter stated that quality of life was more important for her mother and for herself than undergoing an invasive (and potentially dangerous) spinal surgery.

"...so spine it is not straight... The doctor, they say maybe they can do the operation…but they can’t guarantee it will be good...So she say, she’ll enjoy whatever she has right now...and she’s a little bit over weight. I also say why you need to [have surgery], once you lose some weight your back you will be better

Caregivers described trying to fit care plans and treatment options into the daily routines and activities of home, and deciding with their parents which parts of the physicians’ instructions they would follow. One daughter explained how the doctor had a strictly "medical point of view" with regard to what the ‘right thing to do’ was, and that the patient and the caregiver had their own understanding of what the ‘right thing to do’ was. She explained:

"My experience with the doctors was that, they basically attended my dad from the professional medical point of view… Like anything like in terms of the daily activities - I couldn’t think of anything that the doctor would have interfere us…Because we pretty well follow what we think is right…and what our normal routines are".

Another common theme described by caregivers in our study was how their parents tried at times to maintain their independence by excluding the caregivers from their treatment and health related decision-making:
"I know that sometimes my parents go see the doctor...they don’t necessarily tell me everything... because they don’t want us to worry...They don’t want their children to worry".

One son explained that his mother visited the doctor often and chose her residence as close to the doctor’s office as possible. He explained that he felt that this was one way that his mother could exclude him from ‘interfering’ with how she wanted to manage her health, which was primarily with prescription medications. He expressed his feelings that she was ‘overmedicated’, and stated:

“She, she believes in doctors... She trusts doctors to the extent that, she believes the medicine that they give her does not cause her any noticeable harm. I don’t trust her doctor.”

4.3.4 The Changing Nature of Relationships

Our findings suggest that the relationships among individuals involved in chronic illness management can change over time. For example, one of our participants described how the relationship between the doctor, her parent and herself began as one of alignment (i.e., they all deferred to whatever the doctor recommended, including the use of medications) to a swayed relationship where at her urging the doctor was asked to review the medications prescribed to her father. The participant felt that without her “taking more control” of the decision making and putting the doctor on notice that she was there to advocate on her father’s behalf, her father may have died. In this case the relationship moved from alignment to one of sway in which she and her father created an alliance in their distrust of the doctor.

Disease progression also led to changes in interactions and relationships between those involved in managing chronic illness. One participant explained that her father had always been included in the health related decisions that were being made for him in collaboration with his doctors and his family members. He knew about the medications he was taking, the tests that were being done, and when he was to see the doctor. However, when he was diagnosed with cancer, he was not told. The doctor, at the request of the caregiver and the family, colluded with the family and did not disclose the patient’s terminal diagnosis. The daughter said:
"He has liver cancer....I have two sisters. Three of them we stay there. No one there to tell him you have liver cancer...And he asked “am I okay?”, I know that it's bad, but he just say, “how come doctors just come to see me every day and they say, you okay”, and he has a problem – he is dying. That’s it. He has no, no real treatment and nothing. And then later I give him some pain pills...we have no guts to tell him [the truth]"
(Chappell & Bladford, 1991). This negotiation around a health or illness related event is complicated by the need to balance the recommendations, information and sometimes uncertain options presented by others operating within the social field of chronic illness management. Our study highlights that the ongoing conceptualization of interactions between caregivers, patients and healthcare practitioners as static, and based on the assumption that the caregiver and patient (as part of a "unit of care") share similar health related values, beliefs and orientations (Northouse et al., 2012) is problematic as it does not reflect the complexity and variety of the interactions. Our data support the idea that caregivers often have their own preferences with regard to treatment options presented to and for their care recipients (Adelman et al., 1987; Dellon et al., 2009). Our results suggest that caregivers are not value ‘neutral’, and that they play an important role in the care processes and decision making of chronically ill care recipients. Our data also clearly show that one should not assume that the caregiver and the patient share the same values and goals for care, nor can we predict when and how actors will exercise their power, for instance, around the gate keeping of information. The caregiver is a full actor within the social field of chronic illness management, in both the formal and informal healthcare settings; and that caregivers can be expected to attempt to exert their power to influence the course of action taken or the decisions made depending on the context and situation.

In reviewing the effects of having a third person present for a medical interview between the doctor and elderly patient, (Greene et al., 1994) found that caregivers often engaged in conversation with the doctor about the patient instead of with the patient. Also, patients responded less to various topics when a third person was present (Greene et al., 1986b). Yet, very little attention has been paid to power dynamics within the context of chronic illness management and how to capture and present these dynamics. This is especially important when the course of action around a health or illness related event or healthcare decisions directly impacts the healthcare provider, the patient and the caregiver, such as when these dynamics involve decisions about care which the caregiver is expected to perform for his/her parent at home or in another setting. Healthcare providers need to be aware that when a caregiver is involved, the course of action related to chronic illness management becomes a negotiation that must consider the caregiver as a separate actor distinct from the patient.
The Power-Resonance Framework (See Table 3) is introduced here as a means to describe, in a general way, the negotiation of care around a health or illness related event between healthcare professionals, patients and caregivers. We suggest that the various actors engage in a dynamic collaborative process of sharing and exercising differing yet equally important sources of power. As our results suggest, and our differing interaction types (dispersion, alignment, sway) capture, the social field of chronic illness management is a dynamic and highly contested space. Although many healthcare professionals embrace shared-decision making models, the caregiver’s values, preferences, and attitudes towards approaches to health and illness are too often erroneously assumed to be aligned with the care recipient. Caregivers rely on their own set of understandings, cultural references and experiences which may or may not be shared with the care recipient or healthcare professional. Healthcare providers need to be aware that the caregivers may have perspectives that are the same or different than the patients, as these perspectives may shape interaction dynamics. Although the clinical encounter may be, in theory, patient-centered, caregivers in our study viewed themselves as partners not only with the patient, but also with the healthcare professional with regard to the care of the patient.

Guided by our findings, the Power-Resonance Framework is based on the following ideas: (1) various actors in the field of chronic illness management hold the ability to influence another’s ability to do or act; (2) power is context specific and one actor may hold power in one situation, and not in another; (3) the nature and balance of power, and power resources (technical, material, social or knowledge based) are dynamic and contested amongst various actors; (4) interpersonal relationships within the context of health are not necessarily adversarial, and may be shaped by a challenge to the dominant position of another actor, to normative social roles, to monopolized sources of power of another, or in acting on what one sees as in the ‘best interests of the individual’; and (5) increasing the number of participants in the field (i.e., more healthcare professionals involved in care, more caregivers involved in care) may further disperse or sway the power and influence of all the other actors in the social field. The central tenet of the Power-Resonance Framework is that the sharing of power between important actors (what we call alignment) may lead to optimized care and decision-making capacity for all parties involved. However, it is important to note that participants in our study suggested that this state is difficult to achieve.
A number of limitations of this study need to be acknowledged. The small sample size and non-random nature of the sample does not allow us to estimate or predict the impact of any specific type of relationship (i.e., alignment, dispersion or sway) on health related behaviors or health outcomes for care recipients. However, the sample size (N=23 participants) and data collection based on multiple interviews was adequate to reach saturation, or the point of information redundancy (Creswell, 1998, p.64). It also provided us with rich and complex data on caregiver perspectives around the dynamics of chronic illness management. This study has contributed to our understanding of how caregivers for one subset of chronically ill patients (Chinese immigrants), interpret and present their roles and interactions as part of their caregiving experiences, but the application of our findings and framework to other populations needs to be investigated.

4.5 Conclusion

This study enhances our understanding of the different (and dynamic) positions individuals hold within the realm of chronic illness management, and how power relations shape and inform health related decision-making, and patient-professional-caregiver interaction. Understanding the perceived roles caregivers take on as part of the physician-patient interaction is important for the development of guidelines for healthcare professionals embracing chronic care models. Unlike most qualitative studies in the field of chronic illness management, our study was based on maintaining contact with participants over time and consequently we were able to document the changes participants perceived as a result of changes in disease status, relationships and interactions with important others. Acknowledging the various dimensions to being a caregiver involved in interactions with healthcare professionals, is not only essential for improving and maintaining continuity of care, but also in optimizing the ability of caregivers to collaborate effectively with healthcare providers, and patients who are often also their family members.
References


Chapter 5
Results

This chapter was prepared for submission to Patient Education and Counselling, and was submitted on October 26th, 2012. It was submitted prior to the dissertation defence.

I, Raza M. Mirza, performed the entire work, that is, the conceptualisation of the study, the protocol design, the overall study management, the collection, analysis, and interpretation of the data, and the writing of the manuscript, under the guidance of Dr. H. Boon, Dr. Z. Austin, Dr. P.C. Hsiung and Dr. P. Ballantyne.

Questioning the Utility of ‘Cultural Competency’ in Caring for Older Chinese Patients

Raza M. Mirza, MSc, Heather S. Boon, PhD, Zubin Austin, PhD and Ping-Chun Hsiung, PhD.

Abstract
Chinese immigrants to Canada represent a broad array of ethnic, racial, cultural and socioeconomic diversity. The purpose of this paper is to explore the usefulness of “cultural competency” as a way to improve the ability of healthcare practitioners to meet the healthcare needs of elderly Chinese patients. Using a qualitative, phenomenological research design, 49 in-depth interviews with 23 participants were conducted. Our results are organized into six vignettes, which illustrate how “Chinese culture” is not a commonly understood or experienced phenomenon, but that the individual ways in which “culture” is interpreted by patients and healthcare providers does have the potential to impact care. The paper explores how and why cultural explanations are used to justify healthcare-related requests and decisions. The vignettes presented highlight that not all “Chinese patients” have the same “cultural” needs or sensitivities and underscore the need for good communication with patients and their family members to facilitate healthcare providers’ understanding of patients’ needs and values regardless of their ethnic background.

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5.1 Introduction

With expanding cultural diversity in the Canadian population (Flores et al., 2000), ensuring that healthcare professionals that are able to provide appropriate care to individuals from a wide range of cultural backgrounds, commonly described as “cultural competency”, has become a priority within the healthcare system (Williams, 2000). There remains no universally accepted definition of cultural competency. The concept is broadly described by Betancourt et al., (2002; page 3), as “the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients’ social, cultural, and linguistic needs.” One area where cultural competency has been regarded as essential is with respect to communication between healthcare professionals and patients (Brach & Fraser, 2000; Carter et al., 2006). One of the many groups in Canada where language and cultural issues have been identified as creating health disparities are Chinese Canadians, who are now the largest visible minority ethnic group in Canada (HRSDC, 2011). Yet this statistic hides the increasing diversity within this ethnic group.

Ethnically Chinese Canadians may differ greatly with respect to their underlying values, and beliefs depending, for example, on when they immigrated to Canada and from where, or if they are second or third generation Chinese Canadians (Chia & Costigan, 2006). Cultural competency training currently provided to healthcare professionals in North America largely assumes a monolithic “Chinese” culture and provides strategies for communication and adapting care based on this assumption (University of Washington, 2002; Alberta Health Services, 2005). For example, a resource kit for healthcare professionals in Calgary, Alberta, provides the following advice “Chinese want immediate results from medications. May question prolonged Western treatment regimes and may prematurely discontinue taking an antibiotic prescribed for two weeks without immediate results. There is a need for explanation of the importance of follow-up” (Alberta Health Services, 2005, p. 30). With regard to hospitalization, it is suggested that “...the Chinese patient – behaves passively and expects others to care for him/her.” (Alberta Health Services, 2005, p. 31). In another example, cultural “highlights” presented by the University of Michigan Health System, suggests that clinicians can enhance their cultural competency in interacting with Chinese patients by, “...being aware of the importance of the Chinese patient in saving face” (University of Michigan Health System, 2006). Although
attitudes towards medication adherence, patient passivity and the need to “save face” may be relevant in some interactions with some Chinese patients, they are also likely relevant to interactions with patients from other ethnic or cultural backgrounds. And one cannot assume that they are relevant for all ethnically Chinese patients.

