EXIT MUSIC: THE EXPERIENCE OF MUSIC THERAPY WITHIN MEDICAL ASSISTANCE IN DYING

by

SarahRose Mary Black

A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Faculty of Music
University of Toronto

© Copyright by SarahRose Mary Black, 2020
Exit Music: The Experience of Music Therapy within Medical Assistance in Dying

SarahRose M. Black
Doctor of Philosophy
Faculty of Music
University of Toronto
2020

Abstract

Since the 2015 legalization of medical assistance in dying (MAiD), healthcare professionals across the interdisciplinary spectrum have been exploring their roles within this practice, and a number of professions have created guidelines and policies to define their role(s). Many Canadian music therapists also found themselves implicated in care for those requesting MAiD. No prior research has been done to gain insight into the role of music therapy within the context of MAiD. This qualitative hermeneutic phenomenological study, the first of its kind, examines the experience of music therapy within medically assisted dying from three perspectives: the patient, their primary caregiver, and the music therapist/researcher.

Ten cases that vary in duration of involvement of the music therapist, demographic, characteristics, and nature of the music therapy are presented through a hermeneutic phenomenological methodology lens. A total of 24 music therapy sessions and seven caregiver interviews were transcribed and analyzed. A total 28 researcher reflections were analyzed. The analysis of data revealed thematic trends of life reflection activated by the musical interaction (wherein the music functioned as a narrator and a trigger), control (over musical and ritualistic
choices), communication and connectedness (with the self and others through music), and aesthetic pleasure (as a catalyst for therapeutic outcomes such as pain and symptom management). Caregiver participant results revealed trends of immediacy of access to emotion through music, reflection (on personal narratives within music), witnessing (of patients’ emotional and narrative expressions), and unexpected opportunities (for life review through music). Researcher reflection data analyses revealed thematic trends of trusting (in the midst of uncertainty), witnessing (of the unfolding of narratives through music), therapeutic relationship creation (with a sense of immediacy), and support for patients and caregivers in their navigation of their MAiD processes. These results may have implications as to how music therapy is offered, standardized, and implemented in settings where MAiD is provided, as the overarching thematic findings show therapeutically beneficial outcomes in terms of quality of life, life review, and symptom management. Further research is merited to continue to explore the role of music therapy in the context of assisted dying.
Acknowledgments

It takes a village to complete a PhD. I am grateful to many, especially (though not limited to) the following people…

To my co-supervisors, **Dr. Lee Bartel** and **Dr. Gary Rodin**. Dr. Bartel, thank you for believing in me through multiple iterations of academic pursuits, from my undergraduate work through my doctoral studies, and for always seeing a music therapist in me, well before I saw one in myself. You have always had my back and have supported me in times when I felt academically isolated and highly doubtful of this work. I am immensely grateful for your unending care, consistent encouragement, your level-headedness, and brilliant perspective. Words cannot fully express my gratitude to you. Dr. Rodin, thank you for supporting me not only in building the music therapy program at Princess Margaret and Kensington Hospice, but for seeing potential in my role as a researcher. Your unwavering belief in the therapeutic power of music has built my confidence, encouraged my critical thinking, and offered me incredibly unique opportunities. Thank you for instigating a radical and intuitive shift in my dissertation direction. Your ideas and perspective have shaped my clinical thinking, and I am deeply grateful. To my committee members: **Dr. Joanne Loewy**, thank you for your pioneering work in the field of music therapy, and all of your inspirational research and clinical contributions. My deepest appreciation goes to **Dr. Linda Cameron** and **Dr. Brian Abrams**, for their generous support and rich expertise. **Taylor Kurta**, thank you for being the best research assistant! You believed in this data and in the questions we were asking, and I am grateful for all of your efforts and your friendship.

To the University Health Network MAiD coordinators: **R.J. Edralin** and **Jessica Lam**, you two have been a driving force behind my capacity to implement this study and connect with patients and families. **Dr. Madeline Li**, I’m so grateful for your ongoing support of music therapy; your pioneering development of the MAiD program at UHN is inspiring. **Dr. Gerald O’Leary**, your ability to delicately balance the art and science of medicine is unparalleled. It is a tremendous honour to work alongside you, and to learn from you. To my pal **Dr. Joshua Wales**, I have deeply admired the ways in which you have intertwined medicine and music. Thank you for always supporting me. To an incredible group of research colleagues: **Ekaterina An**, **Carmine Malfitano**, **Dr. Sarah Hales**, **Dr. Rinat Nissim**, **Dr. Amy Deckert**, **Dr. Jennifer Bell**, and **Anne Rydall**. You’ve all been so generous in helping me sort out the ups and downs of REB applications, writing up protocols, and generally offering the best support I could ask for.

**Dr. Chana Korenblum**, thank you for dreaming big with me and for working together in the most wonderful, collaborative ways. To my PhD sister **Maxxine Rattner**. Thank you for being there every step of way and for believing in me. I couldn’t have done this without all our chats, shared experiences, and hugs.

To my team at the **Department of Supportive Care, The Princess Margaret Cancer Foundation**, and **PMH 16P**, especially **Drs. John Bryson, Ernie Mak, Breffni Hannon, Chris Blake, Camilla Zimmermann and Jenny Lau, and Trish Murphy-Kane**, thank you for believing in music therapy from day one; **Catherine Dirks** for helping me connect to participants and always supporting my clinical and research pursuits. **16P Nurses**, you are angels and I am privileged to learn from you every day. Thank you to Kensington Hospice: **Drs. Haley Draper, Nadine Gebara, Katie Marchington, and Warren Lewin**; to our heroic nurses, and
incredible volunteers. To Debbie Emmerson, thank you for the autonomy to pursue this path and trusting me in my goals.

Dearest friends: Tanya Andrusieczko, best friend of 19 years, incredibly generous and genius copy editor, my gratitude to you is beyond words. Thank you for always being there with a brilliant, helpful, and compassionate heart and mind, and perfectly timed phone dates. Thank you for taking this dissertation and nurturing it with your expert care. My dearest childhood friends Kim Castellano and Daniela Sinisi for the endless love, and for always celebrating all the big and little moments; Phil Mardimae for supporting me with immense kindness; Stephen Sinisi, for encouraging my writing and holding these narratives close. Matthew Baxter for keeping me honest and asking amazing questions; Kristen Walker for being the most caring and kind cheerleader; Robyn Cross for your incredible generosity of spirit, humour, and care; Amanda Wolfe and Lauren Hutton, professional inspirations and personal phenomenal friends; Sarah Pearson, Aimee Berends, and Naomi Rachlis, my music therapy sisters, with me through every experience, believing in me with such love; Dr. Peter Friedman, for unfailingly lifting my spirits, and always welcoming me into your home with love and a cocktail. And to my marvelous musical counterpart Dr. David Loach, for your clinical inspiration, constant love, ever-present support, and for grounding me in the music we both adore.

Thank you to the University of Toronto’s Faculty of Music, most especially Drs. Bina John, Lori-Ann Doloff, and Amy Clements-Cortes, for always believing in me. To Dr. Colin Andrew Lee, you gave me my footing in the profession, and I am a music therapist because of what I learned from you. Bev Foster and the Room 217 team, thank you for constant kindness. Dr. Max van Manen, your writing has been profoundly influential, and came as a guiding light at a difficult time. Your phenomenology of practice opened my mind and truly is a perfect fit for the nuanced work of music therapy at the end of life.

I feel indebted to the album “Carrie & Lowell” by Sufjan Stevens. It helped me sit with and process the stories, the lives, and the deaths. Catherine Haire, in times when I felt especially isolated, just knowing that we were traversing this path together was incredibly supportive. To a wonderful musician and righteous human, Harley Haskett. Thanks for the title, my friend. I owe you.

I would be nothing without my family. To my Mom & Dad Martha & Patrick Black, thank you for my first boost up onto the piano bench as a little kid. Thank you for never questioning my path, believing in everything music had to offer me and the world around me, and for hundreds upon thousands of hours of listening, supporting, encouraging, caring, and motivating me to work hard, dream big, and care deeply about this work. Michelle, my brilliant sister, the first person to introduce me to Leonard Cohen: you consistently pursue incredible feats of academic, professional, and personal strength, and I have and will always admire you. My brother Paul, thank you for teaching me the power of lyrics, of nostalgia in music, of telling stories. Your ability to narrate human experience has always been a huge inspiration. To my godmother Maria Scavuzzo, thank you for a lifetime of unlimited care, love, and tremendous support. Tony & Mariarosa Ascenzo, my amazing parents-in-law, you’ve supported me, cared deeply about my work and my interests, and have always been there for me through the rollercoaster of this process. Tony, thank you for conscientiously and compassionately editing my work and inspiring me in my writing process; Mariarosa, thank you for always being there to listen to my emotional
ups and downs and hugging me when I’ve needed it most. To Mike, Rina, Meghan, Anthony, our beautiful niece Jacq and nephews Michael, Nathan, Marcello, Alessandro, and James, I couldn’t imagine a better support system. I love you all very much.

A little puppy has been a delightful support throughout these past few years. Bailey, thanks for the constant reminder to always find time to go for a run or have a cuddle.

Finally, to the best person and musician I know, the love of my life Andrew Ascenzo. I could not have done this without you. There are no words to fully express how grateful I am to you for supporting me through this process. For the past fifteen years, you’ve been the most loving, committed, supportive, and caring best friend and husband I could ever imagine. I’m grateful for the countless hours, weeks, months, and years of musical inspiration and support. Thank you for always believing in me, encouraging me when I’ve doubted myself, listening to me no matter how many times I repeated myself, calming my nerves, and loving me no matter what life brings us both. Your brilliance and musicality constantly inspire and motivate me. Here’s to many, many more decades of musical adventures. Thank you, I love you.

Xo, SRB
Land Acknowledgement

As a settler living, working, and researching on stolen land, I come to this research striving to remain vigilant, aware, and awake to the conditions of this land, the traditional territory of the Mississaugas of the Credit, the Anishnaabeg, the Haudenosaunee, the Metis, and the Wendat peoples, which is within the lands protected by the “Dish With One Spoon” Wampum agreement, and which is an enduring home to many First Nations, Inuit, and Metis peoples.

The research presented in this study was conducted in institutions built on this land, and I acknowledge not only the presence of the research itself within the context of a health care system and research tradition(s) which have historically marginalized the people to whom this land belongs, but also acknowledge my positionality and power as a settler within these academic and medical institutions. While I carry unrepayable debts of gratitude to the land on which this research was conducted, and the peoples to whom this land belongs, I acknowledge that those of us with power to challenge settler colonialism and relinquish land for reparations and justice must actively do so. I have attempted to write this research with as much integrity as I felt was possible. It is my deepest hope that the truth of the voices of participants in this study shines forward, and brings with it hope for new and decolonized traditions of research that invite a balance of power and an invitation to deep listening to the narratives explicit and implicit in the qualitative tradition of this work, a methodology with roots in the oral traditions belonging to the first peoples and Indigenous peoples of this land.
Research Sites Acknowledgement

My deepest gratitude goes to the hospitals and the hospice where I was privileged to have been able to conduct this research. My immense thanks to the staff of the Princess Margaret Cancer Centre, Toronto General Hospital, and Kensington Hospice, for supporting my research study. I am grateful to the MAiD teams at the various sites, especially R.J. Edralin and Jessica Lam, and to the primary care teams at all sites who provided exceptional frontline care throughout each patient’s process. Because MAiD’s legalization is relatively new, the research was often challenging for a number of logistical and political reasons, and I am grateful to the clinical, administrative, and research staff who continue to work tirelessly to ensure optimal patient care, and who seek to more deeply understand the experiences of patients, caregivers, and clinicians so as to continue to provide the most ideal care at the most appropriate time.
Dedication

I dedicate this dissertation to my research participants.
Each of you offered your experiences at one of the most
intimate, vulnerable, and intense times in your lives.
Thank you for trusting me, thank you for your stories.

And to the incomparable G.D.
You have taught me so much about Exit Music.

Thank you all for your music.
List of Tables

Table 1.0 Data sources and corresponding participants involved
Table 1.1 Overview of patient participants
Table 1.2 List of music therapy interventions used within participant sessions
Table 1.3 Overview of caregiver participants
Table 1.4 Primary and secondary themes (Patients)
Table 1.5 Primary and secondary themes (Caregivers)
Table 1.6 Primary and secondary themes (Therapist/researcher)
List of Appendices

Appendix A: A Comprehensive Exit Music Playlist
Appendix B: Phenomenological Interview Questions: Patients and Caregivers
Appendix C: “Who really chooses the music?” A music therapist’s reflective essay
Appendix D: Study Introduction Letter
Appendix E: Canadian Association of Music Therapists’ MAiD Guidelines
Appendix F: Patient Consent Forms
Appendix G: Caregiver Consent Forms
List of Abbreviations

MAiD (Medical Assistance in Dying)
UHN (University Health Network)
PM (Princess Margaret Cancer Centre)
KH (Kensington Hospice)
TGH (Toronto General Hospital)
AYA (Adolescent and Young Adult)
# TABLE OF CONTENTS

Abstract ........................................................................................................................................................................... ii
Acknowledgments ................................................................................................................................................................. iv
Land Acknowledgement ...................................................................................................................................................... vii
Research Sites Acknowledgement ..................................................................................................................................... viii
Dedication ............................................................................................................................................................................... ix
List of Tables ....................................................................................................................................................................... x
List of Appendices ............................................................................................................................................................... xi
List of Abbreviations ........................................................................................................................................................... xii

CHAPTER ONE: INTRODUCTION ................................................................................................................................. 1
Introduction to the Topic ....................................................................................................................................................... 1
Need for Study ........................................................................................................................................................................ 3
Central Purpose of the Research ........................................................................................................................................ 5
Rationale .................................................................................................................................................................................. 5
  Central Question .............................................................................................................................................................. 9
  Primary Objective ............................................................................................................................................................ 9
  Secondary Objectives ..................................................................................................................................................... 9
  Implications ..................................................................................................................................................................... 9

CHAPTER TWO: BACKGROUND AND CONTEXT ........................................................................................................ 11
Introduction of MAiD .......................................................................................................................................................... 11
MAiD Process ...................................................................................................................................................................... 12
Researcher Positionality ................................................................................................................................................... 13
MAiD and Music Therapy: Intersections ............................................................................................................................. 15
Positioning the Topic .......................................................................................................................................................... 16
The Motivation to Study Music Therapy and MAiD ......................................................................................................... 16

CHAPTER THREE: LITERATURE REVIEW ..................................................................................................................... 18
Music Therapy ..................................................................................................................................................................... 19
  Music at End of life: A Broad Overview .......................................................................................................................... 20
  Music and Life Experiences ............................................................................................................................................ 21
Psychodynamic Music Therapy: A Clinical Framework ............................................................. 24
My Clinical Approach ............................................................................................................. 25
Music Therapy in Palliative Care: An Overview ................................................................. 25
A Personal Approach to Music Therapy in Palliative Care .................................................. 27

Early Writing and Research ..................................................................................................... 27
Expansion of Research Interests ............................................................................................ 28
Expansion of Methodologies ................................................................................................. 31
Locations of Music Therapy in Palliative and End of Life Care ............................................ 32

Palliative Care .......................................................................................................................... 33

Palliative Care and Suffering .................................................................................................... 35

Medical Assistance in Dying (MAID) ..................................................................................... 36
Overview ................................................................................................................................ 36
Process .................................................................................................................................... 37
Literature on Process and Program Development ................................................................ 38
Literature on MAID Clinician Experience ......................................................................... 38
Literature on MAID Caregiver Experience ........................................................................ 39
Literature on MAID Patient Experience ............................................................................. 40
Literature on MAID and Music Therapy .............................................................................. 41

CHAPTER FOUR: METHODOLOGY ....................................................................................... 43

A Qualitative Approach: A Personal Reflection .................................................................... 43
Interpretive Framework ......................................................................................................... 44
Philosophical Framework ....................................................................................................... 45
Intersections with the Arts ....................................................................................................... 46
Hermeneutic Phenomenology ............................................................................................... 48
Music Therapy and Phenomenology ..................................................................................... 49
A Human Science ................................................................................................................... 51

The Epoché and the Reduction ............................................................................................... 51

Phenomenological Interviews ............................................................................................... 53

Observing Lived Experiences .................................................................................................. 54

Hermeneutic Thematic Analysis ............................................................................................ 55
Analysis Process ..................................................................................................................... 56
Phenomenological Writing ..................................................................................................... 58

Research Reflections ............................................................................................................... 60

CHAPTER FIVE: STUDY DESIGN AND PROCESS ................................................................ 63

Setting and Study Sites ......................................................................................................... 63
Patient Recruitment ............................................................................................................... 63
Caregiver Recruitment .......................................................................................................... 65
Inclusion/Exclusion Criteria ................................................................................................. 66
Participant 1: Marie
Participant 2: John

CHAPTER SIX: THE EXPERIENCE OF MUSIC THERAPY AND MEDICAL ASSISTANCE IN DYING

Table 1.0 Data Sources and Corresponding Participants Involved

Table 1.1 Overview of Patient Participants

Table 1.2 List of Music Therapy Interventions Used within Participant (P) Sessions

Table 1.3 Overview of Caregiver Participants

Overview of Data Presentation

Participant 1: Marie
Participant 2: John
Table 1.5 Primary and Secondary Themes for Caregivers ................................................................. 243

Table 1.6 Primary and Secondary Themes for Therapist/Researcher .................................................... 244

CHAPTER SEVEN: FINDINGS AND THEMES ...........................................................................245

Patients: Cross-Case Findings and Themes ..................................................................................246
Life Reflection (Through Immediacy of Musical Interaction, Music was Narrator and Trigger) ................................................................. 246
Control (Over Physical, Musical, and Ritualistic Choices) .............................................................................. 247
Communication and Connectedness (With the Self and Others through Music) .................................................. 248
Aesthetics (Musical Pleasure as a Catalyst for Therapeutic Outcomes) .............................................................. 250
Through the Lenses of Existentials ......................................................................................................... 251

Symphonic: A Reflection .................................................................................................................. 257

Caregivers: Cross-Case Findings and Themes .................................................................................258
Immediacy of Emotion (Access to Emotion through Music) ................................................................. 258
Reflection (on Personal Narratives via Music) ......................................................................................... 259
Witnessing (of Loved Ones’ Emotional and Narrative Expression) ....................................................... 260
Unexpected Opportunities (for Life Review through Music) ................................................................. 262
Through the Lenses of Existentials ......................................................................................................... 263

Lullabye: A Reflection ....................................................................................................................... 268

Researcher: Findings and Themes across Ten Cases .........................................................................269
Trusting (in the Midst of Uncertainty) ...................................................................................................... 269
Witnessing (the Unfolding of Narratives through Music) ......................................................................... 271
Therapeutic Relationship Immediacy (Formation and Development through Music) ................................. 272
Navigation (of Processes, in Tandem with Patients, Caregivers, and the Music) ......................................... 273
Through the Lenses of Existentials ......................................................................................................... 274

CHAPTER EIGHT: DISCUSSION, CHALLENGES, FUTURE DIRECTIONS ................................. 280

Unique Experiences, Common Themes ............................................................................................. 280

Implications for the Role of Music Therapy in MAiD .......................................................................... 281

Implications for the Field of Palliative Care ....................................................................................... 283

Implications for the Field of MAiD ........................................................................................................ 283

Challenges of Researching MAiD ......................................................................................................... 284

Challenges in Recruitment .................................................................................................................. 287

Personal Challenges ............................................................................................................................ 288

Limitations of the Study ....................................................................................................................... 290
Dual Role of Therapist/Researcher ........................................................................................................ 290
Participant Sample Demographic ........................................................................................................ 292
Paucity of MAiD Research ................................................................................................................... 293
Next Steps and Future Research Questions ........................................................................................................... 294
Enhancing Current Guidelines ................................................................................................................................. 295
Disseminating Information ........................................................................................................................................ 296

Looking Ahead ................................................................................................................................................................. 296

REFERENCES .................................................................................................................................................................... 299

APPENDICES ................................................................................................................................................................. 324
Appendix A: A Comprehensive Exit Music Playlist ................................................................................................... 324
Appendix B: Phenomenological Interview Question Guide: Patients and Caregivers ............................................. 326
Appendix C: Reflective Piece: Who really chooses the music? (November 2018) .................................................. 327
Appendix D: Study Introduction Letter ....................................................................................................................... 328
Appendix E: Canadian Association of Music Therapists’ (CAMT’s) Practice Guidelines: MAiD ...................... 329
Appendix F: Consent Form (Patients) .......................................................................................................................... 333
Appendix G: Consent Form (Caregivers) ........................................................................................................................ 340
All names and certain identifying details have been changed in order to protect participant privacy.
DEATH, be not proud, though some have called thee
Mighty and dreadful, for, thou art not so;
For those whom thou think’st thou dost overthrow
Die not, poor Death, nor yet canst thou kill me.
From rest and sleep, which but thy pictures be,
Much pleasure; then from thee, much more must flow.
And soonest our best men with thee do go,
Rest of their bones, and soul’s delivery.
Thou art slave to fate, chance, kings, and desperate men,
And dost with poison, war, and sickness dwell,
And poppy, or charms can make us sleep as well
And better than thy stroke; why swell’st thou then?
One short sleepe past, we wake eternally,
And death shall be no more; Death, thou shalt die.

– John Donne, *Holy Sonnets, X*
CHAPTER ONE: INTRODUCTION

Music is strange…but I think it’s good.

- Daughter of Participant #1

Introduction to the Topic

Amethyst and flowers on the table, is it real or a fable?
Well I suppose a friend is a friend, and we all know how this will end
Chimney swift that finds me, be my keeper
Silhouette of the cedar
What is that song you sing for the dead?
What is that song you sing for the dead?

- Sufjan Stevens, “Death with Dignity”

Within the scope of clinical music therapy, accredited music therapists commonly work with individuals who have life-threatening illnesses, both in community settings as well as in institutional facilities. Within these contexts, medical assistance in dying (MAiD) is currently available and being administered to patients in Canada who request it and meet the eligibility criteria (CPSO, 2016). Music therapists are frequently called to the bedside to provide care for individuals at end of life, and this professional role now may extend to caring for those choosing to end their lives through receiving MAiD.

Music therapy is defined by the Canadian Association of Music Therapists as a discipline in which credentialed professionals (MTA, Music Therapist Accredited, or MT-BC, Music
Therapist, Board Certified) use music purposefully within therapeutic relationships to support development, health, and well-being. Music therapists use music safely and ethically to address human needs within cognitive, communicative, emotional, musical, physical, social, and/or spiritual domains (CAMT, 2016). Music therapy in palliative care became formalized through clinical practice and academic publication in 1978 by music therapist Susan Munro and physician Dr. Balfour Mount (Munro & Mount, 1978). However, the connections between music and medicine have been noted, observed, and discussed for centuries. The linkages between music and health span centuries of medical, industrial, technological, and even legislative changes such as the legalization of assisted dying (Health Canada, 2019). A growing body of qualitative and quantitative research (Edwards, 2007; Wheeler, 2005) has created a platform for music therapists to expand their clinical practice, the populations they serve, and the settings in which they are served.

Although the decriminalization of MAiD is relatively recent, close to 7000 Canadians have now received this intervention (Government of Canada, 2019). While music may play numerous roles at the end of life, including support for pain management, anxiety reduction, and emotional care (Dileo & Loewy, 2005), there is no formal research on the role of music in MAiD. Music therapy has been practiced in hospice palliative care in a variety of modalities and intervention styles. These include but are not limited to: clinical improvisation, in which client and therapist spontaneously create sounds on various instruments and with voice (Lee, 2000); receptive music therapy, in which client listens to music that the therapist provides (Grocke & Wigram, 2007), also referred to as inter-active listening, (Black, 2014); song-writing (Baker & Wigram, 2007; O’Callaghan, 1996), and active playing (Bruscia, 1998). Music at end of life is not necessarily formalized in the manner of a music therapy session with a trained clinician.
Music can be offered, performed, presented, engaged with, and experienced in countless ways, depending on a patient’s cultural traditions, family/friend involvement, and staff engagement (Gregory, 1997; Nightingale et al, 2014). The spontaneous singing of hymns may occur naturally and frequently at the bedside, or an audio recording may be intentionally played in the middle of a sleepless night. Beyond these practices, music plays an essential role in supporting the dying process, as well as in grieving and mourning in many different cultures (Clements-Cortes & Varvas Klinck, 2016).

There are a number of differences in the dying processes of those who receive MAiD and those who die of a terminal illness without medical intervention, such as having some control over the time of death rather than awaiting physiological changes with unknown timelines. While individual requests for music at end of life are highly unique, so too are the song choices during various clinical interventions. Patients and families have requested live music in these instances for numerous reasons, although a primary motivation is most often to have a soothing, non-invasive distraction to providing relaxation and physiological ease (Klassen et al, 2008). During MAiD, a relatively new addition to the intervention options for patients, music plays its own unique role, which varies from patient to patient. Although no formal research in this area has yet been published, music has been noted to be a trend among those requesting MAiD (Black, 2017).

**Need for Study**

“I think of research as advocacy. It is a tremendous challenge to help people to understand Music Therapy even though to us (Music Therapists) it often seems very natural and sensible. Research is great for helping people understand our work.”

— C. Kenny, personal communication
As an accredited music therapist working in a hospital setting in an urban cancer centre and residential hospice in downtown Toronto, I have witnessed diverse and multifaceted palliative and end of life experiences. Because of the diversity of the population of patients and families that this cancer centre and hospice cares for, the number of different approaches to death and dying vary tremendously. Some patients are entirely private in their dying while others seek out specific services, family members, religious experiences, or rituals which shape and punctuate their dying experience. When assisted dying became legalized in Canada, yet another option became part of the end of life care provided at many of these facilities. Assisted dying was an entirely new phenomenon for Canadian health care, and as such, our interdisciplinary teams and clinicians were required to create guidelines and position statements in order to begin to standardize how each professional service intersected with this new form of care. Organizations such as the Canadian Medical Association (CMA), the Canadian Nurses Association (CNA), and the Canadian Association of Social Workers (CASW) published their positions, including best practices of how to approach assisted dying (Canadian Association of Social Workers, 2017; Canadian Medical Association, 2017; Canadian Nurses Association, 2016). Many music therapists across Canada, myself included, were asked to be present during assisted deaths before practice guidelines were written and without formal support available to us.

In March of 2017, the Canadian Association of Music Therapists (CAMT) published practice guidelines, co-authored by me, Adrienne Pringle, and Karie Rippin-Bilger, (accredited music therapists), and Dr. Madeline Li, psychiatrist (Black, Pringle, Rippin-Bilger & Li, 2017). Canadian music therapists found the guidelines to be informative, helpful and supportive in guiding music therapy within assisted dying. However, no research was available in Canada or in other countries to support further understanding and implementation of best practices in this
field. All information about approaches to music therapy and assisted dying was based on clinical experience and narrative reports, and no research had been done on any aspect of music therapy in the context of this particular form of end of life care.

**Central Purpose of the Research**

The prevalence of assisted dying has markedly increased since its legalization in 2015 and as a result, various health care professions have noted an increase in their involvement in the clinical process of assisted dying (Li et al, 2017). The increase in assisted deaths necessitated a deeper understanding of the procedure in order to streamline not only the process of applying for and receiving MAiD, but also in guiding various health care professionals in how best to support patients and families requesting and receiving this procedure. The absence of research in the field of music therapy and MAiD required developing best practices and understanding experiences of music therapy and MAiD. Hence, the purpose of this study is to qualitatively explore the role of music therapy within the context of MAiD from the perspectives of patients, caregivers, and the music therapist, in order to take the first step in understanding possible best practices within this area, and to further contribute to the clinical availability of interventions for people facing the end of life.

**Rationale**

When faced with imminent threats to our mortality such as a life-threatening illness, humans may seek comfort and support, or affirmations of values and priorities (Lo et al, 2015). The amount of time that we have left to live may be called into question, either imminently or on a spectrum that may range from months to years. When mortality is threatened, humans may tend to engage in a number of behaviours, based on how they have historically responded to threats or
stressful situations. Some tendencies may include increased help-seeking and reflective functioning, a heightened need for authenticity, as well as increased motivation and sense of urgency to address existing interpersonal and existential issues (Hales, Rodin & Lo, 2012). Life review and legacy work may also become a priority, creating an opportunity to reflect on accomplishments, regrets, relationships, and hopes for their loved ones’ futures (Chochinov et al, 2011). Among these priorities are often musical choices. Musicologist David Hesmondhalgh suggests that musical choices represent a meeting point of the private and public realms, providing encounters of self-identity, representing who that individual is and is not, and with collective identity, representing who the group is and is not (2008). These encounters of self-identity are notably manifested in the various interventions provided by music therapists in many different settings, but particularly in hospice palliative care, when a heightened need for authenticity tends to emerge (Hales, Rodin & Lo, 2012).

Music and music therapy at end of life in hospice palliative care provides physical, emotional, spiritual and psychosocial support to patients and their families (Clements-Cortes, 2010; Dileo & Loewy, 2005; Hilliard, 2005; McConnell, Scott & Porter, 2016; Schroeder-Sheker, 2017). Additionally, music therapy is often used alongside various clinical interventions such as pain management in burn treatment (Prensner, Yowler, Smith, Steele & Fratianne, 2001). Because music is used frequently at end of life in various contexts, evidence is needed regarding its benefit, potential usage and outcomes, and how it can best be applied in order to establish practice guidelines and improve its delivery in MAiD. The purpose of this qualitative study was to gain insight into the experience of music therapy (as defined above, with clearly articulated assessments and clinical goals), as initiated/offered by a music therapist for an individual requesting and receiving MAiD. This study is designed to understand the experience of and role
of music therapy before (from the time of the MAiD request from the participant) and potentially (if the participant requests) during this specific clinical intervention, and to inform an evidence-based approach to offering music therapy during MAiD in future cases.

Music therapists may work with individuals requesting and receiving MAiD at various points in their care. The music therapist may engage in music therapy interventions (e.g., receptive, active, psychodynamic, song-writing, etc.) from before the patient requests MAiD to the time of the procedure itself. The therapist may engage in a psychodynamic role of supporting the client/patient in processing emotion before the assessment, or during the reflection period between assessments (please refer to Chapter Two for a more detailed description of the MAiD process of assessments and intervention). Live or recorded music may be provided at bedside before, during, and/or after MAiD, which may involve being present during the administration of the intervention, alongside the client/patient and interventionist, and other requested individuals. Additionally, a patient’s family/caregivers or clinical team may be asked to provide music at the bedside during the intervention. The music therapist may be asked to set up the audio equipment required if the client/patient requests particular recordings of music to be played during the intervention. Finally, the clinical health care team may require support before, during and/or after the MAiD intervention takes place. The music therapist may be asked to engage the staff in a ritual at bedside after MAiD, or at a separate de-briefing session, or in extended staff support through psychodynamic processing (e.g., group improvisation or song-writing).

---

1 This particular modality of staff support was initially developed and piloted with my colleague Sharon Konyen, a spiritual care professional who works with similar populations at the cancer centre where this research was conducted. Together, we organized and facilitated a bedside ritual (after the patient’s family left, and gave us explicit permission to spend time with their deceased loved one) following our first MAiD case in 2016.
Music therapists have a responsibility to provide culturally sensitive and appropriate music in their practice. While music therapists can offer music in a number of forms and modalities, it is critical that music is also offered in a cautious, culturally sensitive way (Stige, 2002). For this reason, in each music therapy session provided by the therapist/research as part of this study, careful attention was paid to cultural aspects of the patient experience, e.g., culturally appropriate music as requested, and adapting to the needs to patients as they varied based on cultural specificity.

Although there is little to no literature specifically on music and MAiD, there are a number of intersections between MAiD and music/music therapy in palliative care, which will be explored in detail within the dissertation. Within the field of palliative care, music therapy is often used as an adjunct form of pain and symptom management, and emotional support, and has become an increasingly utilized form of care in palliative and end-of-life settings (Clements-Cortes, 2004; Hilliard, 2005). Music therapy in palliative care is defined as “the creative and professionally informed use of music in a therapeutic relationship with people identified as needing physical, psychosocial, or spiritual help, or with people aspiring to experience further self-awareness enabling increased life satisfaction and quality” (O’Callaghan, 2004, p. 1041). Within the context of MAiD, little is known about the psychosocial or emotional processes of those who request it, or of their family members and clinicians. However, initial case studies and informal narratives and experiences of MAiD suggest many of the same elements apply, such as use of music in a therapeutic relationship for people identified as needing physical/psychosocial care (Black, 2017; Wales, 2017). Yet, it is unclear whether those requesting MAiD are also seeking to “further self-awareness enabling increased life satisfaction and quality” through music. This will be explored in the data analysis.
This study is the first of its kind in investigating and exploring the role of music therapy in MAiD in Canada. The music therapy profession is growing and developing as a result of ongoing rigorous and thoughtful research, and the knowledge translation of this particular study meets a need not only in the research but also in the clinical work. The intention is to use the information gathered from the study to further promote music therapy as an essential standard of care across the country.

Central Question

This research study poses the following question: What is the experience of music therapy within the context of medically assisted dying, for the patients, caregivers, and music therapist involved?

Primary Objective

To qualitatively explore the experience of music therapy in the context of medical assistance in dying for patients requesting and receiving this procedure.

Secondary Objectives

To qualitatively explore the experience of music therapy in the context of medical assistance in dying for caregivers of those requesting and receiving this procedure, and to qualitatively explore the experience of music therapy in the context of medical assistance in dying for a music therapist providing care for those requesting and receiving this procedure.

Implications

The outcomes of this study and the dissemination of its findings may include an enhancement of our understanding of how to approach music therapy within assisted dying, information which is otherwise not currently available for music therapists and other health care providers involved in MAiD. This study may serve to guide music therapists in providing optimal care for patients and families/caregivers based on qualitative data, grounded in a phenomenological exploration of
experience. The data resulting from this study may provide the initial groundwork for further research into this field.
Caring for the dying is itself a deep contemplation and reflection of your own death.

- Sogyal Rinpoche, *The Tibetan Book of Living and Dying*

**Introduction of MAiD**

On February 6, 2015, the Supreme Court of Canada ruled in response to the case of Carter v. Canada (Attorney General, 2015) that a complete ban on assisted dying was a violation of the Canadian Charter of Rights and Freedoms of competent adults with grievous and irremediable suffering, seeking assistance to end their lives. As a result, parts of the Criminal Code would need to change in order to permit medical assistance in dying (Government of Canada, 2019). At this point, the Supreme Court of Canada allowed the Federal Government until June 6, 2016 to create and implement new legislation, which was accomplished, allowing eligible adult Canadians to request and receive medical assistance in dying (MAiD). To date, assisted dying is legal across Canada, but in the absence of regulation, each province and territory has slightly different policies and procedures (Government of Canada, 2019). Different institutions have different protocols around access to assisted dying, as not all institutions offer the intervention on the basis of moral/religious or logistical grounds. In the province of Ontario, doctors and nurse practitioners can provide MAiD (depending on their practice site) as long as specific policies and procedures are followed, and legislation is upheld.

In accordance with federal legislation, MAiD includes circumstances where a medical practitioner or nurse practitioner, at an individual’s request: (a) administers a substance that
causes an individual’s death; or (b) prescribes a substance for an individual to self-administer to cause their own death (CPSO, 2016). In order for an individual to request and receive this medical intervention, an intervention team must assess the individual to determine whether the individual meets eligibility criteria. Criteria include the following: the individual must have a grievous and irremediable medical condition (including an illness, disease or disability), must make a voluntary request for MAiD that is not the result of external pressure or coercion, and must provide informed consent to receive MAiD after having been informed of the means that are available to relieve their suffering, including palliative care (Government of Canada, 2019).

**MAiD Process**

Typically, an initial assessment is done after a request for MAiD is received, followed by a waiting period in which the individual is meant to take time to reflect on their request. At the end of the waiting period (at least ten clear days, which can potentially be shortened due to an anticipated loss of capacity to provide consent), a second assessment is conducted, and eligibility is reassessed. Once the intervention is approved, the intervention physician or nurse practitioner meets with the individual on the scheduled intervention day, and does a final assessment determining cognitive capability of the individual to make the decision without influence or coercion. During the intervention, the physician and/or nurse practitioner administers up to four medications to sedate the individual, induce coma, and stop the heart. This process generally occurs over a matter of minutes; music is frequently requested to accompany this procedure.

In the brief time since MAiD has been implemented as a clinical intervention in Canada, there has been no other research on the use of music during the procedure, and based on a literature search, there is no literature on the use of music during assisted dying. There is no available research on the role of music during assisted dying in other countries where it has been
legal for a number of years. There are no available guidelines on the use of music during assisted
dying from other countries. However, there have been several documents published on the role
of music during MAiD, including the Canadian Association of Music Therapists’ (CAMT)
Practice Guidelines for Medical Assistance in Dying (Black, Pringle, Rippin-Bilger & Li, 2017).
These guidelines indicate options for the use of music before, during, and after MAiD, as well as
practical and ethical considerations for music therapists involved in the intervention.
Additionally, the Cancer Knowledge Network published a paper based on my personal clinical
experiences (Black, 2017a) on the role of music during MAiD, indicating applications of music
as well as contexts in which music could be applied. An article was published for Ensemble
Magazine (a CAMT publication) regarding the role of music within MAiD, positioning the
impact of music within the setting of assisted dying (Black, 2017b).