We argue in this paper that clinicians should prioritize the individualized needs of patients, regardless of cultural background or ethnicity because the assumption all members of an ethnic group share a culture is problematic. The purpose of this paper is two-fold: to examine the assumption that “Chinese culture” exists by exploring how and why Chinese Canadians caring for elderly parents reference Chinese culture in healthcare requests and health related decision-making; and to explore how including family members in care, a strategy discussed by Brach and Fraser (2000), may improve care for patients.

Much of the cultural competency literature suggests that Chinese immigrant patients and their families approach the patient-physician clinical encounter in Canada with a different set of health values, attitudes and beliefs than patients more familiar with the Canadian healthcare system (Alberta Health Services, 2005). It is argued that these differences have the potential to create challenges (e.g., language barriers, misunderstandings based on culturally-based assumptions) to optimal healthcare within the Canadian healthcare system (Bowman & Hui, 2000; Lai, 2007). According to the principles of traditional cultural competency, in order to address these challenges, healthcare professionals are expected to engage in an ongoing process aimed at improving cultural understandings of the myriad of patients in their practices (Andersen et al., 2003; Johnson et al., 2004; Taylor & Lurie, 2004).

5.2 Cultural Competency

Within the healthcare professions, cultural competency initiatives are generally intended to promote understanding of one’s own cultural background and bias, the patient’s healthcare background and bias, a better understanding of health disparities based on ethnicity or culture (Brach & Fraser, 2000), and to provide a framework to help healthcare providers understand, identify and address cultural barriers in healthcare (Betancourt et al., 2002). The academic literature is replete with examples of barriers to healthcare as a result of healthcare professionals
being ‘culturally incompetent’. Some examples of these barriers include: patients not understanding important information with regard to their diagnosis or medication regimens (Zanchetta & Poureslami, 2006; Seright 2007), patients not being satisfied with their healthcare experiences (Beach et al, 2005), and delays in treatment (Reyes et al., 2004).

In 2000, a review of Canadian medical education indicated that most schools did not offer instruction on cultural issues (Flores et al 2000). In response to demographic changes in North America, the Liaison Committee on Medical Education (LCME) (the accreditation body for medical education in North America) mandated that as of 2002 all Canadian medical schools were required to include cultural competency training in their medical curricula. Similarly, the Association of Faculties of Medicine of Canada (AFMC) developed a social accountability initiative to address issues of cultural diversity education (Health Canada, 2002). To this the American Association of Medical Colleges added in 2005:

"A cultural competence curriculum cannot be an add-on to the present medical school curriculum. If issues such as culture, professionalism, and ethics are presented separately from other content areas, they risk becoming de-emphasized as fringe elements or of marginal importance. The intent of a cultural competence curriculum is to enhance the patient-physician interaction and assure that students have the knowledge, skills, and attitudes that allow them to work effectively with patients and their families, as well as with other members of the medical community. Cultural competence is complicated: Health-care professionals must be educated to avoid stereotyping, but to also be aware of normative cultural values that can affect informed consent and can have serious consequences." (AAMC, 2005, p. 2).

However, Kripalani et al., (2006) found no consensus in the manner in which cultural issues are taught. Others have reported that it culture-related issues are included in lectures, cased based patient exercises, online interactive modules, and workshops (Spencer et al., 2008). This is consistent with our March 2012 review of medical school curriculum in Canada (Table 1). Most Canadian schools (14 of 17) had no information publically available regarding curricular objectives specific to cultural competency publically available. As Dogra et al., (2010) reported, the teaching of cultural issues at most Canadian medical schools remains a small component embedded within the framework of larger courses in the pre-clerkship years.
As it currently stands, cultural competency training is often based on the notion that individuals belonging to various culture sharing groups will have beliefs, actions, customs and values that are reducible to predictable patterns of behavior that healthcare professionals can respond to (Cross et al., 1989; Kleinman & Benson, 2006). Over-generalization of cultural values, attitudes and beliefs that healthcare professionals are to be able to identify and recognize, continue to be found in cultural competency training material. For example, physicians looking to gain licensure in New Jersey may opt to complete a 6-hour self-study and self-assessment program which would satisfy the cultural competency requirements (Informed, 2009). In this training manual, an example is given about interacting with a “…patient of Chinese origin who is brought up to expect a paternalistic relationship with his physician” (Informed, 2009, p. 48). While some patients may expect (or prefer) paternalistic relationships with healthcare professionals, we argue that assuming this is an attribute of all ethnically Chinese patients perpetuates a stereotype that is not accurate and that may hinder the provision of optimum patient care.

These assumptions are also embedded within educational strategies aimed at training healthcare professionals to be better able to use cultural competency to understand patient behavior. Studies have found that stereotyping patients based on assumed cultural beliefs and values (Geiger, 2001; Betancourt et al., 2003; Kleinman and Benson, 2006), not only places emphasis on differences between groups (Kripalani 2006), but also has the ability to affect clinical decision-making. For example, in a study by Van Ryn and Burke (2000), racial stereotyping was found to be correlated to recommendations for, or recommendations against, heart bypass surgery. Other examples include, physician decisions with regard to prescribing opioid (Burgess et al., 2008) or the avoidance of discussion related to high risk sexual behavior (Chin & Humikowski, 2002) being affected by stereotypical views of patients. Healthcare professionals who are trained and socialized in this manner are reported to ‘sort’ or ‘categorize’ patients based on assumed values, beliefs or behaviors in order to treat them (Kripalani, 2006; Betancourt et al., 2003; Tom, 2001).

Emphasis in this paper is placed on the need to treat patients as individuals regardless of their cultural background; and to suggest greater emphasis on dealing with patient socio-culturally diversity as it is presented as part of the illness experience. We argue that ethnicity often tells the healthcare provider little about the beliefs and attitudes of a patient. Fraser and Brach (2000) suggest that involving family members may help improve understanding of patient preferences,
and ultimately improve care. Constructive discussions with family members who may be present with elderly parents may help healthcare professionals understand specific information about that individual patient. Moreover, this approach may also help address issues, for instance the preference for family centered decision-making, which may be assumed by the healthcare professional as culturally motivated but may not necessarily be related to culture.

Using six vignette based examples derived from our qualitative data, we explore the idea that including family members in care practices and healthcare decision-making for patients has the potential to help healthcare providers bridge misunderstandings with patients, and to better tailor treatment to diverse patients. We examine specific examples identified by our sample of caregivers of chronically ill Chinese elderly which highlight the lack of a monolithic “Chinese” culture. We argue that although context, health beliefs and values are important, common cultural competency assumptions and strategies cannot be relied on to predict characteristics of all individuals in an ethnic group, or to predict patterns of health behavior.

5.3 Methods

Employing a qualitative approach, we recruited a convenience sample of 23 participants from across the metropolitan Toronto area who self-identified as caregivers who regularly (at least on a weekly basis) participated in the care of their elderly Chinese immigrant parent(s), and were at least 19 years of age. Adult children who identified themselves as healthcare professionals were excluded from this study as their health knowledge, abilities and attitudes concerning the care of their parents may have been based on their socialization as a healthcare professional and we wished to focus on the lay caregiver perspective.

We conducted in-depth interviews (60-140 minutes in length) with each participant designed to probe their experiences related to assisting their elderly immigrant parents manage their chronic illnesses. Multiple follow-up interviews with 14 of the 23 participants were ongoing for 2-12 months. Interviews were recorded and transcribed verbatim.

Primary analysis of the interview data started with a process of ‘immersion’ into the data through multiple readings of the transcripts and of field notes in order to generate a list of key
categories that emerged from the data (Endacott, 2005). Subsequent readings of the text resulted in a more detailed coding scheme, focusing on broad issues or themes (Bazeley, 2009), including those related to culture, participants’ roles as caregivers, and interactions with healthcare professionals. This process, which involved multiple independent coders, continued until categories become saturated or repetitious (Morse & Field, 1995; Creswell, 1998; Endacott, 2005; Pickler, 2007). All qualitative text derived from in-depth interviews was managed using N*Vivo 7 software (Richards & Richards, 2002).

Following the primary analysis phase, transcript data from individual participants were used to develop vignettes described by Miles and Huberman (1994) as "focused descriptions" or scenarios. The six vignettes presented in the findings section describe the experiences of six of the 23 participants. These six participants explicitly stated that they believed the delivery of care to their parents by healthcare professionals had been inadequate, and explained these concerns using a cultural framework. Although hypothetical vignettes are commonly used for educating clinicians and assessing healthcare delivery (Peabody et al., 2000), the vignettes presented in the findings section are based on the real lived experiences of our participants. The participants’ words were used as much as possible when writing the vignettes which summarize events or examples that were explained by participants in detail often over more than one interview.

5.4 Findings

In this section we first describe our sample (Table 1), and then focus on how and when participants’ made reference to “Chinese” culture in their explanations of the negotiation of care between themselves, their parents and healthcare professionals. All study participants made reference to how Chinese culture and Chinese traditions affected the management of their parents’ chronic illness. We organize our findings as a series of six illustrative vignettes to highlight that: 1) the involvement of caregivers can help healthcare practitioners address individual interpretations of cultural influences on care; 2) being “Chinese” did not necessarily explain behavior or health-related decisions; and 3) caregivers may be a valuable source of information and support, but to it is important not to assume that they share the same views, values and beliefs with regard to healthcare decision-making as their parents. Our key findings are summarized in our BASIC model (see Figure 1), which provides guidance for clinicians
regarding how to involve caregivers to enhance their ability to provide appropriate care to patients.

The 20 female and 3 male participants in this study ranged in age from 25 to 70 years of age. (See table 1). All of the participants were living in the community, with 21 of 23 participants living in the same home as their parent(s). Only 3 participants were born in Canada and the other 20 migrated to Canada after spending their earlier years in China and/or Hong Kong. Translation through a Mandarin interpreter was required for three of the participants; the rest spoke fluent English.

Table 1: Key Demographic Information of Sample

<table>
<thead>
<tr>
<th>Study Participants, N=23</th>
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<tbody>
<tr>
<td><strong>Participant Caregiver Age Range</strong> (years)</td>
</tr>
<tr>
<td><strong>Care Recipient/ Patient Age Range</strong> (years)</td>
</tr>
<tr>
<td><strong>Gender of Caregiver Participants</strong></td>
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<td><strong>Marital Status of Caregiver Participants</strong></td>
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<td><strong>Place of Birth of Caregiver Participant</strong></td>
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<tr>
<td><strong>Living Arrangements of caregiver participants and parent(s)</strong></td>
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<td><strong>Chronic Illness of Parent</strong></td>
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Participants in this study identified 'cultural issues' that they perceived to be important to their parents' (the patients) care and that they described as being overlooked by healthcare providers. In Vignette 1, we review an example provided about a participant’s parent who was
characterized by her attending healthcare professionals as “non-compliant” with her prescribed medication.

**Vignette#1: Warm Water, Not Cold Water!**

Evelyn explained how while in the hospital for the treatment of pneumonia and stomach issues her mother stopped eating and taking her medications creating concern among the healthcare team. Only after Evelyn spent time with her mother in hospital did she discover the reason for this behavior: her mother was given cold water with ice cubes in it at mealtime and when it was time to take her medications. Evelyn stated that this was a big “no-no” for Chinese people. Even the nurse, who was also ethnically Chinese, didn’t pick up on the reason why her mother refused the cold water. Evelyn explained to the healthcare providers that her mother would only drink warm water because she believed it was necessary to maintain body-balance or what she referred to in "Chinese culture" and Mandarin language as 'chi'. It was only after Evelyn came to visit her mother that she realized what the issue was and informed healthcare professionals.

This misunderstanding led the participant of our study to be more involved in the care of her mother, as she perceived that Canadian healthcare providers would have a difficult time understanding and addressing notions of 'chi', and also highlights how individual preferences, beliefs and interpretations of “culture” can have clinical consequences for patients. However, the idea of 'chi' and the importance this one participant placed on the virtues and values of 'chi' were not the same for the other Chinese participants.

Vignette 2 further illustrates how misunderstandings and mis-interpretations of patient behaviors can further exacerbate the perception of differences. This vignette helps to highlight the importance of asking questions (of both the patient and the caregiver) rather than assuming beliefs and attitudes based on the patient’s "Chinese" appearance or behavior.

**Vignette #2: The “White” Doctor Does not Understand**

Pearl, a 60 year old caregiver, helps to take care of her 80 year old mother who is suffering from a number of chronic illnesses, including heart disease. Pearl migrated to Canada in her 30’s and states that she still finds it difficult to understand health and illness in a Canadian context because she believes one cannot separate mind and body when thinking about illness no matter how long you have been in Canada. She became actively involved in the care of her parents when her mother’s ‘white doctor’ complained that her mother would not make eye contact with him, and that her mother remained very passive, saying very little through the clinic’s Mandarin translator. Pearl explained that the ‘white doctor’ interpreted her mother’s behavior to mean her mother was ‘lying’ to him about something or withholding information and ordered a battery of tests to ‘get to the bottom’ of the situation. Pearl explained that she interpreted her mother’s behavior as an attempt to express her respect for the doctor that was common within a Chinese
cultural context. Pearl's perception was that her greater involvement within the clinical context with her mother and her doctor has helped to address any further misunderstandings.

Many of the participants in this study actively sought healthcare providers who were Chinese. One of the main reasons stated was to ease communication. However, when probed, the participants of this study identified both positive and negative aspects of this arrangement. One positive aspect was that patients and caregivers felt that an ethically similar healthcare provider would have a more holistic understanding of their conditions and would better understand their preferences and needs when making treatment recommendations. One participant in this study described how having a Chinese doctor treat her mother for breast cancer meant that there was an unstated 'understanding' that her mother was not to be operated on during the Chinese New Year, or in a surgical room with the numbers '48', both situations which are considered bad luck. Yet, ethnic congruence did not necessarily solve all issues, including those related to communication. In some cases it resulted in the perceived perpetuation of cultural biases.

In Case 3, the experience of one participant helps highlight how ethnic similarities between provider and patient could also have negative consequences due to perceived cultural congruence.

**Vignette#3 The Chinese Doctor won't Understand**

Tanya has been providing care for her 78 year old Chinese father who suffers from mental illness, for the last 20 years, and routinely accompanies him to see the doctor. She feels her father’s mental health conditions are very shameful and stigmatizing for her family. She fears that cultural taboos around these illnesses will affect the care her father receives from a doctor who shares the same Chinese cultural background as her and her father. To address this issue she has a Canadian “white” doctor with whom she is comfortable discussing her father’s mental health and other taboo illnesses with, and a Chinese (Western medicine practicing) doctor with whom she does not discuss the mental health issues. She states that she needs to have two doctors as she sees the Chinese doctor so that her father can be involved in the care processes and decision-making around his other illnesses, including Parkinson’s disease. She expected the Chinese doctor to better understand the needs of her and her father for the more physical health conditions. Tanya suggested that having a Chinese doctor was important, in terms of communication for her father, but also felt that cultural congruence also has its negative consequences as she cannot have a fully open, trusting relationship with the Chinese doctor as she is afraid that she would feel social stigma and blame for her father’s mental health issues.
The caregivers in this study provided many examples of how they thought they were able to help healthcare professionals better understand and interpret what they described as "cultural cues". However, analysis of the data revealed no consistently shared values, beliefs or expectations commonly held by all of the participants in this study (even though they all self-identified themselves as ethnically Chinese). There were also often differences between members of the same family about specific healthcare decisions and with respect to how “Chinese culture" impacted those decisions.

Vignette 4 demonstrates how different members of a single family had very different opinions about whether our participant’s father should be resuscitated and who should make that decision.

Vignette #4: We Must Resuscitate
Grace feels she has no voice when it comes to making decisions for her mother and father. She is the youngest of six children and both her mother and father live with her and her family. She is so well versed in how to care for her parents’ complex healthcare issues, that it is not uncommon for healthcare providers to ask her whether she has formal training in medicine. When her father is told that he needs to undergo a triple-bypass after a heart attack, she is quick to encourage him to have the surgery and to reassure him that she will provide care for him when he is out of hospital. During the surgery her father has complications and the family, who is present at the hospital, is asked by the surgeons how to proceed with regard to resuscitation. Although her oldest brother is not her father’s caregiver, he believes that it is his role to make the decision and suggests that their father would not want to be resuscitated as he may have a poor quality of life if he survives. Grace and her mother object to this suggestion. The disagreement creates a lot of emotional stress amongst the healthcare providers and the family members that Grace attributes to her brother’s cultural expectation that as the oldest male he should be the decision-maker. Ultimately, Grace is able to convince the doctors to resuscitate her father as she is his primary caregiver and also the person with whom her father lives. She successfully argues that she would be in the best position to decide what her father would want. Even though her father made a full recovery, this decision divided the family and tension still exists.

The questions of how and what information should be communicated to patients and healthcare professionals was also discussed frequently by caregivers in our study. It was suggested that there were clear differences around what was expected in Western culture about a ‘bad news’ diagnosis and what they believed would happen in Chinese culture. However, there was no consensus amongst participants on exactly what the Chinese cultural norm would be with respect to information sharing. It appeared in our data that decisions were context dependent and
differed from family to family, and from individual to individual. From our sample, no pattern of behavior, reducible to Chinese ethnicity or culture, could be established.

When the mother of the participant in Vignette 5 was diagnosed with cancer, she assured the doctor that she would tell her mother of her diagnosis, but she never had the intent to do so. The participant stated that she knew that her mother would not want to know that she was going to die.

**Vignette #5: We can’t tell our mother that she has cancer**

Bonnie is a 25-year old social worker from Toronto. She expresses that she feels cultural and familial pressures to provide care for her now elderly parents. Even though her parents have been in Canada for over 30 years, they don’t want to talk to the doctor, they want her to accompany them to clinical visits and to speak on their behalf. Bonnie presented herself as very well informed with regard to her parent’s illnesses and use of medicines. She discusses a culture of denial in her family, and that her and her family have a hard time dealing with issues. When her mother’s test results were reported to her, she stated that she did not have the ‘heart’ to tell her mother that she had been diagnosed with a terminal form of cancer. Within her family, collectively it was decided to withhold the information from her mother. Bonnie explains that before her grandmother (her mother’s mother) died, she too had been diagnosed with cancer and her mother had not told her. This is the basis for which the decision was made for her own mother. She explained that autonomy and full disclosure as principles in medicine are “Western ideals”, and that from a cultural perspective, withholding her mother’s bad new diagnosis was what Chinese people did to protect their elders and family members.

The description of “Chinese culture” and lack of disclosure described in vignette 4 was not universally accepted by other participants in the study. Some caregivers felt that the patient had the right to know about their conditions, while others felt that the patient might not want to know.

Many caregiver participants in our study reflected on how their perceptions of their parents’ beliefs and expectations often differed substantially from their own. In Vignette 6, the experiences of one participant who struggles with his desire to tell his father about his cancer diagnosis are presented.
**Vignette#6: We must tell our father that he has cancer**

Gary feels like he provides care for his parents 24 hours-a-day and 7-days-a-week. When his parents moved to Toronto from China, he knew they were moving here because they needed him to take care of them. Ultimately Gary had to quit work to take care of his parents. Gary made many references to differences between himself and his parents with respect to underlying beliefs and values which he characterized as “cultural issues.” For example, it upset him that his parents do not want to communicate with the doctor, who speaks the same language as they do. His parents prefer that he communicate with the doctor for them. He feels his parents are too passive and submissive. When his father was diagnosed with cancer, his brothers and sisters, who were still living in China and the United States, suggested he not tell his father about the cancer diagnosis. He stated that when the doctor, who was also Chinese, hesitated to tell his father, he made the decision to tell his father directly that he had cancer. Gary explained that his decision was based on truth-telling, openness and transparency. Gary emotionally stated that he struggled with his decision, and wondered whether he did the right thing to tell his father.

Our data demonstrate that one cannot assume that a caregiver who is a family member will have the same beliefs, values and expectations as the patient who is being cared for.

5.5 **Discussion**

Our results suggest conceptualizing cultural competency as a typology of characteristics to describe and predict “what people of a given ethnic group or culture will do” with regard to health and illness is problematic. Participants described much intra-group diversity in their interpretation of cultural norms, and also their understanding of what constituted a cultural issue.

As it stands, cultural competency training may create stereotypical views of Chinese patients and their assumed dependence on family-centered care and decision-making that is dominated by male members of the family (Tom, 2001; Searight & Gafford, 2005). In doing so, cultural competency training and the perpetuation of stereotypical views of patient typologies may actually become barriers to healthcare, and healthcare professionals may develop a pre-judgment or bias towards Chinese patients. We argue that each patient and family is unique and has its own “culture” which may be influenced by a wide range of factors including their country of origin, socioeconomic status, family dynamics and a host of other factors. These factors do need to be taken into consideration when treating patients, and although we agree with Brach and Fraser's (2000) notion that involving family caregivers in the process can increase the likelihood
that appropriate health services are provided, we disagree with the idea that involving caregivers can improve or impact cultural competency per se.

Our findings highlight that assuming that a caregiver or healthcare provider who shares the same ethnicity as the patient, also shares the same cultural identity and values is also problematic. Healthcare professionals need to focus on understanding a specific individual Chinese patient rather than assuming they can understand and predict the needs, motivations and behavior of a patient simply because he or she is ethnically Chinese. Learning about patients’ preferences, values and needs from caregivers rather than through cultural competency 'check-lists' that assume cultural homogeneity may lead to greater understanding and better quality of care for individual patients.

Despite the striking lack of consistency on what exactly Chinese culture is, our participants often referred to their Chinese “culture” as justification for specific requests or decisions. In fact, the same Chinese culture justification was used by different study participants for making completely opposite decisions in several examples; for instance with regard to a 'bad news' diagnosis. We speculate that our participants referred to “culture” in order to legitimize their requests and decisions; and to frame their actions in a manner which moves the issues from a personal level, to that of the Chinese collective.

In the Canadian healthcare system, where “cultural sensitivity” is prioritized, we suggest that participants may have learned that cultural justifications are met with very little resistance from the healthcare providers, perhaps because they are difficult to question on the basis of political correctness. Who can argue with a decision or request that is framed as being “part of the Chinese culture”?