**Researcher Positionality**

In the tradition of reflective practice in therapy (Stedmon & Dallos, 2009) as well as in research
(Mills, Durepos & Wiebe, 2010) I locate myself as a qualitative researcher in the following
ways. I am a thirty-two-year-old Canadian woman identifying as female of East Indian (Goan)
and Southern Italian (Calabrese) heritage (first-generation on my mother’s side; second
generation on my father’s side). I am an accredited music therapist with the Canadian
Association of Music Therapists, a registered psychotherapist with the College of Registered
Psychotherapists of Ontario, a psychosocial oncology clinician, musician, researcher, academic,
teacher, and supervisor with a background in classical piano performance, music education,
pedagogy, and aesthetic/person-centered music therapy. Susan Munro-Porchet’s (2005)
“personal guidelines for end of life work” (p. 227) have been markedly influential and deeply
grounding and shaping in my own practice, and include the following:
• Human beings have no defense against the impact of music, therefore use it with great care.

• Search to discover the “music child” (Nordoff & Robbins, 1977, p. 1-2).

• Allow the patient to lead in the direction that s/he deems to be right. Respect his/her way.

• Music therapy is a process. Don’t push too hard towards goals.

• Risk making mistakes.

I practice as a person-centered medical music psychotherapist, creating clinical goals based on patient request and clinician assessment, with an interest in psychodynamic theory (Berzoff, Melano, Flanagan, & Hertz, 2011) and a strong focus on interdisciplinary collaboration in my work. I have been working in the field of psychosocial oncology and palliative care as an accredited music therapist and registered psychotherapist for six years, with experience in hospital cancer care as well as residential hospice care. As a novice qualitative researcher, I seek to explore lived experience through narrative accounts and expressive arts, and emphasize different modalities of data collection (e.g., music, poetry, and interviews).

Of utmost importance to my professional practice is paying homage to the music therapists and psychosocial clinicians who came before me and built the foundation of the work I am privileged to do today. They are too numerous to name; however, many are highlighted in Acknowledgements section of this dissertation. I also owe a debt of gratitude to my music therapy students whose unique and diverse perspectives constantly challenge and teach me new ways of considering the work we all do and influence my ever-evolving positionality and style of practice. My students have been remarkably inquisitive and have offered brilliant new perspectives on what music therapy stands for and what it means as we engage in new and emergent interventions and ask innovative research questions.
MAiD and Music Therapy: Intersections

Wish the sun to stand still. Reaching out to touch our own being, past a mortal as we, here we can be, we can be here, be here now. Here we can be.

- Yes, “Awaken”

While each individual’s requests for music at end of life are highly unique, so too are their song choices during various clinical interventions. I have been asked to be present at patients’ bedsides with live music for a number of different medical procedures including bronchoscopies, lumbar punctures, intravenous needle insertion, radiation, chemotherapy, dressing changes, bed baths, and medication administration. Patients, families and staff have requested live music in these instances for a number of reasons, but a primary motivation is to have a soothing distraction and non-invasive approach to providing relaxation and physiological ease (Klassen et al, 2008). In the case of medical assistance in dying (MAiD), music plays a unique role, which varies from patient to patient. In my own clinical work, and as of writing this paper, I have been involved in the care of twenty-four patients who have requested and received MAiD. Each patient had a unique relationship to music, as well as highly individual requests for music during their intervention. All but one patient requested specific music during the intervention, and in each case, the music was live (as opposed to recorded) and the music spoke to the patient’s needs at the time.

Music therapists may work with individuals requesting and receiving MAiD at various points in their care. The therapist may engage in a psychodynamic role of supporting the client/patient in processing emotion before the assessment, or during the reflection period between assessments. Live or recorded music may be provided at bedside before, during, and/or
after MAiD, which may involve being present during the administration of the intervention, alongside the client/patient and interventionist, and other requested individuals.

If the client/patient requests particular recordings of music to be played during the intervention, the music therapist may be asked to set up the audio equipment. Finally, the clinical health care team may require support before, during and/or after the MAiD intervention.

**Positioning the Topic**

In my six years working as an accredited music therapist and registered psychotherapist at Princess Margaret Cancer Centre and Kensington Hospice, I have developed an inpatient service with widespread interdisciplinary collaboration including clinical work and research alongside various other healthcare professionals such as physicians, nurses, occupational therapists, physiotherapists, spiritual care professionals, social workers, and psychiatrists. In my daily clinical work, I bring music to people in a time of illness and complexity, often within the context of end of life care. In attending to these situations on a daily basis, I continually ask myself the following questions: what can music do for someone facing end of life, and how does music function as a key factor in someone’s experiences of illness, specifically in the oncology realm? While there are various answers in the literature on music therapy and palliative care, I have begun to develop my own answers, through bearing witness to the daily experience of sitting with patients, which continues to inform how I think about this question.

**The Motivation to Study Music Therapy and MAiD**

When the Supreme Court struck down the ban on assisted dying, the hospital in which I work (Princess Margaret Cancer Centre) began to receive requests and was required to implement a process in order to support patients who wanted an assisted death. Our hospital network’s very
first patient to receive assisted death had chosen a final song to have playing in the background while she received the injections that would end her life. What surprised me and ignited a fierce curiosity was her choice of song, particularly because she shared that it represented how she hoped her family would remember her.

At the time, I had been working as a music therapist for approximately three years and had completed two years of my doctoral work, and I noticed the new questions I had about the experience of music within a planned and controlled end of life; the process was different than any of the palliative, hospice, and end of life situations of which I had previously been a part. Almost one year after our hospital’s first MAiD patient, and after my own experience of numerous MAiD deaths accompanied by music, a casual hallway conversation with one of my doctoral supervisors, Dr. Gary Rodin, led to his suggestion that I change my doctoral thesis research topic; after all, I was the only music therapist in Canada actively writing and publishing MAiD and music therapy content. I had been writing about the experiences and creating and publishing a set of guidelines on behalf of the Canadian Association of Music Therapists in order to provide structure and support for Canadian music therapists choosing to care for MAiD requestees and recipients. With tremendous institutional and academic support, I shifted my research. Over the next two years, ten patient participants invited me into their experience of music therapy in the context of assisted dying, revealing insights, ideas, themes, trends, and phenomenological perspective, resulting in this dissertation.
CHAPTER THREE: LITERATURE REVIEW

The wild swan's death-hymn took the soul
Of that waste place with joy
Hidden in sorrow: at first to the ear
The warble was low, and full and clear;
And floating about the under-sky,
Prevailing in weakness, the coronach stole
Sometimes afar, and sometimes anear;
But anon her awful jubilant voice,
With a music strange and manifold,
Flow'd forth on a carol free and bold.

- Alfred Lord Tennyson, *The Dying Swan*. 
Music Therapy

Music therapy is a professional health discipline in which credentialed professionals use music purposefully within therapeutic relationships to support development, health, and well-being (CAMT, 2016). Music therapists’ mandate is to use music safely and ethically to address human needs within cognitive, communicative, emotional, musical, physical, social, and spiritual domains (CAMT, 2016). Because this definition is quite broad, I suggest that at its most fundamental and basic essence, music therapy is the use of music in a therapeutic relationship to achieve clinical goals. Within my own practice, I define music therapy as consistently involving three core ingredients: the client or patient, the therapist, and music itself. While the practice of music therapy has expanded, shifted, and grown exponentially within the past several decades, music therapy fundamentally deals with human emotion and relationship (Clements-Cortes, 2010). There is an extensive and ever-expanding body of knowledge and research literature that suggests music therapy can have various functions in different health care modalities, including as a neurological rehabilitative modality (Thaut, 2016) and these rehabilitative processes can manifest in a variety of ways including as a trigger for memory, a tool for speech rehabilitation, and a means of rehabilitating gait and physical movement (Thaut, 2005).

The primary focus of this specific music therapy study and the corresponding relevant literature review will be primarily music as a psychotherapeutic tool (Bruscia, 1998; Nolan, 2005), meaning as a vehicle for self-expression (Clements-Cortes & Varvas Klinck, 2016), a catalyst for catharsis (Austin, 2009), a method of perceiving experience (Austin, 2009), a support in times of physical distress (Krout, 2001), a source of presence amidst suffering (Salmon, 2001), a language for articulating emotion (O’Callaghan, 1996), and a canvas to create meaning (Daykin, 2007).
Music at End of life: A Broad Overview

Although Fran Herman pioneered the formalization of music therapy in Canada in 1956 (Buchanan, 2009), and music therapy in palliative care became formalized through clinical practice and an academic publication in 1978 by music therapist Susan Munro and physician Dr. Balfour Mount (Munro & Mount, 1978), the links between music, medicine, healing, and psychotherapeutic care have been noted, observed, and discussed for centuries. Sixth century (BC) Greek philosopher and scientist Pythagoras claimed that daily singing could lead to emotional catharsis and ultimately improve one’s physical and emotional health (Conrad, 2010). Two centuries earlier, Aristotle wrote extensively about music’s various effects on the body, mind, and soul, specifically taking interest in music’s cathartic qualities and abilities to heal and purify the soul through the use of various musical modalities and scales (Aristotle, trans. 1920). Music at time of death has been referenced in literature and art in many ways, including countless references to the “swansong”, the final lament (OED, 2016) sung or performed (both literally and often metaphorically) by someone as a punctuating point of finality. As noted by Meredith and Kozbelt (2014), creators (those who embody the creative arts e.g., music, dance, visual art) approaching death may undergo a profound self-assessment, whereby they are motivated to produce transcendent final works embodying their creative legacy before time runs out, an example of the “swansong phenomenon” and one in which music plays a particular role. The linkages between music and health span centuries of medical, industrial, technological, and even legislative changes.

Music at the end of life is not always necessarily formalized as a music therapy session with a trained clinician. Music can be offered, performed, presented, engaged with, and experienced in countless ways depending on a patient’s cultural traditions, family/friend
involvement, and staff engagement (Nightingale et al, 2014). Sub-specializations of music in health care at end of life include practices such as music thanatology, the practice of prescriptive “music vigils” during which the clinician-musician observes physiological changes, cues, and breathing patterns and synchronizes music (generally offered with harp and voice) to support the patient’s physical condition in dying (Freeman et al, 2006). Beyond these practices, music plays an essential role in grieving and mourning in many different cultures (Clements-Cortes & Varvas Klinck, 2016; Potvin, N., Bradt, J., & Ghetti, C. (2018). A growing body of qualitative and quantitative research (Edwards, 2007) has created a platform for the professional field of music therapy to expand its clinical practice, the populations served, and the settings in which service is provided.

**Music and Life Experiences**

From an ethnomusicological perspective, people connect to music differently for various reasons at a number of different points in their lives. Some songs may represent their childhood, such as lullabies and children’s songs. Some songs may represent their adolescence, such as music associated with young adulthood and the changes that occur therein, and others songs may represent significant experiences of heightened emotion or change, such as weddings, celebrations, changes in relationships, and deaths (Gregory, 1997; Schafer, Sedlmeier, Stadtler, & Huron, 2013). Notably, according to Zatorre and Peretz (2001), musical activities have been present in every known culture on earth, dating back over 250,000 years.

According to Merriam (1964), music can function in a number of ways including giving opportunity for emotional expressions, specifically “the release of otherwise unexpressible [sic] thoughts and ideas” (p. 222). Merriam suggests that music can function as entertainment, communication, symbolic representation, physical response, enforcing conformity to social norms, validation of social institutions and religious rituals, and contribution to the continuity.
and stability of culture (Merriam, 1964). Music that connects us to our adolescence and youth may enhance a sense of self-preservation, self-identity, and wellbeing (Hallam & Creech, 2010). Musicologist Tia DeNora points to the use of music as an aesthetic agent, a cultural resource that may be used for “the mobilizing work of self-construction and the emotional, memory-based, and biographical work such a project entails” (DeNora, 1999, p. 32). DeNora suggests that intimate musical practices (e.g., individualized forms of “human-music interaction”) are an ideal vantage point for viewing music “in action,” (e.g., observing and understanding how music is implicated in the construction of the self as an aesthetic agent). DeNora’s theory can be applied to individualized psychodynamic music therapy techniques (e.g., receptive listening at bedside) as a vehicle for understanding one’s own self-construction and self-identity, because music may bring up surface-level or repressed emotions, memories or biographical representations of self (e.g., legacy work).

Music at end of life may serve a number of purposes such as relaxation, pain and symptom management support, nostalgia, and catharsis (Dileo & Loewy, 2005; Loewy, 2019). Sounds themselves within hospitals may have a profound effect on individual and caregiver experiences (Sen, 2020). The music may also reflect an individual’s life through legacy song-writing, playlist creation, and life review (Clements-Cortes, 2010). Music therapists commonly guide individuals through this style of therapy in hospice palliative care. The music that is chosen often represents moments that were significant in an individual’s life, through various stages, states of being, relationships, and experiences.

The use of music to reflect on one’s life or one’s death may offer a cathartic and therapeutic opportunity for relationship completion (Clements-Cortes, 2009), or a means of processing the emotions they are experiencing in facing death. Musician and professor of sound
studies Michael Bull notes that often people use music to construct their own narratives (Bull, 2006). Bull suggests that these self-constructed narratives may make conscious and subconscious linkages to significant moments of childhood, adolescence and other developmental stages. In reflecting on one’s narrative(s) when mortality is threatened at end of life, musical choice may offer an opportunity for individuals to reflect on their experiences however also create their own narratives based on the immediate experience of dying. Music may also offer an opportunity to engage in a ritualistic practice of marking specifically significant moments, occasions, experiences, or events, such as birth, celebrations, rites of passages, and death/burial (Gregory, 1997). These experiences may be seen to manifest as existential or spontaneous communitas, what is known as a transient personal experience of togetherness, specifically because the process is that which occurs during a unique (non-everyday) activity, namely music therapy within assisted dying (Turner, 2012).

In my clinical work, many patients and/or patients’ families and loved ones have chosen playlists for time of death, whether the death is assisted or not. These playlists are played in the individual’s final hours to days of life. Many patients choose joyous music, while others choose music specifically to create a physiological or mental state (e.g., music for relaxation). In my own clinical experience, the most prevalent style of playlist is that which represents the patient’s life, through songs that contain deeply felt meaning that may take on newly constructed narrative. For example, a patient created a playlist that spanned joyous moments from his childhood and ended with the music he had pre-selected for his funeral service. He told me that the music felt “like a warm blanket made up of my life stories,” comforting him but also reflecting his past, present, and future self. In psychodynamic terms, an empathic mirroring of self occurs when the patient feels the music reflects them and their values or experiences (Austin,
While individuals with varying prognoses and predicted timelines before death may undertake this process, choosing music can also provide an opportunity for narrative construction when death is relatively planned, as it is with MAiD, or when time of death is unknown, as it is with a natural death.

**Psychodynamic Music Therapy: A Clinical Framework**

Psychodynamic music therapy is one of the primary ways in which I navigate my own clinical practice and has been the theoretical basis for my clinical care (assessments and interventions, described in further detail below) throughout this research study. According to Ken Bruscia, psychodynamic music therapy is the use of musical experiences to facilitate the interpersonal relationship of therapist and client as well as the therapeutic change process (1998). Therapist and patient create or listen to music as a primary means of building rapport, communicating, relating to one another, working towards goals, and deepening self-awareness (Bruscia, 1998). Within psychodynamic music therapy, a multitude of techniques may be employed in order to facilitate the therapeutic relationship and promote therapeutic change, including clinical improvisation. Psychodynamic music therapist Mercedes Pavlicevic (2000) suggests that the point of improvisation in music therapy is not to “make good music” as in a performative exchange, but rather to create an intimate interpersonal relationship between therapist and client through the musical event. She explains that “good music” does not necessarily equal an authentic interpersonal relationship in music therapy; the authenticity of the relationship may be generated or portrayed in “unmusical sounds,” if there is an atmosphere of openness, non-judgment, and empathic listening. Colin Lee (2001) defines improvisatory music therapy as the spontaneous creation of music/musical elements by patient and/or therapist, a platform for therapeutic rapport. Music can provide a safe opportunity to explore feelings/experiences in that
undesired or repressed material in a musical form is often not perceived to be as threatening as when it is expressed verbally (Scheiby, 1998).

**My Clinical Approach**

Within my own clinical practice, I adopt and adapt a number of these styles of psychodynamic music therapy with a focus on patient-centered goals, in the context of alleviating and/or supporting the experience of distress related to disease burden and impending mortality (Rodin et al., 2018). In oncology and hospice palliative care, music itself (live and recorded) plays multiple roles at various times. In my clinical work, music therapy in psychosocial oncology typically involves a referral generally from a member of an interdisciplinary health care team (e.g., physician, registered nurse, social worker, and/or allied health team member) on one of the inpatient units of the cancer centre (e.g., bone marrow transplant, malignant hematology, solid tumor, or inpatient palliative care). An initial assessment of the patient’s psychosocial stressors and current needs (as per a chart review, the clinical team’s assessment, and the patient’s and/or family’s/friend’s specifically articulated concerns) is conducted and continues as a fluid process through each music therapy session.

**Music Therapy in Palliative Care: An Overview**

The formal scope of music therapy in palliative care practice is defined as “the creative and professionally informed use of music in a therapeutic relationship with people identified as needing physical, psychosocial, or spiritual help or with people aspiring to experience further self-awareness enabling increased life satisfaction and quality” (O’Callaghan, 2004, p. 1041). This definition is essential to the development of music therapy in the field of palliative care. However, my professional approach, influenced by Rattner & Berzoff’s (2016) concept that suffering may be an intrinsic part of dying and may be unchangeable, is focused more primarily on the use of music in relationship to support patient-driven needs, and not necessarily on
increasing life satisfaction or quality. I position myself as a clinician who moves alongside the patient and family/friend group in order to best support their fluid needs and requests within and around palliative and end of life care.

Interventions in hospice palliative care are typically conceptualized in one of four categories: receptive (listening to music, music for relaxation, guided imagery, etc.), improvisational (empathic and referential improvisations to externalize emotional content), re-creative (adaptations of familiar music, lyrics analysis, life review through song), and compositional/song-writing (Clements-Cortes & Varvas Klinck, 2016). Music can provide physiological support through effective symptom management (Krout, 2001), emotional support through psychodynamic modalities (Daykin, 2007), spiritual support through psycho-spiritual musical processes (Salmon, 2001), strengthening of self-identity, and legacy creation and relationship completion through song-writing and lyric analysis (Clements-Cortes, 2010). In some instances, patients are aware of these clinical goals and request music or intervention styles based on their needs. At other times, family members or loved ones help make the decision(s) if the patient is experiencing fluctuating levels of consciousness. At all times, my personal practice is to remain patient and family centered through the use of music in addressing the various challenges presented by life-threatening illnesses.

Dileo and Dneaster’s 2005 model of music therapy, presented in Dileo and Loewy’s (2005) comprehensive overview of music therapy at the end of life suggests that typical music therapy goals within palliative care are organized according to physiological, psychosocial, cognitive, and spiritual domains, with the caveat that “each domain influences and is influenced simultaneously” (xix-xx). They categorize music therapy goals in end of life care in the following groupings: physiological goals (e.g., managing pain, increasing comfort, and
decreasing agitation), psychosocial goals (e.g., enhancing non-verbal communication and facilitating adjustment to limitations and losses), cognitive goals (e.g., increasing orientation and providing sensory stimulation), spiritual/existential goals (e.g., enhancing creativity and addressing anticipatory grief), and goals for families and caregivers (e.g., assisting with coping and grief/bereavement work) (xx-xxi). These authors present three levels of practice of music therapy in palliative care: the supportive level, the communicative/expressive level, and the transformative level, paralleling the various styles of psychodynamic psychotherapy, such as a supportive/expressive psychotherapy model (Luborsky, 2000).

**A Personal Approach to Music Therapy in Palliative Care**

The music therapy interventions I typically use in my clinical practice are comprised of one or more of the following, based on best practices described in the music therapy literature: receptive music therapy (Grocke & Wigram, 2007), inter-active listening (Black, Zimmermann & Rodin, 2017), clinical improvisation (Lee, 2000), imagery and music (Grocke & Wigram, 2007), song-writing (O’Callaghan, 1994; 1996), active playing by the patient/families (Kordovan, Preissler, Kamphausen, Bokemeyer & Oechsle, 2016), and verbal psychotherapeutic exploration and processing of biopsychosocial stressors (Austin, 2009). Patients and families often have unique agendas and approaches to music therapy and my practice embodies prioritizing these needs in order to enact a patient-centric model to support the “whole person” (Spiegel, 2000).

**Early Writing and Research**

Advancements to the literature on music therapy and palliative care include a number of landmark studies and seminal works, as well as resource-driven compilations. Spearheaded by Munro & Mount’s (1978) ground-breaking publication on music therapy in palliative care, the field has grown exponentially. This publication, based on initial clinical observations,
specifically highlighted the improvement in quality of life for patients with advanced illnesses in a hospitalized setting. Following this, Curtis (1986) looked at the effect of music on pain relief and relaxation in the terminally ill, furthering the empirical evidence and justification for use of music for physiological as well as psychosocial support through music therapy at the end of life. In the years following, the literature expanded, looking beyond the physiological and psychosocial, exploring the opportunities for targeting spiritual care and overall well-being in music therapy at end of life. Notably, Aldridge (1995; 1998; 1999; 2003) discussed music therapy and spirituality within oncology and palliative care extensively in a number of papers in the 1990s, showcasing the impact of music in supporting patients in their existential and spiritual needs in palliative care.

Expansion of Research Interests

As the interest in and opportunities for music therapy in palliative and end of life settings (hospitals, hospices, and home care) grew and formalized in North America, Europe and Australia, so too did the literature. As opportunities evolved, methodologies expanded, and music therapists began employing various styles of research. A landmark study in music therapy and phenomenology came out of Forinash’s (1990) doctoral dissertation, which explored music therapy with the terminally ill from a phenomenological perspective. It was designed to emphasize the complexity of the therapeutic intervention (music therapy) while seeking to understand the role of this intervention in the midst of end of life care, the themes of which were shown to be relationships, the music itself, and the process of the therapy. In another vein of methodological exploration, Lee (1996) published an in-depth musical analysis concerning the experiences of music therapy for a musician with AIDS, chronicling the journey of his terminal illness in the context of music. Lee displayed the outcomes of an aesthetic approach to music
therapy (Lee, 2001), specifically the emotional processing of coming to terms with life and death within the exploration of music itself. In later years, Rykov’s work in music therapy and palliative care included a bibliography of music therapy in palliative care which she configured in collaboration with Salmon (1998), providing researchers and clinicians in the field and in aligning disciplines with a broad overview of the cumulative data underscoring the development of the profession.

As literature and methodology expanded for music therapy in palliative and end of life care, specific outcomes were also beginning to be measured and explored. Magill (2001) looked at the role of music therapy in addressing advanced cancer pain; initial results indicated that music therapy interventions reduced pain associated with advanced cancer. Gallagher (2001) outlined and contextualized music therapy in palliative medicine, and recently published a retrospective study of data collected during previous music therapy sessions in order to understand the impact of music therapy, identify common music therapy goals, and assess effects within cancer and symptom management (2017). Outcomes included statistically and clinically significant effects of music therapy in addressing symptoms and behaviours of people receiving palliative medicine. Hartley explored his own experiences of working as a music therapist with those living with a terminal illness (1999; 2001). Hilliard published extensively on music therapy and hospice care, addressing quality of life (2003), multidimensional needs of hospice patients and families (2001), and empirical data in music therapy and hospice palliative care (2005). Krout (2001) researched and wrote extensively on hospice and palliative music therapy, including examining single session effectiveness in physical symptom management and the role of facilitating release at time of death (2003). Salmon’s contributions to the music therapy and
palliative care literature include exploring music and emotion (1993), and music therapy as a psychospiritual process in palliative care (2001).

As the field of music therapy in palliative and end of life care has continued to evolve and develop, new foci have been established such as further understanding best clinical practices based on previous and current data, specifically exploring certain interventions (e.g., song-writing), and use of a wider variety of research methodologies and styles (e.g., randomized controlled trials). For example, Dileo & Magill (2005) described and outlined a multicultural perspective on song-writing with oncology and hospice patients, offering various styles and cultural models of songs that met the needs of diverse populations. Dileo & Loewy (2005) edited and published a resource of numerous approaches to music therapy in end of life, highlighting clinical issues and specialized populations, music therapy methods, and professional issues within the field, allowing for access to a breadth of literature not previously available, which continues to shape music therapy training and education within this population. O’Callaghan researched the impact of song-writing in palliative care (1990; 1994; 1996; 1997), as well as palliative experiences in music therapy (2001), in additional to the contributions of music therapy to palliative medicine (2003). In 2004, Clements-Cortes explored the use of music in facilitating emotional expression in the terminally ill, highlighting the capacity of music to be a vehicle for emotional expression, resulting in a decrease of depressive symptoms and social isolation, an increase in communication and self-expression, as well as stimulation of life review, and overall relaxation. Clements-Cortes’ (2009) doctoral dissertation on music therapy in the context of episodes of relationship completion in palliative care offered an intimate qualitative look at the role of music in facilitating relationship endings, particularly addressing themes of love, forgiveness, and saying goodbye.
Expansion of Methodologies

An increase in randomized controlled trials and systematic reviews brought quantitative and mixed methodologies to the forefront of music therapy research. Gutsell et al (2013) completed a randomized controlled trial in the field, concluding that a single music therapy session reduces pain in palliative care patients. A 2015 randomized controlled trial to evaluate the effects of music therapy on relaxation found that music therapy was an effective treatment with a low dropout rate, which promoted relaxation and well-being in persons undergoing palliative care (Warth, Kessler, Hillecke, & Bardenheuer, 2015). In 2018, a systematic review by Vesel and Dave suggested that the available evidence supports music therapy as a potential safe and effective non-pharmacological approach to managing symptoms in palliative care. Ramirez et al.’s 2018 EEG-based analysis of the emotional effect of music therapy on care for patients receiving palliative care showed a statistically significant difference in the patients receiving music therapy (versus the control group), and also showed a significant decrease in fatigue, anxiety and breathing difficulties, and an increase in levels of well-being. A 2018 integrative review of patient and health care provider’s perspectives on music therapy in palliative care by Schmid et al. noted themes of patients’ emotional expression (of positive and challenging emotions) and increased well-being, and psycho-physiological change through music therapy. In 2019, Warth and colleagues developed an protocol for an intervention (“SoL: Songs of Life”, which integrates aspects of music therapy, musical life review, and dignity therapy) and plan to assess it within a randomized controlled trial, examining the effectiveness of the technique based on biopsychosocial markers). In 2016, Clements-Cortes consolidated and categorized emergent themes of practice in music therapy and palliative care in the following way: physical (e.g., effective symptom management and promotion of relaxation), psychosocial (e.g., strengthening
self-identity and supporting emotional expression and grieving), and whole-person care (e.g., life review and legacy creation) (Clements-Cortes & Varvas Klinck, 2016, p. 7). This consolidation points to the various areas of clinical care within music therapy and end of life which have been explored, established, questioned, and discussed within the research literature. These diverse and multi-faceted areas of research continue to drive best practices and informed, evidence-based care in a field that is ever-evolving and continuing to grow.

**Locations of Music Therapy in Palliative and End of Life Care**

“Perhaps music’s greatest gift is the open structure it can lend to moments of fragility. There is not a precise route in the journey of unknowns. Our relationship with others is often subtly rooted in the context of music, whether or not we are aware of it. Music therapists have sought to make conscious interventions with an acute awareness of the parameters of mind, body and spirit, as well as cultural and societal interweaving in terms of how music in conceived and implemented.”

– Joanne Loewy, *Music Therapy at the End of Life*

Music therapy in palliative care may take place in many different locations, such as a hospital setting, a home, or a hospice. Many hospitals such as Princess Margaret Cancer Centre have acute palliative care units, where specialized symptom management and end of life care is provided by a palliative care team including physicians, nurses, social workers, spiritual care professionals, physiotherapists, occupational therapists, music therapists, psychiatrists, and others. Other areas of a general (or specialized, e.g., cancer-focused) hospital may consult palliative care services (including music therapy) to offer an assessment and a medical recommendation for patients if the primary medical team requires support managing complex
symptoms or caring for the needs of the patient and the family/friends at the end of life. These consults may take place at a residential hospice or a within a community-based hospice model, in a complex continuing care facility, a long-term care facility, or directly in a person’s home.

Palliative Care

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization [WHO], 2017). Palliative care can be introduced at various points along an illness trajectory, and as indicated above, can take place in a wide variety of locations. Beyond the four walls of a home or an institution, palliative care (including music therapy approaches in palliative care) may also take place for those who are vulnerably housed or have no fixed address, either in shelters or on the street (Giesbrecht et al, 2018).

Palliative care is an approach to care, rather than a type of medical practice that may require certain medications or machinery; health care professionals trained in palliative care approach those for whom they care as whole persons (Watson, Lucas, Hoy, & Back, 2005), an approach spearheaded by Dame Cicely Saunders in her development of the modern hospice movement (CHPCA, 2019). Often, patients are able to choose how and where to die, though whether or not these choices are achievable is influenced by a number of individual, relational, societal and political factors (Zimmermann, 2018). According to Bartel and Clements-Cortes (2014), the addition of music in a palliative care setting can serve as transformative, inviting emotion to be allowed, transforming words through imbuing them with emotion and therefore a unique communicative power.
As a result of Dr. Camilla Zimmermann’s 2014 randomized controlled trial (Zimmermann et al, 2014), it is now known that patients diagnosed with metastatic cancer who receive palliative care early on in their disease trajectory actually experience a better quality of life than those who receive usual standard care. Access to palliative care has become an increasingly relevant and topical issue as the population’s average life span increases (CHPCA, 2015). Seniors make up the fastest-growing age group, and it is estimated that seniors could account for between 23% and 25% of the total population by 2036, nearly double the 2009 proportion of 13.9% (Statistics Canada, 2009).

Literature in palliative and end of life care suggests that people facing imminent death may experience suffering, anxiety, fear, existential distress, and total pain to varying degrees (Wilson et al, 2007; Lo et al, 2014). It has been estimated that between 50 and 80% of terminally ill patients “have concerns or troubling thoughts about death” (Cherny, 2011). According to Dr. Rinat Nissim and her colleagues, psychological well-being is inevitably challenged in individuals with advanced cancer because of the profound and diverse stresses and burdens associated with the disease (Nissim et al, 2012). These invariably include physical suffering and disability, the threat of impending mortality (or, death anxiety), dramatic alterations in support needs and personal relationships, and the challenge of navigating a complex health care system and making treatment decisions that have life and death implications. As is often colloquially discussed in multiple supervision discussions among colleagues and peer groups in my clinical setting, the inevitability of death and its complexities is “the problem that won’t go away” (G. Rodin, personal communication, December 2017).

Fears of cancer emanate from a common view that cancer is a vicious, unpredictable, and indestructible enemy, evoking fears about its proximity, the (lack of) strategies to keep it at bay,
the personal and social implications of succumbing, and fear of dying (Vrinten et al, 2017). The cumulative distress about these issues has been described as existential distress (which may manifest as existential loneliness and/or total pain, as described below) at the end of life; this term has been defined as hopelessness, burden to others, loss of sense of dignity, desire for death or loss of will to live, and threats to self-identity (Lo et al., 2016). Existential loneliness is understood as an intolerable emptiness, sadness, and longing that results from the awareness of one’s fundamental separateness as a human being (Ettema, Derksen & Leeuwen, 2010). Total pain, a concept developed by Saunders recognizes pain as physical, psychological, social and spiritual (Ong & Forbes, 2005). In summarizing the complexities surrounding distress in palliative and end of life care, many clinicians speak of these experiences, both academically and narratively, as suffering (Rattner & Berzoff, 2016). As a result, I strive to approach my clinical work rooted in an empathic stance which I feel is critical in supporting these complex experiences of distress at end of life.

**Palliative Care and Suffering**

It is clear from the descriptions of experiences through narrative accounts that suffering is common in patients near the end of life (Krikorian & Limonero, 2012). Suffering of some extent is universal among people who are dying, even those who have no physical discomfort (Byock, 1997). Because it is known from the literature in psychotherapy that empathy is considered to be a fundamental component of a therapeutic relationship, I have emphasized that dimension in my clinical work in palliative and end of life care. As informed by my clinical experience and by Rattner’s (2018) research on suffering and dying, I suggest that because of the nature of advanced disease and how it affects patients’ lives, clinicians cannot necessarily eliminate suffering or the inevitability of death, but we can empathize through attending and attuning.
In connecting this perspective to palliative and end of life care, I am further drawn to the research of social workers Maxxine Rattner and Joan Berzoff (2016), who suggest sitting with suffering as a paradigm shift for palliative care providers. They write that suffering at end of life may very well be intrinsic, and therefore an unchangeable part of the dying process. This suggestion of refocusing and shifting paradigms connects beautifully to Dettmore and Gabriele’s (2011) appeal: “Don’t just do something, sit there.” Oftentimes, there is nothing we can do to change or fix the situation. Attending and attuning to suffering does not necessarily mean we must change it or fix it; in fact, it may be deeply intrinsic suffering. However, we can “sit there” empathically; this approach may have a therapeutic and supportive effect. This sitting with suffering and attending and attuning to the dying process may require us as clinicians to become aware of our own fears, sadness, anxieties, feelings of helplessness and overwhelm, and may in fact provide an empathic window into what clients may be experiencing. Rattner and Berzoff suggest that this empathy is requisite to sit and stay with suffering.

**Medical Assistance in Dying (MAiD)**

**Overview**

In response to Carter v. Canada (Attorney General) (2015), the Supreme Court of Canada considered whether the criminal prohibition of physician-assisted death (currently referred to as “medical assistance in dying” or MAiD) violated the Canadian Charter of Rights and Freedoms of competent adults with grievous and irremediable suffering who seek assistance to end their lives. On February 6, 2015, the Supreme Court unanimously decided that an absolute ban on medical assistance in dying is a violation of Charter rights; as a result, the federal government enacted legislation in order to establish a framework for medical assistance in dying in Canada. In accordance with federal legislation, medical assistance in dying includes circumstances where
a medical practitioner or nurse practitioner, at an individual’s request: (a) administers a substance that causes an individual’s death; or (b) prescribes a substance for an individual to self-administer to cause their own death (CPSO, 2016).

In order for an individual to request and receive this medical intervention, an intervention team who determines whether the individual meets eligibility criteria must assess the individual. Criteria includes the following: the individual must have a grievous and irremediable medical condition (including an illness, disease or disability), must make a voluntary request for medical assistance in dying that is not the result of external pressure or coercion, and must provide informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

**Process**

Typically, an initial assessment is done after a request for MAiD is received, followed by a waiting period in which the individual is meant to take time to reflect on their request. At the end of the waiting period (between five and ten days depending on the individual’s physical and cognitive status), a second assessment is conducted, and eligibility is reassessed. Once the intervention is approved, the intervention physician or nurse practitioner meets with the individual on the scheduled intervention day and does a final assessment determining cognitive capability of the individual to make the decision without influence or coercion. During the intervention, the physician and/or nurse practitioner administers up to four medications to sedate the individual, induce coma and stop the heart. This process generally occurs over a matter of minutes; as noted above, music is frequently requested to accompany this procedure.
Literature on Process and Program Development

Because of the recent legalization of the procedure, the research and resulting literature on assisted dying is limited. However, a number of Canadian researchers and clinicians have looked at several aspects of assisted dying in the context of research studies. Although MAiD was declared legal in 2016, with a governmental plan for a five-year review of the processes (S.C., s 10, 2016), health care facilities and organizations were required to develop their own policies, procedures and approaches, with very little research data to support this process, and no clinical experiences in this regard. Frazee and Chochinov (2016) noted a number of challenging shifts in clinical practice as a result of the move from “lawmaker’s workbench to the more challenging realm of clinical practice,” also highlighting the relatively “patchy” data on MAiD at the time.

A number of studies and articles on experiences of clinicians (specifically attitudes, expectations, education and challenges) and on program implementation have been published in Canada since the legalization of assisted dying. In 2017, Drs. Madeline Li and Gary Rodin published an overview of the implementation of a hospital-based MAiD program at Princess Margaret Cancer Centre, outlining the institutional framework that was created to streamline the MAiD assessment and delivery process and structure equitable and consistent access to MAiD across the University Health Network (Li et al, 2017). Wales et al. (2018) published a retrospective review of the first year of a home-based palliative care program’s experience with assisted dying, providing an overview of the logistics of the provision of MAiD including statistics on who provided and received MAiD, along with various factors that influenced these outcomes.

Literature on MAiD Clinician Experience

With regard to the literature on clinician experience, several studies have explored the perspective of medical students’ and front-line clinician staff perspectives on their experiences
with MAiD. A 2017 exploratory cross-sectional survey of Canadian medical students found that medical students generally supported and would be willing to provide means for MAiD but wanted more directed medical education on it (Baxter, Philpott & Costa, 2017). The first cohort of physicians to offer MAiD in British Columbia were interviewed in an exploratory qualitative study in 2018. The results of this study showed that physicians felt participation in MAiD was rewarding and satisfying, though they acknowledged the structural and emotional challenges related to the work. They highlighted the need for legislative changes to make MAiD more accessible to a broader population in order to align it with the original intent of the Carter decision (Shaw, Wiebe, Nuhn, Holmes, Kelly & Just, 2018).

A 2018 article outlining some of the challenges specific to psychiatry in the context of MAiD explored the issues surrounding MAiD qualifying eligibility of patients with mental health challenges (Jones & Simpson, 2018). In a qualitative study, Khoshnood et al. (2018) explored Canadian physicians’ experiences of providing MAiD in which they described challenges associated with MAiD provision, including its impact on their relationships with objecting colleagues, and the straining related to inadequate financial compensation and increased workload. Clinical experiences and outcomes from the perspective of healthcare providers were outlined in a scoping review to inform nursing practice, which highlighted the importance of effective health care professional engagement with individuals requesting MAiD, and the ongoing need to provide educational support to nursing staff involved in MAiD (Suva, Penney & McPherson, 2019).

**Literature on MAID Caregiver Experience**

A 2007 study conducted in the Netherlands outlined relatives’ perspectives on providing care during their loved one’s euthanasia (Georges et al, 2007). This study found that 92% of the relatives interviewed reported to have considered euthanasia or physician-assisted suicide to
contribute favourably to their loved one’s quality of life. A 2009 study explored mental health outcomes of family members of Oregonians who requested physician aid in dying and found that aid in dying did not have negative effects on family members, and that these family members felt more prepared and accepting of death than comparison family members (Gazini, Goy & Pringerton, 2009). A 2018 qualitative study in British Columbia found that caregivers were supportive of their loved ones’ wishes for MAiD, and shared experiences of the time before death as being embedded with various rituals: goodbyes, ceremonies, poems, singing, etc. (Holmes et al., 2018).

**Literature on MAiD Patient Experience**

A number of case reviews and description of demographics of cases (Robertson, Pewarchuk, Reggler, Green, Daws & Trouton, 2017; Rossa, Huyer & Walker, 2017), as well as studies of caregiver experiences of MAiD, and clinician impressions, experiences, and preferences for the provision, education, and practice of MAiD have been published. However, there is relatively little published research on the patient experience of MAiD. One published review of reasons for requesting MAiD showed that disease-related symptoms, loss of autonomy, loss of ability to enjoy activities, and fear of future suffering were primary reasons for MAiD requests (Wiebe, Shaw, Green, Trouton & Kelly, 2018). A 2011 study in Oregon examined the quality of death and dying in patients who requested physician assisted death, via the caregiver’s retrospective rating of the dying experience of their loved one (Smith, Goy, Harvath & Ganzini, 2011). A 2011 study explored the perspectives of patients who requested assisted dying using a qualitative grounded theory approach, finding that “unbearable suffering” and “hopelessness” were key factors in the decision to pursue assisted death (Dees, Vernooij-Dassen, Dekkers, Vissers & van Weel, 2011). In 2018, Nuhn and colleagues looked at the experience and perspective of people
who pursued medical assistance in dying, and found that patients chose this in order to have autonomy and control over their end of life and because of a self-perceived unacceptable quality of life; some also expressed fear of future suffering (Nuhn, Holmes, Kelly, Just & Shaw, 2018). There are currently research studies underway at both the University Health Network in collaboration with Sunnybrook Health Sciences Centre by my colleagues Dr. Sarah Hales and Dr. Madeline Li, examining the experience of caregivers in the context of MAiD, as well as exploring a longitudinal process of MAiD requests and interventions from patients’ and caregivers’ perspectives.

**Literature on MAiD and Music Therapy**

While music is occasionally referenced or mentioned in the context of ritual provided before or after assisted dying (Holmes et al., 2018), and music is often included in media accounts or through personal narratives when describing a MAiD process, there has been no formal research on music in the context of assisted dying until this current study. Current media stories such as Dr. Joshua Wales’ narrative on his experience as a clinician providing assisted dying, offer a personal look into his experience of an assisted death and of the music that permeated the experience for both patient and clinician (Wales, 2017). Personal narrative accounts publicized by media sources include patient perspectives on why they chose MAiD and some of the rituals and experiences that accompanied their assisted deaths, including music. A musician from British Columbia received assisted dying and had a friend play Led Zeppelin’s “Stairway to Heaven” at his bedside as he was receiving the final injections (Bowie, 2019). Meaghan Jackson-Doucette, a Vancouver-based music therapist, spoke about her personal and professional experience of providing music therapy during assisted dying on a Canadian Broadcasting Corporation (CBC) talk show (Vermes, 2018). An interview with a Vancouver-based man in
2017 highlighted his wishes for an assisted death: “It would be without drama, hopefully, without a lot of footprints left on their hearts because of my desire for things to be this way or that way. I'll need to surrender to what's possible. And there should be singing.” (Nelson & Hoath, 2017) He died an assisted death in September of 2018.

The only publications on music therapy and MAiD are clinical overviews of the process (Black, 2017a), conference proceedings (Black, Borgal, & Salmon 2017; Black & Wales, 2019), and practice guidelines published via the Canadian Association of Music Therapists (Black, Rippin-Bilger, Pringle & Li, 2017). A reflective narrative based on my own early experiences with music and MAiD was also published in October 2019, specifically regarding the use of music therapy in MAiD with regards to pain management and psychosocial support (Black, 2019). These publications share narrative accounts, both clinical and personal, as well as current practices in music therapy and assisted dying based on clinical experiences. To date, there has been no formal research or publications on music therapy and medical assistance in dying.
CHAPTER FOUR: METHODOLOGY

I’ve looked at life from both sides now

From win and lose, and still somehow

It’s life’s illusions I recall

I really don't know life at all.

— Joni Mitchell, “Both Sides Now”

A Qualitative Approach: A Personal Reflection

All researchers bring certain beliefs and philosophical assumptions to their research (Creswell, 2013), and I am no exception. In my initial pursuits of research as a novice music therapist and junior graduate student, I was conflicted as to how to “best” and “most accurately” approach a research study, particularly because I wanted to use research to justify the professional practice I was entering. Music therapy has historically experienced a divide between qualitative and quantitative inquiry, pitting evidence-based models of research against narrative and experience-based studies (Magee, 2019). My initial foray into qualitative research manifested in a phenomenological study of the experience of music therapy on an acute palliative care unit, the foundation of my master’s thesis that took place in the hospital where I work (Black, Zimmermann & Rodin, 2017). In the midst of encountering patient stories and narratives and sitting with the ambiguity and uncertainty of their suffering (Rattner & Berzoff, 2017) and their daily challenges, I questioned the roles of both quantitative data in capturing the patients’ voice, and qualitative data in capturing the patients’ objective symptomatic trends in response to music
therapy. I continually asked myself how music therapy might be quantified, and how best practices might be established for the field of palliative care. At the same time, I questioned how clinicians and researchers could ever capture the uncatchable, the moments that felt inexplicable through words alone. The more embedded my own clinical practice became in the music therapy and psychosocial oncology literature, the more I understood music therapy research as existing within two sides of the same research coin: quantitative and qualitative approaches hold significant merit of their own accord, and when blended, can create a completely new and unique opportunity for coming to understand research questions and collected data (Wheeler, 2005).

Within my own clinical practice as a psycho-dynamically informed music-centered psychotherapist, I became invested in qualitative modes of inquiry as I felt they connected most intimately with the ambiguity of the questions and experiences that arise in end of life care. As I continue to navigate my clinical experience as a novice researcher, I am pulled towards qualitative inquiry, understanding this methodology as a vehicle to honour the voices of the participants in a way that parallels the work of the music therapist: often ambiguous, nuanced, and inexplicable in words alone. As Dr. Carolyn Kenny remarked, “When music comes to me, I sincerely believe that all my attempts at description will be futile, and yet I am totally grateful that this is so” (Kenny, 1982, xiii).

**Interpretive Framework**

My worldview as researcher and clinician is best represented in social constructivism, also described as interpretivism (Denzin & Lincoln, 2011), or interpretive inquiry. A social constructivism approach seeks to understand the world in which the researcher lives and occupies, and seeks to develop subjective meanings of experiences, which are complex, multiple, varied and often broad, allowing participants’ views and voices to remain at the forefront of the
The meanings that are gleaned and the experiences that are embodied and described are not embedded onto or designated for individuals; these meanings are constructed through social interaction, embracing and taking into account historical and cultural normative frameworks that are at play within individual experiences (Lincoln & Guba, 2000; Moustakas, 1994). Within this approach, researchers inductively develop a theory or derive meaning formed through interactions with the participants, embedded in historical and cultural norms (Creswell, 2013).

This study uses a framework for understanding philosophical positionality and assumptions originally created by Denzin and Lincoln (2011) in order to position the assumptions within five phases of research. In Phase One (The Researcher as a Multicultural Subject) the history and research tradition is outlined and described, including the conceptions of self and other, and the ethics and politics of the research, as described in Chapters One and Two of this dissertation. In Phase Two (Theoretical Paradigms and Perspectives), this study positions itself as embodying social constructivism, interpretivism, and hermeneutics. In Phase Three (Research Strategies), this study uses hermeneutic phenomenology (van Manen, 1997; 2006; 2011; 2014). In Phase Four (Methods of Collection and Analysis), this study uses interviewing and observing (Creswell, 2013). In Phase Five (The Art, Practice, and Politics of Interpretation and Evaluation), this study uses writing as interpretation (Denzin & Lincoln, 2011, p. 12; van Manen, 2002).

**Philosophical Framework**

The overarching framework of this research is rooted in the tradition of interpretive-descriptive hermeneutic phenomenology, as both a philosophical framework and a methodology of practice (van Manen, 2014). Informed by Max van Manen’s phenomenological approach, this study has
been designed as “a method of abstemious reflection on the basic structures of the lived experience of human existence” (p. 26). The method to which van Manen refers is reflected in the attitude towards which the phenomenon is approached. He uses the term “abstemious” to refer to the practice of “reflecting on experience while abstaining from intoxicating the reflections with theoretical, suppositional or emotional perspectives” (p. 26). Van Manen indicates that the use of the term “hermeneutic” (which stresses the primacy of the text in understanding experience) suggests the act of reflecting on the experience in question must aim for discursive language and intentionally sensitive interpretive devices that allow for analysis, explication, and description in an intelligible fashion (2014). He suggests that “lived experience” refers to phenomenology that questions the pre-reflective or pre-predicative life of human experience as living thorough it.

**Intersections with the Arts**

We have art in order not to die of the truth.

– Nietzsche, *Will to Power*

While this study is not traditionally designed as arts-based research, this study has multiple intersections with the arts, and aligns with arts-informed research, in that it is influenced by the arts (Knowles & Cole, 2007). Arts-related research is defined broadly as research that uses the arts to explore, understand and represent human action and experience, with a strong focus on reflexivity and using the work of creating art to generate knowledge (Savin-Baden & Wimpenny, 2014). This specific study did not use arts-based methodology, but it did make use of art (specifically, music) for the purposes of generating data, within a situation where it may not have
otherwise been used. The art (music) used within the study is an inherent component of the phenomenon being studied (music therapy in the context of assisted dying).

Arts-based inquiry emerged primarily from the 1970s and onward, during a period in which researchers adopted a more diverse range of inquiry styles (Denzin & Lincoln, 2005), including but not limited to hermeneutics, on which this current study is based. Although this study was not methodologically situated in this philosophical framework, the clinical work (music therapy) that makes up the bulk of the collected data exists within arts-based modalities. Each patient participant session has an iteration of live music, provided by a combination of the music therapist, the patient participant(s), and the caregiver(s). This music therapy sessions function as data and as the foundation of the MAiD and music therapy lived experience which is the phenomena in play within the study design. However, the music itself is not used as the actual arts-based data. There are various forms of arts-based representation of the data. This data will be represented in “Exit Music Playlists” at the end of each case narrative. These playlists are a cumulative list of songs that played a significant role either in the therapeutic process leading up to the participants’ assisted death, or within or during the assisted death itself. Further to this, song lyrics, poetry, and other artistic mediums are interspersed throughout this dissertation, as they supported my intention of gaining a deeper sense of the experience of the participants: their presence in this dissertation may ideally allow the reader to experience a similar phenomenological effect. Hermeneutic phenomenology may borrow from fiction and the arts as sources of experiential material which host themes such as love, loss, grief, joy, celebration, birth, death, illness, struggle, and faith, and it is through the vehicles of artistic mediums that we, the readers or observers (or researchers) may potentially feel “invaded by the same mood” (van Manen, 2014, p. 319) as the protagonists or subjects. This may therefore invite a closer sense of
the experience of medical assistance in dying and music therapy).

**Hermeneutic Phenomenology**

In the tradition of the existential and phenomenological writings of Jean-Paul Sartre (1984; 2013), Simone de Beauvoir (1949), Albert Camus (1988), Maurice Merleau-Ponty (1962), and Martin Heidegger (1962), this qualitative study adopts a phenomenological approach (van Manen, 2014), rooted in a hermeneutic phenomenological methodology, a “phenomenology of practice” in the style of van Manen (1990, 1997, 2006, 2014). This approach to phenomenology is described by van Manen as “a method for questioning, not a method for answering or discovering or drawing determinate conclusions” (2014, p. 29). Phenomenology itself as a philosophical method of study is defined as “the study of the development of human consciousness and self-awareness as a preface to or a part of philosophy” or “a philosophical movement that describes the formal structure of the objects of awareness and of awareness itself in abstraction from any claims concerning existence” (“Phenomenology,” 2019).

As a research approach, a phenomenological study describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon (Creswell, 2013). Phenomenologists focus their interests on exploring individual units in order to reveal complex and holistic meanings (Creswell, 1998). With philosophical origins in the traditions of Rene Descartes (2003), Immanuel Kant (1999), Georg Friedrich Hegel (1977), and Friedrich Nietzsche (1968), the phenomenological movement was launched in the early 20th century by Edmund Husserl and Martin Heidegger. Phenomenology in the context of qualitative research seeks to describe human experiences and multiple realities while not attempting to capture these experiences with a fixed methodology or set of procedures (van Manen, 2014). The
phenomenological inquirer seeks to collect data from those who have experienced the phenomenon in question, attempting to develop a description of these experiences with a focus on “what” they experienced and “how” they experienced it (Moustakas, 1994). Van Manen (2014) states that “all or much of phenomenology has hermeneutic (interpretive) elements – but not all hermeneutics is phenomenology” (p. 26).

Hermeneutics as a methodology of interpretation is focused on understanding meaningful human actions and their subsequent products, specifically and most importantly texts as a lens for interpretation (Mantzavinos, 2016). Hermeneutic phenomenology originated in the work of philosophers Hans-Georg Gadamer (1900-2002) and Paul Ricoeur (1913-2005). Gadamer elaborated on the work of “philosophical hermeneutics,” originated by Martin Heidegger, suggesting that hermeneutic experience is fundamentally dialogical. Gadamer posited that “meaning” emerges as an event that results from the interaction of both the object that lies in the textual manifestation of the experience as well as in the interpreter of that text (2004). Ricoeur’s work in hermeneutic phenomenology was mainly concerned with the intersection of hermeneutic and phenomenological practices, suggesting that closing the gap between the text and the textual interpreter would lead to a furthered understanding of both the self and the other (1978). This theory lays the foundational groundwork for this study’s approach to studying lived experience.

**Music Therapy and Phenomenology**

A number of music therapy clinicians, scholars, and writers have used phenomenological inquiry as a methodology for studying music therapy experiences over the past several decades (Forinash & Grocke, 2005). According to Racette (2004), music therapists were specifically drawn to using phenomenology because of its potential to describe, explore, and represent the complex and subjective experiences inherent within music and music therapy. In the 1980s, music therapist
Even Ruud and the late music therapist Carolyn Kenny authored doctoral dissertations which pushed the boundaries and broke new ground in the practice of music therapy research. Kenny (1982) used the phenomenological method of free imaginative variation to “uncover essential essences of the music therapy process” (Edwards, 2016). Ruud (1987) was the first music therapist to make use of Ferrara’s (1984) method of phenomenological analysis, which he adapted to the analysis of musical improvisation. Ferrara’s method was also used in Forinash and Gonzalez’s (1989) phenomenological analysis of music-centered music therapy. The first music therapy study to employ phenomenology in the study of music therapy for a terminally ill patient was conducted by Forinash and Gonzalez (1990). A large number and wide variety of phenomenological studies in music therapy have since been published, bringing new and varied perspectives to the field and to phenomenological inquiry. These studies include explorations of patient, caregiver, and music therapist experiences. Examples of various phenomenological studies in music therapy include the following: Amy Clements-Cortes (2009) completed a doctoral dissertation that examined the lived experiences of relationship completion through song in palliative care, in which she facilitated clinical work with terminally ill patients and their caregivers. Other studies with similar foci include Lindenfelser et al. (2008) who explored experiences of mothers whose terminally ill children received music therapy prior to end of life, as well as Jonsdottir (2011), who used hermeneutic phenomenological analysis to examine the experience of mothers of children with special needs who attended weekly music-caring sessions based on the concept of “musicking” (Small, 2011). A number of other music therapists and music and health researchers have conducted studies that have used various phenomenological approaches (Dillard, 2006; Economos, 2018; Hsiao, 2011; Jackson & Gardstrom, 2012; Marom, 2004; Kim, 2008; Muller, 2008).
**A Human Science**

In the tradition of phenomenological philosophers who use empirical methods derived from the social sciences, such as Sartre’s (1977) use of observational stories from his own experiences, and Merleau-Ponty’s (1962) and Derrida’s (1995b) use of experiential materials from myths and literature, this study adopted a practice of “human science phenomenology” (van Manen, 2014). This concept can be understood as an approach that aims to gather pre-reflective accounts of human experience, meaning an account of that which is lived through, as opposed to a reflection that is embedded in a response to the lived-through event. The gathering of the accounts of the pre-reflective experience was based in experiential empirical material, rooted in practices such as interviewing, observation, and participation (all borrowed from the social sciences). The primary difference between the use of these methods for phenomenological inquiry (versus social science disciplines) is that phenomenological approaches aim to gather pre-reflective accounts, and need to be conducted while the researcher is in the practice of adopting a phenomenological attitude, meaning a commitment to staying open and receptive to receiving what is given (Finlay, 2008). This phenomenological attitude adopted amidst the practice of analyzing the collected lived experience data must be, according to van Manen (2014), “integrated with the method of the epoché and the reduction” (p. 312).

**The Epoché and the Reduction**

In order to gain access via phenomenology to the pre-reflective experiences in their naturally occurring spheres, the philosophical methods of the “epoché” and the “reduction” are employed (van Manen, 1997). Husserl offered the reduction and the epoché as a central method for the practice of phenomenology: the reduction can be defined as an “attentive turning to the world when in an open state of mind, effectuated by the epoché” (Husserl, 1931), wherein the
researcher avoids abstraction, theorizing, generalization, and belief in what is constituted as real or not real in order to bracket their own understanding of knowledge in order to evoke concreteness of living meaning (van Manen, 2011). Van Manen suggests breaking through what researchers tend to embody as a “taken-for-grantedness” in order to get to the meaning structures of the experiences we are considering (van Manen, 2014, p. 215). The term epoché is a Greek word that translates to “abstention” or staying away from taken-for-granted beliefs, suspending them in order to open oneself up. In this space, Husserl suggests, we might experience insight. In phenomenologically describing his experience of the remembrance of childhood, specifically the memories evoked by walking home through autumn leaves rustling and crunching underfoot, van Manen (2014) describes the reduction and epoché as follows:

“Phenomenologically, I need to open myself (the epoché) and try to bracket my presumptions, common understandings, and scientific explanations; at the same time, I need to regard the phenomenon that was given in my experience (the reduction) and observe how the remembrance emerged as it were from the leaves under my shoes. Thus, I need to describe how my feet literally kicked the memories up from the layer of leaves on my walk through the field.” (p. 216-217)

In the study design, the data collection occurred in several iterations, including first and foremost an observation of lived experience, as I (researcher/therapist) was physically and therapeutically present in the room during every session, interview, and for several assisted deaths. This observing of lived experiences necessitated my use of the reduction and epoché within this study. Within the observing of lived experiences, the reduction and the epoché were a fundamental component of this phase of the study through the continuous reflexive practice (reviewing cases with my supervisors and colleagues from a clinical perspective and recognizing assumptions,
biases, and limitations) and reflective writing (formally after each session as part of data
collection and informally in narrative journal writing to process experiences that occurred and to
prepare for new experiences). Through these practices, I as researcher attempted to attend to each
session openly with bracketed presumptions regarding my current role as a music therapist, and
the biases I carry as a clinician and as a person. While I continue to recognize my own
limitations in the inherent subjectivity of being both therapist and researcher, I actively sought
out a practice of reflexivity in order to bracket and remain open as much as possible in my
attempt to employ the reduction and the epoché.

**Phenomenological Interviews**

As a methodological approach to collecting data within the triadic data collection model (as
described below), each participant engaged in a phenomenological interview process (if able to
do so, e.g., some participants were too physically unwell to engage verbally for extended periods
of time, so a significant portion of the data collection in those cases was based in observing of
lived experiences, as described below). A phenomenological interview was used as a means for
gathering experiential material via narrative, stories, reflections, or anecdotes, in the style of van
interview is distinguished from other styles of qualitative interviewing by the focus on pre-
reflective experience; the focus of the formal and informal interview questions (e.g.,
intermittently inserted through music therapy sessions for patients, and formally presented to
caregivers several months after their loved one’s/the patient’s death) was on the experience as
being “lived through” versus hearing about the experience from a reflective standpoint. For
patient participants, the phenomenological interview questions were embedded within the
therapy sessions, meaning that questions about what it was like to live through the experience of
music therapy within the context of assisted dying were presented with immediacy within the
experience itself in order to reflect the temporal nature of the data collection, and the fact that
patient participants were facing impending death.

As a researcher, I structured questions ahead of time to bear them in mind throughout the
patient therapy sessions, while remaining fully open to the therapeutic process and allowing the
patient to direct the conversation as they saw fit. The phenomenological interviews for caregivers
were much more structured in that a time was set for the purpose of the interview alone, without
a therapeutic intent in mind. Please see Appendix B for list of interview questions. The interview
questions were constructed based on van Manen’s approach to phenomenological interviewing,
consistently keeping the phenomenological intent of the interview in mind, which in this case
refers to what it was like to live through the experience of music therapy in the context of
assisted dying. Further to this, a primary focus was on maintaining alertness to the emergence of
stories while staying grounded in the research question. In instances when phenomenological
interviewing was not an optimal approach, specifically with patients who were functionally
declining, observing lived experiences remained at the forefront of the data collection
methodology.

Observing Lived Experiences

As suggested by van Manen (2014), “the best way to enter a person’s life world is to participate
in it” (p. 318). The practice of observing lived experiences through “close observation” (van
Manen, 2014) functioned as a primary methodology within the data collection process. Because
the primary participants in this research study (people who requested assisted dying) were often
physically and functionally limited due to their declining health and other biopsychosocial
stressors and continuous shifts in their health status, they were not always able to fully
participate in the phenomenological interview process, and often were not able to even speak at
great length, if at all. Because my relationship with all participants was contextualized within the
process of their death, and because I bore witness to their deaths in many cases, close
observation was a fundamental component of the data collection. As a colleague observed and
commented partway through my data collection, the privilege of researching participants who die
poses a whole host of unique methodological challenges. Van Manen (2014) suggests that in
order to engage in close observation, one must be a participant and an observer at the same time,
while maintaining an orientation of reflectivity (p. 318). In light of my clinical and
psychotherapeutic background, this approach was familiar to me; a psychotherapist often must
bracket or shelve their assumptions in order to fully engage in the lifeworld of the client/patient
(McWilliams, 2004). I attempted to participate in each participant’s lifeworld experience in
conjunction with maintaining a phenomenological attitude, while holding close the concepts of
the reduction and epoché in order to bracket my own assumptions and emotional responses.
These emotional responses were not suppressed; they were instead compartmentalized
appropriately to the situation so I could act as both participant, researcher, observer, and therapist
maintaining a therapeutic rapport (Price, 2017) while holding a containing space (Austin, 2009).

**Hermeneutic Thematic Analysis**

The approach to the thematic analysis of the collected data was based on principles of
hermeneutic thematic analysis in the style of van Manen’s phenomenology (2006; 2014) in order
to “uncover and recover structures of meanings that are embodied and dramatized in human
experience represented in a text” (p. 319). Each component of the data texts (session and
interview transcriptions in addition to researcher reflections) were treated as sources of meaning
from the perspective of the entire narrative/full story. Thematic analysis was furthered during a
process of phenomenological writing of each triadic case, which was done following the completion of the collection of all data (see Chapter Six, Data Analysis). This style of writing served to allow for themes from the hermeneutic thematic analysis to be verified as well as to allow new insights to emerge. Van Manen suggests that the integration of several reflective methods of thematizing and meaning analysis must be integrated with the method of the reduction and the epoché, all of which must manifest and “prove itself” within the phenomenological writing. This hermeneutic thematic analysis took place with the transcriptions of all recorded data and the researcher reflections, which were written immediately following each patient session and caregiver interview, in addition to several reflections unprompted by a singular research event. These reflections were often written as a result of a particular stimulus external to the research events (e.g., watching a movie, sharing a narrative with a friend or family member, hearing a song on the radio that reflected a case I was involved with, or reading a news story about assisted dying). The exploration of themes and insights were conducted according to van Manen’s phenomenological approach in the following way.

**Analysis Process**

Following the audio recording transcriptions of all patient sessions and caregiver interviews, and compilation of researcher reflections, all data texts were read and re-read a number of times (at least three, up to approximately nine or ten, depending on the length and initial impressions of the data). The first three readings of the data were as follows:

Initially, a wholistic reading approach of the text as a whole was done, exploring the answer to van Manen’s (2014) question, “How can eidetic, originary, or phenomenological meaning or main significance of the text as a whole be captured?” The wholistic reading resulted in broad, overarching themes and subthemes reflecting the hermeneutic experience of participants (see
Chapter Six, Data Analysis). Secondly, a selective reading approach was completed, asking, “What statements or phrases seem particularly essential or revealing about the phenomenon or experience being described?” The selective reading resulted in quotes, phrases, actions, and statements from participants that were elaborated on via reflective interpretive-descriptive paragraphs. Thirdly, a detailed reading approach was used in order to examine each sentence in detail, asking, “What may this sentence or sentence cluster be seen to reveal about the phenomenon or experience being described?” (p. 320). During a line-by-line reading of the transcripts, the following question was asked of each sentence: “what does this statement/phrase/sentence say about the experience of music therapy and medical assistance in dying?” The detailed reading approach was further assisted by the employment of the “existentials,” what van Manen (2014) identifies as “universal themes of life” (p. 302), in that these notions of lived relation (body, space, time, and things, among others) belong to everyone’s lifeworld. These existentials form the basis of a guided existential inquiry, a component of phenomenological exploration (Merleau-Ponty, 1962; 2012) that was employed to heuristically explore the phenomena in question (music therapy in the context of medical assistance in dying). The following existentials were used as thematic guides within analysis: lived relation (relationality), lived body (corporeality), lived time (temporality), lived death (dying). The process and outcomes of this component of the data analysis are presented in Chapter Seven (Findings and Themes), and Chapter Eight (Discussion).

The results of the wholistic reading are presented with overarching themes and sub-themes. The results of the selective reading are presented initially as quotes or actions from the participant or clinician as applicable, followed by reflective interpretive-descriptive paragraphs. The results of the detailed reading are presented as several specific phrases from the participant,
followed by specific thematic outcomes that resulted from the line-by-line reading of the transcripts, as per van Manen’s approach (2014, pg. 320–323).

**Phenomenological Writing**

According to Max van Manen (2014), phenomenological reflection cannot be separated from phenomenological writing; in other words, phenomenological reflection is writing (p. 365). The foundations of phenomenological writing, as with phenomenology itself, originate in the discourse of philosophers such as Heidegger (1982), Wittgenstein (1982) and Ricoeur (1976). The origins of the importance which van Manen’s phenomenology of practice places on writing are rooted in philosopher Jacques Derrida’s approach, in which he “loosened the boundaries between philosophy, literature, ethics, and critical approaches in the arts” (van Manen, 2014, p. 366). Derrida critically approached Husserlian phenomenology, and questioned the roles of logic and rhetoric, placing a stronger emphasis on rhetoric in his exploration of philosophical concepts. In his published conversations with Italian philosopher Maurizio Ferraris (Derrida & Ferraris, 2001), Derrida suggests that writing is essential to all philosophic reflection and that it is worthwhile to think about the relation between phenomenology or philosophy in general and writing in general. Out of the playful and curious volleying of discourse between Derrida and Ferraris emerged questions of where writing intersects with philosophy. Ferraris asks how writing enters philosophy, and Derrida responds by stating that writing did not ‘enter’ philosophy; it was already there (p. 8).

Each triadic case study will be presented initially in a narrative format, employing phenomenological writing (van Manen, 2002), the practice of “entering and traversing the space of the text, of darkness … exploring and interpreting many sources of meaning and mobilizing many ‘techniques’” (p. 7). Phenomenological writing offers an invitation into the experiences of
the patients, the caregivers, and the music therapist, all of whom often engage in both verbal and nonverbal practices to build therapeutic rapport, address therapeutic goals, and exist in a space that invites a suspension of time. This writing is meant to allow for insights and new questions and wonderings to emerge. Van Manen (2006) suggests that “to write is to reflect, and to write is to research” (p. 20), positioning phenomenological writing as a tool that can be used to express the inexpressible: “Writing creates a space that belongs to the unsayable” (van Manen, 2006). My intention as therapist/researcher is to invite the reader directly into the experience of music therapy in the context of medical assistance in dying. I invite the reader to step into the room, be at the bedside, sit next to the keyboard, sing along to the songs, and feel immersed in the experience through the words and the narratives.

**Triadic Approach to Data Collection**

In her discourse on decolonizing methodologies, Tuhiwai Smith (1999) stated that “the term ‘research’ is inextricably linked to European imperialism and colonialism,” suggesting that the process of research is inherently embedded in a privileged position, often displayed from the vantage point of the colonized (p. 1). Denzin and Lincoln (2005) suggest that qualitative research in many if not all its forms serves as “a metaphor for colonial knowledge, for power, and for truth”; they argue that research provides a foundational representation of “the Other” (p. 1). The purpose of designing this current research from the perspective of the patient requesting and/or receiving MAiD, along with a primary caregiver as/if identified by the patient, and the music therapist was to provide a wholistic perspective without positioning the researcher as expert. The intent was to create a platform in which all parties’ voices are represented, and all individuals who are participating in the research are experts in their own experiences. Aluwihare-Samaranayake (2012) suggests that both participant and researcher have “two diverse but
intertwined epistemological perspectives”; within this particular scope of research, I argue that the addition of the patient’s chosen primary caregiver (as applicable) also has a separate, diverse though intertwined epistemological perspective. The legalization of assisted dying is relatively recent, making the research body of knowledge fairly scarce within this field, and there is little if any published research reflecting the patient voice and experience within the context of MAiD. For a number of reasons, capturing data from the perspective of a person requesting and receiving MAiD poses several challenges, including the primary fact that the person will die if MAiD is completed, and no follow up member-checking or additional data collection is possible. However, very little research from the patient’s perspective has been documented, therefore this current study placed an emphasis on capturing data from multiple lenses to understand the lived experience of music therapy within the context of MAiD. The patient’s voice is first and foremost in each case, followed by the caregiver’s voice, and finally the music therapist’s voice adds its own layer to the triad.

Research Reflections

The world is not what I think, but what I live through.

– Maurice Merleau-Ponty, *Phenomenology of Perception*

As a critical component to the research process, I undertook a process of researcher reflections throughout the data collection period. Van Manen (2014) suggests that there is an “inseparableness of phenomenological inquiry or research from phenomenological writing or textual reflection” (p. 389). The researcher reflections were written as responses to each session and interview conducted as part of the data collection, and were organized in two parts:
a) A fieldwork-style observation based on a Stone Sunstein & Chiseri-Strater (2012) model of reflective fieldwork practice. This observation was structured into four sections, with the addition of a fifth music-related section relevant to this study:

i. Jottings: An overview of the overall specific details (date/time/place) and facts (site/patient diagnosis), followed by researcher sensory impressions, a personal response, specific words, phrases or language that summarized the conversations, as well as questions about people or behaviours in the context of the data collection.

ii. Description: An overview of all that can be remembered from the event/occasion (in this study, either the patient therapy session OR the caregiver interview) as related to the guiding research question.

iii. Analysis: A description of what was learned within the setting: early preliminary links, connections, possibly conclusions were made here.

iv. Reflection of a personal nature: Answering the questions related to what it was like for the researcher to be doing the research: what was comfortable/uncomfortable? How were connections made with participants? These reflections occurred more than once in most of the cases. (As per van Manen (2014), the visual and auditory languages of images, art, cinema, and music were also employed within this component of reflection. Some of these reflections manifested as artistic pieces such as poems, songs, and various musical iterations. Others were inspired by art as a catalyst for a journal entry that related to the research questions.)
v. List and description of musical choices: A list of all musical selections that were requested/played/sang/featured in any way during the course of the participants’ involvement in the study.

b) Narrative phenomenological writing, as informed by van Manen’s approach to phenomenological writing (van Manen, 2014). These narrative pieces served as opportunities for reflection.

Components of the researcher reflections are presented throughout this dissertation; the narrative phenomenological writing for each case can be found in Chapter Six (Data Analysis), and various artistic manifestations of researcher reflections can be found throughout the dissertation (primarily at the beginning of chapters or headings) and in the appendices.
CHAPTER FIVE: STUDY DESIGN AND PROCESS

As artists, our job is to look where others don’t.

— Alfonso Cuarón

Setting and Study Sites

This study took place in a multi-site capacity, as recruitment was opened up between Princess Margaret Cancer Centre (PM), Toronto General Hospital (TGH), Toronto Western Hospital (TWH), Toronto Rehabilitation Institute (TRI), as well as Kensington Hospice (KH). These sites encompass the University Health Network (UHN) as well as Kensington, an affiliated residential hospice (KH). UHN was an optimal site for recruitment as it is a leader in implementing guidelines and protocol for the practice of MAiD in Canada (Li et al, 2017). Multiple MAiD requests have been processed and many interventions have been performed, with numbers varying from month to month since the law was passed (Li et al, 2017). Because of the well-organized, structured, and streamlined MAiD process at UHN, involving a centralized MAiD coordinator with easily accessible information on the UHN website for patients, care providers, clinicians etc., UNH was an ideal location to conduct this study, which is the first of its kind in the world.

Patient Recruitment

To protect patients’ privacy, the Research Ethic Board (REB) at UHN suggested that research teams should not approach patients directly, but rather have a member of the patient’s circle of care introduce the study to potential participants. Patients who wished to learn more about the study were subsequently approached by a member of the research team.
The recruitment and follow-up process was organized as follows: (i) eligible patients were identified by their clinical teams, including clinicians involved in their care, e.g., physicians, nursing staff, social workers, or the UHN MAiD coordinator (and shared with research staff via secure email communication, or in person at weekly interdisciplinary patient rounds) and/or research staff were provided with patient lists or access to hospital databases (e.g., Electronic Patient Record, inpatient paper chart) for pre-screening of patient records to confirm eligibility; (ii) the clinical team (clinician within the circle of care) or MAiD coordinator introduced the study to eligible patients and requested permission for research staff to approach patients about the study. If permission was granted, a study team member (this study’s research assistant) met with the patient at an appropriate time for the patient, and provided them with a letter introducing the study (see Appendix D, Study Introduction Letter), and asked patients if they would accept being approached for research purposes (assuring them that declining participation would not impact their care or the MAID process). The introductory letters were signed by the MAiD Program Director. This letter informed the potential participant(s) about the various studies on MAiD being conducted in the Department of Supportive Care (as of Fall 2018, this included the present study on music and assisted dying as well as an additional MAiD Experience study and the possibility that s/he would either be approached by research staff at an upcoming hospital visit or reached by telephone to further explain the research and to request participation. Patients who declined approach for research purposes were not approached. The member of the MAiD clinical team who had introduced the research to the patient provided me with the patient contact information. The Music Therapy study team was notified of the number of individuals approached for the study, the number of individuals who refused, and those individuals who consented to their study. Fifteen patients were approached and ten consented.
Ten caregivers were approached, and eight consented, however only seven completed the interview as one was lost to follow up.