This is especially the case when a healthcare provider might lack experience working with Chinese patients or may fear that they might seem insensitive or "culturally incompetent". Our findings suggest that it is important to reflect more about the use of, and reactions to, culture as a justification for what are in reality idiosyncratic wants, needs, and preferences. This can be especially important when patients’ lives are at stake like in the resuscitation decisions described above. The issue of when and how patients evoke culture in the clinical context, and how healthcare professionals should be trained to respond, is clearly an area where further research is warranted. Our findings highlight that healthcare practitioners need to be respectful of patients’
(and their families’) requests and needs, but not necessarily acquiesce to them simply because they are justified by references to culture.

Our vignettes demonstrate that there are clinically important implications related to culturally-derived misunderstandings, and we learned from our participants that there were practical ways in which healthcare providers could help address some of the issues. We present a practice framework with the acronym "BASIC" in Figure 1 that summarizes these findings, highlighting how involving caregivers may help improve healthcare providers’ ability to understand the unique perspectives of patients. The framework also includes a caution that there are differences between every patient, their caregivers and providers, in terms of values, beliefs and practices that need to be recognized. We suggest that asking questions that provide an opportunity to explore these issues may provide insights into patient preferences that can help improve the quality of care and ultimately patient outcomes. Although the sample for this study was based on Chinese participants, we have developed the framework with a set of questions aimed at de-emphasizing the sorting and categorization of cultures, and suggest our approach may help healthcare professionals learn to identify and address preferences of patients from any cultural or ethnic background.

An important point of consideration in the framework is the idea that the involvement of the caregiver has to be balanced with creating space for the patient to share information or ask questions privately without the presence of the caregiver. It is also important to note that not all caregivers want to be, are prepared to be, or should be involved in the care of the patient, especially when the patient is a parent. The caregiver can be a valuable resource for information, may help to interpret and translate, but may also hinder the delivery of care by withholding information or editing out information when placing their values or beliefs in priority over the patient's.

This study has contributed to our understanding of how caregivers for one subset of chronically ill patients (limited by unique migration status, ethnicity, and language), interpret and present how they perceive culture to influence interactions, care practices and healthcare decision-making. The sample, although small, was appropriate to achieve depth in qualitative analysis and it proved to be adequate to reach thematic saturation. It also provided us with rich and complex data on caregiver perspectives around the dynamics of culture and chronic illness management.
5.6 Conclusion

This study uses a Chinese patient population to question the role of “cultural competency training” programs based on the assumption that there is a “Chinese culture” that one can become proficient at understanding. The ethnically Chinese participants in this study reported highly variable descriptions of what constitutes “Chinese culture.” Although our participants evoked “culture” as a justification for many of their healthcare-related requests and decisions, the content of the requests and decisions varied as much as the descriptions of Chinese culture. In a healthcare system where providers pride themselves on providing high quality care to a very diverse population, cultural justifications of healthcare decisions may be too readily accepted at face value. The findings of this study suggest that more focus needs to be on patients as individuals who interpret and shape their own ideas of “culture.” The utility of “cultural competency” as it is currently often taught in healthcare professional training programs needs considerable re-thinking.
References

American Association of Medical Colleges. (2005). Medical Education and Cultural Competence: A Strategy to Eliminate Racial and Ethnic Disparities in Health Care, supported by The Commonwealth Fund; Pipeline Projects, Division of Diversity Policy and Programs, Association of American Medical Colleges.


Figure 1:

**BASIC:** Practical ways healthcare providers can explore the individual 'life contexts' of their culturally diverse patients

**AVOID BIAS:**
- Avoid "culture think": do not assume that culture shapes identities, relations and practices of all members of a culture sharing group in the same way
- Acknowledge your own culture, and recognize how it may be perceived by the patient and caregiver

**ASK QUESTIONS:**
- Caregivers are an excellent source of information about symptoms, medication use and diet
- Caregivers may be able to interpret important information and cultural cues with regard to the individual patient's values, beliefs and attitude
- Ask the patient about his/her level of comfort sharing information with the caregiver, acknowledge that the caregiver may withhold information from the healthcare provider for personal or cultural reasons

**CONSIDER SEPARATELY the values, beliefs and views of the patient and caregiver:**
- The patient and caregiver should not be treated as a single unit, and the healthcare provider should address the concerns of the patient and the caregiver separately if possible.

**INCLUDE the caregiver**
- To learn more about the patient and how health is managed by the patients and/or family at home
- Do not assume that a caregiver wants to be involved in decision-making for and with the patient; include the caregiver if they wish to participate and the patient wants them to participate, acknowledge that caregivers may find this role difficult
- As an interpreter, the caregiver has the ability to edit out information. Do not assume that the caregiver wants to, or can, effectively interpret on behalf of the patient

**COMMUNICATE:**
- Acknowledge that patients and caregivers may want information communicated to them in different ways, especially with a "bad news" diagnosis; asking questions will best help assess how to communicate with that particular patient
- Acknowledge that certain Western medical terms may not be translatable in other languages or contexts; and that certain 'cultural' terms or concepts may not be understood or easily explained
Table 2: An Overview of Cultural Competency Training in Canadian Medical Schools

| University of Toronto | University of Ottawa | Queen’s University | University of Western Ontario | McMaster University | Northern Ontario School of Medicine | Dalhousie University | Memorial University | University of British Columbia | University of Calgary | University of Manitoba | University of Alberta | McGill University | Laval University |Université de Sherbrooke | University of Montreal |
|-----------------------|----------------------|-------------------|-------------------------------|---------------------|----------------------------------|---------------------|---------------------|-------------------------------|-------------------|------------------|---------------------|----------------|----------------|-------------------|----------------|----------------|
| Cultural Competency Training | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Core/ Elective/ Voluntary** | Core | Core | Core | Core | Core | Core | Elective | Core | Core | Core | Core | Core | Core | Core | Core | Core |
| Pre-clerkship (MS-1, MS-2)** | MS-1 | MS-1 | MS-1 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 | MS-1, MS-2 |
| Clerkship (MS-3, MS-4)** | -- | -- | -- | -- | -- | MS-3 | -- | MS-3, MS-4 | -- | -- | -- | -- | MS-3 | -- | -- | -- | -- |
| Teaching Method | Lecture, Field Visits | Lecture | N/A | N/A | Problem Based Learning | Lecture, Field Visits | Clinical Teaching | Lecture | Lecture | Lecture | N/A | N/A | Lecture, Small group activities | N/A | Problem based learning, lecture, field visits |
| Evaluation Criteria | Written work, presentation, examination | N/A | N/A | N/A | N/A | OSCE | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A |

*describes whether the cultural competency training was taught as a course or as a component of another course  
**describes whether the course was part of the required core curriculum, was an elective, or was voluntary  
***MS-1 refers to year 1 of medical school, MS-2 refers to year 2 of medical school, MS-3 refers to year 3 of medical school, MS-4 refers to year 4 of medical school
Chapter 6
Discussion and Conclusion

This study has contributed to our understanding of how caregivers for one subset of chronically ill patients (limited by unique migration status, and ethnicity) perceive, interpret and present their experiences related to the management of their parents’ chronic illness. This study adds to our limited understanding of how caregivers negotiate within the context of the patient-practitioner interaction. It also highlights the way “culture” (in this study “Chineseness”) was used by our participants to explain and frame their experiences, as well as to justify healthcare decisions.

In this final chapter, the discussion section, a summary of the main findings from the results chapters (Chapter 3, Chapter 4, and Chapter 5) is presented. This review of the main findings is followed by two sections of discussion that provide an opportunity to explore two key issues raised in this study: 1) Re-conceptualizing the Patient-Practitioner-Caregiver interaction, and 2) Culture and the Chinese Patient. In the first discussion section of this chapter, Re-conceptualizing the Patient-Practitioner-Caregiver Interaction, the focus is on understanding how the dynamics of the doctor-patient relationship change with the introduction of the caregiver or third person into the interaction. The section titled Culture and the Chinese Patient provides an opportunity to further explore how and why participants in this study evoked "Chineseness" in their interactions with healthcare professionals, and researchers. The chapter ends with a reflection on methodological issues, the strengths and limitations of this study, and a summary of the conclusions drawn from this study based on the original purpose and objectives.

6.1 Overview of Key Findings

In the first chapter of the results, a key finding was that participants presented themselves in the context of their perceptions of normative cultural roles and responsibilities of adult Chinese children. All of the participants in this study referred to Chinese culture to frame and explain their expected roles and their experiences. The discussion focused on addressing when individuals in this study may have evoked culture to explain their thoughts or actions.
In Chapter 4, the second results chapter, it was argued that the participation of a caregiver in chronic illness management with the doctor and care-recipient was not necessarily a collaborative endeavor. Using data from this study and a theoretical framework based on Bourdieu's (1990) notion of the social field and Foucault's (1980) conceptualization of power/knowledge, a more complex and dynamic relationship in healthcare triads than that which currently exists in the literature was presented. This framework was used to capture and demonstrate how shifts in power within the social field of chronic illness management could affect the course of action taken with regard to chronic illness management. As a conclusion, it was proposed that training and support for patients, caregivers and healthcare professionals is needed to increase awareness of the complex dynamics involved when children take on caregiver roles for their chronically ill parents.

The final results chapter was based on vignettes developed from the interview transcripts summarizing participants’ examples of clinical challenges that they described to be related to culturally sensitive issues. It was argued in this chapter that “Chinese culture” is not a commonly understood or experienced phenomenon, and that it is problematic to view Chinese culture as a monolithic entity. It was concluded that there is a need to underscore the importance of good communication with patients and their family members, and to work with patient's families to facilitate health care providers’ understanding of individual patients’ needs and values regardless of their ethnic background.

6.2 Re-conceptualizing the Patient-Caregiver- Healthcare Professional Interaction

One of the aims of this study was to explore and critique some of the assumptions about the role of family members in collaborative care. The Power Resonance Framework, described in Chapter 4, was used to describe the negotiation of healthcare decision-making between doctors, patients and family members as part of a dynamic collaborative process of sharing and exercising differing yet equally important sources of power within the formal and informal healthcare setting. Generally speaking, the need to better understand and describe the changing nature of the relationships between healthcare professionals, patients and their caregivers has arisen from two concurrently occurring trends: the shifting nature of care that was previously delivered within the
clinical setting that is now relegated to the home setting, and an aging population which shows
greater reliance on caregivers to deliver and participate in this care (Health Council of Canada,
2012).

The Power-Resonance Framework is based on the results from this study and provides a new
lens on the nature of collaborative care. In contrast to the tenets of collaborative care described
in the literature (Bodenheimer et al., 2002), the assumptions of consensus and collaboration
among the participants are shown by the results of this study to be highly contested and not easy
to achieve. The framework is used to highlight that managing care for the patient, in
collaboration with a healthcare provider and caregiver(s), is a dynamic and negotiated process.

Although many healthcare providers embrace shared-decision making models, the values,
preferences, and attitudes towards approaches to health and illness of the healthcare provider,
patient and caregiver, are often very divergent which leads to the need for negotiation of
decisions. Furthermore, the influence of the caregiver is oft overlooked, and the clinical
encounter continues to be conceptualized around the simple relationship between the healthcare
provider and the patient (Sketris et al., 2007).