Patients could refuse approach by telling the research assistant, contacting the research team via telephone, email, or through their primary clinical team. The research assistant identified patients who did not express concerns, asking if they wished to know more about the study. Research staff only noted the names of patients who agreed to hear more about the study. If patients became distressed as a result of this recruitment strategy, support was available through a referral to psychosocial services (Department of Supportive Care, specifically via a general referral form for distress/psychosocial support, which was then triaged by Supportive Care staff and directed to the appropriate professionals, e.g., social work, psychiatry, or psychology); (iii) eligible patients who wished to learn more about the study were re-approached by research staff who described the study, conducted the informed consent process; (iv) research staff documented the number of eligible patients, but refused to participate in the study, however, did not include any identifying details; (v) participants were given all contact information for the researcher and once consent was obtained, the researcher scheduled initial music therapy session(s); (vi) music therapy sessions took place at participants’ convenience, with a number of options provided by the researcher who conducted the intervention; qualitative semi-structured, open-ended interviews took place following each session; (vii) participants could schedule follow up music therapy sessions with the researcher based on their needs/interests/requests. The researcher was also able to offer ongoing sessions as long as the participant felt they wanted to participate.

**Caregiver Recruitment**

To further understand the role of music therapy within the context of MAiD, and to gain more insight into and information about music therapy and MAiD for patients, the study team
recruited patient caregivers (as identified by the patient participants who consented to participate in the qualitative study). The recruitment process was as follows: i) patients enrolled in the qualitative study were asked to identify their primary caregiver or companion (e.g., spouse/partner, family member or close friend), and to indicate if that person would agree to be approached by the research team in order to be asked to take part in the study; ii) the research assistant approached the identified caregiver in person or over the phone, described the study and conducted the informed consent process with those who agreed to participate. As some patients did not wish to inform caregivers of their participation in psychotherapy or MAiD, patients were not required to identify a primary caregiver, and were still able to participate in the study if they did not include a caregiver. The therapy component of the study was not described in the caregiver consent form, so as to protect patient participant confidentiality related to their therapeutic process. If the patient consented, the caregivers were invited to participate in patients’ music therapy session; however, this was left up to the patient and not mandatory for the study outcomes measures.

In order to obtain fully informed consent, the research assistant explained the study to the potential participants/caregivers, and outlined the process of music therapy sessions in detail, describing risks and benefits, possible length of sessions, the interview process, and the option to opt out of the study at any point.

**Inclusion/Exclusion Criteria**

The following sections describe the participant inclusion and exclusion criteria details based on the UHN study protocol designed in conjunction with the Research Ethics Board standards.

**Patient inclusion criteria.** Patients were considered eligible to participate if they met the following criteria: i) patients (inpatient or outpatient) who requested medical assistance in
dying (MAiD) through their clinical teams at UHN; ii) have a grievous and irremediable medical condition, whose deaths are reasonably foreseeable; iii) age 18 or older; iv) fluency in English; and v) no cognitive impairment indicated by the medical record or by the most responsible physician (MRP).

**Patient exclusion criteria.** Patients were considered ineligible if they had evidence of a cognitive impairment (e.g., unable to consent to or pursue a MAiD assessment) as assessed by their primary health care team.

**Caregiver inclusion criteria.** Caregivers were considered eligible to participate if they met the following criteria: i) persons caring for a patient who has consented to participate in the primary study; ii) age ≥18 years; iii) fluency in English; and iv) no cognitive impairment.

**Caregiver exclusion criteria.** Caregivers were excluded from participating and from being approached if they were known to have major communication difficulties (e.g., severe hearing impairment or inability to speak) as assessed by the researcher, or if the patient declined having a caregiver participant as part of the study (e.g., reasons of privacy or because the patient was cautious of not wanting to upset the caregiver).

**Ethics**

This study was approved by the UHN’s Research Ethics Board (REB) (ID 18-5171, September 2018 through August 2019) and subsequently by the University of Toronto’s Research Ethics Board. Both Ethics Board approvals were renewed until August 2020.

**Informed Consent**

Participants were given as much time as necessary/requested to review the study information and ask questions before being asked to give consent. Informed consent was obtained from respondents before participation. Consent forms described the study and its objectives in lay terms, outlining potential benefits/risks to participants, indicating that participants were free to
withdraw at any time without adversely affecting their clinical care at that point or at any point in the future, and outlined what safeguards were taken to maintain confidentiality of data. (Please see Appendix F and G for patient and caregiver consent forms). Participants could choose to receive the intervention without having to participate in the study, if they preferred. A signed/witnessed consent form was obtained from each recruited patient; separate consent forms were obtained from companions/caregivers who agreed to participate in the caregiver portion of the study. One copy of each signed consent form was given to participants, and the other was retained by the study team. The principal investigator’s (Dr. Gary Rodin) and therapist/researcher’s (SarahRose Black) names and telephone numbers were provided on all consent forms as a resource for participants to ensure their understanding of informed consent. Contact information of the UHN research ethics office was indicated on all consent forms. The research assistant who recruited the participants into the study also signed the consent forms to witness that these participants had provided informed consent.

All participants were coded via an ID number for tracking purposes. Patients’ identifying information (specifically names or medical record numbers) did not appear on any study related documents, with the exception of the consent forms by means of the participants’ signature, and the documents (stored on encrypted devices) used to track and contact study participants. These documents and electronic forms were accessible only to the research assistant, the therapist/researcher, and principal investigator. All other study documents in paper copy format (e.g., source notes etc.) were accessible only to the research team (research assistant, therapist/researcher, and principal investigator). Research data as well as all collected audio recordings of sessions were identified by ID number only and, when not in active use, were safely stored in a password-protected database on secure network servers at PM or encrypted,
backed up, and securely stored hard-drives that were also password protected. All research computers and any other data storage devices at PM had also been encrypted for added security. All paper copies of documents were consolidated in standardized folders and stored in locked cabinets located in locked offices at PM. Data that is published will in no way identify the individual participant or disclose their identity. Participant identity information was primarily used to confirm study inclusion/exclusion eligibility criteria (e.g., confirm MAiD request), or to contact the participant with regards to follow up session times. Any information related to recruitment was securely stored and subsequently destroyed following completion of recruitment, data consolidation, and verification. All paper-copy data is currently securely stored and will be destroyed ten years after study completion, or for seven years if it does not contain personal health information, or five years after publication of findings (whichever occurs last). The specified time for data retention will meet minimum requirements for the UHN Research Ethics Board and the BC Cancer Research Ethics Board.

The music therapy intervention sessions were all audio recorded (participants were given an option to decline but all participants consented to audio recording of sessions); audio files or transcriptions of audio files are only being used for research purposes. The music therapy sessions were delivered by the therapist/researcher who is highly trained in music psychotherapy; she was supervised if/as needed by Dr. Gary Rodin, psychiatrist and head of the Department of Supportive Care (PM). Audio recordings were made using digital recorders with encryption capabilities as required by the UHN Privacy Office. As per suggestions from the UHN Privacy Office regarding an optimal recording device, the researcher used one recommended by both the Privacy Office and UHN Information Security. All qualitative interviews with patients and caregivers were audio-recorded and transcribed. Transcripts were filed according to the
participants’ IDs and also securely stored in secure servers at PM or in locked office filing cabinets in locked research offices at PM. Audio-files and transcripts will be securely stored and destroyed 10 years after study completion.

Consent forms also described the study and its objectives in lay terms, outlining potential benefits/risks to participants, indicating that participants were free to withdraw at any time without adversely affecting their clinical care, and outlined what safeguards would be taken to maintain confidentiality of data. Potential participants were able to receive music therapy even if they declined participation in the study.

**Sample Size Rationale**

Because of the qualitative nature of this study, it is not always necessary to define the exact sample number prior to commencement of the study, but rigorous methods were employed in order to guide adequate sample size (Bruscia, 2005; Malterud, Siersma & Guassora, 2016). The general aim for the sample size was between ten to twelve patients and eight to ten caregivers, for a total of 18 to 22 participants. Recruitment ceased once saturation of themes was achieved. The total number of participants was 18, plus the addition of the therapist/researcher (SRB) for each participant’s case study.

**Timeline**

Research Ethics Board (REB) approval was obtained at the end of August 2018. Recruitment began in September of 2018, and was completed in April of 2019; however, the study is remaining open via the REB until August of 2020 for purposes of accessing chart review data in order to verify patient information if needed. All sessions were audio recorded and transcribed by either the researcher (SRB) or the research assistant (TK). Data analysis was embedded into the process of data collection (e.g., data was analyzed during and after each transcription) but the majority of the data analysis occurred following completion of transcription of all sessions.
Thematic outcomes were validated and triangulated by several members of the study team including Dr. Lee Bartel, Dr. Gary Rodin, and Taylor Kurta (research assistant to primary researcher SarahRose Black).

**Data Analysis Overview**

Data (including the transcribed sessions, both words and music, follow-up interviews, and researcher reflections) was analyzed using hermeneutic phenomenology (van Manen, 1997, 2006, 2011, 2014): initially, themes were described as “structures of experience” in a wholistic sense, followed by a “selective/highlighting” approach to statements and phrases. This analysis process was followed by a detailed reading of the data wherein each sentence, phrase, and cluster was examined while exploring what was being described as lived experience, while capturing thematic expressions, phrases, and narratives (van Manen, 2014, p. 320). An extraction and interpretation of themes in tandem with a consideration of the wholistic thematic content constitutes the “hermeneutic circle” (Sloan & Bowe, 2014; Smith et al, 2009; van Manen, 1997).

Wheeler and Kenny (2005) describe hermeneutic inquiry as “wholistic in nature, and an unending circle of knowledge creation” (p. 66). They go on to describe the hermeneutic circle as a form of expression of circular thinking, with elements of experiences, wholes, contextualizations, parts, integrations, and a loop back to the original experiences (2005).

In addition to examining the data via the hermeneutic circle, this research draws on elements of van Manen’s “existentials” (1997), themes that can act as reflection guides for the data. These were used to support the analysis process: themes included lived space, lived body, lived time, and lived dying. Further to this, each participant’s experience was described through “phenomenological writing” (van Manen, 2002), wherein the practice of writing each case in a phenomenological style allowed for thematic emergence, inviting patients’, caregivers’, and the
researcher’s voices to emerge. Findings for each participant were discovered and explored through these processes.

**Qualitative Interviews**

Caregivers were invited to participate in one or more qualitative “phenomenological interview(s)” (van Manen, 2014) during the course of their loved ones’ (the patient participant’s) involvement. Caregiver interviews were completed approximately three to four months after the study patient’s MAiD intervention, as per best practices in the research literature around approaching bereaved family members for interview purposes (Bentley & O’Connor, 2015). The interviews used a series of open-ended, discovery-oriented questions relating to the experience of music therapy in the context of caring for patients requesting/receiving MAiD, from the caregiver’s perspective. This was explicitly stated on their consent form (see Appendix B). As part of the interview, caregivers were invited to reflect on the experience of music therapy in their loved one’s life at this particular time (requesting/receiving MAiD). The caregiver was able to decline this portion of the interview process, or able to opt out at any point even if they did consent. Interviews were also recorded for later transcription. Researcher reflections were done specifically following each session and interview and were also completed intermittently throughout the data collection process as appropriate and relevant to the research’s engagement with the data. The following table (Table 1.0) outlines all the different data sources used, as well as which type of participants’ experiences were captured with the various types of data.
Table 1.0 Data Sources and Corresponding Participants Involved

<table>
<thead>
<tr>
<th>Data Source</th>
<th>Participants involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session data (audio recorded and transcribed)</td>
<td>All patient participants</td>
</tr>
<tr>
<td>Phenomenological case narrative (written by researcher after completion of all sessions)</td>
<td>All patient and caregiver participants (integrated to one narrative per case)</td>
</tr>
<tr>
<td>Researcher reflections (written by researcher after each session with each patient and caregiver participants)</td>
<td>All patient and caregiver participants</td>
</tr>
<tr>
<td>Caregiver interview (audio recorded and transcribed)</td>
<td>Caregivers for the following patient participants: 1, 4, 5, 6, 7, 9, 10</td>
</tr>
</tbody>
</table>

Data Collection Software and Storage

All study-related data was collected on paper and/or through an audio-recording device recommended by the UHN Privacy Office; patient information (assigned patient ID) was tracked through a Microsoft Excel document stored on a secure, password protected and encrypted server at PM. Session recordings (audio recorded music therapy sessions and subsequent qualitative interviews) were recorded on an audio recording device recommended by the UHN Privacy Office, and data was regularly transferred and stored on a secure, password protected and encrypted server at PM; access was only available to the principal investigator, the research assistant, and the therapist/researcher. No data needed to be transferred, with the exception of the
audio recording device which was kept with the therapist/researcher at all times. Once the audio files were downloaded onto the secure PM server, if the data had to be transferred, it would have been transferred via an encrypted USB. Notes were scribed by the therapist/researcher in addition to the audio recording, for reference (without patient identifiers or any identifying information); in this case, the hand-written notes were immediately be transferred to a Microsoft Word document on a secure, password-protected PM server.

**Study Team Members and Roles**

The following is an outline and description of the study team members and their varying roles within the study process.

**Doctoral Advisor/Supervisor.** Lee Bartel, PhD. Professor Emeritus of Music; former Associate Dean-Research at the Faculty of Music, University of Toronto; Founding Director of the Music and Health Research Collaboratory. **Role:** Co-supervisor; Dr. Bartel supervised the researcher and supported and guided the research process from a methodological perspective.

**Principal Investigator/Co-supervisor.** Gary Rodin, MD. Head, Department of Supportive Care, PM, a member of the University Health Network (UHN); Senior Scientist, PM Research Institute; Professor of Psychiatry, University of Toronto (UT); UT/UHN Chair in Psychosocial Oncology and Palliative Care; **Role:** Co-supervisor; Dr. Rodin supervised the researcher and had overall institutional responsibility for all aspects of the study.

**Therapist/Researcher/Doctoral Candidate.** SarahRose Black, RP, MTA, PhD (c). Accredited music therapist and registered psychotherapist (Department of Supportive Care, PM and KH); Music Therapy Supervisor, Wilfrid Laurier University, PhD Candidate, University of Toronto, Faculty of Music; **Role:** Therapist/researcher, conducted the intervention for patients (e.g., music therapy sessions) and collected data (conducting semi-structured qualitative
interviews following each session; data transcriber, data analyst, responsible for interpretation; responsible for study write-up as part of doctoral dissertation).

**Research Assistant.** Taylor Kurta, BMusTh, MA, MT-BC. Board-certified music therapist (Kensington Health Centre, Long Term Care); Research assistant via University of Toronto, Faculty of Music, and the University Health Network; **Role:** Research assistant, met with study participants, obtained informed consent, data transcriber, provided triangulation/validation during data analysis.

Because this study was designed in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Music and Health Sciences (University of Toronto, Faculty of Music), the supervisory committee (co-supervisors Drs. Lee Bartel and Gary Rodin along with committee member Dr. Joanne Loewy) monitored and guided the process as it progressed, supervising the structure, ethical integrity, as well as research design throughout recruitment and data analysis.

**Patient Participant Information**

Of 15 potential participants who were approached to be involved in this study, ten patients and eight caregivers consented (seven caregivers completed the study). Table 1.1 outlines demographic information about each participant, including age, diagnosis, type of death (MAiD or natural death), location of death, caregiver participant in the study (if applicable), and the initial clinical goal of the music therapy session(s). The mean age of the participants was 66.2. All participants had metastatic disease progression of their initial cancer diagnosis. Two had comorbidities that contributed to their terminal illness: Participant #7 was in organ failure (lung) following a double lung transplant 13 years ago, in addition to metastatic lung cancer. Participant #8 was living with HIV/AIDS in addition to metastatic adenocarcinoma cancer. Of the three participants who died natural of disease progression, two lost capacity due to functional,
cognitive and medical decline, and therefore were not able to consent to MAiD. One participant changed her mind about MAiD when she was transferred to a residential hospice. Of the seven participants who received MAiD, I was present in the room during MAiD interventions for three (highlighted in Table 1.1, specifically Participants 6, 7, and 10). Of those three participants who received MAiD but did not have me (therapist/researcher) in the room, one had MAiD in her home (Participant #1), one had only immediate family members in the room (Participant #2), and the other two (Participant #8 and #9) had no family or friends in the room, only the intervention physician and the assisting Registered Nurse.

The following table (below) outlines the patient participants’ demographic and clinical information. In the table, the acronym “PM” refers to Princess Margaret Cancer Centre; the acronym TGH refers to Toronto General Hospital. The abbreviation “Met” refers to metastatic disease progression, referring to a metastasizing (spreading) of the cancer to parts of the body other than the primary site of diagnosis. The letters “CA” under the “Diagnosis” column are an abbreviation for cancer.
Table 1.1 Overview of Patient Participants

* Therapist/researcher was present for the MAiD procedure.

<table>
<thead>
<tr>
<th>#</th>
<th>Age</th>
<th>Diagnosis</th>
<th>Total # of Sessions</th>
<th>Death</th>
<th>Death Location</th>
<th>Caregiver</th>
<th>Initial Clinical Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>57</td>
<td>Met Ovarian CA</td>
<td>2</td>
<td>MAiD</td>
<td>Home</td>
<td>Daughter</td>
<td>Reminiscence</td>
</tr>
<tr>
<td>2</td>
<td>69</td>
<td>Met Prostate CA</td>
<td>1</td>
<td>MAiD</td>
<td>PM</td>
<td>Daughter</td>
<td>Comfort</td>
</tr>
<tr>
<td>3</td>
<td>60</td>
<td>Met Lung CA</td>
<td>5</td>
<td>Natural</td>
<td>PM</td>
<td>N/A</td>
<td>Symptom management</td>
</tr>
<tr>
<td>4</td>
<td>66</td>
<td>Met Lung CA</td>
<td>1</td>
<td>Natural</td>
<td>PM</td>
<td>Wife</td>
<td>Symptom management</td>
</tr>
<tr>
<td>5</td>
<td>60</td>
<td>Met Ovarian CA</td>
<td>3</td>
<td>Natural</td>
<td>Hospice</td>
<td>Partner</td>
<td>Song-writing/Legacy</td>
</tr>
<tr>
<td>6</td>
<td>67</td>
<td>Met Pancreatic CA</td>
<td>2</td>
<td>MAiD*</td>
<td>Hospice</td>
<td>Friend</td>
<td>Symptom management</td>
</tr>
<tr>
<td>7</td>
<td>69</td>
<td>Met Lung CA</td>
<td>3</td>
<td>MAiD*</td>
<td>TGH</td>
<td>Daughter</td>
<td>Reminiscence</td>
</tr>
<tr>
<td>8</td>
<td>53</td>
<td>Met Anal CA</td>
<td>2</td>
<td>MAiD</td>
<td>TGH</td>
<td>N/A</td>
<td>Reminiscence</td>
</tr>
<tr>
<td>9</td>
<td>86</td>
<td>Met Lung CA</td>
<td>1</td>
<td>MAiD</td>
<td>Hospice</td>
<td>Daughter</td>
<td>Reminiscence</td>
</tr>
<tr>
<td>10</td>
<td>75</td>
<td>Met Ovarian CA</td>
<td>1</td>
<td>MAiD*</td>
<td>Hospice</td>
<td>Husband</td>
<td>MAiD Music</td>
</tr>
</tbody>
</table>

**Description of Initial Clinical Goals**

Each participant was referred to the study either via a clinician from their primary care team or the MAiD coordinator. Two participants had a previous experience with music therapy (Participants #5 and #9) but music therapy was a new experience for all of the other participants. Music therapy was introduced, and the initial clinical goal was a therapeutic starting point, as
determined by the patient in collaboration with the therapist/researcher, depending on the patient’s primary needs, concerns, and requests at the time of connection to the therapist/researcher. The following is a description of the initial therapeutic goals of the ten patient participants.

**Initial Goal: Reminiscence**

Description: The patient participant initially requested music that would support a reminiscing or reflecting on earlier memories (Bradt & Dileo, 2010; Clements-Cortes, 2010). Often, this music was linked to the participant’s identity, or significant life events.

**Initial Goal: Comfort**

Description: In this case (Participant #2), the patient participant requested music that would feel “relaxing” and “soothing,” which I as clinician often broadly categorize as “comfort” (Hilliard, 2005). The music requested when comfort is the initial clinical goal is often related to meaningful memories, the participant’s identity, or may have a slower tempo, supporting an ease of breath/heart rate (Etzel et al, 2006).

**Initial Goal: Symptom Management**

Description: For patient participants whose initial clinical goal was symptom management, they were typically experiencing discomfort related to pain, nausea, or from a somnolence/fatigue perspective. Music was initially provided to support distraction/diversion, as well as deepening of breathing in order to support a slowing of the heart rate and relaxation of muscles in order to reduce pain and symptoms (Gutsell et al, 2013).

**Initial Goal: Song-writing/Legacy Work**

Description: Two patient participants engaged in song-writing (#3 and #5). One patient participant (#5) requested legacy work through song writing as her initial clinical goal, using original music (composed during the sessions with the therapist/researcher) to share specific
sentiments and messages with her loved ones. Prior to these sessions, she had engaged in song-writing in music therapy and wanted to continue this process in the context of assisted dying. Participant #3 engaged in song-writing for purposes of creative self-expression. Song-writing typically involves therapist-led/patient-directed composition of original music based on themes, ideas, messages (e.g., leaving a “legacy” for a loved one), or sentiments (O’Callaghan, 2005).

**Initial Goal: MAiD Music**

Description: This clinical goal refers specifically to music determined and set for the MAiD procedure (Black, 2017a). In the case of Participant #10, she was interested in connecting to music therapy for the purpose of pre-determining and discussing how to incorporate music during the MAiD procedure.

**Music Therapy Interventions**

The following is an overview of the various music therapy interventions that were employed during the therapy processes. Table 1.5 outlines which participants engaged in certain interventions. These interventions were chosen to reflect evidence-based music therapy practice, in tandem with the clinical approach and style of the therapist/researcher.

**Inter-Active listening (IAL).** Inter-Active Listening, or IAL (Black, Zimmermann & Rodin, 2017), also referred to as receptive music therapy (Wigram & Grocke, 2005), involves the therapist playing or singing while the patient/client is listening inter-actively, and the therapist responds empathically based on the patient reaction(s) and outcomes. The patient may be listening for a purpose (e.g., relaxation, diversion/distraction) or may have requested music in order to reflect on significant life memories or events. IAL is typically done by the therapist as a solo musical intervention, and may be comprised of familiar pre-composed music (requested by patient or family/friends, or suggested by therapist), unfamiliar pre-composed music (suggested
by therapist), or improvised music played by the therapist based on patient indicators and suggestions for mood, theme, or outcome (Lee, 2003).

**Singing.** Music therapists commonly use vocalization techniques in various forms (Austin, 2009) or singing of familiar or improvised songs (Bruscia, 1998), based on various models of care, and client/patient needs. Within the context of these sessions as related to MAiD, participants would either listen to the therapist sing songs that were familiar or would listen to the therapist improvise vocally depending on the clinical goal at the forefront of the clinical interaction. Receptive singing was used (Wigram & Grocke, 2005), and improvisational singing was used (Lee, 2003). At times, the participants and/or the family/friends who were present would also sing, engaging a group model of music therapy (Pavlicevic, 2016). Songs were either chosen by the participants, the family/friends who were present, or the therapist depending on the context of the session, the participant’s needs, and the clinical goals.

**Lyric Analysis.** Some participants would engage in lyric analysis, a process of striving to understand that which holds meaning or importance in a patient’s life (O’Callaghan & Grocke, 2009), by choosing lyrics to a meaningful song and exploring significance of the words as they relate to the participant’s experiences (Gardstrom & Hiller, 2010; Yinger & Springer, 2016). Words, sentences, phrases, or ideas were explored in a psychotherapeutic fashion, as the therapist prompted investigation into the significance of the words as they connected to the participant’s understanding and interpretation, as well as memories and associations (Silverman, 2009). Participants and family/friends did this spontaneously at times, reflecting on the lyrics of a song after the therapist had sung it, or would otherwise be directed by the therapist or occasionally by the family/friends present during the session. In two cases (Participant #7 and Participant #10), the family members and the participant (respectively) asked that lyrics to
significant songs be printed out and distributed amongst those present during the MAiD intervention, so that group singing could be facilitated.

**Musical Reminiscence/Life Review.** Life review is generally defined as an evaluation of one’s life and is a commonly experienced process for those facing death (Butler, 1963). Several participants engaged in structured or unstructured musical reminiscence or life review, during which they reflected on significant life events and matched a song to the event. These processes usually involved recall of memories triggered by singing, playing, and listening to music, sometimes followed by verbal discussions/processing in order to explore significance of life events (Hilliard, 2001; O'Callaghan, 1996; Sato, 2011; Sato, 2010). Structured musical reminiscence or life review was facilitated by the therapist, based loosely on an adapted Musical Life Review (MLR) Model (Sato, 2011) used generally in hospice care, within which participants used music to express feelings, lift mood, and explore identity. Unstructured musical reminiscence or life review involved the participant or family/friends spontaneously connecting musical selections to significant life events and reflecting on those events through the springboard of the musical choice. The therapist could then either delve further into this reflection and ask probing questions or invite the family/friends and participant to reflect on their own terms and at their own pace.

**Verbal Psychotherapeutic Processing.** The style of music therapy upon which the majority of these interventions have been based is music psychotherapy (Bruscia, 1998). This style typically utilizes music to engage in a sense of greater self-awareness, emotional release, self-expression, deeper insight, cognitive restructuring, and development of healthy relationships, among other clinical goals (Bruscia, 1998). According to Bruscia, music may be used in psychotherapy, as psychotherapy, or alongside verbal psychotherapy, and within each of
these models, many different approaches and techniques may be used based on various theoretical orientations (1998, pp. 2–3). Nolan further (2005) suggests that verbal processing can be used in music therapy as an opportunity to increase awareness or understanding of internal thoughts and external events within the music and interpersonal areas of experience. As a registered psychotherapist (RP) with the College of Registered Psychotherapists of Ontario (CRPO), I often engage patients in verbal psychotherapy in tandem with music therapy, as the processing of emotion through verbalization may offer opportunities for themes and insights to emerge. In the context of MAiD and music therapy, some participants engaged in aspects of verbal psychotherapy; this intervention style is defined by Bruscia (1998) as follows:

The therapeutic issue(s) are accessed, worked through, and resolved primarily through verbal discourse. Music experiences may be used in tandem, to facilitate or enrich the discussion, but are not considered germane to the therapeutic issue or treatment of it. (p. 3)

Some sessions relied more heavily on verbal psychotherapy, while others used moderate aspects of verbal psychotherapy; still other sessions used very little if any verbalization/discourse. The use of verbal psychotherapeutic processing was dependent on the clinical goals and the direction in which the participants wanted or needed to go in the therapy.

**Song-writing.** Song-writing is a common technique used in adult cancer care, as well as in palliative and end of life care, among other populations (Dileo & Magill, 2005; O’Brien, 2005; O’Callaghan, 1996, 2005;). Song-writing may involve brainstorming ideas around the patient’s experience, possibly collected through free association or other techniques, followed by a transforming of ideas into a song structure, including melodies, rhythms, patterns, and harmonies (O’Callaghan & Magill, 2016). These songs are often recorded and shared with loved ones,
sometimes in the presence of the patient, and at other times posthumously. Within the context of
music therapy and MAiD, two participants (Participant #3 and Participant #5) wrote songs to
articulate and express the experiences they were encountering, including searching for peace and
expressing sentiments to a family member, respectively. Table 1.2 (below) outlines all the
interventions used, and which participants used certain interventions.

**Table 1.2 List of Music Therapy Interventions Used within Participant (P) Sessions**

<table>
<thead>
<tr>
<th>INTERVENTION</th>
<th>PARTICIPANT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>P.1 Marie</td>
</tr>
<tr>
<td>Inter-Active Listening</td>
<td>♫</td>
</tr>
<tr>
<td>(Familiar)</td>
<td></td>
</tr>
<tr>
<td>Inter-Active Listening</td>
<td>♫</td>
</tr>
<tr>
<td>(Unfamiliar and/or improvised)</td>
<td></td>
</tr>
<tr>
<td>Singing: Familiar music</td>
<td>♫</td>
</tr>
<tr>
<td>Singing: Unfamiliar and/or improvised</td>
<td></td>
</tr>
<tr>
<td>Lyric Analysis</td>
<td>♫</td>
</tr>
<tr>
<td>Musical reminiscence/Life review</td>
<td>♫</td>
</tr>
<tr>
<td>Psychotherapeutic processing (verbal)</td>
<td>♫</td>
</tr>
<tr>
<td>Song-writing</td>
<td>♫</td>
</tr>
</tbody>
</table>
**Instruments Used in Sessions.** The therapist used a combination of an electronic keyboard (Yamaha 76 keys NP-V60 “Piaggero”), several Tibetan singing bowls pitched at various tones, and vocals (singing).

**Caregiver Participant Information**

Of the ten patient participants, eight consented to have a caregiver of choice approached as part of the research process. The two who declined (Participant #3 and Participant #8) declined for two different reasons: Participant #3 did not want her family members to have to discuss MAiD, as it was emotionally challenging for the family, so preferred they not be approached. Participant #8 did not want any family or friends involved in the MAiD process and had asked them to stop visiting prior to the MAiD intervention, so was not in contact with any family or friends at the time of our meeting. Participants 1, 2, 4, 5, 6, 7, 9, and 10 all consented to have their various caregivers approached. Of those approached (eight), seven completed the follow up interview approximately four months after the death of their loved one. One (Participant Caregiver #2) was not contactable after several attempts, therefore considered lost to follow up. Table 1.3 (below) provides a demographic overview of the caregiver participants.
Table 1.3 Overview of Caregiver Participants

<table>
<thead>
<tr>
<th>#</th>
<th>Relationship to Patient</th>
<th>Age Range</th>
<th># of Attended Sessions</th>
<th>Reason for Opt-out (as applicable)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Daughter</td>
<td>30-35</td>
<td>2/2</td>
<td>N/A</td>
</tr>
<tr>
<td>2</td>
<td>Daughter</td>
<td>35-40</td>
<td>1/1</td>
<td>Patient’s daughter consented however was unreachable after patient’s death.</td>
</tr>
<tr>
<td>3</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>Patient did not want son or husband to participate; MAiD was not openly discussed, and she was concerned about their emotional well-being.</td>
</tr>
<tr>
<td>4</td>
<td>Wife</td>
<td>50-60</td>
<td>1/1</td>
<td>N/A</td>
</tr>
<tr>
<td>5</td>
<td>Partner</td>
<td>50-60</td>
<td>1/3</td>
<td>N/A</td>
</tr>
<tr>
<td>6</td>
<td>Friend</td>
<td>50-60</td>
<td>2/2</td>
<td>N/A</td>
</tr>
<tr>
<td>7</td>
<td>Daughter</td>
<td>30-40</td>
<td>1/3</td>
<td>N/A</td>
</tr>
<tr>
<td>8</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>Patient was extremely private about MAiD and declined all visitors/supports.</td>
</tr>
<tr>
<td>9</td>
<td>Daughter</td>
<td>40-50</td>
<td>1/1</td>
<td>N/A</td>
</tr>
<tr>
<td>10</td>
<td>Husband</td>
<td>70-80</td>
<td>1/1</td>
<td>N/A</td>
</tr>
</tbody>
</table>
CHAPTER SIX: THE EXPERIENCE OF MUSIC THERAPY AND MEDICAL ASSISTANCE IN DYING

Intimate musical practice or private one-to-one human-music interaction may link us to our most intimate self, through a reflexive and introspective process of reflection.

— Tia DeNora, *Music in Everyday Life*

It is precisely in the process of writing that the data of the research are gained as well as interpreted and that the fundamental nature of the research questions is perceived.

— Max van Manen, *Phenomenology of Practice*

**Overview of Data Presentation**

The overall thematic outcomes of the hermeneutic phenomenological analysis will be presented in Tables 1.4 and 1.5. Each case (encompassing the patient, caregiver as applicable, and the therapist/researcher) and subsequent data analysis is presented through a narrative writing piece, written primarily from the therapist/researcher’s perspective, informed by van Manen’s approach to phenomenological writing (van Manen, 2002). Names and identifying details have been altered to protect the privacy of each participant. Each narrative piece is followed by what I have termed an “Exit Music Playlist”, a listing of all the songs used as part of the music therapy sessions (and in several cases, during MAiD). Of note, all of the music on each “Exit Music Playlist” was played live for the participants at some point during their participation in the music therapy sessions prior to (and in several cases during) MAiD.
The narrative writing pieces are designed for two primary purposes as informed by hermeneutic phenomenology practice (van Manen, 1997). First, the process of the writing itself was a critical component of the data analysis, allowing thematic emergence and for the therapist/researcher (also one of the research participants in each case) to engage in what van Manen calls the main task of phenomenology: interpretive description (van Manen, 2014). Secondly, phenomenological writing invites the reader into the essence of the lived experience by bringing them into the lifeworld of the participants. Each narrative is written in a slightly different style, as I (as therapist/researcher) attempted to allow an ongoing adoption of a phenomenological attitude while staying true to van Manen’s (2014) suggestion that we as researchers are “au monde,” in and of the world simultaneously, in that we cannot ever step out of the world and view it from a detached vista (p. 62). The narrative case presentations are followed by a textual analytic description of the wholistic, selective, and detailed readings of the primary texts (transcripts, audio interviews/sessions, and music embedded within each session) for each participant (patient, caregiver as applicable, and therapist/researcher). A further reflection based on a guided existential inquiry is presented in Chapter Seven (Findings and Themes). Quotes from poetry, literature, music lyrics, and other arts-based sources punctuate many of the narrative cases as a further invitation to explore the experience of the participants. When referring to the role of writing in inviting glimpses or “Orphean gazes” into experience, Van Manen invites the phenomenological writer to consider Derrida’s concept of writing as a window into phenomena which is fundamentally difficult to represent, perhaps even unrepresentable:

“Writing creates a space that belongs to the unrepresentable, and it is within this writerly space where there reigns the ultimate incomprehensibility of things, the unfathomable
infiniteness of their being, the uncanny rumble of existence itself, but in this fleeting
gaze, we also sense the fragility of our own existence, of our own death, that belongs to

This “fleeting” window into that which is “unrepresentable” is the space that I as
therapist/researcher and writer attempt to enter and represent in the following phenomenological
writing and data analysis. It is my phenomenological intention that the participants’ voices²
(including those of the patients, caregivers, and therapist/researchers) are provided with the
opportunity to be heard within this Derridian space, created by writing, which ultimately allows
the reader to sense the fragility of their own existence and death, which fundamentally belongs to
each individual interacting within this Derridian space.

The results of the **wholistic reading** are presented with a phrase to represent the
phenomenological meaning or main significance of the text as a whole. The results of the
**selective reading** are presented initially as quotes or actions from the participant or participating
caregiver or clinician as applicable, followed by interpretive-descriptive reflective paragraphs
which describe intersections with and connections to the main thematic findings (as presented in
Table 1.4, 1.5, and 1.6). The results of the **detailed reading** are presented as several specific
phrases from the participant, followed by specific thematic outcomes that resulted from the line-
by-line reading of the transcripts, as per van Manen’s approach (2014, pp. 320–323). While not
all lines from each transcript are presented in this dissertation (given the length restrictions of the
dissertation, a full line-by-line analysis of each transcript and researcher reflection is not feasible

² Each case involves either the patient and their caregiver and the therapist/researcher, or the patient and the
therapist/researcher (no caregiver participant). Each case is identified and named initially by the patient participant’s
pseudonym.
to present in this context), select lines have been chosen to represent the process and outcomes of the detailed reading.
Participant 1: Marie

Oh child, will you know this song when I’m gone and I fade away? Will you sing it back, know it word for word, back to your child one day?

– Robin Schulz & Piso 21, “Oh Child”

Marie: A Narrative

“No matter how old you are, you will always be my baby,” Marie whispered, her voice weakened from fatigue.

She smiled; exhaustion apparent on her face.

“Oh, Mom…,” her adult daughter whispered back, tears rolling down her cheeks. I sat quietly behind my keyboard, bearing witness, holding space. Over the past 30 minutes or so, Marie had shared stories of her youth, her life in Vietnam, her deeply felt connection to music that lifted her spirits in the midst of trying to escape a war-torn country in order to build a new life for herself, all the while maintaining a sense of identity.

Marie was sitting up in a chair beside her hospital bed, her untouched tray of puréed food in front of her. Her daughter was seated beside her, and I in front of them both, my keyboard between us.


Chiquitita, tell me what’s wrong

You’re enchanted by your own sorrow
In your eyes, there is no hope for tomorrow

How I hate to see you like this

There is no way you can deny it

I can see that you’re oh so sad, so quiet...

A song for herself? A song for her daughter?

I softly played and sang Chiquitita, reflecting on the words as I shaped and connected each phrase, moving carefully through the harmonies, and gently integrating and connecting multiple ABBA songs into what became a personalized medley. Dancing Queen. Thank You for the Music. The Winner Takes It All.

The gods may throw a dice

Their minds as cold as ice

And someone way down here

Loses someone dear...

Whenever I paused, Marie applauded, a tiny smile forming on her tired face. I carried on, leaving room for breath, for silence, for reaction, for tears. Her daughter dabbed the corners of her eyes, holding her iPhone up in her hand, capturing these last weeks, her mother’s final chapters, her last experiences. I musically circled back to Chiquitita, completing the medley with her initial request.