Our results indicate that caregivers were frequently present within the clinical context with their
parents, and were involved in interactions with various healthcare providers and other family
members. This is consistent with previous findings in the literature on the involvement of
caregivers in the care practices of patients (Fellows et al., 2004; Morhardt et al., 2010), and with
Bourdieu's (1990) conceptualization of the social field being based on the primacy of
relationships. Furthermore, participants in this study perceived their roles as important in terms
of: providing continuity of care for their parents from one setting to another, improving
communication between healthcare providers and their parents; and addressing and resolving
issues related to cultural idiosyncrasies and health literacy with healthcare providers.

One of the central tenets of The Power-Resonance Framework is that the sharing of information
(or knowledge) between important actors has the ability to shift power dynamics, and may lead
to differences in decision-making capacity for all parties involved. The idea that individual actors
that have knowledge, also have power is a position established by Foucault (1980). Furthermore,
that individuals have the ability to control, restrict or gate-keep information or knowledge, points
to what Foucault (1980) suggests is the implicit fact (yet obscured from view under the guise of
collaboration) that all parties involved, in theory, can exercise power to achieve their own goals and needs separately and in parallel to the need to help the patient achieve well-being. What needs to be recognized is that there are positive and negative elements to the inclusion of adult children in helping manage a parent’s chronic illness.

Future studies may continue the line of inquiry described in this study, building on the Power-Resonance Framework with regard to the factors that may affect the dynamics of healthcare triads. The usefulness of the Power-Resonance Framework that was developed from the results of this study should be explored with other groups of varying ages and gender, both ethnically diverse and non-ethnically diverse, to broaden understanding related to the factors that can shift the dynamics of the healthcare professional-patient-caregiver relationship; and to gain an understanding of what implications these shifts in dynamics have on health behavior or health outcomes. Furthermore, the use of this framework to understand the experiences of other groups may help to illuminate patterns of similarity and differences that may emerge.

While asymmetrical power relations between the doctor and the patient may exist in the clinical context as Schaufel et al., (2009) suggest, the introduction of the caregiver into the equation and the changing context from the clinical setting to the home setting creates a complexity that has not been addressed previously. Given the current interest in collaborative care within the clinical community, the Power-Resonance Framework may provide a more comprehensive picture of the interconnected, yet separate, informal healthcare system and formal healthcare system that actors involved in chronic illness management may be negotiating. On the one hand, the doctor may hold greater power within the clinical context, but this power may be diminished when faced with the views of the patient and the caregiver; and alternatively, another dynamic may play out within the informal healthcare setting where the caregiver may hold greater power and the patient and the doctor may be powerless.

A key implication of the Power-Resonance Framework is that power, like interpersonal relationships, is dynamic and context specific. Whereas the current conceptualization of the healthcare professional-patient and caregiver relationship (Sketris et al., 2007) is based on the assumption that this relationship is static, the Power-Resonance Framework illustrates that the nature of relationships can change and that these changes may have implications for health behavior. Data collection for this study, which included multiple interviews allowed us to
uncover evidence that the relationship between various actors can change. This is the first study to report the shifting nature of power dynamics between a healthcare professional-patient and caregiver. More research into the factors which can shift the dynamics between actors is warranted.

Participants in this study maintained that not all information needed to be shared with healthcare providers and patients, which is consistent with the findings of Giacalone et al., (2009). What is interesting is that Giacalone et al., (2009) suggested that the ideal that all information should be shared amongst the doctor, patient and caregiver was linked to “autonomy” being prioritized in “English speaking cultures”, and that in other cultures (Italian culture in the Giacalone et al., 2009 study) it was not seen as inappropriate to withhold information, specifically when it related to a poor or terminal prognosis. Culture was clearly an important theme in this study as well. Within the context of the Power-Resonance Framework, the cultural background of the patient and caregiver was a factor that could shift the dynamics of the relationship between the patient, the healthcare provider and the caregiver. Participants in this study used culture to frame and present experiences which we interpreted as a way to attempt to control external pressures related to their involvement in their parents’ care.

6.3 Culture and the "Chinese Patient"

While we did not approach this study with the assumption that culture would be an important factor related to the experience of being a caregiver, every one of the participants in this study used culture to frame their experiences. Many of these individuals evoked Chinese culture to explain healthcare decision-making on behalf of their parent(s) and their interactions with healthcare professionals.

Previous studies looking at the experiences of Chinese immigrants in the Canadian healthcare system provide some additional insights into the role of culture (Lai & Chappell, 2007; Quan et al., 2008; Lai, 2009; Lai & Surood, 2009). Research by Lai and Surood (2009) found that many health beliefs, and modes of health action (i.e., use of traditional Chinese medicine) of older Chinese people in Canada remained tied to the practices they had traditionally adhered to in China. Furthermore, a study by Malzohn et al., (2005) found that individuals’ adherence to
traditional cultural beliefs about death and dying meant that discussions around organ donation were rare within Chinese families, and that organ donation refusals were framed within the context of leaving the "body intact" out of respect for ancestors. Similarly, participants in this study often perceived and presented their parents’ approaches to the clinical encounter in Canada as being based on a different set of health values, and a different way of thinking of their bodies, and potential treatments options than their children and their healthcare providers. As discussed in results chapter 5, discussion of contentious issues may be circumvented by individuals by framing these issues as cultural (and thus "off limits" to a non-Chinese) when they may be personal or idiosyncratic concerns.

The strong emphasis on cultural issues raised by participants taken together with the findings of the Power-Resonance Framework suggests that cultural issues within chronic illness management may play a role in shifting power dynamics, and that patients and caregivers may actively use cultural explanations or justifications to empower themselves in situations where they may perceive being disempowered. It is important for healthcare providers to gain an awareness of the fact that what is presented as “culture” may be interpreted, presented and evoked in a non-standard or unpredictable way by patients of a given ethnicity. This leads to the argument that in lieu of cultural competency on the part of healthcare professionals, what is required is awareness of culture as one of many factors that make up individual personal belief and value systems which may not necessarily be shared with all those who identify as ethically Chinese. Involving family caregivers in the patient-practitioner relationship has the benefit of identifying more appropriate health services for each patient, and is an excellent opportunity for healthcare professionals to gain first-hand knowledge of the beliefs and expectations of that Chinese patient.

The finding that some participants in the current study stated that they preferred ethnically similar healthcare providers, is consistent with the findings of Leong et al, (2010), who found that members of some ethnic groups preferred this arrangement, in part, because they reported feeling more comfortable discussing sensitive issues with a culturally similar healthcare provider. Some participants in this study perceived that cultural congruence between patient and provider improved communication, and understanding between the patient, healthcare provider and caregiver. In contrast, other participants from this study did not want treatment from an ethnically similar healthcare provider for reasons related to stigma and shame. These
participants did not perceive communication or sensitivity to cultural needs to be heightened by having a Chinese doctor. Culture within the context of the Power-Resonance Framework, could shift the dynamic towards greater alignment amongst all actors or could disrupt and sway the dynamics depending on how it was perceived, interpreted or evoked by participants.

The results from this study suggest that caregiving experiences are often framed using cultural explanations. Linking participants’ use of cultural explanations to describe their experiences within the context of their interactions suggests that to better understand their experiences, attention needs to be focused on those situations and contexts where individuals may feel the need to evoke culture or to prioritize it as an important aspect of their identity.

6.4 Methodological Insights

Positionality and researcher identity were important elements of the research process. As first discussed in Chapter 2, the process of inquiry for this research was context dependent, and as a researcher, I had to be conscious of the fact that the participants and I were interactionally linked. Fontana (2004) argues that researchers need to recognize that, whether intentionally or not, they may have an influence at all stages of the research process. A process of reflection and reflexivity, which meant I always was aware of my positionality and my identity as a researcher, was embedded within the research design of this study. How this affected my role as a researcher and how my identity potentially influenced the various stages of this study is explored in this section. Reflexivity allows for greater transparency in the research process, and as such is important for rigor. Questions of rigor are discussed in this section as follows: 1) making the research process transparent; 2) the emic and etic view, and 3) the importance of conducting a research study that is useful for researchers and research participants.

From the interpretivist perspective, social realities are constructed, and subjectivity within the research process is described as something that can be used "actively and creatively" (Denzin, 1989). Reflexivity allows for an awareness of the process of making these realities known. As Denzin (1989) suggests, it is often that a research topic has personal significance to the individual, which extends beyond intellectual curiosity that determines what we want to study. With regard to the design of the research study, as a caregiver to an elderly parent, I do have
practical familiarity with this area of study; I have also coordinated a large study looking at the medication use experiences of older Chinese adults, so I had previous experience working with this population group. It is true that I used my previous experiences to present my motivations to potential participants and to gain access and build rapport with research participants.

During interviews, my experiences allowed me to feel comfortable and confident with regard to the subject matter. However, a number of issues did arise during interviews that may have influenced the production of knowledge. One of these issues, also discussed in the methods section, was that participants often expected me, as a caregiver, to understand things about their caregiving experiences with little or no explanation. For instance, it was assumed by a number of participants that I understood the overwhelming nature of taking care of a parent without them providing a thick and rich description of what was so overwhelming as they might have to someone whom they thought might not understand. And although the interviews felt spontaneous and natural, and more like a conversation, I had to ensure that the participants’ interactions with me as a person, who they saw as a fellow caregiver, were balanced with me as a researcher within the context of the interviews, where the goal was to generate detailed data. The other important point with regard to being seen as a caregiver interviewing a caregiver by research participants is that it might have led to participants to perceive that I might judge their decisions, beliefs or health related behaviors that they were discussing with me.

Even though I avoided including my own judgments about what I felt or believed throughout the course of interviews, I speculate that this fear of judgment when participants were revealing sensitive or their self-perceived contentious issues to another caregiver, led to them use cultural explanations that I was not expected to understand or be in a position to judge. For instance, in one interview, a participant revealed that against the wishes of her family and healthcare professionals, she had asked that her father's "do not resuscitate" orders be overridden, and that he be revived. She followed up this statement by saying that I wouldn't understand why she had to do this because I was not Chinese; but also stated that since she thought we were of the same religion, that I might understand.

It was often quite challenging to remain neutral and to deal with my strong feelings, especially when I could relate to participant's experiences and when I did greatly empathize with their situations. Keeping detailed field notes, a reflexive diary and remaining focused on capturing and
revealing the experiences of my study participants helped me remain focused during the research process. With regard to data analysis, I recognized prior to reviewing the data transcripts that many of the issues raised by participants that had resonated with me during interviews might also reflect what I thought was important. In order to stay true to what participants were saying, data were organized around repetition in themes. Using the open-ended questions from the interview guide allowed me to use an element of the research process that participants had the most control over-- how they wanted to portray themselves when answering the questions. To further ensure that I was not simply seeing the data to reflect my views and understanding, the data were reviewed by my thesis supervisor and a committee member. As such, I was able to discuss the themes with individuals who were at an arm's length from the interactions and interviews, and we decided together what was important in terms of the data.

The issue of data interpretation and analysis is also important with regard to how I presented my findings. As mentioned earlier, I shifted from the insider (emic) perspective to the outsider (etic) perspective throughout the course of collecting the data, and I recognized that I needed to be more objective when presenting the data to give voice to my participants, and not necessarily to me as a researcher (Pike, 1990). Reconciling the emic and etic dichotomy within the context of my interviews, was especially challenging since the emic perspective of participants was often engaged with my emic position as a caregiver in co-creating knowledge. To begin to resolve this issue, I looked for components of the participant's account which were based on their self-understanding, specific to that participant, and where my voice was at least balanced with theirs. What is of importance from the constructivist perspective is that the researcher's voice not be excluded or necessarily neutral (Guba & Lincoln, 1989, p. 12).