How the heartaches come and they go and the scars they’re leaving...

You’ll be dancing once again, and the pain will end...you will have no time for grieving...
When I stopped, Marie smiled and started to applaud. I smiled back.

“Can I ask you about Chiquitita? Why that song in particular?” I asked.

“When I was in a refugee camp —”

“A Bangkok refugee camp,” Isabelle interjected.

“A Bangkok refugee camp, yes. When I was there, I made some friends, they were older than me, and they knew these songs, I was about 17 or 18 but they were already 20, 30, so they knew ABBA songs really well. They played them every day, night and day, and at night when they would play ABBA songs. We would listen, and they would be dancing. Those were really good memories. Really, really good memories. So that’s why sometimes when I hear the music, I remember that time.” Marie leaned back in her chair.

To be young, alone, and uncertain of what the future would bring, I thought. And to be accompanied by music, by friends who embodied the music through dance, through camaraderie, in the midst of navigating displacement, immigration, and isolation. And to bring that to the fore, providing an opportunity for her daughter to bear witness to some of her most memorable experiences. Why do these moments surface when death approaches, I wondered silently?

I began to play.

“Dancing queen, young and sweet only 17,” I sang quietly, matching her breathing patterns. Her daughter silently held up her phone and began recording.

“Oh, it brings back such good memories, the people, the place…” Marie smiled. “Canada finally accepted me, after five months,” she said. She shared the process of sponsoring each of her
family members over the next seven years, her determination to not let anything hold her back. I commented on her courage, her resilience. She brushed it off politely. She requested songs from movie soundtracks that had moved her as a young girl, and songs that she liked to listen to when her own three daughters were growing up. Love Story. House of the Rising Sun. Somewhere Over the Rainbow. “They really take care of me now, daughters. I just want to go peacefully. This disease, it’s only getting worse, not better,” she said matter-of-factly.

At Marie’s request, I played and I sang, gently supporting her slow but steady breathing patterns to guide the tempo of my music. She mouthed the words along. After a few harmonically interwoven songs, I paused. “We are born, so we must die. I am lucky that I have a choice and I can choose how. Some people, they get hit by a car, they don’t have a choice. But I do. You know, I was very brave when I was 17,” Marie said, tears rolling down her cheeks.

“You still are, Mom. You still are,” her daughter said, taking her hand.

Marie’s musical requests seemed to prompt a spontaneous life review, providing an opportunity for the 57-year-old Marie to reflect on pivotal life events, in the presence of her daughter and me. Months later, her daughter confided that although she had heard these stories before, there was something different about her mother’s reflections within the context of the music.

“She wasn’t saying much during that time, it was hard to know what to talk about, but when you came in with the music, well, it gave her a whole new way to share her life.”

At our first session, Marie had planned to have an assisted death, though no date was yet set.
“Come back again, when you can?” she asked. We went on to have a second session the following week, this time with two of her daughters curled up on either side of her in her hospital bed. I played through song after song, as her daughters lay quietly next to her.

“I see skies of blue, clouds of white, the bright blessed day, the dark sacred night, and I think to myself, what a wonderful world,” I sang. After 20 minutes of music, I paused. Marie opened her eyes.

“When you sing, it’s like I’m dancing with the angels. No anxiety, no worries. I just leave it all in the music,” she smiled. I smiled back. “I’m dancing on the clouds,” she whispered.

I knew from the clinical team that Marie was planning to be discharged home and would likely receive MAiD there. Months later, her daughter said to me, “The first time that you played for her, you know, the ABBA, she started speaking a lot, and I don’t know why she did, but it was suddenly a lot more than usual. I think it helped for her to think about her happy memories. It was hard for me, I was tearful because I thought it might be the last time my Mom and I would experience something like that together. I just didn’t want to ruin the moment for her either, like I just wanted her to enjoy it as much as possible because she loved the choices, the way you were able to segue into different songs, you know, the Love Story, the ABBA, everything, it’s all her style of music, she loves that, but for me, it was a combination of my childhood...kind of like a summary of everything, I don’t really know how to express it.” I could hear her crying over the phone.

Was it the combination of meaningful musical memories in tandem with facing end of life that created these opportunities for deeply felt emotions and shared experiences? And how is it that music so quickly creates moments for shared memory processing?
Marie was poised, elegant in the way she articulated her request for MAiD and her reflections on her past.

She was clear, yet she embraced the abstract.

Courageous and honest.

Marie had an assisted death in her home in October of 2018 with her daughters by her side.

**Exit Music Playlist**

The following songs were used in Marie’s music therapy sessions (played/sung by me):

- ABBA: Chiquitita
- ABBA: I Have a Dream
- ABBA: Mamma Mia
- ABBA: Dancing Queen
- ABBA: The Winner Takes it All
- Francis Lai: Theme from Love Story
- The Animals: House of the Rising Sun
- Boney M: Rasputin
- Boney M: Mary’s Boy Child
- Boney M: When a Child is Born
- Harold Arlen: Somewhere Over the Rainbow

**Patient Information Overview**

Marie was a 57-year-old woman with metastatic ovarian cancer. She was first diagnosed with ovarian cancer in November of 2014 and was referred to music therapy during her admission to the palliative care unit of PM in September of 2018. Marie was supported by her three adult daughters; her husband died several years prior to her diagnosis. She was assessed and approved for MAiD in September of 2018, however ultimately decided to defer the intervention to the following month. She received two music therapy sessions at the cancer centre where she was admitted, the first approximately 45 minutes in length held in the late morning, and the second
held mid-afternoon, approximately 35 minutes in length. Shortly after her second music therapy session, she was transferred back home where she received MAiD. I was not present during her MAiD intervention. Her family (specifically her daughters) played some of the music listed in the “Exit Music Playlist” above during her time at home, but as per her daughter, she chose to not have music during her MAiD intervention.

**Analysis: Patient (Marie)**

The following wholistic reading, selective reading, and interpretive-descriptive reflections resulted from a hermeneutic phenomenological analysis of Marie’s two sessions, the follow-up caregiver interview with her daughter approximately three months after Marie’s death, and the researcher reflections written immediately after each session and the caregiver interview.

**Wholistic reading: Overview**

Marie invited specifically chosen music as a catalyst to reflect on various life events, linking them to her current relationships (particularly with her daughters, especially with her eldest daughter who was present for both sessions), and commented regularly on the importance of control and choice about death decisions in the context of life reflection. She engaged with the aesthetic experience of live music to experience specific imagery related to a physical sense of freedom and ease. Marie chose familiar songs that had specific connections to her experiences as an adolescent, which held significance for her later in life, as well as for her daughters in their adolescence. She reflected on her own experiences but made many references to the experiences of her daughters, and her relationships with each of them. She commented on her gratitude for their support and reflected on stories of her own youth which she wanted them to hear and remember throughout their own lives. She was calm and exhibited an intentionality in her requests and needs.
Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect Marie’s experiences of music therapy throughout her sessions.

Statement. (Session 1): “I don’t feel any regrets or anything, I just want to go peacefully.”

Interpretive-descriptive reflection. In this moment in the session, Marie shared that she was feeling ready to let go of her life and die peacefully; she had noted her extensive treatment and exhaustion from these experiences. She said she had no feeling of regret. This is notable as she did not state, “I don’t have any regrets”; she stated, “I don’t feel any regrets” (my emphasis). This highlights a marked difference in feelings versus facts: whether she did or did not have regrets is not information we as observers/readers have access to, however she did note that she wanted to “go peacefully” and die within the context of not feeling “regrets.” This statement is connected to the theme of having control over the choices related to her own life and death, as she feels she can choose the option of a peaceful death.

Statement. (Session 1): “We are born, then we die, it’s a cycle, and I’m so lucky that I can choose how. A lot of people just die accidentally, you know, they get hit by a car or something. But for me, I get a choice.”

Interpretive-descriptive reflection. Marie shared her approach to the cyclical nature of birth, life, and death. She commented that she felt “lucky,” perhaps a sign of gratitude, that she could choose the way in which she was able to experience the death component of the birth-life-death trajectory. She also suggested a factuality about living and dying, which perhaps hints at the theme of death acceptance. Her comment about choice is connected to theme of having control over her choices around death.
Statement. (Session 1): “Everyone is really growing now. But you’ll always be my baby, in my heart.”

Interpretive-descriptive reflection. Marie appeared to be looking forward while holding the past and the present close: she stated that everyone is growing, perhaps suggesting aging or the passage of time. However, she reminded her daughter that she will “always be her baby,” “always” perhaps suggesting a timelessness to their relationship and connection. Thinking of her daughter as a baby could have been suggestive of holding a reflective essence of the past, the characterization of her eldest daughter as her child, though she is now an adult. This statement is connected to the theme of life cycle reflection, as she notes the growth of her children, as well as the theme of relationship: she shares this reflection on her relationship to her adult daughter, elaborating on their enduring bond despite age.

Statement (Session 1): “When I was there [Bangkok refugee camp], I made some friends, and they were older than me, and they knew these songs, I was about 17 or 18 but they were already 20, 30, so they knew ABBA songs really well. They played every day, night and day, and at night when they would play the ABBA songs, they would dance. And those were really good memories, really, really good memories.”

Interpretive-descriptive reflection. Marie had begun to narrate her experience of being in a Bangkok refugee camp as a teenager and reflected on the associations she had with the music of ABBA, rooted in that particular context. She noted that these memories were “really, really good,” though she alluded earlier to being displaced, away from family, and in need of a perpetual bravery and sense of courage. This statement is connected to the theme of life cycle reflection as triggered by the theme of catalyst of the musical choices that prompt memories, and link to identity representation. She spoke throughout the session of her courage at that young age.
and commented on the music of ABBA and the musical associations in what appears to be a joyful and positive way. She shared that the music itself brought her directly into her memories and provided a springboard from which to elaborate on these experiences that held developmental and meaningful significance to her.

Statement. (Session 1): “We liked listening to ABBA in the refugee camp, and, what else … Boney M!” Caregiver (daughter): “She loves Boney M! That brings me back to my childhood!”

Interpretive-descriptive reflection. As Marie continued to reflect on her experience in the refugee camp, her daughter was video- and audiotaping the session, capturing the details as her mother recounted this part of her life. Her daughter immediately connected some of the songs Marie listened to as a teenager to her own childhood, suggestive of an intergenerational sharing of musical resources: the music of Marie’s meaningful life moments played a role in her daughter’s own upbringing. Both mother and daughter entered into a co-reflective space wherein they appeared to be communicating with each other while engaging in their own individual experiences of life reflection.

Statement. (Session 2): “There is a lot of pain. When I listen to the music, I just forget everything. I can imagine the birds dancing when you sing. I’m dancing with the angels. Very peaceful. No worries. No anxiety.”

Interpretive-descriptive reflection. Marie noted a physical and cognitive shift when listening to the music I played. She spoke of being able to “just forget everything,” and though she did not elaborate on what “everything” referred to, she did speak about the pain she experienced and its absence in her mind. She explicitly stated she felt she had “no worries, no anxiety” and a feeling of peace, which immediately followed a musical intervention (receptive
listening). This experience represents the primary theme of aesthetic musical pleasure, linked to the subtheme of music as a physical experience of pleasure, resulting in symptom management (pain, worries, and anxiety).

**Detailed reading examples.** The following examples are direct lines from the patient participant session transcripts, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- **Patient: “I just leave it all in the music. Such a good voice, and good music. Very, very relaxing. I’m flying. It’s very light.”**
  - **Phenomenological response:** the aesthetic musical experience (the experience of listening to the music itself, which appeared to be experienced as positive, enjoyable, and preferential in terms of musical choices) functioned as a container for experience, and a release, a lightening which invokes imagery of flight, and potentially a sense of freedom.

- **Patient: “The music is really helpful when I sleep, it’s peaceful. Especially when there’s a little bit of pain, then my whole body settles. When you play, I don’t feel the same. I feel much better.”**
  - **Phenomenological response:** the aesthetic experience of music created a sense of ease, physical settling, and relief. Marie noted a shift from when music was present versus when it was not present, specifically with regards to the sensations in her body.
Analysis: Caregiver

The following analysis presents the experiences of Marie’s primary caregiver (her eldest daughter) based on a follow up caregiver interview held four months after Marie’s death.

Wholistic Reading Overview

Marie’s daughter was present for both sessions and was interviewed approximately four months after Marie died. The interview lasted approximately 50 minutes. The primary themes within her interview were based on the reflections her mother experienced as a result of listening to the music that was tailored to match her experiences. She noted that her mother had not been speaking as much and had been somewhat quieter within that timeframe (leading up to MAiD) but was surprised and delighted to witness her opening up and sharing life reflections immediately after the music within the first sessions. Her daughter also reflected on how challenging it was for her to hold both the pleasure of witnessing her mother enjoy the music and feel relaxed and comforted, and her own feelings of grief and anticipatory loss that were present during the session. Marie’s daughter noted an experience of a parallel process of her own reflections, nostalgia, and revisiting of memories, while witnessing her mother’s reflections, nostalgia, and sharing of memories.

Selective Reading: Statements and actions

The following statements and actions describe moments that reflect Marie’s daughter’s experiences of music therapy throughout her sessions, and her reflections on her own experiences within the sessions, as well as in her bereavement. All statements and actions described are based on a single 50 minute follow up interview.

Statement. “I think it was helpful for her to think of her happy memories again, because that’s the kind of music she’d play, you know, on Saturday mornings…”
Interpretive-descriptive reflection. Marie’s daughter understood her mother’s nostalgia to be a positive link between music and the meaning it held in her life before her illness. She also noted her own experiences of waking up on Saturday mornings and hearing this music, which connected her to her own reflections and nostalgia. The term “happy” is notable as there were many tears within this session, and because in the midst of planning this assisted death, Marie’s daughter felt that Marie had the experience of connecting to happy memories. This did not necessarily indicate that Marie’s shifted mood state lasted beyond the session, but it is notable that she was connected to her “happy memories” within the music itself.

Statement. “For me, it was so lovely, it was different because it was live music. Hearing you play music right there in front of me, that was a pleasurable experience. It was different because it was the way you portrayed it. I felt, you know, how you were feeling, and my Mom was thinking about all those things. And I was just thinking, it was the last time I was able to experience something like that with her. Music is strange, but … I think it’s good.”

Interpretive-descriptive reflection. Marie’s daughter commented several times specifically on the fact that the music she experienced in the sessions was live and spoke about the effect of having live music present in the room: she sensed there was an empathic exchange, and that we were sharing feelings. Perhaps I as music therapist was mirroring her feelings within the music. She alluded to the fact that the way I portrayed the music made her daughter feel how I was feeling (perhaps a psychotherapeutic moment of transference), and she sensed that her mother was thinking/feeling the same things. She cried while talking about these experiences, and she commented directly on the anticipatory grief of knowing that this would be a final experience of live music together.
Statement. “What you played, it was everything she loved, but for me, it was a combination of my childhood, kind of like a summary of everything.”

Interpretive-descriptive reflection. The music that Marie chose held meaning for both her and her daughter, and within this statement, her daughter suggested that it was primarily a significant meaningful experience for her mother (“everything she loved”) but also had connections to her own childhood, linking her to memories of her past. She noted that the music was able to hold all of these memories and experiences in a summative way (“kind of like a summary of everything”).

Detailed reading examples. The following examples are direct lines from the caregiver interview transcript, followed by an interpretive response to the phenomenological question, “what does this sentence say about the experience of music therapy within medical assistance in dying?”

- Caregiver: “I think it was just the right timing when you came.”
  - Phenomenological response: Marie’s caregiver experienced the music therapy sessions as appropriately timed, given the context (impending death, emotions at the surface). Timing felt critical, in order to balance patient’s needs (e.g., symptoms, fatigue) and enter into the space therapeutically while assessing patient/caregiver needs.

- Caregiver: “She was just kind of absorbing it and just listening … so I think she really enjoyed it.”
  - Phenomenological response: Caregiver noted patient’s enjoyment of the music itself, as well as the impact of the receptive style of music therapy: the
“absorbing” and “just listening” (a common receptive music therapy style) led to enjoyment.

**Analysis: Therapist/Researcher**

The following wholistic reading, selective reading, and interpretive-descriptive reflections resulted from a hermeneutic phenomenological analysis of the researcher reflections written immediately after each session and the caregiver interview.

**Wholistic Reading Overview**

As therapist/researcher, I arrived at my first participant’s session with an unusual sense of trepidation and uncertainty. While the process of engaging a new patient in music therapy is typically comfortable and familiar to me, I noted an uneasiness in myself at first, perhaps because of the uncertainty of how my dual roles (as therapist and researcher) would affect the therapeutic process, but I also picked up on the intensity in the room. Marie’s daughter was sitting quietly with her mother, who looked quite frail. But once I sat down, and once the music began, an intimacy unfolded, and I felt I was containing a beautiful space with a powerful mother-daughter interaction, driven by Marie’s musical choices and her daughter’s willingness to journey alongside her mother. My mind was in a state of wonder, curious about the direction, noticing the paths along which Marie was taking us, while also recognizing the ability of the music to navigate and steer those paths.

**Selective Reading: Statements and Actions**

The following statements and actions describe moments that reflect my own experiences of music therapy throughout Marie’s sessions. All statements and actions described are based on a series of reflective journal entries following each session.
Statement. “Curiosity and wonder about my purpose, motivation to connect. I am struck by how cachectic\textsuperscript{3} she is. Her daughter is my age. She looks so sad. Countertransference?”

Interpretive-descriptive reflection. I noted my own uncertainty, my visceral and emotional reactions to the situation, and the age-related identification to Marie’s daughter in a counter-transferential way. I entered into the space with curiosity and wonder about my purpose, in keeping with my personal style of music therapy, attempting to be self-aware of my own responses. However, this “wonder about my purpose” may have deeper roots, and may be connected to a sense of uncertainty, a potential parallel to the patient process.

Statement. “Eager and excited to hear the musical requests; emotionally and lyrically complex choices. I’m nervous about the research part of all this: what of the dynamic (if anything) changes, now that I have this additional role? She is engaged, present. Am I researcher? Am I therapist? Am I both?”

Interpretive-descriptive reflection. This statement indicates a further reflection on my emotions, as I found myself to be anticipating both the musical requests in an excited manner but anticipating the role of my researcher self in the context of this session. I wondered if the researcher role affects my presence as a therapist. I did not intuitively sense this, but I continued to wonder and remain hyper-vigilant to this possibility. I continued to carry a sense of concern and curiosity about the roles I played, however I also recognized this uncertainty about my role(s) as linked again to deeper roots, in that music therapists are often asking ourselves and others about the exact purpose of our work. Music is a broad term, and incredibly difficult to define, and therapy is also a broad and challenging word to define. Naturally, then, music therapists often find themselves in this state of wonder about the role of the work.

\textsuperscript{3} Term referring to extreme weight loss or muscle wasting, as a result of a chronic condition such as cancer.
Detailed reading examples. The following examples are direct lines from the researcher reflections and journal entries, followed by an interpretive response to the phenomenological question, “what does this sentence say about the experience of music therapy within medical assistance in dying?”

- (After Session 1): “How will her daughters remember these events, this music, especially after Marie dies?”
  - Phenomenological response: I noted my own wonderment about the role of the music therapy sessions (and the music itself) after the therapist (I) had left the room. I noted a curiosity about the possible role of these sessions beyond the sessions themselves. I sensed a questioning of whether there is longevity in the effects of the session, and as well as a wondering about the role of music therapy in anticipatory grief and in bereavement.

- (After Session 2): “The room felt warm and inviting: we had established this therapeutic rapport in Session One, and the closeness of the family, the warmth in the room, and the invitation by Marie to participate in this experience felt like a beautiful privilege.”
  - Phenomenological response: I sensed palpable, visceral feeling of closeness and of invitation. As therapist, I reflected on the impact of Session One in creating this therapeutic rapport, which could be felt and experienced in a rich way in Session Two. I noted the sensations in the room as I experienced them and tried to recognize my own responses to the environment into which I entered.
Participant 2: John

I see, just see skyward, great cloud-masses,

Mournfully slowly they roll, silently swelling and mixing,

With at times a half-dimm'd sadden'd far-off star,

Appearing and disappearing.

(Some parturition rather, some solemn immortal birth;

On the frontiers to eyes impenetrable,

Some soul is passing over.)

— Walt Whitman, *Whispers of Heavenly Death*

John: A Narrative

When I entered the room, John, a 69-year-old man with metastatic lung cancer, lay curled up in bed with his eyes closed, covers pulled tightly up around his neck.

“Mr. Giacomo? John?” I asked quietly. He looked at me. “I’m SarahRose, I’m the music therapist…” I trailed off as he looked at me quizzically. “I play the piano, and I understand you have some pain today. I wonder if maybe I could play the piano for you?” I gestured with my hands making a motion as if to play a keyboard.

He sat up slightly.

He shrugged. “Ok.”
When I arrived back with my keyboard, John’s daughter was seated next to him. I introduced myself.

“Oh, Dad loves Italian music! He worked as a chef in a restaurant for years, and the music that played in the restaurant was so important to him. I’m sure he didn’t tell you, but he loves to sing!” I looked at John. She continued. “He used to sing for his customers. Didn’t you, Dad?” He shrugged. I smiled and sat down.

Over the next 40 minutes, I played as many traditional Italian songs as I could, noticing his subtle smiles, and the way his toe tapped when I began to play a tarantella. His daughter watched, occasionally wiping away tears from her eyes.

“He really loved music...well, loves music, I guess I should say,” she said. I knew that he was going to have an assisted death the following day.

“I understand from Dr. McWilliams that MAiD is scheduled for tomorrow,” I said. I explained my role, offering music at bedside at the intervention. His daughter nodded. “I’ll talk to my Dad and to my sister, I’m not sure but I’m grateful for the offer,” she said.

“Totally up to your Dad and all of you, of course. Would you like me to continue playing for now?” I asked.

“Yes, if you could, do you know “Somewhere Over the Rainbow”? I like it, and Dad likes it.” John nodded.
A man of few words, or was that just today? Just in this hospital room? Just in this context? John clapped his hands and winked as I finished played. I went over to him and sat at the edge of his bed.

“Thank you, John, thank you for inviting me in.”

“Grazie, grazie,” he said quietly, his eyes glistening. John died the next day with his family by his side. He opted to have a quiet death, no live music present.

Exit Music Playlist

The following songs were played/sung by me during John’s music therapy session.

- Capurro/Di Capua: O Sole Mio
- Teodoro Cottrau & Pete Rugolo: Santa Lucia
- A. Mazzucchi & E. De Curtis: Torna a Surriento
- Simon Franglen / Traditional: Funiculi, Funicula
- Allessandro Giovannini / Pietro Garinei / Renato Ranucci: Arrivederci, Roma
- Harold Arlen: Somewhere Over the Rainbow

Patient Information Overview

John was a 69-year-old man diagnosed with adenocarcinoma of the lung in March 2018. His disease was widely metastatic and had extensive radiotherapy in April 2018. He was supported by his three adult daughters and extended family members; he was divorced. John was admitted to a medical oncology inpatient unit at PM in September of 2018 for shortness of breath and significant fatigue. He had a total of one music therapy session. He received MAiD the day after his first and only music therapy session at the cancer centre where he was admitted for end of life care.
Analysis: Patient (John)

The following themes resulted from a hermeneutic phenomenological analysis of John’s single session.

Wholistic Reading Overview

John was a man of few words during our first and only session together. It was apparent that he was fatigued, and yet, he invited me and music into his hospital room. I recognized the familiarity in the nodding of his head while he listened to Italian music he used to sing. His daughter, also present in the room, engaged in a spontaneous life reflection, triggered by the musical choices that represented her father, encompassing components of his identity (Italian heritage, professional chef, lover of music). John noted an ease in his body when he was listening to the music, an ease that was also apparent to me. His shoulders relaxed, his face softened, and he physically turned towards me, sitting up slight in bed while I was playing.

Selective reading: Statements and Actions

The following statements and actions describe moments that reflect John’s experiences of music therapy throughout John’s session. All statements and actions described are based on a recording of his only music therapy session.

Action. John turned towards me and nodded his head when asked if he recognized the music and mouthed along the words to several songs; he also began to applaud at the end of the first song I played.

Interpretive-descriptive reflection. There was a subtle but connective engagement between John, his daughter, me, and the music. He was curled up in bed on his side when I arrived, but as soon as the music began, he moved his body out of fetal position, and appeared to relax his shoulders. He made eye contact, which was a change from my initial entrance and greeting in his room. He nodded his head in acknowledgement of the familiarity of the music,
sang along softly, and applauded when the music stopped, perhaps to show appreciation, perhaps to acknowledge the connection, or perhaps as a cultural/societal expectation. He continued to maintain eye contact after this point, which felt therapeutically connective and engaging.

**Statement.** Therapist: “How does that feel, John? Would you like the music to continue or would you like the music to stop for now?”

John: “A little more, please.”

Daughter: “A little more! That’s great!”

**Interpretive-descriptive reflection.** Though John said very little during the session, his body language was indicative of engagement, and when he did engage verbally, he asked that I continue to play, though when I first entered the room he appeared quite fatigued, and disengaged (e.g., body turned away, bed sheets pulled up close to his face). His request for more music felt indicative of perhaps an engagement, or a connection to the music; however, his minimal words make this difficult to fully understand or interpret. His daughter appeared to take comfort in the fact that he was engaged and commented on this in a positive way.

**Detailed reading examples.** The following examples are direct lines from the researcher reflections and journal entries, followed by a phenomenological response to the phenomenological question, “what does this sentence say about the experience of music therapy within medical assistance in dying?”

  - Phenomenological response: Though John seemed initially hesitant to participate or engage in music therapy, the fact that he physically and verbally showed appreciation for the music by applauding and making eye contact, and
acknowledging an aesthetic enjoyment of the music perhaps indicated a sense of connection within the therapeutic relationship and a willingness to engage with the music and the music therapist.

Of note, John’s daughter initially agreed to participate in a follow up interview, however she was lost to follow up as I was unable to contact her in the months after John’s death.

**Analysis: Therapist/researcher**

The following themes resulted from a hermeneutic phenomenological analysis of John’s single session and the researcher reflections written immediately after each session and the caregiver interview.

**Wholistic Reading Overview**

My initial sensory impressions were that of tension, pain, and discomfort in the patient, a disconnect between the patient and the room/situation as he was turned away with the covers pulled up close to his face, and a sense of urgency in that he wanted MAiD to happen very soon. I knew this from the brief interaction I had with his MAiD physician prior to coming into the session. His daughter was quite tearful in the hallway when speaking to the MAiD physician. In general, I sensed a lack of desire to engage verbally, both from the patient and from his daughter. I sensed initial hesitancy from the patient with regards to inviting music into the room, though I noticed an immediate ease once I began playing music. He shifted in bed so as to face me, and began to smile, which I felt broke some of the tension in the room (his daughter arrived in the room shortly after I began playing). He spoke little but made prolonged eye contact with me as I was playing and asked me to stay a bit longer when I asked, which I took to be a sign that the music was impacting him in a way that felt supportive. His daughter was tearful through the session, however, began to tell stories about her father and laughed as she recalled memories and
thoughts. It was a quiet, heavy, emotional session, as John was scheduled to have MAiD the next day. The music appeared to provide an opportunity for catharsis in that John’s daughter cried while the music was playing, later apologizing stating that she had not been crying throughout this whole MAiD process until the moment music entered the equation. Though he ultimately declined music on his last day, he did ask that I come back and check in with him and his family before the procedure, which I did.

**Selective reading: Statements and Actions**

The following statements and actions describe moments that reflect John’s experiences of music therapy throughout Marie’s sessions. All statements and actions described are based on a recording of his one music therapy session.

**Statement.** “Music can seemingly access areas of emotional experiences without the assistance of words. But this takes enormous courage and trust on the part of the patient. And the caregiver. And the therapist.”

**Interpretive-descriptive reflection.** I was quite intrigued by that which was not said, and in my own reflections I acknowledged the courage and trust that it takes to invite someone into your hospital room, on your penultimate day of life, with little to no sense of what might come up and out in the music. And yet, John and his daughter invited me in, and appeared to connect to the music. I witnessed this in the shift in body language, the tears from his daughter, and the sharing of stories.

**Statement.** “I found our time together to be full of things unspoken. However, when the music started, I felt a gentle release, a settling, a calm, maybe a letting go? John and his daughter smiled as soon as they heard the Italian music…”
Interpretive-descriptive reflection. I continued to be curious about what remained unspoken, as well as the immediate physical and what seemed to be an emotional shift as soon as the music began (perhaps ten to 20 seconds after the music started). The tension was palpable, but so was the release of that tension. Would this have been the case if the music was not familiar? There are multiple factors that may influence the release of tension, including the style, volume, tempo, and content of the music, but perhaps it was a result of the familiarity. Perhaps it was a result of the non-pharmacological approach to pain management, as I carefully matched John’s breathing in a way that perhaps allowed his body to rest in the sonic experience. While the musical factors that influence physical ease were not specifically studied in this research, it is notable that the music created a physical experience of ease in what appeared to be a tangible way.

Detailed reading examples. The following examples are direct lines from the researcher reflections and journal entries, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “What was happening in the silence?”
  o Phenomenological response: I felt a keen sense of curiosity about the experience of silence, and the latent content, e.g. that which was not said aloud. There is often much that is assumed within silence or noise; this session was filled with moments of silence in between musical content, but many subtle and obvious shifts happened physically in the space (e.g., deep breaths, eye contact, tears).
- “Maybe the therapist intuits, maybe a chart is read, maybe assumptions are made. But the truth of what is experienced perhaps always remains a mystery. I’ll never fully know the patient experience, or the caregiver experience.”
Phenomenological response: This felt like an experience of reflecting on what we
may never know, despite best efforts. There is a privacy and intimacy about
experience that may not ever be available to anyone other than the person
experiencing the phenomenon. Try though I may as a therapist and researcher,
capturing experience feels like trying to hold water in the palm of my hand.
Participant 3: Yvette

The evil, it spread like a fever ahead
It was night when you died, my firefly
What could I have said to raise you from the dead?
Oh, could I be the sky on the Fourth of July?

— Sufjan Stevens, “Fourth of July”

Yvette: A Narrative

“Um, can we not talk about it right now?” Yvette asked, glancing over at her son.

I immediately realized what she was implying.

“Of course, Yvette,” I said quietly.

Yvette, a 60-year old woman with metastatic lung cancer, had requested MAiD during her admission to the acute palliative care unit at the hospital, clear in her intentions but aware that her physical and cognitive functioning was quickly declining. We had a total of five sessions together, using receptive music therapy techniques, song-writing, and music-centered psychotherapy to explore various emotions connected to her pending death. Though she knew exactly how she wanted to die, she was weary of discussing it with her family. She was referred to music therapy right before her second assessment, and her sessions continued into her reflection period. Our final session was held with her 40-year-old son present. He sat quietly in the corner watching his mother, who was sitting at the edge of her bed. Yvette had requested several meaningful songs, then asked her son what kind of music he wanted to hear. He looked at me with tears in his eyes.
“It’s whatever my mother wants, I guess, but, anything quiet, peaceful, smooth; does that make sense?”

I nodded. I realized Yvette was conflicted about sharing her MAiD experience with her son and her husband. Although they knew of it and ultimately were supportive of her, she later shared that she knew any discussion about MAiD would be difficult for her family, and she preferred to keep her thoughts and questions separate from them.

Though she was a woman of relatively few words, Yvette carried herself with a quiet but assured energy, a grace that was exemplified in the way she invited me into her hospital room, and the gentle but emotional way she invited me into her life narrative by sharing associations with various songs and soundtracks.

“Do you know the movie The Sound of Music?” she asked during our third session.

“Oh, I love The Sound of Music!” I laughed.

Together we sang through multiple songs from the score. Yvette oscillated between being directive and asking for her preferred music, and being receptive, asking me to choose music that matched her mood or energy level. She was openly and obviously anxious at times about the MAiD process, in part because she knew her cognition was changing. She was aware that she would likely not be eligible for the procedure if she did not retain her full cognitive capacity right up until the MAiD procedure.

“I’m experiencing a lot of change,” she said softly during our second session. “It’s a lot for my husband. Maybe you can play something happy. So much is hard right now.”
Her hesitancy to discuss MAiD with her family seemed to parallel her hesitancy to explore the emotions she was experiencing surrounding MAiD. She did, however, share some of her thoughts and feelings about MAiD in the context of the music, in the way that she asked for certain mood states, and when she would speak about her worries and fears in between songs. At the beginning of our fourth session, I asked her how she was feeling.

“I’m fine today, it’s just that I’m getting worried about this memory. How come I speak with someone, and then minutes later, I get all mixed up? I don’t even know if I can do this, do I even qualify for MAiD anymore?” she asked me one afternoon. We discussed various factors that might be contributing to her memory challenges, and I assured her that her medical team was aware of her concerns.

“In a way, I’m afraid I will die before I get MAiD, what if that happens?” she asked. “Maybe, maybe you could play something peaceful?” I offered multiple improvisations in the styles she requested, focusing on regulating her breathing and providing soothing, predictable, and gentle improvisations.

“This is very nice, very relaxing,” she commented while listening on a rainy Wednesday morning. I had just finished playing “Let It Be” by the Beatles, a common request of Yvette’s. “I can concentrate on the words, it’s familiar, and I like that.” Her brow unfurrowed, her face relaxed. During our fourth session, I introduced the concept of song-writing.

“If a song could say anything, and say exactly what you are feeling, what would that song sound like? What might it say?” I asked her.
Over half an hour, I guided Yvette through expressing her thoughts, feelings and emotions in her own words, within her own song. I sang it back to her once she felt she said all she needed to say.

“Peace, I look for peace. Just peaceful, I hope each day is calm.

Peace, I look for peace. Just peaceful, I hope each day is calm.

Sometimes I worry about the future. In a way, I am afraid.

Will I go before it’s time? Will I die before it’s time?

Stay calm, stay calm.

Peace, I look for peace. Just peaceful, day by day.

Try to stay calm and peaceful. Try to stay calm.

I look for peace.”

“I’ll see you next week,” I told her after our fifth session.

“Yes, and we can keep talking about music, maybe during my procedure you can play?” she asked.

“Of course, I will see you then,” I assured her.

Following the weekend, I came back to the hospital, and was told that Yvette had died. A fall over the weekend had precipitated a subdural hematoma, or a bleed in her brain. Because of how frail she was before this fall, the brain bleed had been fatal. She died before receiving MAiD.
Exit Music Playlist

The following is a list of songs that I played/sang during the course of Yvette’s music therapy sessions.

- The Beatles: Let it be
- The Beatles: Hey Jude
- John Lennon: Imagine
- Sound of Music selections:
  - The Sound of Music
  - Do-Re-Mi
  - Edelweiss
  - My Favourite Things
- Bill Withers: Lean on Me
- Ben E. King: Stand by Me
- Harold Arlen: Somewhere Over the Rainbow
- Yvette’s Song (Peace)

Patient Information Overview

Yvette was a 68-year old woman diagnosed with metastatic pancreatic cancer in December 2017. She was a retired chemist, married with one son. Yvette was admitted to the palliative care unit of PM in August of 2018 for symptom management. She was also diagnosed with major depressive disorder. She had a total of five music therapy sessions, ranging in length from 20 minutes to 50 minutes. She died several days before her MAiD procedure due to a fall and subsequent brain bleed.

Analysis: Patient (Yvette)

The following themes resulted from a hermeneutic phenomenological analysis of Yvette’s five sessions.

Wholistic Reading Overview

In Yvette’s first sessions, the air was quiet and heavy; initially Yvette said little, but over the course of five sessions, she shared details of her emotional experience, her concerns, fears, and hopes around assisted dying, and her worry for her family’s emotional well-being. English was
not Yvette’s primary language, so at times words were few and far between, but she indicated that she felt at peace in simply listening to the music. Yvette stressed that she wanted to feel peaceful and shared that she sought a peaceful and happy experience in the music. My sense was that so much of her experience was rife with stress and uncertainty. She told me she found the music therapy “soothing, relaxing, and familiar,” but she noted that she was fighting against fear and concern that she would die before MAiD and die in pain. She used the music as a physical support to slow her breathing, an outlet for the expression of emotion, and a catalyst for retrieving and sharing meaningful memories, both with me and with her son in our final session.

**Selective Reading: Statements and Actions**

The following statements and actions describe moments that reflect Yvette’s experiences of music therapy throughout her five sessions.

**Statement.** (Session One, when asked by therapist if Yvette had any thoughts in her mind while listening to the therapist play): “No ideas in my brain. It doesn’t seem to want to think. So, it’s nice to just listen. Because people ask me questions, right? Doctors, you know, and all that. So, it’s so nice to be able to relax in this way.”