Reconstruction of lived experience is an important aim of inquiry under the constructivist paradigm (Guba & Lincoln, 1989), and this reconstruction of participant's experiences, which are the foundation of the results of this thesis, is based on the voices of not only the participants but also of the researcher. However, to ensure that my interpretations were reflected the experiences of participants, I completed a member check with three participants who were long-term participants in the study. Data analysis procedures as well as preliminary results from the study were reviewed with the participants who all agreed that the data were presented and interpreted appropriately by me to be closely reflective of their experiences.
Finally, with regard to the collection and analysis of this data, I have tried to ensure that this research study has been a responsive inquiry that has resulted in something useful for participants. One of the most important aspects of the ethics of this study was with regard to emotional or sensitive disclosure. It was anticipated that participants might become quite emotional while describing their experiences of caring for and making decisions for, and on behalf of, their chronically or terminally ill parents. Within the research design, participants were given control over what they said and whether they wanted to discontinue participation in the study. I recognized quickly that participants often just wanted to tell their story, and that having the opportunity to share their experiences was cathartic, a means to acknowledge and give meaning to what they had gone through, and a chance to reconstruct their sense of self.

This study was responsive to the needs of participants, who often were overwhelmed with emotion and asked for tape recording to be stopped, but for me to continue to take notes, in that it gave them voice. Although quotes in the findings sections were not derived from these notes and were not used directly in the findings, these notes did provide another source of data and also helped to situate the emotional nature of the participant's experiences. Based on this work, much of the significance is that the accounts that have helped to shape the findings of this study are from those individuals who really wanted to tell their stories, and for their realities to be known and shared.

6.5 Study Limitations

A number of factors limit the findings of this study. These limitations include: 1) the convenience sample was identified from one metropolitan region and not stratified by gender; 2) sample attrition; and 3) focus on a single cultural group. It is important to point out that the results from this study are derived from a convenience sample of adult Chinese children who were involved in the management of a parent's chronic illness in Toronto. As such, the findings, based on the experiences of this sample may have limited representativeness with regard to the experiences of all adult Chinese children who participate in chronic illness management. Yet, this sample size is cited in qualitative literature as appropriate (Sandelowski, 1995), and is consistent with a range presented by Creswell (1998, p. 64) who suggested that phenomenological studies should be based on a sample size of 5-25. Furthermore, data
collection continued until saturation was achieved suggesting that a larger sample would be unlikely to lead to the identification of additional key themes.

The sample for this study consisted of three male participants and 20 female participants who were more likely to be unmarried and living with the parent(s) for whom they were providing care than might be typical in Chinese Canadian families based on census data. This is a limitation as it is suggested in the literature that gender (Leung & McDonald, 2007) and socioeconomic status (Lai, 2004) of Chinese and non-Chinese caregivers may influence their experiences. In particular, the results from this study may not reflect the experiences of male caregivers for elderly Chinese parents. Recruiting through the community agencies that were serving the needs of the Chinese community allowed for first-hand observation of the composition of caregivers attending programs, accompanying elderly parents and interacting with healthcare professionals. The gender of these caregivers was predominantly female and thus the findings presented here likely accurately reflect the experiences of this specific group of Chinese Canadians in central Toronto.

Many similarities and differences across data from all of the participants suggested that the scope of the study, and the nature of the topic was appropriate for exploring the experiences of adult Chinese children, without necessarily assuming that gender differences or age variations amongst participants needed to be specifically addressed or required special investigation.

Sample attrition meant that long term involvement was only possible with some of the participants and not all of them. This is a limitation as the results may be derived more heavily from the experiences of those participants that stayed on in the study longer. However, it was ensured that data from all participants were used to address findings before additional data from those participants who were involved long term were used. Furthermore, having fewer participants completing multiple interviews and remaining involved long-term with the research allowed for very in-depth information about the needs, experiences and concerns to be collected.

Although the purpose of the current study was to use participant’s accounts to provide in-depth and rich data about the lived experiences of being a caregiver, the results of this study are based on a sample of participants who self-identified as Chinese. The sample was diverse in terms of age and duration in role as a caregiver; however the results from this study may not be applicable to caregivers of other ethnic backgrounds. The literature suggests that despite ethnic differences
caregivers often share similarities in experiences (Avalong, 2004). It is possible that the finding that participants used culture to help manage their identity and influence individuals whom they felt would judge them may also be applicable to other ethnic groups, but this would need to be tested in additional studies.

6.6 Strengths

This study has a number of strengths including data collection based on multiple interviews with participants; the large variety in the participants’ levels of experience in managing their parents’ chronic illnesses; and the use of a variety of theoretical vantage points to interpret and understand the complex experiences and perspectives of research participants. The design of this study, based on multiple interviews, allowed for greater involvement with participants, and for data collection to parallel the dynamic nature of chronic illness management. This design also facilitated the ability to identify and understand the changes in participant experiences and roles in interactions with their parents and healthcare practitioners over time.

Being in direct contact with participants in the field over a longer period of time allowed for the inquiry to remain ‘naturalistic’ and also allowed for results to be contextualized around participants’ interactions with important members of the care team, to various settings where care was being managed, and to explore the dynamic nature of the experiences of participants. Also, the approach to fieldwork taken for this study, with an awareness for context, time, setting and place, allowed for a more holistic understanding of individual’s experiences. Furthermore, as Bryman (1988) suggests, greater time spent in the field and interaction between researcher and subject allows for rapport to be developed, for data to more likely to reflect the essence of the experiences of participants, and for the researcher to gain a better understanding of the complexities of the phenomenon being studied (Baruch, 1981).

Another strength of this study is that the sample of participants recruited were at various stages of managing the chronic illnesses of their parent(s), and thus there was representative of a wide variation in expertise, involvement and range of experiences. This meant that some participants, at the time of their involvement with this study, were just beginning to help their parent manage a newly diagnosed chronic illness, while others had longer term experience helping to manage
their parent’s chronic illness, or were retrospectively reflecting on their experiences (as part of the interview) of managing a chronic illness for a parent that was now deceased and were currently assisting the other living parent. Again, as this study was based on longer-term involvement with participants, many of the changes in the participants’ perceptions of their experiences were captured.

Not only did data sources vary for this study in terms of time and place, many different types of data were collected including interview data, observations, and reflexive memos pre- and post-interaction with study participants. Multiple theoretical approaches were also used to initially frame and subsequently interpret the data from this study. Using these approaches has allowed for a more thorough explanation of the issue of how adult children perceive, and present their experiences, and has allowed for greater insights into the phenomenon under study.

6.7 Directions for Future Research

Adult children who help to manage a parent's chronic illness take on important and influential roles that warrant further attention, and this study provides a foundation for future studies. Future research may need to focus on understanding the value and importance individuals ascribe to social expectations as providing guidelines for behavior. For instance, it might be important to consider how and why certain individuals take on, or are relegated to, the role of caregiver, versus those who are not. In this study, structural factors such as proximity of care recipients to caregivers or single marital status were identified by participants as some of the most important factors determining who provided care, yet this seems to contrast with narratives of how things are normally done in ethnically Chinese families. Further exploration of which factors determine who becomes a caregiver, and possible similarities or differences across ethnic groups and healthcare systems, would help the design of support systems for caregivers in different contexts. The experiences of participants in this study were often described in negative terms. Future studies looking at how to better prepare and support caregivers to be partners in healthcare are warranted, particularly with regard to understanding how and if negative attitudes or feelings may hinder the participation of caregivers in the collaborative care process.
Building on the idea of partnerships, healthcare triads that include the healthcare professional, patient and caregiver, may not necessarily be collaborative, and further inquiry into the factors that may affect the dynamics of healthcare triads is needed. In general, research looking at the dynamics of the healthcare professional, patient and caregiver interactions should build on our finding that all actors involved are independent and dynamic. The results from this study clearly indicate that caregivers do not necessarily have the same values, beliefs and attitudes about health and healthcare decision-making as patients and healthcare providers, and future inquiry guided by with the Power Resonance Framework may help further our understanding of the unique and often changing dynamic that emerges through triadic healthcare interactions.

This research reaffirms the need to better understand and address how issues of culture are addressed by healthcare professionals, and how cultural issues are presented by patients and their caregivers, and for what purpose. Expanding the current line of inquiry to other cultural or ethnic groups could provide more insight into how and when patients and or family members prioritize their cultural identity in healthcare settings. Another related area of study that warrants further investigation, was the discrepancy between the expectations that participants described with regard to the caregiving role, and the reality of their actions and behaviors with regard to actually providing care for their parents Future inquiry may be based on questioning this discrepancy, and trying to unpack the purpose that presenting oneself in a certain light serves, even if it clearly contradicts how participants describe their experiences.

The findings related to the sometimes pronounced issues of culture raise more questions than they potentially answer. This research reaffirms the need to further explore how issues of culture are addressed by healthcare professionals, and how issues of culture are presented and/or prioritized by immigrant patients and their caregivers, and for what purpose. Continued exploration of how and why people turn to cultural explanations and justifications for healthcare decisions, and how healthcare providers respond to this, is an area worthy of further study.
6.8 Conclusions

How do adult children of elderly immigrant Chinese parents experience the management of their parents’ illnesses? Participants in this study described their caregiving experiences as complex, multifaceted, and as penetrating many aspects of their lives.

Participants described difficulties transitioning into the caregiver role, and suggested that their roles and responsibilities were mostly burdensome and negative. Participants' experiences were not only shaped by structural factors such as their living arrangements and marital status, but by their perceptions of their cultural identity which was highlighted in their narratives. In this study, participants appeared to use cultural explanations to explain their behavior.

The second objective of this study, addressed in Chapter 4, was to explore how the presence of a caregiver could affect the healthcare professional-patient relationship. Participants in this study suggested that they held important (and powerful) roles within the context of the healthcare professional-patient relationship. An important conclusion is that patients and their caregivers cannot be assumed to share the same values, beliefs and attitudes. Furthermore, the involvement of caregivers changes the dynamics of the interactions between healthcare professionals and patients. The introduction of the third person can lead to alignment, where all three actors share similar values, beliefs and goals on how to proceed; can lead to dispersion, where, opinions about how to proceed are not in agreement and power is dispersed among more actors; or sway where two of the three actors agree on a course of action, leading to unequal sharing of power.

The third and final objective of this study was to explore how cultural explanations are used by caregivers to explain healthcare-related requests and decisions. The ethnically Chinese participants in this study reported high variability in their descriptions of what constitutes “Chinese culture.” Furthermore, although our participants evoked “culture” as an explanation for many of their healthcare-related requests and decisions, the content of the requests and decisions varied as much as the descriptions of Chinese culture.

In conclusion, it is clear that healthcare professionals dealing with chronically ill patients and their caregivers will need to pay closer attention to not only the needs of the patient, but also to the needs of the caregiver. Participants’ experiences related to the management of chronic illness for their parents, including their interactions with healthcare professionals were not
always positive. Although many participants referenced specific issues that they related to Chinese culture, for instance the issue of filial responsibility, and of withholding bad news, it remains problematic to assume that these are “Chinese issues”. The idea that Chinese identity is fixed creates a typology of patient and caregiver values and beliefs which may not reflect their actual experiences, needs, and orientations towards healthcare and treatment.