**Interpretive-descriptive reflection.** It seemed as though Yvette was fatigued and overwhelmed by the administrative aspects of MAiD, as she had gone through a lot of paperwork and assessments to determine her eligibility. Multiple healthcare providers had recently visited Yvette to explain various aspects of the process, and within this context, Yvette shared her relief at “just listening.” Yvette felt she could relax while listening, without having to do or say anything. In this context I sensed an ease, a letting go, and an opportunity to relax without expectation.
*Statement:* (Session Two, after a health care provider spoke with Yvette about MAiD for an extended period of time): “Well, after talking about it for a while, I feel like listening to something happy.”

*Interpretive-descriptive reflection.* Yvette shared that she wanted to listen to “happy” music, and implied that this music would be in contrast to the conversation she had just had earlier that day (about MAiD). She requested this emotion, and it was not fully clear whether she wanted to hear happy music because that emotion matched her current mood, or if she wanted to hear happy music as a contrast to her current mood. In any case, Yvette sought out a specific emotion in the music, likely for a specific reason in the context of her MAiD experience. These specific requests seemed to be an opportunity for Yvette to exercise control over her experience (e.g., by selecting music that she wanted).

*Action.* Yvette sang along quietly to many of the songs played/sung in sessions.

*Interpretive-descriptive reflection.* Though English was not Yvette’s primary language, she did share that she felt connected to music with English lyrics, specifically The Beatles’ music and the score/soundtrack to *The Sound of Music*. Oftentimes when I played and sang, Yvette would quietly sing along with me, her vocalizations barely audible, but it was obvious that she knew almost all the words to the songs she requested. Though she did not want to sing loudly or even say much during the sessions at times, she did notably participate by mouthing the lyrics. The song she sang the loudest (though still quite softly) was The Beatles’ “Let it Be,” which she highlighted as one of her favourite songs, and noted that she found it particularly soothing at this point in time because it made her feel peaceful, the emotional request that carried through all five of our sessions. It’s possible that the repetitiveness and content of the lyrics to the song (“Let it
be, let it be, let it be, let it be; there will be an answer, let it be”) provided what Yvette was 
looking for in these moments (e.g., soothing, peace, calm).

**Statement.** (Session Three). “Things are ok. I’m just getting worried about my memory. 
How come I talk to someone and then I get all messed up? Everything is changing. I don’t even 
know if I can even do MAiD or qualify for it, never mind the end date!”

**Interpretive-descriptive reflection.** Worry was apparent in this statement and had been 
prevalent throughout all five sessions. Yvette was worried that she would not be eligible for 
MAiD due to a cognitive or functional decline, and expressly articulated that she was concerned 
about her memory. Yvette was acutely aware that this would affect her chances of having MAiD. 
There was a vulnerability in her sharing of this worry with me, as she tried to mask memory 
issues in the last week of her life by fighting to remember details and writing things down when 
she could. Sharing this information with another healthcare provider who had a stake in whether 
she would qualify for MAiD would potentially have different consequences. Confiding in me felt 
like a safe and inconsequential opportunity, because though she had developed trust with me and 
I had an understanding of the MAiD process, I had little to no stake in her MAiD decision or 
eligibility.

**Statement.** (Session Four). This statement was made after the concept of song-writing 
was introduced: “A personal song! Oh, ok! All right. That’s such a great idea. Something 
peaceful, just peaceful. I just hope every day is calm.”

**Interpretive-descriptive reflection.** When I introduced the concept of song-writing, Yvette 
was initially hesitant (as many patients are), but once the process was described, she seemed to 
take to the idea. Within this personalization, she focused on peace, as she had done in her song
requests and her previous sessions. She seemed to use the song-writing as an opportunity to focus on that which felt important and comforting in a time of uncertainty and challenge.

**Detailed reading examples.** The following examples are direct lines from the researcher reflections and journal entries, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- (Session 5) Son: “What do you want to hear, Mom?”  
  Yvette: “Oh, I’d actually like to listen to the *Sound of Music*. I really like this movie, it shows the mountains, the mountains are so beautiful.”

  o Phenomenological response: Yvette had asked for selections from *The Sound of Music* in each session, and shared reflections on her feelings toward the movie. During this request, her son was present and very tearful while listening to the music. The experience of Yvette’s memories of this movie, and the images they brought forth was the driving factor behind these choices. She was sharing the experience with her son this time, her final time.

- (Session 4, after hearing her personal song which she had just written with me): “Oh, thank you. You just came at the right time, so I could hear this nice song.”

  o Phenomenological response: Yvette experienced the timing of this emotional self-expression opportunity as ideal, as she had consistently been asking for music that would support her in feeling peaceful. She noted that she was able to access these feelings in this session.
Analysis: Therapist/Researcher

The following wholistic reading, selective reading, and interpretive-descriptive reflections resulted from a hermeneutic phenomenological analysis of the researcher reflections written immediately after each session.

Wholistic Reading Overview

I was musically aware of Yvette’s focus on experiencing peace and familiarity within the music, and I used the concept of peace as a springboard for her musical requests and her song-writing. She sought out familiarity in the music (in her requests for songs that not only felt peaceful but felt familiar). There was a sense of anticipation, of waiting and uncertainty, but she noted that what she looked for in the music was in response to this: a peaceful, soothing, quiet, and relaxing experience that invited a sense of being emotionally “picked up” and feeling “something happy.” My challenge was to create the space for Yvette to feel the moods she sought out, while also acknowledging the challenges she was facing.

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect my own experiences of music therapy throughout Yvette’s five sessions.

Statement. (Session One): “Yvette shared quiet appreciation, gratitude, enjoyment, a preference for the familiar, and a sense of relaxation during the music.”

Interpretive-descriptive reflection. As therapist/researcher, I was picking up on what I interpreted to be Yvette’s experience. It was difficult to determine whether this was in fact Yvette’s precise experience or not. She did note she appreciated the music and connected to songs she knew well from meaningful life events and felt a physical experience of relaxation. I wondered if as therapist, I was picking up on both her implied and her direct experience. Her
body language indicated her ease as much as her words, but words were few and far between so I as therapist had to rely on non-verbal indicators as much as verbal ones.

**Statement.** (Session Two): “There was a comfort and trust that was developing between us in our therapeutic relationship, perhaps an “allowing” of sorts that gave the opportunity for Yvette to settle into the music and not have to use words or use words very minimally.”

**Interpretive-descriptive reflection.** As therapist/researcher, I reflected on Yvette’s limited use of language and how much was transmitted via non-verbal indicators and body language as well as gestures. I did note that I was developing trust, and notably early on in the therapeutic process (this statement was taken from a researcher reflection on the second session). The idea of creating a holding space that allows for opening, trust, and engaging in the music was a permeating theme in many of these sessions, and I continued to ask myself if this “allowing” that I referenced was a manifestation of Yvette’s settling into the music, or a manifestation of her developing trust with me. This was likely a combination of multiple factors.

**Statement.** (Session Three): “Tension and anxiety; uncertainty; music seemed to be a point of concentration and focus in the midst of uncertainty, a focus point in the midst of discomfort, stress, and feeling as though she was losing her ability to concentrate.”

**Interpretive-descriptive reflection.** While there was an ongoing palpable sense of trust, I began to pick up on tension and anxiety, particularly in relation to Yvette’s changing cognitive status, of which she seemed to be aware. This sense of uncertainty felt vulnerable, as she shared with me how scared she was about dying before her MAiD intervention and seeking out peace and comfort as much as possible. Within this session, she asked for music to support her in feeling comforted and staying focused. Her mouthing along to the lyrics of “Let It Be” felt like an expression of her needing to concentrate and focus while staying calm and relaxed.
Statement. (Session Four): “She seemed more open, appearing more relaxed. I think it was because she had a date set for MAiD. She really opened up in the song-writing process. Was it the clarity around the date? Or the music/song-writing? Or both?”

Interpretive-descriptive reflection. In Session Four, I noted a clear and obvious shift in Yvette’s emotional state, and she had shared with me that a date had been set for her assisted death. I wondered in my reflections whether she felt this relaxation as a result of the information about her assisted death, as I assumed was the case. The uncertainty about the date and the questions of whether she would continue to remain eligible as her cognitive status changed were clearly weighing heavily on her mind. It was within this session that she invited an exploration of the song-writing process, and wrote a song about feeling peace and feeling comfort.

Statement. (Session Five): “I think I was witnessing a mutual protection: mother trying to protect son by not acknowledging his emotion (as evidenced by body language, non-verbal communication). But clearly the music was a catalyst for non-verbal expression and connected to meaningful memories that both Yvette and her son shared.”

Interpretive-descriptive reflection. In Yvette’s fifth and final session, a number of moments and situational actions led me to believe that Yvette was trying to protect her son’s feelings, and vice versa. While this is a commonly witnessed phenomenon in my work, I was curious about the impact of MAiD on protection of feelings between family members. Yvette would not talk about MAiD in front of her son, and her son said very little during the session, but he cried quite a bit when listening to various songs, especially selections from *The Sound of Music*. Although he did not explicitly state it, I wondered if his own memories surfaced while listening to these songs, because in earlier sessions, Yvette alluded to the fact that she listened to these songs and watched this movie with her family.
**Detailed reading examples.** The following examples are direct lines from the researcher reflections and journal entries, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “So much is unspoken between family members.”
  - Phenomenological response: Family dynamics are brought into the room and heightened in acute situations. MAiD can be a complicated and intense series of emotional situations, and it was obvious that Yvette and her family were not always communicative about MAiD for a number of reasons, some of which I could glean, and others which were and will remain unknown.

- “Mother and son, a quiet energy shift in the room. Comfortable, but emotionally charged. Why?”
  - Phenomenological response: I sensed an unspoken emotion that was evident through non-verbal body language (e.g., tears, lack of eye contact, sighs). I felt a sense of curiosity amidst uncertainty.

- “She seemed frantic, confused, and scared. She seemed to hold on to the words of ‘Let it Be.’”
  - Phenomenological response: In the experience of seeing oneself begin to lose capacity to maintain optimal cognitive function, Yvette sought reassurance, grounding, familiarity, and perhaps comfort. In these moments, “Let it Be” appeared to provide these experiences for her. I was witnessing, providing the music and the holding space for Yvette to feel grounded.
Participant 4: William

The way a crow

Shook down on me

The dust of snow

From a hemlock tree

Has given my heart

A change of mood

And saved some part

Of a day I had rued.

— Robert Frost, “Dust of Snow”

William: A Narrative

“Melancholy with an upward turn,” said William, a quiet, scholarly man in his mid-60s. “That’s what I would like.”

What does this mean, I wondered, and what might it mean in the context of this man’s illness?

William was in the process of requesting MAiD. He had completed his first assessment and was in the midst of the mandatory ten-day reflection period. He was declining. It was obvious in his
quiet demeanor, his slow movements, his overall fatigue evident as he struggled to move in bed. I slowly helped him adjust his pillows. The air in the room felt heavy.


Melancholy with an upward turn.

Melancholy, I thought. Makes sense. Awaiting a final verdict, awaiting death. Why the upward turn? It could be anything. Seeking out something soothing? Something hopeful? Some source of joy or of meaning? Or perhaps it had to do with the people around him.

“Oh, hello there!” came a bright, friendly voice from the doorway. I turned around.

“Jennifer, hi, I’m SarahRose. I’m the music therapist here.”

“Oh! Great! How exciting,” said Jennifer. “I’m his wife. Maybe I can benefit from your music, too?”

Melancholy with an upward turn. The phrase kept repeating in my head. Was the upward turn perhaps reflective of this warm, bright, and hopeful voice? Jennifer’s devotion to William was apparent from the moment she entered the room, their connectedness obvious as she moved carefully around the hospital bed, finally settling in next to him and planting a kiss on his forehead.
I explained my role on the team. “If there’s anything you would like to hear, or any mood you’d like me to capture, let me know at any time,” I said to Jennifer.

“Well, I’ll follow where William is leading,” said Jennifer.

William spoke inaudibly, barely a whisper. “What’s that, dear?” asked Jennifer.

“She’s wonderful,” William said in a louder voice. I smiled. I continued to play. Arpeggiated major key improvisations, modal mixture.

Familiar music.

“À la claire fontaine, m’en allant promener, j’ai trouvé l’eau si belle, que je m’y suis baigné…” Jennifer began to sing with me. We moved through multiple songs, in French and in English, I accompanied gently with broken chords and rocking patterns. We ended quietly, I in the upper register of the keyboard. Jennifer wiped away tears from her eyes.

Silence.

“William, I was struck by your word ‘melancholy’,” I told him. Jennifer nodded.

“It’s a really powerful word.” Jennifer held his hand. “That song really captures it, ‘À la Claire Fontaine,’” she said.

I asked William what it felt like, listening to the music for that period of time.


Throughout our first and only music therapy session, Jennifer shared numerous stories about the significance of music in their lives: the role of music in raising their son, in embracing both the
Francophone and Anglophone sides of their relationship and cultural backgrounds, and the power of music in telling their love story.

“The Water is Wide! Oh god, well now I had better get more Kleenex if we’re going to be singing that one,” Jennifer laughed, tears rolling down her cheeks. Together, we sang that song which had been played on their wedding day. We sang Stan Rogers’ “Northwest Passage,” Jennifer adding harmonies, and at times, pausing to dry her eyes. William was her ardent focus, her total commitment. He drifted in and out of sleep, occasionally opening his eyes and smiling. Our first and only session. An hour and a half of music, stories, tears, reflections.

Melancholy with an upward turn.

Did I manage it, William? Did it happen as you had hoped?

In those moments, William was changing. His increasing somnolence told our medical team that he might not maintain capacity to consent to MAiD in a matter of days. Reflection periods, protocols, barriers.

“That day with you? That was his last really good day,” Jennifer told me, months later during our follow up interview. “He really became unwell that next day, and actually irritable. But that day was unbelievable.”

I knew that William had died naturally, without being able to access assisted dying, due to the change in his functional status. His somnolence in the midst of the ten-day reflection period precipitated a rapid decline.
“You know, the music for his funeral had been quite a stressor for me, because I knew he wanted music, and yet, he didn’t bring it up. I wanted to follow his lead and so I didn’t feel I could broach it, there never seemed to be a right time to say, ‘Hey what about that funeral music?’” Jennifer laughed. “I guess, I don’t really know how…I think I managed to broach it…and, it was probably triggered by the music therapy. And you know, it just allowed some kind of opening that felt natural enough, and then we were able to do that. We spent the evening going through his funeral music. And that was really very special, so…that was a gift that you left me, and us, you know?”

Melancholy with an upward turn.

Death did not happen the way you anticipated, William. But maybe blissful moments arose unexpectedly. I’ll never really know. As we spoke over the phone months later, Jennifer recounted the days, hours and moments leading up to her husband’s death. He held on for several days with apneic breathing in an unresponsive state.

“And so, I thought, maybe he just needs my permission on some level to let go. My son would come in, and he kept going in and out of the room, and he’d say, ‘Je t’aime Papa,’ since they had this French relationship together. John was the francophone and I was the anglophone in the family, and, so he’d say, ‘Je t’aime Papa,’ and then he’d say, ‘Fais do-do,’ which is what you might say to little kids when they’re going to sleep. Nighty-night, kind of, and then I thought, you know what, I’m going to just do that, and I started to sing him lullabies. I was tentative, but I did it. I sang softly, just the way he would have sung to our son. And that’s when he died.”

Melancholy with an upward turn.
Fais do-do, Papa.

Il y a longtemps que je t’aime…jamais je ne t’oublierai.

**Exit Music Playlist**

The following is a list of songs I played/sang during William’s music therapy session. A variety of improvisational pieces were also used.

- A la Claire Fontaine (Traditional French)
- James Taylor: The Water is Wide
- Henry Mancini: Moon River
- Stan Rogers: Northwest Passage
- Carol King/James Taylor: You’ve Got a Friend
- Traditional: All Through the Night
- Stan Rogers: Barrett’s Privateers
- Loch Lomond (Traditional Scottish)
- Fiddle Tune Medley (St. Anne’s Reel/Big John MacNeil/Whiskey Before Breakfast)
- J.S. Bach: Suite in G Major for Solo Cello (Prelude)
- Jay Ungar: Ashokan Farewell

**Patient Information Overview**

William was a 66-year-old man with metastatic gastroesophageal carcinoma and was admitted to the palliative care unit of PM for symptom management and pain crises. He was supported by his wife and son. While admitted, he had a total of one music therapy session which lasted approximately 90 minutes. Though he was hoping to have his MAiD procedure, he died naturally before he was able to receive MAiD, as he became gradually more confused during his reflection period. A medical workup identified a likely aspiration pneumonia, which was treated with antibiotics however precipitated a significant clinical decline, leading eventually to his death. His wife was at his side when he died.
Analysis: Patient (William)

The following themes resulted from a hermeneutic phenomenological analysis of William’s single session.

Wholistic Reading Overview

William’s request for music that was “melancholy with an upward turn” in our first and only music therapy session invited a number of pieces of music that held meaningful memories which he and his wife shared. William gave the first indicators of what he wanted the music to sound like, and once his wife arrived, she was able to further direct reflective moments, share stories of her life with William, and utilize music as a catalyst for memories. Though we only had one music therapy session together, it was prolonged (approximately an hour and a half) and invited a communication to develop between William and his wife as the music acted as an opportunity to express emotion and narrate part of their life experiences together.

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect William’s experiences of music therapy throughout his sessions.

Statement/Action. William: (When asked by the therapist/researcher what came to mind, if anything, while listening to the music): “It was just … bliss.”

William’s wife (in response): “Music has always been a very big thing in our lives. It’s always there. Always. Always. Anywhere we go. And it just triggers all sorts of memories.” (His wife was tearful at this point.)

Interpretive-descriptive reflection. William noted the experience of “bliss” when articulating what he felt in the music. Though it was one word, the word itself felt loaded, as I entered the room knowing he had been dealing with challenging symptoms, in the midst of an
uncertainty as to whether he would live long enough to receive MAiD. I was aware that he was quite symptomatic, and rapidly approaching the end of his life. The word “bliss” surprised me, especially as he spoke about feeling “melancholy” earlier in the session. His hope to have an “upward turn” in the midst of the melancholy affected how I used music (e.g., the style of music I played and the improvisations I used). I was hopeful that the feeling of bliss was an extension of what was experienced within the music. His wife’s response regarding the importance of music in their lives felt significant, as she commented not only on the presence of music, but the triggering of memories that music provided.

**Statement.** William: “I want to share it. Music is there to be shared.”
William’s wife (tearfully): “To share? With me?”
William: “Yes.”

**Interpretive-descriptive reflection.** Within this moment in the session, William articulated a desire to connect with his wife by sharing the music they were experiencing. He indicated that he felt the larger purpose of music was to share it with others, and in what felt like an intimate moment of closeness and connection, William explicitly stated that he wanted to share the music (perhaps the songs, perhaps the emotion connected to the songs, perhaps the session as a whole) with his wife.

**Action.** William’s wife shared a number of memories related to the songs she requested, which prompted other song requests (e.g., A la Claire Fontaine, the French folk song. This led his wife to speak about William’s love of Quebecois folk music, and about the fact that the song captured the mood William was looking for: “melancholy with an upward turn”). His wife then requested other French-Canadian songs that represented other moments and memories.
Interpretive-descriptive reflection. Music functioned as a narrator and a trigger for William’s wife, as she began from a place of William’s directed experience, sharing stories that connected to the music he enjoyed, and using those memories as a springboard to other memories. In her interview months later, she noted that this time of reflection through music served as an “opening” towards another larger conversation about music at William’s funeral, which he did not want to speak about until after the music therapy session. Music began as a catalyst for memories and became a narrator of various life experiences.

Detailed reading examples. The following examples are direct lines from the patient participant session transcripts, followed by an interpretive response to the phenomenological question, “what does this sentence say about the experience of music therapy within medical assistance in dying?”

- William’s wife: “SarahRose, you’re going to stay for a while, right? Because this has been lovely.”
  - Phenomenological response: An invitation and a request to prolong the experience of music therapy as an experience of “loveliness,” in the hopes of extending it.
- William’s wife: “Barrett’s Privateers….it was when I was going into labour, and one of the things they suggested was that I find a song that’s very long and memorize it all and just keep singing it and, that was my song!
  - Phenomenological response: An experience of connecting a song related to an artist discussed/performed within the music therapy session (Stan Rogers) to a major life event (the birth of their son).
**Analysis: Caregiver**

The following holistic reading, selective reading, and interpretive-descriptive reflections resulted from a hermeneutic phenomenological analysis of the caregiver interview.

**Wholistic Reading Overview**

Because William was quite fatigued during the music therapy session, his wife engaged in conversation and shared a number of stories and memories in the context of musical requests. She shared songs that were linked to her life with William, such as songs from their wedding, as well as songs that were personally meaningful to her, in addition to songs that were connected to her life as a teenager. Upon reflecting on the session several months after William died, his wife spoke about the outcomes following the session, such as planning William’s funeral music. She noted that she felt the music therapy session was a gateway to the conversations about William’s funeral. She also noted that although William did not die as planned via MAiD, as he lost capacity, music was present in his dying moments as she sang to him.

**Selective Reading: Statements and Actions**

The following statements and actions describe moments that reflect William’s wife’s experiences of music therapy throughout her sessions.

*Statement.* (During music therapy session, when she arrived in the hospital room): “I’m excited, maybe I can also benefit from your music?”

*Interpretive-descriptive reflection.* Jennifer immediately connected to the concept of music therapy as a support not only for her husband (the patient) but also for herself. This comment was made before she had heard any music or heard William’s response to the music. She entered into the therapeutic relationship with excitement and hope, perhaps an indicator of a
need for support or an eagerness to participate in an intervention that would be mutually beneficial in the midst of a challenging time.

**Statement.** “Well, it was actually spectacular. I guess he’s always been a sceptical of programming, so I was afraid that he was not going to allow himself to be taken away with the music. I thought he might even turn you down all together, and in sharp contrast to that, when I walked into the room, and you had already been there for about half an hour or 45 minutes, and you just gave me a quick summary of what you’d been talking about and doing, and then you kept playing, and when you asked him what word came to mind and he said, ‘Bliss’… I thought, oh my god, like, that was just unbelievable! Here is a dying man, and you’ve managed to evoke this, you know, this blissful feeling! It’s just incredible. So, I went home that night and I thought, you’re only there three days a week, maybe I can hire you for the other two, or you know, other four! I knew he didn’t have much time left, and I thought, my god! Something that makes him feel blissful. That’s unbelievable!”

**Interpretive-descriptive reflection.** William’s wife articulated her surprise at William’s willingness to participate in music therapy, and her particular amazement at his articulated feelings of “bliss.” The contrast in her mind between the experience of dying (“Here is a dying man”) and the experience of bliss (“and you’ve managed to evoke this, you know, this blissful feeling!”) stood out as significant, given that she articulated wanting to access this support for William on an on-going basis. She noted the unexpected opportunity to provide support in a surprising way.

**Statement.** “So, what you precipitated, which you didn’t know, was that I was able to say, ‘William, you know what, you’ve told me you want music at your funeral, why don’t we talk about that?’ And we spent the entire evening with him telling me what he wanted played,
and I would look it up on the internet and play it for him, and we had a lovely musical evening as a result, and I ended up with the program for his funeral, which was lovely. Like, sort of weird, weird to say that that was lovely, planning his funeral…but it had been quite a stress for me, because I knew he wanted music and yet he didn’t bring it up and I wanted to follow his lead, but I didn’t feel I could broach it…so the session we had just allowed some kind of opening that felt natural enough, and then we were able to, to do that, and that was really very special, so that was a gift that you left me, and us, you know?”

Interpretive-descriptive reflection. The theme of unexpected opportunity arose again as William’s wife articulated the challenges of trying to work out the musical details of William’s funeral prior to the music therapy session. She acknowledged a sense of an “opening” that felt natural, and the resulting “lovely musical evening,” which she noted was a “gift.” The retrospective reflection during the session perhaps invited an extended life review that was experienced during the evening after the session. William’s wife was bearing witness to William’s current and past experiences and created her own holding space as an extension of the music therapy session.

Detailed reading examples. The following examples are direct lines from the caregiver participant session transcripts, followed by an interpretive response to the phenomenological question, “what does this sentence say about the experience of music therapy within medical assistance in dying?”

- “My iPod, I feel like it’s this thing that is so precious, I better not lose it, and it’s got William’s music. It’s really … our music, but … I kind of feel like I’m carrying around a piece of him when I go out of town on the weekend. He comes with me.”
• Phenomenological response: This reflection seemed to connect to a physical representation of William’s life narrative through the iPod, as well as an intersecting of narratives (William’s life experienced posthumously through music, and his wife’s ability to reflect and experience her own grief and varying emotions through accessing this music).

• “You got me to tell you a bunch of stories about us on that day, and um, you know what, some of that became the stuff of my … I did a eulogy for William and some of that became the kernels of that, which is kind of neat.”

• Phenomenological response: William’s wife experienced the therapeutic outcome of being invited to share her narratives (stories) which intersected with William’s experiences on that day during the session, and both of their life trajectories. This entire process intersected with a post-death experience of connecting the life review to the eulogy she created.

• “Your reactions, like, ‘oh that’s so special’… that was the word that you used SarahRose, but your reactions kind of helped me go ‘Yeah, you know what, that was special! That was a really neat story!’”

• Phenomenological response: This appeared to be an experience of validation of her narratives, perhaps inviting further reflection and retrospection, and an opportunity to delve deeper into the life review.

• “Maybe that was partly the music, it must be. It gave an opening. Very, very special. So, thank you, thank you for that.”

• Phenomenological response: William’s wife experienced the music/music therapy as an opportunity and an opening, leading to further life review, and unexpected
outcomes such as funeral planning, deeper and extended conversations, and a sense of gratitude for the experience.

Analysis: Therapist/Researcher

The following wholistic reading, selective reading, and interpretive-descriptive reflections resulted from a hermeneutic phenomenological analysis of the researcher reflections written immediately after each session and the caregiver interview.

Wholistic Reading Overview

In reflecting on the therapist/researcher experience, themes of intimacy, reflection, tenderness, and storytelling were prominent. As therapist/researcher, I felt privy to an intimate unfolding of a life review, and felt I was able to bear witness to a particular form of communication between husband and wife: sharing memories, and expressing emotions, both verbally and non-verbally. While William was quite fatigued and unable to speak very much, he did make several comments that gave me pause to reflect on what was happening in the room. William’s wife spoke at length in a vulnerable and trusting way about her life with William, inviting me into their various emotional experiences. William gave us all direction, and she elaborated on the themes that arose in the music. I as therapist/researcher held space and offered possible routes to different emotional experiences (e.g., asking prompting questions, remaining curious about their experiences, and empathically responding to the varying emotions that manifested in the session).

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect my own experiences of music therapy throughout William’s music therapy sessions.
**Statement.** “A full spectrum of emotion: laughter, tears, calm, ease, grief, comfort. Some were more obviously articulated than others, some I aimed to reflect in the music, the lyrics, the conversation. Witnessing an unfolding of emotional response, holding space for what arose.”

**Interpretive-descriptive reflection.** I took note of the range of emotion that manifested in the room during our session, and was acutely aware of the role I played in recognizing the emotion that was explicitly articulated, and the emotion that was represented non-verbally (e.g., in subtle body language, tears, laughter, etc.). Part of how I see my role as a psychotherapeutically oriented music therapist is to witness and provide space for that which emerges emotionally, as there is an uncertainty implicit in being with other human beings in the midst of difficult and challenging life events (e.g., serious illness, terminal illness, facing the end of life).

**Statement.** “William spoke in a muted whisper, it was difficult to understand him but when he spoke, I sensed intentionality and thoughtfulness in his articulation of what he wanted.”

**Interpretive-descriptive reflection.** So much of what happens in a music therapy session is non-verbal, especially when working with populations that are impacted by physical factors that affect energy levels, fatigue, and speech-language functions. William’s fatigue was increasing, and his energy levels were decreasing, however I sensed there was a thoughtfulness behind his words. This manifested in the time he took to answer my questions; the eye contact he made when speaking with me (notable because he had his eyes closed for much of the rest of the session).

**Statement.** “While William was reflective and thoughtful, Jennifer was also careful to follow his lead, and I felt they both trusted me and trusted the music. What did this allow? Did they go somewhere in the music that they would not have been able to go without the music?”
Interpretive-descriptive reflection. This statement offers a description of the trust that I felt between patient and caregiver, between myself and the patient-caregiver dyad, and within the music itself. Many of the reflections held more questions than statement/answers to any of the situations I was in, and I note my constant curiosity about the role of music. While there is much that is evidence-based and clear in intention and direction (in terms of clinical goals, especially), there is always so much unknown, and so much that requires trust within the process of music therapy itself.

Detailed reading examples. The following statements were taken directly from my reflective journal entries and writing, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “So moving, to be trusted with William’s musical requests, and his wife’s reactions: I felt deep sadness, as I knew deep down that William wouldn’t get to his MAiD procedure. I think I knew he would die before it.”
  
   - Phenomenological response: I was experiencing an sense of empathizing with the uncertainty of the MAiD process, and the possibilities that William’s request would not be fulfilled due to reasons beyond his control. This empathic response was embedded in the trust that I felt from William and his wife, and the mutual understanding that anything could happen or change in the days ahead. This session felt opportunistic in that William was relatively alert and able to participate; as revealed later in the caregiver interview, William declined physically and functionally after this session.
• “I arrive in the room as a neutral insider: I know the MAiD process, but I can sit with the natural death process, and the uncertainty in between it all.”
  o Phenomenological response: I continue to experience uncertainty; however, I am aware of the processes: I recognize the importance of understanding the uncertainty of the MAiD process within my role as music therapist, and understand my neutrality in that I am not in a position to make decisions around MAiD. However, I am able to recognize multiple layers of the MAiD process as an “insider” in the health care system.

• “I knew I was witnessing something very honest.”
  o Phenomenological response: This felt like a visceral experience of the patient and caregiver’s vulnerability in embarking on a life review with the music as a navigator.
Participant 5: Alice

For even if I'm far away
I hold you in my heart
I sing a secret song to you
Each night we are apart
Remember me
Though I have to travel far
Remember me
Each time you hear a sad guitar
Know that I'm with you
The only way that I can be
Until you're in my arms again
Remember me

— Miguel, “Remember Me”

Alice: A Narrative

I had known Alice a while. A year, to be exact.

Alice was referred to me through a colleague who had been providing psychotherapeutic support to her for several months. I was told that Alice was interested in legacy work and hoped to write a song for her daughter, whom she worried about. Alice was 52 years old. She had been concerned about both her daughters for quite some time, as she knew she was functionally declining, and that her expected survival was now a matter of months. Alice loved to talk about
her family, constantly and excitedly sharing a deep sense of pride in her daughters and her partner. In our initial work together (well before her hospitalization and MAiD request), Alice and I wrote three songs, one for each of her daughters, both in their 20s, and one for her partner. She had shared the songs with her eldest daughter and her partner in the hopes that the songs would communicate her love, care, and concern for each family member, and that the sentiments in the songs would support her family long after she was gone.

“It’s the younger one I worry about most, you know,” she told me as we were getting set to record the final versions of these songs. “I’m not quite ready to give her the song. Not yet. I know she’ll be ok, but I’ve been the one to take care of her all her life. Who does she have if she doesn’t have me? It hasn’t been easy for her, she’s had the odds stacked against her.” I knew she was worried. Her youngest daughter was dealing with her own set of challenges, and Alice feared that if she wasn’t there for her, no one would be. “We’ve always been really close, you know, her dad isn’t around the way I am, so I need her to know I’ll be there even after I die.”

Alice wrote lyrics about the traits she admired: determination, uniqueness, resilience, beautiful blue eyes. “Don’t rely on others to make you happy, take care of yourself, let happiness come from within,” said Alice. “Can we use those words?” she asked.

I took Alice’s ideas, word for word, and added melodies, harmonies, and rhythms based on Alice’s non-musical suggestions. “What do you want your daughter to feel when she listens to these words?” I asked.

“Loved. Held. Supported,” said Alice. I set the tone with a gentle, rocking 6/8 metre, and warm major seventh chords. A lullabye. Alice dabbed her eyes with tissues. “I think she’ll love it. I want her to feel like I’m holding her when she hears this song.”
Almost a year after we had completed the three songs, Alice was readmitted to our hospital’s palliative care unit, as she was in frequent respiratory distress at home and found it impossible to manage.

“Hi sweetheart!” she said warmly as I walked into her room. “I’m so glad to see you.” She had an oxygen mask on and was propped up on pillows in bed. “Are you coming to play?”

I sat with her, keyboard by my side, and heard about the events and challenges of the past year. I played, as she asked me for soothing music to comfort her and help her breathe. “That one you sing about the little birds, and that everything is gonna be alright, you know the one, right?” I smiled and sang her Bob Marley’s famous melody. She often had difficulty breathing, an experience which she herself noted was both “physical and emotional.”

She was anxious. “I don’t have much time now…have you heard much about the MAiD program?” she asked. She was determined and hopeful that she might be eligible. “You know, it’s because I refuse to live this way, this isn’t living!” she said firmly. She had her first assessment the following week. I returned regularly to provide bedside music therapy to ease her breathing, an overall physical relaxation, and supportive-expressive psychotherapy at bedside. She spoke at length about her daughters.

“My oldest, she just loves the song, she treasures it. She told me it was the nicest gift I could have ever given. That means a lot coming from her!” Alice smiled. She was spunky, opinionated, loving, fierce. She enjoyed long conversations, especially with her night nurses, and had fun teasing our staff at any chance she got. “You gotta have fun, you know what I mean? I’m like, so what if I’m gonna kick the can? Sure, it’s all shit right now but what do I have if I can’t smile and laugh?”
She was scheduled for her second MAiD assessment the following day. She shared that she wasn’t too sure anymore. Our team had been able to provide excellent symptom management and she had gone from an oxygen face mask to occasional oxygen nasal prongs, as needed. She enjoyed visits from family and friends, and felt she needed to live while she was alive but wanted MAiD as an option if possible. She knew the risks.

“I know I might be approved but then might not be able to get it when the time comes, right? That seems a bit unfair.” I nodded. No advanced directives available at this time. Either you were cognitively able to consent at the time of the intervention, or you were out of luck. “What kind of choice is that?” she asked me. “I want to live while I’m alive, but the way I couldn’t breathe before, that’s not living. There’s no point to that. Needless suffering,” she sighed. “But if I’m here, maybe it’s for a reason. There are definitely some things I need to patch up. You know how we wrote those three songs? What are the chances we could write another one? To my ex? I need to communicate some things to him.” “Of course, Alice, let me grab my notebook,” I said. Relationship development and completion is an incredibly common experience in palliative song writing. Sometimes the song-writing is really more about the song-writer’s healing process.

Over the next couple of days, Alice and I worked on a final song, one that expressed her confidence that her ex-partner had the potential to live a good life and be a good parent. Alice was tearful as she shared how much confidence she had in him. “Just because we couldn’t make it work, doesn’t mean he can’t be there for our daughter, and for himself,” she said quietly, wiping away tears. Compassion. Empathy. Communicating a type of care and support that would outlast her own life. She and I shared the song with him one cool autumn afternoon. He cried. She cried. She was getting sicker.
“I just want him and her to have the best relationship and I want him to feel empowered to help her when I’m not here,” she told me later that day after he had left. She was scheduled to be transferred to a residential hospice. She had been approved for MAiD, but felt she wasn’t ready for it.

“I wish I could keep it on the backburner, and pull it out when I needed it, but it doesn’t work that way, does it?” she asked.

“Unfortunately, no,” I said.

“The problem is that when I want it, I won’t be able to get it, you know what I mean, sweetheart?” she asked. I paused. She faced unbearably difficult circumstances and limited options.

No two MAiD requests are the same. No two MAiD experiences ever look exactly alike. And so many patients had shared with me that they wished they could include MAiD in their advanced care planning. Maybe one day, I keep thinking to myself. Maybe.

She moved to hospice the next day. A few weeks later, she died a natural death with her partner at her side, as she lost capacity to consent to MAiD. I thought a lot about her sentiments, and her wish to share as many messages as possible to the people who mattered most to her. I admired her eagerness to seize the moment and use music to connect to her past, present, and future.

“It’s hard to describe actually. I think the music helped her an enormous amount, let’s just put it that way,” her partner told me several months after she died. “I think the fact that she could talk to you, you know, somebody completely neutral, for want of another term, and say what she wanted to say, because I know damn well she could have said it to me, and she did say it to me,
some of the words that were in the song that you did. She’d said to me on a number of occasions, but she just couldn’t communicate with her eldest daughter, so I don’t know if she did a song for her eldest daughter, but if she did, that probably gave her a way to express what she really wanted to say to her,” he said. “I think it gave her some sort of closure to a point of being able to put it into a song. I know I could listen to those words at any time,” he said. I could hear him crying. “I will listen to it, you know what I mean, now and again…”

Before she died, Alice shared that she wanted some control over her death, so MAiD aligned with her values and her needs. In the midst of feeling conflicted over when and how she would die, given that she sought after as much “life” as possible, she noted that if she could not control when MAiD would happen, then perhaps she could control what emotional sentiments and messages she shared, and with whom. The four songs she wrote seemed to reflect a sense of wanting to be present, even after death, in a way that felt supportive, caring, and loving. The songs lasted beyond her own physical existence and created what she felt was a gateway to her love, as a mother and a partner and a co-parent, in life and in death. Though she was not able to take control of the timing of her dying, she was able to offer her family something beyond her lifespan: love that lasted beyond life. Music carried that love forward.

**Exit Music Playlist**

The following songs were sung/played by me during Alice’s music therapy sessions.

- The Beatles: Here Comes the Sun
- Jimmy Cliff: I Can See Clearly Now
- Bob Marley: Three Little Birds
- Three songs written by Alice:
  - For her two daughters
  - For her partner
  - For her ex-husband
Patient Information Overview

Alice was a 60-year-old woman with high-grade serous ovarian cancer, with widespread metastases. I had met with Alice for outpatient music therapy sessions in the summer of 2017. Alice was supported by her partner, as well as her two daughters. She received a total of three music therapy sessions during her time on the palliative care unit of PM, where she was admitted for shortness of breath and to support a transition to a long-term palliative care unit. She transferred to a residential hospice and died naturally several weeks after her transfer.

Analysis: Patient (Alice)

The following examples are direct lines from the patient participant session transcripts, followed by a phenomenological response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

Wholistic Reading Overview

From a wholistic overview of all of Alice’s sessions, themes which arose include a sense of reaching out to communicate and connect with her family members through music, in the form of song-writing and legacy work, amidst a time of uncertainty and challenge (emotionally and physically). Alice shared deep concern for her family members and sought out music as a form of control and a way to connect. Together, we used aesthetic aspects of music through song-writing (melody, lyrics, rhythm, harmony, etc.) to communicate a broad range of sentiments and emotions. Alice also sought out the aesthetic experience of music as a form of symptom control (e.g., helping to regulate her breathing).

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect Alice’s experiences of music therapy throughout her three sessions.

Statement. “I want my daughters to know it’s ok to be afraid, because we all are.”
Interpretive-descriptive reflection. Alice shared her fear and normalized the role of fear amidst the interpersonal dynamics prevalent throughout her care. She noted a sense of urgency in wanting to communicate with her daughters and allowing them an opportunity to feel and express the range of emotions that came along with witnessing their mother’s decline. She acknowledged her own fear in a time of moving towards death and sought out music to not only communicate with family, but to explore different aspects of their relationship(s). Alice shared much about her hopes for her daughters with me as her therapist but did not always share these sentiments directly with her daughters. She used music as a tool to do this.

Statement. “We’re doing my story — the story’s important because that’s what the song is: it’s the story with the music. It’s something they’ll have forever.”

Interpretive-descriptive reflection. As she completed her fourth song with me, she noted the role of narrative, her “story.” She articulated the significance and importance of the story itself, and the pervasive nature of the story combined with song: she sensed intuitively that this form of communicating her feelings would be long-lasting, and shared a hope with me that her family would always have something not only to find comfort in, but to remember her by. From a psychotherapeutic perspective, I sensed a deep fear in Alice regarding her mortality, and a worry about being forgotten. The music potentially offered a venue to represent a part of her identity and give her some semblance of control over the longevity of her legacy.

Statement. “I’m wasting my time talking about this shit. Let’s do some music.”

Interpretive-descriptive reflection. Alice was deeply connected to music, and though we spent quite a bit of time processing her feelings and experiences through verbal psychotherapy, it was apparent that she looked forward to the musical aspects of our interactions, often noting that the music felt connective, and that she wanted to be in the music as much as possible. Perhaps
this experience of being in the music brought not only comfort, but the ability to decide when to talk and when to use music offered her a form of control.

**Detailed reading examples.** The following statements were taken directly from the session audio-recording transcripts, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- (Regarding the song she wrote for her ex-partner): “Oh my god. I love it. The beat is really … it’s uplifting. It’s not depressing.”
  - Phenomenological response: Alice focused on creating an “uplifting” mood when writing the song for her ex-partner. She shared that it was important to her to not be “depressing” as she already felt she had experienced enough that made her sad and brought about a low mood. She shared that the experience of the song she wrote was something that lifted her mood: I also sensed a form of protection over her ex-partner’s feelings, in that she wanted him to experience the music as something positive.

- “My daughter said, ‘You know Mom, whenever I’m lonely and thinking of you, I’m going to play it and think about you.’ I thought I’d share that with you.”
  - Phenomenological response: Alice shared this experience of relief in hearing these words and noted that it was validating to know that her intentions (to create the song as a source of comfort in the midst of her family’s anticipatory and upcoming grief) were manifesting in the song. She had shared many times with me that she hoped the song would act as a support when she was no longer living,
and from her daughter’s words, she sensed that the song would function the way she intended.

**Analysis: Caregiver**

The following wholistic reading, selective reading, and interpretive-descriptive reflections resulted from a hermeneutic phenomenological analysis of the caregiver interview. The interview was conducted approximately four months after Alice’s death, and lasted approximately one hour.

**Wholistic Reading Overview**

Alice chose her current partner as her primary caregiver to be involved in this study. Themes that arose from his experience of music therapy in the context of Alice’s assisted dying request included a sense of interconnectedness between him and Alice through the music; though he was not always present during our sessions at the hospital, he was involved because Alice shared our sessions with him, whether over the phone or the next day during his visit. He also shared a deep gratitude for the role of music in Alice’s life, noting that she was not always able to share her deepest fears and concerns with her family, as she was protective of them and their feelings, so he felt grateful for the therapeutic relationship that Alice and I shared. He noted several times that music gave Alice an opportunity to express that which was most difficult to express, and to create legacy beyond her physical presence, and long after she died.

**Selective Reading: Statements and Actions**

The following statements and actions phenomenologically describe Alice’s partner’s reflections on the experience of music therapy, several months after Alice’s death.

*Statement.* “I think it gave her a, a way of expressing what she wanted to say, without just writing it.”
*Interpretive-descriptive reflection.* In this statement, Alice’s partner noted the opportunity music provided for self-expression, particularly intentional expression of feelings related to her family members. He emphasized the addition of music to the words as an aspect of significance within the therapy, that there was something beyond the writing of her feelings that enhanced the experience, or somehow further articulated her thoughts.

*Statement.* “It just basically confirmed what she had been saying to me. I think it gave some sort of closure to a point to be able to put it into some sort of song. Those words, I could listen to at any time. It is something that for all intents and purposes, well, it’s everlasting, isn’t it? You know, she’s not around to say it, but the song’s there, and it says it for her. So yeah. It’s good.”

*Interpretive-descriptive reflection.* Alice’s partner acknowledged the longevity of the songs, and the songs’ role in articulating that which Alice can no longer articulate in her death. He noted the validating aspect of the lyrics, in that the song affirmed and confirmed her sentiments. He highlighted the accessibility of the song, in that he can return to it any time even though she is no longer physically present.

*Detailed reading examples.* The following statements were taken directly from the caregiver’s interview transcript, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “So, keep doing what you’re doing, SarahRose, because it does cheer people up. Ok?”
  - Phenomenological response: This statement signals an experience of gaining a sense of positivity, and possibly highlights the mood enhancing quality of music therapy; Alice’s partner shared a hopefulness that the work of music therapy
might continue onwards in the lives of future patients, as the undertone of this statement points to an experience of support for both the patient and the caregiver.

- “What they (funding agencies/government) need to realize is the after effects, not just while the person’s still alive and they can express their wishes, it’s the ability for the carers to still … listen to what that person had to say, even though they’ve passed over…”

  o Phenomenological response: This statement emphasizes the experience of Alice’s partner after her death, which he notes is significant for him beyond the experiences Alice had in the moment during the therapy itself. He articulates that those bereaved caregivers who are still living can still be connected to the sentiments of their loved ones despite their death, as the song acts as a representation of them and their feelings, sentiments, and wishes.

**Analysis: Therapist/Researcher**

The following wholistic reading, selective reading, and interpretive-descriptive reflections resulted from a hermeneutic phenomenological analysis of the researcher reflections written immediately after each session and the caregiver interview.

**Wholistic Reading Overview**

In my own therapist/researcher experience, I noted the length of my therapeutic relationship with Alice, and the sense of safety that I interpreted or pick up on within our rapport and our music making. It was notable that we had known each other longer than other participants, as this may have impacted the immediacy of our connection and the depth of our therapeutic work/clinical goals. Themes that arose in my own reflections include questions about the process of MAiD and Alice’s experience of the role of legacy work, as well as a curiosity about the role of music.
during her life and in her death. I found myself to be wondering about all the unknowns, and asking questions that yielded more questions, as outlined in the statements and examples below.

**Selective Reading: Statements and Actions**

The following statements and actions describe moments that reflect the researcher’s experiences of music therapy throughout Alice’s sessions.

**Statement.** “Music therapy seems to become a safe space for Alice to discuss, emotionally process, etc. This has been the case consistently throughout our therapy time together, a longer relationship than other participants.”

**Interpretive-descriptive reflection.** Of note is the difference in length in the therapeutic relationship between me and Alice, versus the other participants in this study. I acknowledge this, in addition to the consistency of the safety created within music for Alice to consider her emotions, needs, thoughts, fears, intentions, and concerns. It is unclear whether the longevity of our relationship impacted the therapeutic process within the context of her assisted dying request, as her situation was unique to this study. However, I found it notable that she consistently appeared to find safety in the musical space, allowing various fears and vulnerabilities to come forward (e.g., fear of being alone, fear of being forgotten, concern for her children and partner and their well-being after her death).

**Statement.** “What role is legacy work playing in Alice’s life? Is it control? Is it communication? Does it stem from fear? Does it stem from love? I think it stems from both. All of the above.”

**Interpretive-descriptive reflection.** As was consistent with a number of my therapist/researcher reflections, I left the sessions with more questions than answers or insights and was aware of the multiplicity of dynamics and emotions that permeated each therapeutic
encounter. In the context of MAiD, so much is unknown despite the control patients have in putting forward their request for the intervention. There are numerous concerns, fears, and emotional experiences that come to the fore in this context, and I asked myself where legacy work (through song-writing) fit in. I aimed to bring a curiosity to each encounter, and acknowledge the patient as expert in their own feelings: this attitude comes first and foremost from within my own process as therapist/researcher, so I am perpetually curious about the role of the music therapy interventions in the context of each person’s care. This curiosity may have reflected a curiosity within the patient experience as to the role of music in a new and novel situation (MAiD) and may have even paralleled these patient/participant experiences.

**Detailed reading examples.** The following statements were taken directly from the researcher reflections, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “Alice’s sense of fear was pervasive in our session. Fear of being alone, dying alone, not being cared for. She’s focused on her songs and continues to hope that her songs will impact her family. Will she ever know the full extent of how much the songs will provide support after her death? Will I ever know?”
  - Phenomenological response: There was a sense of experiencing ongoing unknowns and curiosities in the midst of a time of uncertainty; however, this statement may have represented a sense of the therapist holding and empathizing with the patient/participant experience, while acknowledging the unknown and the uncertainty of the process. There was also a broader acknowledgement of the ongoing potential for impact of the music therapy interventions, which perhaps
neither the patient/participant nor the therapist/researcher ever know, only the bereaved caregivers.

- “She expresses deep gratitude for music therapy, in the midst of her needs and challenges. I feel deep gratitude for the music as a co-therapist, it holds all the complexity in a way that nothing else can.”
  - Phenomenological response: This reflective statement offered a window into the intersections of emotion within the therapeutic relationship, in that my experience as a therapist/researcher has parallels to the patient/participant experience. In this case, gratitude was the shared experience within the relationships: the relationships between the therapist/researcher and the patient/participant, and between the therapist/researcher and the music itself (which I refer to here as my “co-therapist”).
Genius Death your art is done
Lover Death your body’s gone
Father Death I’m coming home
Guru Death your words are true
Teacher Death I do thank you
For inspiring me to sing this Blues.

– Allan Ginsberg, “Father Death Blues”

Rob: A Narrative
I went in with assumptions. But, who doesn’t?

Bad therapist, I muttered to myself as I rubbed my hands together with hand sanitizer. Stop assuming. I fought against myself as I knocked on the door of Rob’s hospice room. He’s so not going to want music therapy. He’s not. I have nothing to offer. Music therapy doesn’t have a place for him right now. He declined other supports and he’s just got too much going on and he’s about to have MAiD and what am I even doing here? My mind was racing.

“Hi Rob…I’m SarahRose, I’m the…music therapist.”

Silence.
Rob looked at me quizzically. As a music therapist, I have become all too familiar with this look.

I waited. I have also become intimately familiar with silence, with waiting, with holding space.

Rob squinted.

“I…I play music for many of our residents here. I was wondering if I could, I could…come in and tell you a little bit more about what I do?” I stammered. I don’t usually stammer. Pull it together, I told myself. Do not assume. Hold the space. He closed his eyes and lay back in bed. I moved slowly to the centre of his room, then forward towards his bed. “May I sit down for a moment, Rob?” I asked quietly. He opened his eyes and locked them with mine.

“Ok”, he whispered, barely audible. He was declining quickly; Dr. Sandberg had told me this earlier that day. “He won’t make it through the reflection period at this rate, we’re trying to expedite things because he’s really changing.” Now, face to face with Rob, I saw what she meant, and was horrified at the alarming rate of his decline and concerned that he would potentially be denied his final wish.

I sat quietly with Rob for a few moments before going on to explain my role on the team, and in the MAiD process. “So, would you feel like having a little bit of live music in your room now?” He sighed. I mentally prepared myself to get up and leave. “Well…yeah,” he whispered. “Ok.”

Never assume.

Our first session was filled with classic rock, songs from the 1960s and 1970s that made him smile. He even mouthed the lyrics along with me. He was weak, and getting weaker, and I was careful not to push him too far, not to stimulate the sound environment too much. I played for about 20 or 30 minutes, an entry point into a short but intentional therapeutic relationship that
would carry us through to his death. Two days later, I met with him again. His dear friend was present, along with her German shepherd who positioned herself comfortably across my feet as soon as I sat in front of my keyboard.

I began with Gordon Lightfoot. He had asked for it during our first session. “If you could read my mind love, what a tale my thoughts could tell…,” I began to sing. I paused but continued to play softly. “Is this ok, Rob?” He nodded. I continued. “In a castle dark, or a fortress strong, with chains upon my feet … you know that ghost is me.”

His friend began to sing along. “Never thought I could feel this way, but I’ve got to say that I just don’t get it…” she sang. I smiled.

“And you won’t read that book again because the ending’s just too hard to take…” I continued. His friend smiled, wiping away tears as she told me that Gordon Lightfoot was one of their favourite singers.

“We’re old folkies, you know?” she laughed, dabbing her eyes.

The ending. It’s just too hard to take.

Rob watched me as I played. He was extremely cachectic. He said little, occasionally grimacing and shifting in his bed, sometimes closing his eyes and appearing to drift off. He looked exhausted. He perked up at times, requesting favourite artists, which delighted his friend.

“Jesse Winchester,” he said softly. “Oh! Very good idea!” his friend gushed. I pulled up lyrics and sheet music. We sang together. Rob moved his mouth in tandem with my voice. “So, after years and after tears, and after summers past, the old folks tried to warn us, how our love would
never last. And all we'd get was soaking wet from walking in the rain and singing sham-a-shing-a-ling again.”

A nurse came in to adjust Rob’s pain pump.

Rob’s friend gently gave him juice from a tiny sponge.

He told us he was nauseous. We sat quietly with him, adjusting pillows as he tried to find some reprieve from the discomfort. I offered to leave and come back another time. He asked me to stay. And so I stayed.

“Turning back the pages to the times I loved best, I wonder if she’ll ever do the same. Now the thing that I call living is just being satisfied, with knowing I got no one left to blame.” We all quietly sang the chorus of Gordon Lightfoot’s “Carefree Highway.” I slowed the song down to match Rob’s shallow breathing. He asked me to play Neil Young as he closed his eyes. Neil Young, The Byrds, The Beatles…. He smiled at times. He sighed at times. An hour later, I rose to leave. He reached his hand out and “fist pumped” me. Everyone laughed. He asked me to come in the following day, the day of his MAiD procedure. I told him I would be there, ready to play. If he wanted. If he needed. And if he changed his mind, I would be ready to give him space. If he wanted. If he needed.

Never assume, I thought, as I quietly unplugged and packed up my keyboard. Never assume. I was so sure he would not want me present. He had declined other visitors, other supports. But he wanted the music. He wanted the songs.

His second assessment would take place tomorrow, immediately before the intervention. The process had been expedited because of his rapidly deteriorating health, and his health care team
had worked tirelessly to advocate for him. If he was well enough to consent tomorrow morning, he would have the assisted death he had requested.

The next morning, Dr. Sandberg called me at the hospital. “Rob’s been approved,” she said. “And he wants music. Specifically, live music. He wants you here, can you come?” I told Dr. Sandberg I would be at the hospice in 15 minutes.

I met with a family member and a friend outside his hospice room. Her friend reached out for my hand. “A lot of friends are here, they’re with Rob right now. I think it would be great if you could be with Rob and his friends … and all of us … before. Before it happens. And during the procedure. He’s not doing too well, he’s got a lot of pain right now and he’s pretty tired, but he’s relieved. And it will be over soon.”

I knocked softly on the door and walked into his room. “Rob? Hi. Hi everyone.”

A group of six had gathered around Rob’s bedside. “Oh! The music lady!” one of his friends joked. “What are you gonna play?” he asked.

“Rob’s faves, I think,” I grinned. After I set up my keyboard in the corner of the room, I walked over to Rob’s bed and sat down next to him. He reached out his hand. I held it in mine.

“It’s good to see you,” I smiled.

“Good to see you. Thanks for coming,” he whispered slowly.

“I can play what you’ve been asking for, same style, same songs, and you can tell me if you want anything else, ok?” I asked him.

“Perfect,” I read on his lips. He barely made a sound.
I moved to the keyboard and I sat down and began to play.

“To everything, turn, turn, turn, there is a season, turn, turn, turn…”

Everyone sang along.

“There are places I remember, all my life, though some have changed…”

Friends passed around a Kleenex box.

“And when the night is cloudy, there is still a light that shines on me, shine until tomorrow, let it be…”

I transitioned through songs and various keys and remember smiling as friends looked up lyrics on their phones and sang along quietly. I matched Rob’s breathing with the music, carefully watching his inhales, his exhales.

“You just call out my name, and you know wherever I am, I’ll come runnin’ to see you again…”

A phone rang. It was a friend wanting to say a final goodbye. Rob could barely speak as another friend held the phone up to his ear and mouth. “Ben says he loves you, so much,” she said, tears streaming down her cheeks. Rob smiled. “He’s smiling Ben…he hears you!” she whispers.

I gently started again.

Dr. Taylor arrived 30 minutes later.

“I’m sorry Rob, I know you’ve been waiting. I’m going to put the intravenous in; the music can continue while I do it,” he said gesturing to me. I smiled.
“That ok, Rob? Do you want me to keep playing?” I asked. Rob nodded. I continued to play softly in the background. Erik Satie’s “Gymnopedie No. 1.” Gordon Lightfoot’s “Carefree Highway.” Neil Young’s “Heart of Gold.”

Dr. Taylor inserted the IV. I sang.

“I wanna live, I wanna give, I’ve been a miner for a heart of gold…”

The music is punctuated by sounds of medical tape, shuffling and movement, pain pumps being pressed. Dr. Taylor steps out momentarily. I am alone with Rob. The clock reads 2:42 p.m. I walk over to his bed and sit down again. “You mentioned you wanted the music for the actual procedure,” I say softly. Rob smiles, eyes closed. “Anything in particular or the same style as we’ve been doing?” I ask. Rob opens his eyes and looks at me. “The one … from before, Rolling Stones?”

“‘Wild Horses’?”

Rob nodded. “Sure. Yeah.”

I take his hand. He squeezes mine. “We’ll all be here with you. And I’ll sing you ‘Wild Horses,’ Rob.”

Dr. Taylor came back, bringing with him Rob’s family and friends, Dr. Sandberg and Dr. Dawson, a friend and colleague of mine. She and I had done this together several times before.

“What are you going to play?” Dr. Dawson whispers.

“Wild Horses,” I tell her.
“Wow.”

“Rob?” says Dr. Taylor. “Try not to be scared.” Rob nods.

Sounds of sniffling. Movement. Family, friends gather close. Dr. Dawson is standing close beside me, and I am grateful. I am comforted. Friends hold each other’s hands. Dr. Taylor takes Rob’s hand in his own. I marvel at the compassion. The human touch. The art of medicine. Herein lies that art. I gently play an instrumental introduction to “Wild Horses.” “All your friends are here with you, Rob,” says Dr. Taylor, underscored by the music. “All your friends are surrounding you.”

Dr. Taylor looks at me and nods. I begin to sing.

“Childhood living....”

Dr. Taylor speaks softly to Rob as he handles the syringes and prepares to inject them. I continue to play.

“Is easy to do...”

“There isn’t going to be any pain.”

“The things you wanted...”

“The hurt is almost over, Rob.”

“I bought them for you...”

“This will be over soon, Rob.”
“Wild horses…couldn’t drag me away…”

“He’s resting now, like he’s asleep, but he can still hear you. Is there anything else you want to say? Now’s a good chance to.”

“Wild, wild horses…couldn’t drag me away…”

“We love you!” sobs a friend.

“We love you Rob,” whispers another.

“You’ve brought so much meaning to my life,” says another.

“Couldn’t drag me away…wild, wild horses…we’ll ride them someday…”

I cradle with instrumentals. I soundtrack the last moment, the last breath. Dr. Taylor slowly pushes the medicine into Rob’s veins. I sing. We wait.

Pause.

“He…is gone. He has died. I’m very sorry for your loss.” Dr. Taylor looks around the room. “It was tough for him, but it’s tough for you. So, thank you for being here for Rob,” he says softly.

Tears.

“Thank you, Doctor.”

I continue to play quietly. Wild, wild horses. They couldn’t drag me away.

Music fades. I stay for a few minutes as nobody moves very much.
A friend speaks to Rob. “If you can hear us wherever you are, we love you.”

Dr. Taylor gently consoles. “You didn’t want him to go, but you didn’t want him to suffer.”

Murmuring of agreement.

A quiet communication of next steps. The coroner’s call. The funeral home. Encouragement to stay as long as the friends and family need to. A dissipating of the music.

I quietly leave, whispering a thank you to Rob in my mind, and speak a soft thank you to his friends as I step away.

Wild, wild horses. We’ll ride them someday.

**Exit Music Playlist**

The following songs were played/sung by me (and Rob’s friends) during his music therapy sessions and his assisted death. Many improvisations (primarily with keyboard and voice) were used as well.

- Gordon Lightfoot: If You Could Read My Mind
- Gordon Lightfoot: Carefree Highway
- Gordon Lightfoot: Early Morning Rain
- Gordon Lightfoot: Song for a Winter’s Night
- Jesse Winchester: Shama-lama Ding Dong
- Eva Cassidy: Songbird
- Neil Young: Harvest Moon
- Neil Young: Heart of Gold
- Neil Young: Old Man
- The Birds: Turn, Turn, Turn
- The Rolling Stones: Wild Horses
- The Rolling Stones: Paint it Black
- The Beatles: Let It Be
- The Beatles: Hey Jude
• The Beatles: Here Comes the Sun
• The Beatles: In my Life
• The Beatles: Penny Lane
• John Lennon: Imagine
• Bob Dylan: The Times, They are A-Changin’
• Bob Dylan: Blowin’ in the Wind
• Bob Dylan: Mr. Tambourine Man
• Sting: Fields of Gold
• Simon and Garfunkel: Scarborough Fair
• Simon and Garfunkel: Bridge Over Troubled Water
• Joni Mitchell: Both Sides Now
• Carol King: So Far Away

Patient Information Overview

Rob was a 67-year old man with metastatic pancreatic cancer, who was admitted to a residential hospice for end of life care. He was diagnosed initially in October 2018, admitted to hospital for a workup and to explore treatment options, however his disease progressed rapidly, resulting in hospice admission and request for MAiD. Rob was supported by a number of close friends and a sibling. He received a total of three music therapy sessions, each approximately one hour in length, and died via MAiD at the hospice.

Analysis: Patient (Rob)

The following themes resulted from a hermeneutic phenomenological analysis of Rob’s three sessions.

Wholistic Reading Overview

Psychosocial support through non-verbal communication became a primary theme throughout the music therapy sessions with Rob. He was symptomatic each time I had a session, experiencing pain, nausea, and fatigue. When I began to play music that he recognized, there were moments of deepened breathing, prolonged eye contact, and a request from him to continue the music even in the midst of his discomfort. The music itself represented various parts of his own life narrative, as shared by his friends and occasionally by him directly. Memories arose and
were processed verbally by the friends and family present in the room, and often, Rob would drift off and fall asleep during the music, unfurrowing his brow and appearing to be relatively relaxed within the specifically chosen music. Of note, Rob and I spoke in slightly more detail during our first encounter, which was prior to my obtaining research consent; Rob had a steep physical decline and became increasingly somnolent after this first encounter, and the subsequent sessions were largely non-verbal on Rob’s part. His friends were his advocates and sharers of memories and stories that represented much of Rob’s experience, however many of the songs I used in the subsequent sessions were based on my conversations with Rob from our very first encounter.

**Selective Reading: Statements and Actions**

The following statements and actions describe moments that reflect Rob’s experiences of music therapy throughout his three sessions.

**Action.** When asked if Rob wanted the music to continue, he nodded his head and rested it back on his pillow, unfurrowing his brow and smiling.

**Interpretive-descriptive reflection.** Music therapy was offered at a time when Rob was experiencing a number of symptoms; he appeared to be physically uncomfortable each time I met with him. The music seemed to offer a reprieve as the receptive music therapy style appeared to relax and calm Rob. The subtle indicators of Rob unfurrowing his brow, smiling, and moving his body towards rest, ease, and relaxation are often significant markers within a non-verbal relationship; Rob appeared comfortable, and in a time of dis-ease, discomfort, and physical/emotional challenges as he was quickly losing his window to consent to MAiD, these subtle indicators felt significant.
Action. About ten minutes before his MAiD procedure, Rob was waiting for the physician to come back into the room, and he and I were alone. I continued to play quietly in the background. Rob was extremely fatigued and hardly opened his eyes. I said, “We are all going to be here with you, Rob. And I am going to play you ‘Wild Horses.’” At this point, Rob opened his eyes and smiled at me, and maintained eye contact for a few moments, until he once again closed his eyes.

Interpretive-descriptive reflection. Rob was unable to speak very much during the course of our time together, however as a result of his friends and family sharing his musical preferences, and his subtle non-verbal gestures, we developed a therapeutic relationship through the music. He smiled in response to my comment about playing “Wild Horses,” his requested MAiD song, and I found it notable that he opened his eyes and maintained eye contact, given his fatigue and somnolence, and the ongoing symptoms he was experiencing.

Detailed reading examples. The following examples are direct lines from the patient participant session transcripts, followed by a phenomenological response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- Rob whispered, “I’m going to rest now;” his friend asked if he wanted the music to be playing while he rested, and he said, “Yes.”
  - Phenomenological response: Though Rob was unable to speak very much, his comments, body language, and statements served as indicators of his experience. His request to rest within the music indicated a possible ease, which he felt as a result of the music playing in the background.
Analysis: Caregiver

The following themes resulted from a hermeneutic phenomenological analysis of the follow-up caregiver interview with Rob’s friend approximately three months after Rob’s death. The interview was conducted over email at the caregiver’s request, as she felt she would better articulate herself.

Wholistic Reading Overview

Rob’s chosen caregiver (a close friend) shared that she felt the music therapy sessions were a point of focus, something to look forward to and anticipate, and something within the MAiD experience that relieved pressure in that Rob did not have to speak, and no one had to speak to him or feel verbal communication was necessary in the midst of his extreme fatigue. She shared that music provided ease and brought up positive emotions in a very emotionally challenging time.

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect Rob’s friend’s (caregiver) experiences of music therapy throughout Rob’s sessions.

Statement. “It went so far beyond anything we would have expected or strived to have that it seemed almost surreal.”

Interpretive-descriptive reflection. Rob’s caregiver shared a sense of surprise as she noted the music therapy process was “surreal,” and indicated that it surpassed expectations in a way she did not expect. This potentially points to the unique nature of the interventions and the therapy, but also to the way in which it was received, as something effectively outside of the boundaries of what hospice care and/or end of life care might typically be perceived to be.
Statement. “For a few moments we could focus on the music and sort of forget the tragedy.”

Interpretive-descriptive reflection. This statement perhaps points to a diverting/distracting element of the music, and a sense of relief, perhaps that the focus the music provided acted as a vehicle to disrupt the process of being emotionally steeped in the tragedy. Rob’s caregiver did not allude to completely forgetting the tragedy; instead she suggests that there was a “sort of” element, perhaps a part-way or a half-felt forgetting, which possibly speaks to the fact that once immersed in the experience of assisted dying, one may not be able to ever fully leave the experience. But perhaps music can allow for a sort of forgetting, at least for a few moments.

Statement. “Having music provided to us at a time when we wouldn’t have thought of it ourselves was brilliant, like everything else at Kensington.”

Interpretive-descriptive reflection. This statement indicates that music was not necessarily top of mind for the participant and/or caregivers who were present. However, it does suggest that the provision of music was what was effective. It is known that caregivers experience a great deal of stress when caring for a loved one who is dying (McDonald et al, 2018), and seeking out resources may not always be available or accessible in terms of the caregivers’ energy and time. Rob’s caregiver indicated that a significant component of the care was the provision of music therapy by the staff, as opposed to going to seek it out themselves.

Detailed reading examples. The following statements were taken directly from the caregiver’s interview transcript, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”
• “The music served to brighten a very hard and painful time.”
  o Phenomenological response: The experience of music (perhaps the aesthetic, perhaps the quality, perhaps in part the live performative aspect) during this time that was described as very difficult served as functionally allowing for that which the caregiver describes as “brightening,” perhaps indicating that the music brings something light, positive, perhaps acting as a support amidst a difficult circumstance.

• “I never had the opportunity to think about assisted death before, and it never occurred to me that positive things could be provided that could help relieve some of the stress and hard emotions.”
  o Phenomenological response: This experience may have been one of surprise, as the music was unexpected, as was its sense of being “positive.” It was clear that Rob’s caregiver saw the music as “positive” and noted the positivity eased the stress and the emotional burden.

Analysis: Therapist/Researcher

The following wholistic reading, selective reading, and interpretive-descriptive reflections resulted from a hermeneutic phenomenological analysis of the researcher reflections written immediately after each session.

Wholistic Reading Overview

The broad themes that emerged from the therapist/researcher reflections indicated an experience of attuning to the non-verbal as a space within which connection was formed, and support was provided. The space was experienced as comfortable, and effectively experienced by several members of Rob’s friend/family circle, given that the friends and family were expressive of
gratitude for what music provided. Themes of trust in the music emerged (in the midst of a largely non-verbal relationship with Rob), especially in the context of the challenging atmosphere of a room full of individuals having their own experiences, surrounding Rob, whose experience was at the forefront of my intentional actions as a therapist.

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect my experiences of music therapy throughout Rob’s sessions.

Statement. “I sensed music allowed for space, for non-verbal comfort in the silence without having to do, to be, or to say anything; I was humbled by the gratitude and appreciation shared by the family and caregiver.”

Interpretive-descriptive reflection. In revisiting these therapist/researcher reflections, I note the sense of ease that was experienced, which I wrote about in my post-session journaling. Part of my experience was certainly trepidation at first, particularly when unclear about how Rob would initially receive music therapy, however it was clear that I experienced a sense of ease and a sense of non-verbal comfort within the music.

Statement. “It’s always a fine balance between being over-stimulating with the music and being wholly present and attuned to a patient’s experience in order to provide physical/emotional support, as well as hopefully relief and comfort. I feel the challenge of holding the space for a room full of emotion that feels different for each and every person in the room. Music is the container and I feel it takes a lot of trust to use it in the ways I know how to, but also to read the room and the situation moment-to-moment, and to anticipate the needs but respond to requests. Very complex yet so apparently simple on the surface.”
**Interpretive-descriptive reflection.** In this paragraph, I reflected specifically on the experience of holding. I was balancing holding space for a room filled with numerous individuals all experiencing their own specific emotions, thoughts, and sensations in the context of MAiD. As a music therapist, I often feel it is my role to hold this space, as the music fills it acoustically, and I am the vessel through which the music emerges. It is also notable that I mentioned the apparent simplicity underscored by the reality of the complexity of the role. I felt the acute need to trust completely in the midst of the unknown.

**Detailed reading examples.** The following statements were taken directly from the researcher reflections, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “Friends at bedside, all open and willing to invite me in. Music clearly plays a role: how do I determine exactly what that role is? Maybe this is a new role for music to play.”
  
  o Phenomenological response: The experience of curiosity, wondering, questioning, and taking chances on what and how I enter into a space; I am grounded in the knowledge of what music can do, but the experience of walking in to a new phenomenon leads me to enter in by asking what exactly that might be, and allowing for new concepts and opportunities to emerge.

- “I felt myself to be saddened by the losses experienced in the room and inspired by the way both Rob and his best friend were able to communicate with each other.”
  
  o Phenomenological response: An experience of sadness, an experience of witnessing communication and connection between Rob and his community. This statement in the therapist/researcher’s reflections points to my own experience of
witnessing loss, while also holding the experience of inspiration in the midst of challenging yet effective communication.

• “I knew in my heart that Rob would not live long, and so appreciated his need for control over the ending of his life.”
  o Phenomenological response: I noticed Rob’s need for control, and experienced a sense of his impending death, given his profound fatigue and physical weakness; these experiences for Rob were notable in my own perception, and this statement points towards an experience of empathy towards Rob’s end of life choices.
Participant 7: Frank

I am much too alone in this world, yet not alone enough
to truly consecrate the hour.
I am much too small in this world, yet not small enough
to be to you just object and thing,
dark and smart.
I want my free will and want it accompanying
the path which leads to action;
and want during times that beg questions,
where something is up,
to be among those in the know,
or else be alone.

— Rainer Maria Rilke, The Book of Hours

Frank: A Narrative

Frank’s palliative care physician put in the referral for music therapy.

“I know this gentleman absolutely loves music, and I think he’s really having a difficult time
right now. Is there any chance you could see him?” he asked me over the phone on a cold
Tuesday afternoon in December. I met Frank the following day.
Frank was 69, a devotee of classical music, a father of two adult children and a grandfather of four young kids. As I introduced myself, Frank nodded slowly. “I look forward to whatever music you can offer me,” he said stoically. “I love music, especially the classics.”

I explained my role and my availability to be present before and during his assisted death, which was scheduled to be the following Monday. Frank sat up a bit in bed. “There are so many I love,” he said and began to list his favourite composers and pieces of music. Bach, Beethoven, Dvorak, Chopin, and Debussy. “Can you really play all this?” he asked, eyes wide. I laughed.

“I’ll try, Frank, I’ll do my best.”

“Merci beaucoup, SarahRose. I so look forward to it. And I know it will be helpful.” Frank was exhausted. “Can you also come later this week as well when my family is here? Maybe you can call my daughter to schedule a time.” I agreed to return the following day and offered to connect with Frank’s family around planning sessions.

I arrived the next day, keyboard in tow. Frank was lying in bed with his eyes closed.

“I’m awake, it’s ok, please come in, I just might keep my eyes closed,” he whispered. “But please, if you have time, please play for me.” He looked so different than he had the day before. I placed my keyboard near the foot of his bed, plugged it in, and began to play.

I played through segments of some of the most famous compositions written by the composers Frank had so excitedly spoken about the day before, combining them and modulating through different keys for about 25 minutes until I finally arrived at and ended with Canon in D by Johann Pachelbel, a particular favourite of Frank’s. His head nodded and he smiled each time he recognized a song. I stopped. I waited. Frank lay still.
“I could listen to you all day,” he whispered. “You hit the playlist right on the nose,” he said, smiling. I asked Frank whether he might have a specific song in mind for his MAiD procedure, as he had already indicated that he wanted music on that day.

“It doesn’t really matter,” he said, shrugging. “But, well, there is that one piece that really gets to me.”

Frank went on to describe his relationship to the Canon by Pachelbel. He spoke of the family vacations to western Canada, the drive from Calgary to Banff and then on to Jasper, over to Vancouver, Victoria, then back via the Okanagan Valley, and finally arriving in the Fraser Valley.

“And that’s where we could stop on the side of the road, and I would look down there and see a river, and the CN Rail train that was barely this high,” he said making a gesture with his index finger and thumb. “And then you turn around and you couldn’t even see the top of the mountains. How small are you at that point? I would listen to that Canon and ... how small are you in the universe? You’re just so very small in those mountains. It’s just beautiful. I revisit it every time I listen to the Canon.”

The imagery was vivid, striking. Frank agreed that he wanted the Canon to be the last thing he heard before he died. I asked him if his children, now 39 and 37 years old, might remember this particular piece of music when they heard it.

“Oh yeah, they’re remember it as ‘Dad’s mountain music.’ Dad’s mountain music. Musique de la montagne, his wife and children would say fondly on the day of his procedure. Frank shared
his background, his early life in the Eastern Townships of Quebec, his career as an accountant, his nearly 47 years of marriage.