The main conclusion from this study is that all participants in the field of chronic illness management for a patient have the ability to influence interactions, treatment decisions and potentially health outcomes. By understanding factors drawn from the Power Resonance Framework, a clearer sense of how to respond to shifting and changing power dynamics may be gained. In sum, caregivers of elderly Chinese immigrants perceived and presented their role as essential. However, it is also important to note that the values, beliefs and needs of the caregiver may not necessarily be aligned with the healthcare professional and patient, and thus the involvement of caregivers in chronic illness management has the potential to positively or negatively affect the dynamics of care.
References


Appendices

Appendix A: Study Participant Recruitment Records

Date:________________________________________ Time:__________

How did you learn about this study? ________________________

**Participant Information**

Name:________________________________________

Phone #_______________________________________

Sex: M F

Age:_______

**Study Information to be read to participant:**

``I am a PhD student at the University of Toronto`s Faculty of Pharmacy. I am not a healthcare professional.``

``The purpose of this study is to learn about the experiences of adult children who help a parent or their parents manage an chronic illness, are involved in decision-making for and with their parents about their chronic illness, and who may accompany their parents to see doctors, to help get their medicines or to assist with daily activities. I hope to use the information collected in this study to help healthcare professionals and researchers better understand whether/how families work out health problems together and this might lead to better ways of delivering healthcare to families and individuals. I would like to learn more about the needs and experiences of adult children who are helping their parents deal with health problem(s), and to improve services to the many older people and their families who may require support.``

``If you are interested in finding out if you are eligible to participate in this study, I will ask you a few short questions to confirm your eligibility``
Still Willing To Participate in Study? Yes or No

Eligibility Check:

``Thank you for your interest in my study. I will ask you a few questions to determine whether you are eligible to participate``

1. Are you an adult child of an elderly Chinese immigrant (65+) who is managing a chronic illness (I.e., diabetes, hypertension, heart disease, arthritis or other)? Yes or No

   Parental Chronic-Illness: ______________________

2. Are you English fluent (oral and written)? Yes or No

3. Are you 19 years of age or older? Yes or No

4. Do you provide any sort of assistance, perspective or help to your parents’ medical processes, or participate in the management of their chronic illness, and healthcare decision-making? Yes or No

   Notes: ____________________________________________

5. Are you willing to complete an in-depth interview, and be involved in follow-up discussions for up to 4 months? Yes or No

6. Are you a healthcare professional? Yes or No

7. When possible, would you be willing to introduce the study to your elderly parents, family members and healthcare providers and ask them whether they would consent to non-participant observation? Yes or No

Eligible to Participate? Yes or No

*If recruit responds `no` to any of questions 1-5 above, individual is NOT ELIGIBLE.*

Explanation for each question if recruit asks why they are ineligible:

1. This study will specifically explore the experiences of adult children of elderly Chinese immigrants who are helping their parents manage their newly diagnosed chronic illness.
2. Interviews and discussions will be held in English and therefore participants must be English fluent.
3. Participants have to be adults, 19 years of age and older.
4. Participants need to be involved in helping their parents’ manage their chronic illness.
5. This study is based on an initial in-depth interview and weekly follow-ups and.

*If recruit responds `yes` to question 6, individual is NOT ELIGIBLE.*
5. This study will explore lay perspectives and experiences, and therefore healthcare professionals are excluded from this study.

**If recruit responds `no` to question 8, and responds ```yes``` to questions 1-5, and ```no``` to question 6, recruit participant and revisit question after first in-depth interview**

Meeting Information

```
I would like to set up a time to meet with you. At this first meeting I will go over all of the information that I have discussed with you in greater detail, and will obtain your informed consent to participate in this research. This first meeting may last from an hour to an hour-and-a-half. When is a convenient time for us to meet?
```

Date:_________________________________

Time:_________________________________

Location:____________________________

Address:____________________________

Privacy and Confidentiality

“Please know that I respect your privacy, and that your name, identity and anything we have discussed or will discuss will be held in strict confidence. Confidentiality will be maintained in the following ways: your name and phone number will not be known to anyone except for myself and my graduate supervisor, Professor Heather Boon. Your name will not be used in the interview, or in any written reports (interview tapes and printed copies will identify participants with a code number or fictitious name). Tapes of interviews, and interview transcripts will be stored indefinitely in locked files in a research office at the University of Toronto’s Leslie Dan Faculty of Pharmacy, and will be accessible only to myself and Professor Heather Boon (Tapes and all paper files are anonymized--no names attached, all identifying information removed, except a code number or name--prior to analysis of data or storage of it). A master list of names of all participants in the study will be stored in a separate location, but also in locked storage. All computer files will be password protected, and access to study files will be restricted within the limits permitted by law.”

Do you have any questions?

Notes
Appendix B: Information Sheet and Consent Form

A STUDY OF THE EXPERIENCES OF ADULT CHILDREN HELPING THEIR ELDERLY PARENT MANAGE A CHRONIC ILLNESS

This page introduces the study being conducted by Raza Mirza, a PhD student at the Department of Pharmaceutical Sciences, University of Toronto. The purpose of this study is to learn about the experiences of adult children who help a parent or their parents manage chronic illness, are involved in decision-making for and with their parents about their chronic illness, and who may accompany their parents to see doctors, to help get their medicines or to assist with daily activities. I hope to use the information collected in this study to help healthcare professionals and researchers learn more about the needs and experiences of adult children who are helping their parents deal with health problem(s), and to improve services to the many older people and their families who may require support.

You are being invited to participate in this study because you are aged 19 or over, you are English fluent, with an elderly parent (65 and over) who is a Chinese immigrant with a diagnosed condition. For example, a chronic illness could include: diabetes, high blood pressure, heart disease, arthritis (or other chronic illnesses). Participants in this study will also be providing some sort of assistance to their parent in dealing with medical processes and/or participating in the management of their chronic illness, and healthcare decision-making.

I hope we can talk about your experiences of managing your parents’ illness and how you assist them. All participants will complete one face-to-face interview and a weekly informal follow-up discussions.
During the interview, I will be asking you very general questions about your experiences, and will want to know about your understanding of your parent’s chronic illness, how your relationship with your parents and healthcare professionals has changed since your parent has been diagnosed with an chronic illness; how you see your involvement as being influential in your parent’s management of their illness and also the role you play with regard to decision-making for and with your parent. To protect your parents’ right to confidentiality and privacy, I will ask that you not use your parents’ name during our discussions. During the follow-up discussion we have, which might simply be over the phone or in person, I will ask you to elaborate on ideas that we discuss during the interview or at other times we meet, and follow-up on other issues that I might need you to clarify for me.

If you agree to participate in the study, your first interview will be arranged to take place at your home or any location convenient for you and will last from one to one-and-a-half hours. The follow-up interviews will be shorter. With your permission the interviews will be tape-recorded. In asking you about your experiences, I recognize that I am asking you to discuss private matters with me. However, your participation in this study is completely voluntary. You are free to withdraw or discontinue your participation in the study at any time, or to end any of the interviews at any time, and to decide not to participate in the later discussion. If you are uncomfortable with the questions I ask, you do not have to respond to them, and you may request that I stop tape recording at any time. If you find an interview too long or tiring, feel free to tell me, and we can take a break, or re-schedule the remainder of the interview for another time.

Also, if you are interested, I would like to observe your interactions with your parents, and possibly come with you when you take your parents to see healthcare professionals, when you and your family meet to discuss your parent’s health and healthcare, or when you go to get medicines for your parent. I will ask that you help me introduce this study to your parents, family members and healthcare professionals. I will provide you with an information sheet, similar to this one, and If they agree to speaking with me, and I receive their voluntary consent, I will be able to gain greater insights to how families help elderly members manage their health, and what role you play. I will also
ask that we speak on a weekly basis briefly as a follow-up to the things that we discuss and about the things that I observe if and when I accompany you.

No risks to participants are foreseen by the researchers and there are no direct benefits to participating in the study, other than the chance for you to discuss your experiences in helping your parent(s) manage their chronic illness, healthcare and medicines, and in telling us what has worked well for you.

However, you should know that I respect your privacy, and that your name, identity and anything we discuss will be held in strict confidence. Confidentiality will be maintained in the following ways: your name will not be known to anyone except for myself and my graduate supervisor, Professor Heather Boon. Your name will not be used in the interview, or in any written reports (interview tapes and printed copies will identify participants with a code number or fictitious name).

Reports from this study may use excerpts from our interview, however a pseudonym will be used. What we discuss during the interview will not be reported in a way that others will be able to identify you. For instance, your views will be reported along the views of other participants taking part in this study.

Tapes of interviews, and interview transcripts will be stored indefinitely in locked files in a research office–at the University of Toronto’s Leslie Dan Faculty of Pharmacy, and will be accessible only to myself and Professor Heather Boon (Tapes and all paper files are anonymized--no names attached, all identifying information removed, except a code number or name--prior to analysis of data or storage of it). A master list of names of all participants in the study will be stored in a separate location, but also in locked storage. All computer files will be password protected, and access to study files will be restricted within the limits permitted by law.

A summary of the results of the study will be distributed to interested participants.

If you have any questions, or if you require more information about this project, please contact me on my personal (confidential) line at (416) 508-0215. You may also obtain information about ethical considerations relating
to this research by contacting the office of research ethics at 416-946-3273, or emailing them at ethics.review@utoronto.ca.

*********************************************************

**Participant Consent Form**

I have read the information letter about the study on the “EXPERIENCES OF ADULT CHILDREN HELPING THEIR ELDERLY PARENT MANAGE CHRONIC ILLNESS”. All questions that I have asked have been answered to my satisfaction and I have agreed to participate. I understand that my interview will be tape-recorded. I also understand that there are no direct benefits in to my joining the study. I have been assured that the information I give will be kept confidential and that any reports published or presented will not disclose my identity.

I understand that my participation in this study is voluntary and that I have the right to withdraw at any time, even after signing this form. I understand that if I decide to withdraw from the study, the information collected during the study before I withdrew will be retained. No further information will be collected after a study participant has withdrawn from the study.

I understand that if I choose to withdraw my participation before the completion of the study, I will still be offered an honorarium of $20 as compensation for my time.

I understand that the researcher has a legal obligation to report information revealed by a participant with regard to physical, psychological or social harm or abuse. Confidentiality will be maintained to the limits of law. I understand that a disclosure of confidential information as required by law shall not be considered to be a breach of this agreement.

Name:  

___________________________________

Signature:  

___________________________________

Date:  

___________________________________

Witness:  

___________________________________
Appendix C: Interview Guide

To better understand participant’s experiences of helping their parents’ manage their chronic illness, in-depth personal interviews with adult children will follow a semi-structured interview format.

Note: Encourage participants to tell the story in their own way and in their own words.

At start of interview, collect basic demographic information: age, length of residency in Canada, level of education, living arrangements, marital status, number of siblings, who is the oldest sibling, how close do family members live to each other.

1. I’m interested in knowing what it is like to be an adult child of an elderly parent who is living in his/her own home or living with you and managing a chronic illness. Could you please tell me about your experiences?

2. Could you explain your understanding of health? Goals for health?

3. What is your understanding of your parents’ health?

4. Tell me about your parent’s [specific condition] chronic illness?

6. When an elderly parent is diagnosed with a chronic illness, a lot of things can change, not only in the life of the individual but also in the lives of others. How have things related to everyday activities, healthcare and life in general changed since your parent was diagnosed with [specific condition] a chronic illness? Describe the changes for you and for your parent.

6. Adult children who help their parents manage a chronic illness [or specific condition] may be in a position to influence and affect their healthcare practices. Does, and if so how does your role in helping your parent manage their health influence the healthcare decisions that they make?