“It’ll be 48 years in May of next year, but I won’t be alive to see that. I don’t know where I’ll be, somewhere far away, I imagine,” he sighed. “I don’t know either, Frank,” I offered. “Well, when I find out, I’ll try and figure out a way to let you know,” he laughed. I smiled. We spoke about his children, and their love of music that he was so proud to have provided to them. He shared his gratitude for the music at this particular point in his life.

“The music today was...incredible,” he told me as I was leaving our first session. Was it the music or the stories, the associations, I wondered, or some combination of both?

I returned two days later for a session with Frank and his wife.

“You know, it’s not an easy time, not easy at all, but we really try to focus on the nice time we’ve had, and everything we’ve received,” she told me. She went on to describe Frank’s double lung transplant, his 13-year survival before the chronic rejection and cancer diagnosis, and the meaningful moments shared in the hospital over the past couple of weeks. “We did Christmas in November for the grandkids, so they would have a last Christmas with him,” she told me softly. “The music is very soothing right now, could you continue playing if you have time?” she asked me. I played. She shared stories. I listened. Frank moved in and out of sleep, occasionally opening his eyes and smiling or gently clapping his hands to show his engagement and appreciation.

“You can come on Monday, right?” she whispered as Frank had fallen into a deep sleep. I assured her I would be there with all the musical selections that their daughter had requested
during a phone call earlier that day. Cat Stevens, Antonin Dvorak, Nina Simone, Johannes Pachelbel. I would be there. She hugged me before I left. “Merci beaucoup,” she said as she took my hands in her own.

Monday. Noon.

I arrived with my keyboard, my sheet music, and copies of lyrics for each family member, at Frank’s daughter’s request.

“Maybe we can start with ‘What a Wonderful World,’” Frank’s daughter suggested. Over the next hour and a half, we sang through the list of songs curated by the family, and I listened as they shared stories of his life, his career, his greatest joys, his remarkable resilience in the face of intense health challenges, and of course, his mountain music. “Father and Son,” “Moondance,” “Heart of Gold,” “Old Man.” Family vacations, his love of nature, his feeling of immense magnitude and a sense of insignificance standing in the shadows of the Rocky Mountains. How small we are. How small, in the midst of the mountains, and the music. Musique de la montagne.

At 1:15 p.m. Dr. Taylor arrives. I am comforted by his presence. I am reassured by his humanity and his kindness. He gently asks the family to leave so he can once more verify that the patient does in fact want to have an assisted death. No coercion, no influences.

“Been a long weekend, a tough weekend, hey Frank?” Dr. Taylor said softly, empathically. Frank nodded. He was almost too weak to speak. “I’ll bet,” Dr. Taylor sighed. “Listen, Frank, I have to do this, I have to be sure, but if you change your mind, it doesn’t matter. Not to me, not to her,” motioning to me, “not to your family, and not to anyone else. You just tell me what you want. Are you sure you want to go ahead with this and have an assisted death?”
Frank breathed slowly and nodded purposefully. “Yes,” he whispered. “Yes, I’m ready.” Dr. Taylor nodded. “That’s all I need Frank, you can relax, you can keep your eyes closed.” Frank nodded, barely moving his head.

The family re-entered this room.

“So,” he began, “I’ve explained how it is going to go, but feel free to ask me any questions if you want, ok? I understand we’re going to have some music as well. What’re you going to play, SarahRose?” Dr. Taylor asked turning towards me.

“Oh, we’ve got a combination of songs, but the main one will be Canon, by Pachelbel,” I told him. Dr. Taylor nodded.

“Do you have any idea what this is doing for her career?” Dr. Taylor joked. “Some audience she’s got!” They giggled, then began to laugh. I allowed myself to laugh. It broke the tension.

We all breathed deeply. It was time.

Dr. Taylor had a remarkable way of gauging the situation and inviting humor into the room in a kind and compassionate way. The family gathered around Frank, and they held hands, Frank’s wife holding Frank’s right hand, while Dr. Taylor held his Frank’s left hand, and cradled his left arm where his intravenous site was ready to receive the medicines that would end his life. The family said a prayer, first in French, then in English. I played softly in the background. “He can still hear you at this point,” Dr. Taylor said to the family as he began injecting midazolam. He looked at me as if to cue me, to signal the beginning of a symphony. A conductor poised with baton held anticipatorily in the air. And I began. *Musique de la montagne* filled the room as medicines filled Frank’s veins; he looked so comfortable. It was only a few moments. A few
moments of mountain music. And he slipped away. It was so subtle, but so intentional. So gentle yet so direct.

And how small are you in that moment, Frank? How small am I? How small are we in the universe, standing in the shadows of the mountains, but when you hear that Canon…

**Exit Music Playlist**

The following pieces of music were played/sung by me during Frank’s music therapy sessions and during his assisted death. A number of improvisations with keyboard/voice were also used.

- J. Pachelbel: Canon in D
- F. Chopin: Fantasie Impromptu in C# Minor
- J. Brackett: Simple Gifts
- J.S. Bach: Prelude in C Major
- J.S. Bach: Aria from “Goldberg Variations”
- J.S. Bach: Minuet in G Minor
- J.S. Bach: Suite for Solo Cello (Prelude)
- J.S Bach: Minuets I & II in G Major
- J.S. Bach: Wachet Auf (“Sleepers Awake!” BWV 140)
- J.S. Bach: Jesu, Joy of Man’s Desiring
- J.S. Bach: Gavotte in D Major
- W.A. Mozart: Eine Kleine Nachtmusik
- W.A. Mozart: Sonata in A Major KV 331, 1st Movement
- A. Vivaldi: Spring, from “The Four Seasons”
- A. Vivaldi: Winter, from “The Four Seasons”
- S. Rachmaninoff: Rhapsody on a Theme by Paganini, Op. 43, 18th Variation
- A. Dvorak: Humoresque
- E. Satie: Gymnopedie No. 1
- Cat Stevens: Father and Son
- Cat Stevens: Morning Has Broken
- Nina Simone: Feelin’ Good
- Traditional: All Through the Night
- Louis Armstrong: What a Wonderful World
- Harold Arlen: Somewhere Over the Rainbow
- Neil Young: Heart of Gold
- Nat King Cole: Unforgettable
- Neil Young: Old Man
- Leonard Cohen: Hallelujah
Patient Information Overview

Frank was a 69-year-old man who received a total of three music therapy sessions, each approximately 40 to 60 minutes in length. Frank was diagnosed with squamous cell carcinoma of the scalp and face with metastases both locally and to his neck. This diagnosis followed a bilateral lung transplant in 2005. Frank was experiencing chronic rejection with a recent pneumonia and a projected prognosis of approximately two months. Frank was supported by his wife and two adult children. He died via MAiD at the general hospital where he was admitted.

Analysis: Patient (Frank)

The following themes resulted from a hermeneutic phenomenological analysis of Frank’s three sessions.

Wholistic Reading Overview

Frank’s sessions were filled with a lot of music, music specifically related to his family and his experiences over his adult life. He expressed aesthetic enjoyment of various pieces I played, sharing that he felt connected to memories of raising his family, narrating vivid descriptions of images connected to certain pieces. He spoke at length of gratitude for his relationships, and his life experiences including his double lung transplant 13 years prior. He articulated music’s presence in his life as a constant escape, a source of solitude, and an access point for various memories. Both the hour before his death and his final moments were filled with songs of his and his family’s choosing, as he wanted to relive memories in the midst of his dying.

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect Frank’s experiences of music therapy throughout his three sessions.

Statement. “I could listen to you all day, you hit the playlist right on the nose. I am remembering so vividly.”
Interpretive-descriptive reflection. Frank was lying in bed listening to the music with his eyes closed, and once the first set of music was finished (approximately ten minutes), he opened his eyes and shared that he could listen to it all day. During the music, he appeared relaxed, breathing deeply and slowly. He noted that the images he was seeing while listening to the music were vivid and clear, and he felt connected to the music he requested, as he felt the choices I had made reflected the style he loved. While Frank did request one or two very specific classical music pieces, he also asked that I played whatever I felt was in the same style as the pieces he requested. Initially he told me he knew the pieces once he heard them but could not always remember their titles. His comment about “hitting the playlist on the nose” was seemingly related to the connection he felt to the pieces I chose. Within this statement there was a comment on the aesthetic of the music, as well as the connection to the personalized pieces and style, along with the images and memories the music created.

Statement. (Session 1): “And you listen to that Canon and how big are you in the universe? I mean, you’re so very small in those mountains, it’s just so beautiful. Everybody should see that. I’ve been there twice, and I revisit it every time I hear that Canon.”

Statement. (Session 2, Frank’s wife): “When we traveled in the Rocky Mountains with the kids, the kids were young, nine or ten years old or something like that. And in the car, we’d listen to Canon de Pachelbel, and the kids didn’t know the name so when they heard the music, they always just said, ‘Mountain music of Dad’!”

Interpretive-descriptive reflection. Though she had not been present during the first session, Frank’s wife shared a very similar story and sentiment in the second session. They both had a fundamental connection to the Canon in D by Pachelbel, but beyond this, they appeared to be in synchrony with regards to specific music and the memories the music brought up. Frank
noted that through the music itself, he was able to revisit the same feelings and images that he
first experienced when listening to that music and commented on how profound the images were
for him. Frank’s wife linked the music not only to the landscapes Frank spoke about, but also to
their children, which Frank had also done in the first session. The memories associated with the
piece of music were multi-layered (imagery, personal and familial narratives, nostalgia, etc.) and
appeared to be deeply meaningful, to the point that Frank requested this as his final song, the
song he wanted playing when he died. It appeared to be embedded into not only his own personal
life narrative, but into his family’s narrative.

*Action.* For approximately one hour before Frank’s assisted death, his family (wife,
daughter, son-in-law, son, and daughter-in-law) sang along, mouthed along the words, or sat and
listened to most of the songs in the songbook I created at Frank’s daughter’s request.

*Interpretive-descriptive reflection.* Frank’s family participated actively, through singing
or listening and following along with the lyrics, and sonically surrounding Frank with the music
that he and his family chose as his final soundtrack. Frank appeared to be comfortable and lay
still for much of this last hour with his eyes closed. His daughter spoke of meaningful memories
attached to many of the songs. In addition, she and I had spoken on the phone the previous day
and she had outlined exactly which songs she wanted added to her father’s playlist for his final
hour. There were many tears but also many laughs and reflections on Frank’s life and
experiences. For example, we sang Louis Armstrong’s “What a Wonderful World,” which was
Frank’s father-daughter dance at her wedding. This hour-long playlist of live and participatory
music created what I felt to be a montage of scenes from Frank’s life, providing opportunity to
share memories, stories, reflections, and narratives.
**Detailed reading examples.** The following examples are direct lines from the patient participant session transcripts, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- Frank’s daughter-in-law, addressing her husband, Frank’s son (Session 3, during the hour of music before Frank died): “I realized I want to be closer to you.”
  - Phenomenological response: This particular statement was said during my singing of “Somewhere Over the Rainbow.” There was an overall shifting of various family members towards one another (physically) at times during the music, but at this moment in particular, this family member articulated that she sought out closeness in the midst of the music. This may point to the theme of music as an invitation to connectedness, but also may be linked to the intensity of emotion triggered by the music. The music may have led this family member to feel a need to be close to her husband as a grounding/coping strategy.

- Frank (Session 1): “They’d remember the Canon as Dad’s mountain music”
  - Phenomenological response: Memories were triggered, and narratives were shared. Frank invited me into his memory and his family’s connection with this piece of music, sharing an image that would ultimately be the one he chose to have accompany him to his death.

- Frank’s wife (Session 2): “Would you write all these pieces down for us, if you don’t mind? I’d like to have them.”
  - Phenomenological response: Frank’s wife requested a tangible representation of the music that narrated Frank’s life and death; she acknowledged her hope to be
able to revisit these songs, perhaps within the context of Frank’s memorial or perhaps later as she reflected on Frank after his death. This life reflection during a time of moving towards Frank’s death seemed to allow an experience of retrospection.

Analysis: Caregiver

The following themes resulted from a hermeneutic phenomenological analysis of the follow-up caregiver interview with Frank’s daughter approximately four months after Frank’s death. The interview lasted approximately 50 minutes and was conducted by phone.

Wholistic Reading Overview

The prominent themes that are arose when Frank’s daughter reflected on her father’s music therapy experience within MAiD included music as an unexpected surprise, but a “great addition” to the experience. She shared that this was primarily because music had been very prominent in her family for as long as she could remember, and she noted that because music was so important in Frank’s life, it made sense for it to be important as part of Frank’s death. She cried when relaying her experience and shared that music within MAiD was emotionally evocative, even in just thinking and talking about her father’s music at end of life. She shared that music filled the space in a time when words were difficult and acted as if to hold the space in a time of waiting (prior to the death itself). She spoke of intimacy in the connection she felt to certain songs that were played and found the personalization of the music comforting and supportive. She expressed a strong sense of gratitude for the option to have music as a part of her father’s end of life/MAiD.
Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect Frank’s daughter’s (caregiver) experiences of music therapy throughout his sessions.

Statement. “I think it provided comfort and peace and obviously at the end it was difficult. People might have expected that time period to be filled with silence, and there’s really nothing to say. I don’t know if we would have fared as well sitting in the silence. I loved it, I think it helped support and kind of fill that void of what do you say, what do you do.”

Interpretive-descriptive reflection. Frank’s daughter reflected on the emotional impact of the music (provision of “comfort and peace”) and contextualized these feelings in terms of filling the silence and holding the space, noting that she would have found the silence uncomfortable had there not been music to accompany the death and the time before the death. She alluded to the fact that words may not come easily at this time of waiting for death, but also noted that it was difficult to know not only what to say, but what to do.

Statement. “It was a lot of memories of growing up, and stuff like that. Some of the Cat Stevens songs are very “apropos” as we say, because my father was often very absent. I think he was a bit surprised by some of the ones I chose, when you started playing.”

Interpretive-descriptive reflection. Frank’s daughter reflected on her own personal narratives in the context of listening to the music prior to her father’s death. While many of the songs held great significance for Frank, they were particularly meaningful to his daughter in potentially very different ways. She commented on the memories both positive and challenging, and noted Frank’s surprise at her choices. Through our conversation, the playlist emerged as an intersection between Frank’s life and the lives of his immediate family members, as his daughter chose music intentionally to trigger memories that held meaning specifically for her.
**Statement.** “Things were very humane, like, things that don’t even seem integral to what MAiD is like, the MAiD coordinator didn’t even mention you at all, it’s like you never existed, and suddenly Peter [social worker] is like, “Have you thought about music therapy?” and we’re like, “What’s that? That’s actually available?” I think there’s a better way to boast about and advertise what you do. I think your work and what you were able to bring to us in those last few hours, and the previous week too, the work you did with my Dad was remarkable [daughter was tearful at this point] and it’s just unfortunate because you’re probably the only one, so you’re probably in super high demand with not enough time on your hands to take care of everybody, so that’s another challenge.”

**Interpretive-descriptive reflection.** Frank’s daughter expressed several times that she was surprised by the offer of music therapy, and did not know what to expect, but felt that the integration of music therapy into her father’s care was a very important component of his experience. She became very tearful when talking about the impact she felt and shared that she was aware of the challenges of understaffing in the health care system, and the gaps in care that meant an uneven distribution of resources/a lack of equitable access to resources. She was right when she stated that she imagined I was the “only one” (meaning only music therapist on site, and I do not practice regularly at that hospital, Toronto General, but had met Frank because of my research), and she was right when she said I am probably “in super high demand with not enough time to take care of everybody.” Perhaps this speaks to a larger challenge within healthcare, wherein hospitals are not adequately resourced and communication about available services is not yet at its optimal point. To add an additional layer onto this, MAiD is a new service (relatively speaking) and is often misunderstood by various healthcare teams and providers, so staffing MAiD cases has its own unique challenges.
**Detailed reading examples.** The following statements were taken directly from the caregiver’s interview transcript, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “People don’t know where to begin or how to approach it (MAiD); it’s something that should be discussed more openly and the services available should actually be boasted about.”
  - Phenomenological response: The experience of MAiD was enhanced by the provision of various clinical services, specifically in the realm of supportive care, including music therapy, however the lack of accessibility was flagged as an issue, given that music therapy is not yet a standard of care in MAiD.
- “You incorporated a lot of the songs I had suggested, which was nice, because for me, it was something that I knew, it was something I had shared with my father or my husband or brother at some point, so there were pieces that were known, if not to all of us, then to most of us, so it was kind of nice to bring a bit of intimacy to the memories of those songs, of that music…”
  - The experience of music therapy was personal, intimate, and catered not only to the patient’s reflections and life experiences, but directly to the caregiver’s (daughter’s, in this case) reflections and life experiences.
- “Afterwards, my mother was like, ‘I knew a lot of those songs but I didn’t know the authors’ and she asked what I thought of them, and I said, well, it was just music that I enjoyed, and I remember hearing it with you guys…”
o Phenomenological response: Experience of familiarity, but more specifically, relatability and connection to specific memories and experiences that the family had gone through together. Frank’s wife and daughter acknowledged multiple layers of connection between the songs and various family experiences and dynamics.

Analysis: Therapist/Researcher

The following themes resulted from a hermeneutic phenomenological analysis the researcher reflections written immediately music therapy sessions with Frank, and the caregiver interview.

Wholistic Reading Overview

The experience at Frank’s assisted death was embedded with vivid memories which I as therapist was able to bear witness to alongside Frank’s family. In my reflections, I noted the intimacy that developed quickly through the music, and the immediacy of the sharing of memories within the context of specific musical requests. I felt that both Frank and his daughter’s sharing of their musical preferences and their hopes that I would play/sing them in a way that suited their needs was an act of trust, especially in what felt like a sacred and emotionally intense week in this family’s narrative.

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect my experiences of music therapy throughout Frank’s sessions.

Statement. (After Session 1): “Music seems to provide an intimacy in a very quick and direct way. His physical reaction was remarkable as well. Ease was apparent within the music, and the memories appeared to be quite comforting.”
Interpretive-descriptive reflection. This immediacy of connection and perhaps vulnerability through sharing of music seemed to affect not only Frank’s emotional status but his physical being too. Perhaps I was picking up on or sensing the ease myself. Could it be that I was comfortable with the musical selections therefore I allowed myself to find ease in the music and project this on to Frank? Objectively, his shoulders relaxed, his brow unfurrowed, and his face softened, leading me to consider the fact that the music invited a physical ease. To be objective in this highly subjective situation/role, I also did not feel particularly at ease the entire time I was playing/singing, because some of the songs were less familiar, and I felt a weight of carrying the room, the family, and Frank through that last hour of his life. I felt the heaviness likely from picking up on the family’s intense emotional experiences; within these moments I was also invited in to an intimate and intense time, bearing witness to (and acting as a vehicle for) the memories that represented Frank’s life in his hour of death.

Statement. (After Session 2): “There was tremendous life review and reflection, sharing of narratives both within and outside of the music in a way that seemed to connect to Frank, but also allowed him the freedom to rest, with ease, and to not speak if preferred.”

Interpretive-descriptive reflection. I noted a palpable sense of ease when I first told Frank that he “didn’t have to speak at all” during music therapy. I noted a sigh of relief. Many patients tell me that they are exhausted from the administrative burden of MAiD, in that there is a large amount of paperwork, not to mention the stress of having to present oneself in a certain way in order to be deemed eligible to have an assisted death (through the assessment process). So, to have time when no words were required, and no action needed to be taken on the part of the patient seemed to be a relief for Frank. I often tell patients that they literally do not have to do
anything at all during music therapy, they just have to breathe, and just be. This is often a relief, but apparently especially so in the context of the intensity of MAiD.

**Statement.** (After Session 3): “This session was intense for me physically and emotionally as I was playing while standing for one and a half hours straight (why do I keep doing this to myself?) and obviously emotions were running high for family, so I felt I was again holding the space, acting as a sonic backdrop, a container, and support for whatever emotions emerged.”

**Interpretive-descriptive reflection.** It was challenging to read this and reflect on it, even though it felt cathartic and therapeutic to write it shortly after Frank died. This “holding space” theme that recurs throughout the analysis gives me pause to reflect on what that means, and how it manifests. Is it an emotional holding? Do I stay emotionally grounded in order to play for several hours and be open to the heightened emotional responses of the patients and families? Or is it in a way a physical holding? I stand at the keyboard (sometimes I sit) and I sing, employing my hands, my body, my lungs, my vocal cords, and often my memory which houses lyrics, scores, and forms of songs. I say this to highlight the physical holding we as music therapists embody, which often gets overlooked. I am physically creating a space and holding it steady.

**Detailed reading examples.** The following statements and actions describe moments that reflect Frank’s wife’s experiences of music therapy throughout the sessions.

- “Frank and his family felt uniquely participatory in music but in multiple ways: singing, listening, even in his daughter’s requesting of the lyric sheets.”
  - Phenomenological response: The experience of music led by therapist and engaged in by patient and family was a participatory one, involving various styles of “musicking” (Small, 1998) and a wholistic approach to what it means to be
involved in music (beyond solely performing or listening, including being present to the music in a multitude of ways).

- “There was a unifying nature to the music which felt like a culmination of all of our past sessions.”
  
  Phenomenological response: The experience of the music on the day of the MAiD procedure brought together various aspects of the sessions leading up to MAiD. The songs came from the other sessions (and new ones were also added) and the content (memories, images, reflections) had been primed and discussed prior to the final session. Perhaps this is not only part of the therapist’s role, but a crucial and significant aspect of the role itself.

- “It was easy to work with [Dr. Taylor] as we had worked together before with great ease: he acted almost as a conductor, which felt fluid and connected.”
  
  Phenomenological response: The experience of working alongside another clinician who played a different but intersecting role was comfortable, familiar, and felt fluid. This aspect felt critical, because the ease with which the clinicians worked together no doubt had an impact on the process of MAiD.
**Participant 8: Michael**

This is a weeping song

A song in which to weep

While we rock ourselves to sleep

This is a weeping song

But I won't be weeping long.

— Nick Cave, “The Weeping Song”

**Michael: A Narrative**

Dear Michael,

Thank you for inviting me into your hospital room. It was crowded, not because you had many visitors (you pushed them all away by the end) but because you shared a ward room with three other people, all of whom you wanted to benefit from the music as much as you told me you did. I had to squeeze myself and my keyboard between your tray table and the hospital room curtain, trying not to knock anything over and trying not to disturb anyone else. I tried to be as invisible as I could to the other patients.

You weren’t having it.

“Hey everyone, get ready for the concert!” you announced loudly, laughing. I flinched, anxious about disturbing them. You kept laughing. “I just want them to enjoy it, you know? Because I think everyone could benefit, I really do.”
I remember smiling. You told me that what I did was more powerful than medicine. Thank you for inviting me in.

“I’ve had HIV since 1986, were you even alive then? Like really! You’re so young. And me? I’m done. I’m so done,” you laughed as you shook your head. You invited me into what you found meaningful. “Music means different things to different people; I’ve got so many stories. And, well, listening to you right now? Very beautiful. Very hard right now. But very beautiful. Helped me get some of the emotion out, I’ve been carrying it pretty close.”

At the end of our first session, that intense hour and a half, the only session in which we used music, you told me that next time we would “blow the roof off this joint” with our rendition of Tina Turner’s “Proud Mary.” We both laughed. And I think we both knew we would not ever have that chance.

Thank you for inviting me into your experience. You were brutally honest and forced me to show up to that honesty in my music with the same intensity with which you showed up to assisted dying.

“I have a shelf life,” you told me. “I have an expiration date.” You laughed. I loved hearing you laugh. You were 53 years old. You asked me to play the ballads and the anthems that brought your story to life. You asked me to close my eyes and picture you casting a spell over a crowded bar when you got up and sang Peggy Lee’s “Fever.” We sang the chorus together. I remember holding your hand as you cried. You tested me to see how I would react when you shared the intimate details of your romantic relationships. You trusted me to sit next to you as you wept.
“The tears... I’m sorry, I’m just really getting some of this emotion out. These songs, they’re reminding me of things that are important to me: the good, the bad. It makes it easier; you know what I mean? You picked all the right songs,” you said wiping away your tears. “That’s kinda cool. Kinda interesting. You’ve done this before, I guess?” you grinned. I grinned back. You wanted to hear “Hallelujah.” I sang, matching your breathing. “That song, it’s speaking to me, as I’m trying to fortify my decision, and making sure I agree with it; making sure I’m doing the right thing; you know, and all that good stuff, and I am. I so am.”

You told me you were scared. Scared that you would not be approved. You awaited your second MAiD assessment with anxiety and discomfort. You asked me to sing a Sarah McLachlan song. “Those words,” you said, tearing up. “I will remember you. Wow. It’s just those little things in the song, you know, they are pulling emotions out of me, they’re helping to stabilize me emotionally. I think, I think they’re preparing me for the next interview, all that kind of stuff, so I find it very… I like music, I just, I hadn’t even thought about even listening to music while I was here…” you trailed off. “What matters to me is getting through the next interviews and being able to say yes. And, you know, it’s nice to listen to the music, it makes me feel better, even though I’m weeping, it makes me feel better in the long run; it calms me, relaxes me, you know, I actually didn’t think about the pain in my back for a while.”

We talked about MAiD. We talked about HIV/AIDS. We talked about music. We talked about incurable gastrointestinal cancer. We talked about death. You told me stories of dancing to 54/40 with your friends at a laundromat in Vancouver waiting for your clothes to dry. You told me you didn’t want anyone to visit you. You asked your friends to stop. You told me you were ready to die, that if fact you had been ready to die for a long time. “So, this, this music, it’s been cathartic,
really cathartic. I’m remembering things I hadn’t bothered to remember because I’ve been so focused on my goal.”

The next day, you completed your second assessment. You were approved. And you began to decline. The next day, I had one of your songs stuck in my head, repeating on a loop that forced me to think about your life and your death over and over again as the songs played over and over again.

*Every time I look at you, I go blind, every time I look at you, I go blind.*

Over and over again.

*In the morrrnninggg I get up, and I try to feel alive, but I can’t...*

Over and over again.

*I don’t know what it is, something in me just won’t give it a channnnnce...*

I came to see you after they moved you to a private room. You welcomed me in but were too weak to talk.

*I think it's that I feel more confused by the deal*

*Love has shown meeeeee*

“Is there any music I can offer you right now? I would be glad to play if you like?” I said as softly as I could. “I think ... I think I am just going to be quiet right now. I’m so tired. Thank you…” you whispered.

I leaned in. “Thank you, Michael.”
What do you think that life is like?

I think it’s cause I’ve seen the fuss and it’s no big deal

Hold me hold me cause I wanna get higher and higgghhhher

You came so close to death before MAiD, but on that Wednesday afternoon, you died so peacefully, exactly the way you wanted to, exactly how you chose to. So thank you, Michael.

Thank you.

Exit Music Playlist

The following is a list of songs that I sang/played for/with Michael during his music therapy session. I also included keyboard/voice improvisations within the session.

- Leonard Cohen: Hallelujah
- Sarah McLachlan: I Will Remember You
- Sarah McLachlan: Angel
- Sarah McLachlan: Building a Mystery
- Sarah McLachlan: Sweet Surrender
- Three Dog Night: Joy to the World
- 54/40: I Go blind
- Alanis Morissette: Thank You
- Alanis Morissette: Ironic
- Alanis Morissette: Head Over Feet
- Tina Turner: Private Dancer
- Tina Turner: Proud Mary
- Peggy Lee: Fever

Patient Information Overview

Michael was a 57-year-old man with metastatic urothelial carcinoma with liver metastases. He was initially diagnosed in early 2016. Michael was supported by a strong circle of friends, but specifically chose not to share his medical condition with his family. He was admitted to the
Toronto General Hospital in November of 2018 and received a total of three music therapy sessions while hospitalized. He died via MAiD at the hospital.

**Analysis: Patient (Michael)**

The following themes resulted from a hermeneutic phenomenological analysis of Michael’s music therapy session (we met three times however we only incorporated music into the first one; the second two sessions were brief, approx. ten minutes each, and primarily verbal).

**Wholistic Reading Overview**

The personalized music requested and experienced together by Michael and the therapist/researcher provided a space for reflection on Michael’s life, as he prepared for death, and prepared for the intermediary assessment steps prior to MAiD, an ongoing source of anxiety for him. There was a visceral sense of Michael’s emotional experience within and between song choices, as he was very tearful, yet very grateful for the opportunity to express his emotion.

**Selective Reading: Statements and Actions**

The following statements and actions describe moments that reflect Michael’s experiences of music therapy throughout his sessions.

Statement. “It helped get some emotion out … which was important, reminded me of things that are important to me, the good, the bad, it makes it easier, you know what I mean?” (He became very tearful at this point.)

*Interpretive-descriptive reflection.* Michael shared that the music supported an expression of emotion (perhaps a catharsis) and found the music to be associative as he shared memories and stories related to each song; this particular statement shows Michael’s connecting of the music to that which he found important, without placing value judgements on any of the memories.
Statement. “Yeah, so it has, just a connection. You know, we’d go to the laundromat, and well, that was a long time ago, so we’d have like a tape player, we’d put 54/40 on and we’d dance around the laundromat, all of us, while all the laundry was getting done, and it was out in Vancouver…”

Interpretive-descriptive reflection. The memories triggered by Michael’s musical choices served as an opportunity for his reflection on various meaningful moments in his life. The music in his life reflections played a prominent role and provided a space for him to share parts of himself and his identity as it manifested in his life experiences, his travels, his relationships, and his social connections. His re-telling of specific stories with specific friend groups elicited laughter, tears, and a sense of sharing what felt identifying and personally connective to him.

Statement. “I guess there has really been a soundtrack to my life.”

Interpretive-descriptive reflection. Michael was reflecting on various memories and chose music that he felt represented him most accurately. His strong associations with music as punctuation throughout his life allowed for a sense of life reflection, which he acknowledged he had not really given much thought to as he was so focused on the administrative side of MAiD (e.g., assessments, timing of the reflection period, etc.).

Statement. “And you know, I don’t want to call it a distraction, because that would be a cacophony. Noise is a distraction: this was beautiful music that took my mind off things that were concerning to me.”

Interpretive-descriptive reflection. Michael commented directly on music as an opportunity for symptom management, music as a physical experience, and music as a way to ease the stress of what he was experiencing. He commented on the aesthetic of the music several
times, noting he found it “beautiful.” He acknowledged the power of the music to function as a
distraction but seemed intent on distinguishing distraction from diversion through aesthetic.

Statement. “We should sing but we should wait until everybody who wants to visit comes here, and we’ll have you come and play music! It would be so funny; you could sit there, and we could do a big concert for the whole room!”

Interpretive-descriptive reflection. Michael declined all visitors shortly after this session, but it struck me as significant that on several occasions, he not only shared stories related to his social circle and his various relationships, he also tried to include his hospital roommates in the music, hopeful that they might benefit in some way. He jokingly shared he would enjoy having his friends and visitors partake in the music. These comments and examples suggest a reaching for human connection, which he spoke about several times in the context of how music “brings people together” (which he stated prior to research consent being obtained, so the precise quote was unavailable as it was not recorded). He did allude to the fact that he was always drawn to music because of its capacity to bring people together, in a way that was inclusive, integrated, and emotionally powerful.

Detailed reading examples. The following examples are direct lines from the patient transcripts, followed by an interpretive response to the phenomenological question, “what does this sentence say about the experience of music therapy within medical assistance in dying?”

- (Michael was crying at this point) “I made the right decision. But, you know, it’s just... Sarah McLachlan and Alanis Morissette, just those beautiful voices, you know. Beautiful thoughts in their music.”
  - Phenomenological response: Michael was sitting with and thinking about his decision, as he mentioned this many times, and yet he was connecting to both the
aesthetic of the music I sang (songs which he chose) and the thoughts he had about the lyrics these singer-songwriters wrote. The decision to pursue MAiD and the process surrounding it were evidently at the forefront of Michael’s mind and thoughts as he regularly referred to the decision itself throughout our conversations.

- “So today was a good day. The interview^4 went well. But I recognize that I’m grieving. And the music this evening has certainly helped, helped with the crying and grieving process.”
  - Phenomenological response: Michael shared that he was experiencing grief though many times he stated he was sure of his decision and clear in his intentions. He acknowledged the grief he was feeling and noted several times that the music was cathartic in supporting the processing of his grief.

- “It was nice, really nice to hear, and as I said, beautiful, just beautiful. I wasn’t focused on the pain at all. I was more focused on … lyrics, my crying, you know, just listening to the music…”
  - Phenomenological response: A connection to the aesthetic experience (in part, if in fact this is what Michael was referring to as “beautiful”) but also a clear diversion away from the physical pain he was so clearly exhibiting at the beginning of the session (he was curled up on his side in bed). The music was experienced as a focal point providing a concentration on a stimulus other than the pain itself.

- “I guess there really has been a soundtrack to my life … a very eclectic soundtrack.”

^4 Michael was referring to his first of two MAiD assessments when he spoke about his “interview.”
Phenomenological response: Michael experienced the conversations around music and the specific music within the session as representative of his life narrative, or the songs which created his own personal soundtrack (reflecting various meaningful and/or significant moments in his life).

Analysis: Therapist/Researcher

The following themes resulted from a hermeneutic phenomenological analysis of the researcher reflections written immediately after Michael’s sessions.

Wholistic Reading Overview

The therapeutic interactions with Michael brought up a number of feelings within my own experience, including a strong sense of connectivity, relational dynamics, and an intimate invitation into his lifeworld. Michael presented as open to the research but also vulnerable in the midst of sharing and experiencing music with another human being in the room. There was an unfolding of narrative, and he shared a number of life stories through musical anecdotes and lyric analyses. This reflection was punctuated several times with commentary from Michael on his feelings about MAiD, his nervousness regarding being approved, and his thoughts on feeling it was the right course of action at this point. He invited me, the therapist, into these reflections in what felt like a fast and immediate way.

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect my experiences of music therapy throughout Michael’s sessions.

Statement. “Michael was extremely open minded, open hearted, and willing to invite music and me into his hospital room.”
Interpretive-descriptive reflection. I was particularly struck by Michael’s openness to music therapy, given that he was so physically unwell, and was notably focused on energy conservation so as to be fully present to the process of MAiD assessments. He was open-hearted in that he invited me into the experiences triggered by the music. In the brief therapy model that I typically use in psychosocial oncology and palliative care (given the brevity of my therapeutic relationships with most of my patients due to their fluctuating statuses), it is often the case that patients are forthcoming about their willingness to participate in music therapy. Time is generally limited, whether because of a brief hospitalization or because someone is approaching end of life. Michael’s openness and invitation to bring me in not only to his hospital room but to his experience felt like a huge privilege in the context of his limited time. I often wonder if the music is the catalyst for the quick development of relationship, or if the therapeutic fit is the more likely factor. The answer is likely a combination of both of these factors.

Statement. “He shared his life through a narrative arc, a story told in music. And we barely knew each other an hour.”

Interpretive-descriptive reflection. This researcher reflection revealed a marvelling at the immediacy of Michael’s sharing of his life narrative. He appeared to be keen to tell stories that linked to the music, and each time he requested a different song, he had more stories that connected the music to his life. He shared many experiences of social gatherings wherein music was the most important part of the event. He cried when sharing how closely connected he felt to the lyrics of many of his favourite artists. He frequently linked his tearfulness with a catharsis related to how much he was thinking about with regards to MAiD. He was quick to share. It may be that Michael lived his life this way, and perhaps he quickly connected to most people in this fashion, but later in the session he alluded to the fact that he was frustrated by friends coming by
and making small talk, sharing that he found our (music therapy focused) conversations to have meaning beyond the mundane chatter he had been experiencing.

**Detailed reading examples.** The following examples are direct lines from the researcher reflections, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “I feel moved by his tears, which he seemed to allow music to trigger. I sense a loneliness in his experience.”
  - Phenomenological response: I felt I experienced Michael as lonely, but also deeply connected to his emotional experience. He articulated his thoughts and feelings in what felt to be a clear and powerful way, as though he had been reflecting on them for some time. And yet there was a palpable sense of deep sadness in the room that emerged throughout and after each song.

- “Might music be a friend and empath in this time?”
  - It seemed as though Michael was pushing away immediate visiting friends, yet constantly sharing stories about his social circles and his social experiences. In the midst of what I perceived as his profound loneliness, I wondered if music, and specifically the songs he had chosen to listen to, felt empathic, connective, and understanding, in the way a friend might exemplify these traits. However, with music, he did not have to respond, or be anything other than his true emotive self, with no social constraints or expectations.
Participant 9: Jo

Death is the dark backing that a mirror needs if we are able to see anything.

— Saul Bellow, *Humboldt’s Gift*

**Jo: A Narrative**

“Tomorrow I’m going to ... pull the plug, so to speak,” said Jo. “So, you can go ahead.”

Jo was 86 years old, feisty, determined, unapologetic, and fiercely clear in her intentions and request for assisted dying. She didn’t think she would want music at the time of her death, but she did want to hear her beloved favourite hymns before she died. She