7. I am interested in knowing more about your experiences related to your parents` visits to doctors, to hospitals, and with regard to your parents’ use of medicines and management of illness. Could you describe the role you play when your parent visits the doctor? Uses medicines? Daily Management of illness?

8. Describe your relationship with your parents’ healthcare provider. How would you describe your role in interacting with your parents’ healthcare professionals? How has this been influenced by your parents diagnosis with a [specific condition] chronic illness? How would you describe your parents’ healthcare providers’ approach to using medicines in managing your parents’ health?
If there is something we discussed today that you want to discuss with me further or elaborate on, please feel free to contact me.

I would like to follow-up with you in about a weeks time about some of the things we talk about. When would be a good time for me to contact you?

In the meantime, if something new arises with regard to your parent`s health or the management of their health, feel free to call me or email me and I will follow-up with you. Also, I am very interested in being present when you and your parent, family members and healthcare professionals are `actively managing` health; for instance, before during or after a doctor`s appointment or at any other time you see suitable, please let me know and I will arrange to be present.
Appendix D: Follow-Up Questions

General Questions:
Note: Paraphrase conversations when necessary

1. Managing health is sometimes a complex process. How have things changed since we last spoke? (probe: if nothing has changed, what has stayed the same and why?)

2. I would like to know more about some of the activities related to your parents’ health. Could you tell me about some of the activities related to your parents’ health that you or your family have engaged in this week… (refer to previous interview details)

3. I would like to know more about some of the decisions related to your parents’ health. Could you tell me about some of the decisions made around your parents’ health since we last spoke…. (refer to previous interview details)

4. I would like to spend a few minutes going over some of the things we have talked about up to this time… (refer to previous interview details)

5. I would be happy to spend some time going over anything else that you would like to add, including any questions, comments or concerns that you have…

Use quotations to directly represent what is being said, however only identify what is being said and by whom in a general manner (i.e. Doctor said, Mother said, Son Said)

Things to consider during follow-up:

Interesting/ significant informal or formal issues/ themes/ conversations/ events?
from text data/ discussions/ observations
- why interesting or significant?
- key aspects
- what are people doing?
  - how are they doing it?
- what are people saying?
- what might be the meaning/ importance of what I hear/ see?

Is what I hear/ see representative of the literature?
- is this an anomaly situation? Why?
- Does what I see fit a pattern/ break a pattern?

What did I learn?
- did this knowledge challenge my assumptions? Reinforce assumptions?
Problems or challenges?
- Were problems related to something about the phenomenon being studied, or about research methods?
During the review of our interview transcripts for our study, we identified key concepts and themes related to the experiences of participants. At this point we are not looking to generate new data, but rather we are checking in with participants about whether the themes we have identified and focused our attention on represent the most important information that participants like you shared with us. We also want to make sure that our interpretations make sense to you.

As always, you are free to choose to participate or not. This member check will be very brief and focused around specific questions.

**Question Set #1:**
One topic many of our participants talked about was how Chinese culture influenced their experiences. How do you think being of Chinese descent impacted your experience of caring for your parent? What if anything is different for you than you think it would be for children from other cultural backgrounds caring for elderly parents who are ill?

**Notes:**

**Question Set #2:**
During our interview(s), I also asked you about your interactions with healthcare professionals while you assisted your parent manage their chronic illness. My interpretation has focused on how the involvement of adult children influenced and affected the interactions. Using the data I collected from participants, I have developed a way to illustrate the interaction between healthcare professionals, patients and caregivers. [Show and explain various figures from Power Resonance Framework]. Does this make sense to you? [Use participant’s interview data to identify which figure(s) might reflect what they said to me]. Did I understand and present appropriately what you were describing to me?

**Notes:**
**Question Set #3:**
The perception of many of the participants in this study was that healthcare professionals needed to take cultural factors into consideration when treating patients, and that involving family caregivers in the process had the benefit of allowing for more culturally appropriate health services, and an excellent opportunity for healthcare professionals to gain first-hand knowledge of care practices for “that Chinese patient”.

I would like to review and hear your opinion on 3 key points that I have focused on:
1) Having a Chinese doctor is sometimes better and sometimes not. *Would you agree? How can I make better sense of this?*
2) Western values may conflict with the values and system of socialization that Chinese patients and their families are familiar with. *Would you agree? How often does this seem to happen in your experience? Can you help me better understand this?*
3) Can you suggest anything you would like healthcare professionals to do to help address cultural misunderstandings?

Notes:
University of Toronto
多伦多大学
Appendix F: Translated Documents and Consent Form

给成年孩子参与者的信件及同意形式

一项关于成年孩子帮助年长父母管理慢性病症经历的研究

这一页将介绍多伦多大学药科学博士生Raza Mirza的研究。这项研究将得知成年孩子帮助他们的父母（们）处理慢性病症的经历。成年孩子参与父母慢性病症的政策制定，伴随父母看医生，帮助取药物，或协助日常活动。我希望这项研究收集的信息能够帮助医疗保健专家和研究者学到更多成年孩子在帮助他们父母应付健康问题时的需要和经验，并改进对需要支持的老人和他们家庭的服务。

这项研究的参与者须年满19岁，英语流利，有一位是中国移民，并被诊断有慢性病症的年长父母（65岁以上）。慢性病症包括：糖尿病，高血压，心脏病，关节炎（或其他慢性病症）。同时，这项研究的参与者也会在医疗过程中协助并且/或者参与他们父母慢性病症的管理和医疗保健政策的制定。

我希望我们可以谈论您处理您父母病症的经验，您是怎样协助他们的。所有参与者将完成一次面谈和每周不拘形式的后续讨论。

在采访期间，我会询问一些有关您经历的普通问题。我想了解您对父母慢性病症的理解，您与父母和医疗保健专家的关系怎样因为您父母的诊断而改变，您怎样看待您在父母病症管理中的重要介入，和您在您父母医疗政策制定中的扮演角色。为了保护您父母的隐私和机密，请在我们的讨论中不要使用您父母的姓名。在后续讨论中（也许通过电话或面谈），我将请您详尽地阐述并且说明采访期间或其它时候的一些论点。

如果您同意参与这项研究，第一次采访将被安排在您家或任何对您方便地点，采访将持续一到一个半小时。后续采访将会是更简短的。经您允许，采访将被录音。在询问您经验的同时，我明白我们讨论私事。然而，您是完全自愿参与这项研究的。您有自由在任何时候退出或中断参与，或者在任何时候结束采访，和决定不再
参加过后的讨论。如果您对我问的问题感到不悦，您不必回答，同时您可以在任何时候要求停止录音。如果您发现采访太长或令人感到疲劳，请马上告诉我，我们可以小休，或者重新安排另一时间再进行采访。

如果您感兴趣，我希望能观察您与您父母的互动，或允许我随同您和父母去看医疗保健专家，当您与家人谈论父母健康和医疗保健时，当您为父母拿药时，我会请求您帮助我把这项研究介绍给您的父母、家庭成员和医疗保健专家。我将为您提供您所需的资料（类似这一篇文章），如果他们同意与我对话，同时我也得到他们的自愿承诺，我将更进一步的了解一个家庭怎样帮助年长成员管理他们的健康问题，以及您在其中所扮演的角色。我将要求我们每周简单对话一次，谈论一些当我伴随您时所讨论到的和观察到的事。

研究员们预测这项研究对参与者既没有风险也没有直接利益，除了使您有机会谈论在帮助父母（们）管理慢性病症、医疗保健和医药的经验，从中告诉我们那些方面得到了很好的处理。

您知道我尊重您的隐私，您的名字，身份和任何讨论的话题会得到严格保密。机密性将会以以下的方法所维护：除了我和我的导师，PeriBallantyne教授，您的名字不会被任何人所知。您的名字不会用于采访或书面报告（采访磁带和打印的拷贝将用编码或参加者的假名辨认）。

从这项研究中得到的报告也许会使用采访录音，假名将会被使用。报告使用采访期间的内容不会使您被他人辨认。例如，您的观点将与其他参与者的观点一同报告。

采访的笔记和磁带将被无限期的保存在带锁的文件中，存放在多伦多大学LeslieDan药学院研究办公室，只有我自己和Ballantyne教授能够使用（磁带及所有文件将被匿名，没有名字附带，所有可辨认的信息会被取消，除了编码号或名字，在对数据分析或存贮之前）。所有研究参与者名字的清单将被存放在一个分开的地点，而且锁定存放。所有计算机文件将加密保护，对研究文件的使用将在法律允许的范围内。

研究结果的总结将会分发给感兴趣的参与者。

如果您有任何问题，或您需要更多关于这个项目的信息，请与我联系，我的个人专线（保密）是416.508.0215。您也可以通过研究道德规范办公室得到关于这向研究的道德规范，请联系416.946.3273或者发电子邮件到 ethics.review@utoronto.ca。

参加者同意形式
我已经阅读了关于成年孩子在帮助他们年长父母处理慢性病症经验研究的信息。我的所有问题都得到了满意的回答，我同意参与。我知道我的采访将被录音。我也知道加入研究对我没有直接利益。我得到保证我所提供的信息将被保密，同时任何出版或发表的报告不会透露我的身份。

我了解我是自愿参与这项研究，我有权利在任何时候退出，即使在签署了这个形式以后。我也了解，如果我决定退出研究，在我退出研究之前收集的信息将被保留。在参加者退出研究之后，详细信息将不会被继续收集。

我理解，如果我选择在研究完成之前退出，我将得到$20作为对我时间的补偿。

我知道研究者有法律责任报告参加者所透露的对物理，心理，或社会有伤害或滥用的信息。机密将在法律范围内得到维护。我也知道经法律要求所透露的机要信息不是违反协议。

姓名：____________________________________________________

签名：____________________________________________________

日期：____________________________________________________

证人：____________________________________________________
University of Toronto

Appendix G: Procedure Map

**Study Advertised:**
Recruitment based on Word of Mouth, Posters, Advertisements, Partner agencies

10-25 Adult Children Recruited Based on Inclusion Criteria and eligibility check

Follow-Up By Phone or In Person To Outline The Study and To Obtain Informed Consent

**Conduct Interview and Assess willingness to participate in study long-term:**
Ask whether it will be possible to observe family discussions around management of health, accompany during visits to healthcare professionals, to get medications, health promotion programs etc.

Follow-up informal conversations/questions with adult children: in person, by phone or email

Member Check
A Study of **Adult Chinese Children** Who Help Their Elderly Parents Manage Chronic Illness

Is your parent an elderly (65+ years old) Chinese immigrant?

Do they have an illness that you help them manage?

Are you English fluent?

Are you 19 years of age or older?

Would you like to help healthcare professionals and researchers learn more about the experiences of adult children who help their parents deal with health problems?

**If you answered *YES* to any of these questions, you may be eligible to participate in this study. For more information please call Raza Mirza at 416-5XX-0XXX or via email at raza.mirza@utoronto.ca**

Your interest and participation is appreciated. An honorarium will be provided to eligible participants who complete the research.
I _______________ certify that as an interpreter for the study titled “A Qualitative Study of Elderly Chinese Immigrants’ Management of Chronic Illness, Use of Medicines, and Healthcare Decision-making: The Role of Adult Children”, my sole interest will be to facilitate discussions between the study researchers and the study participants.

I understand that participants in this study may reveal highly personal information about their family member’s or their own health status and their healthcare utilization. Furthermore, I agree that I will hold all information conveyed in each interview in which I act as an interpreter in strict confidence.

Print Name:

Signature:

Date:

Witness: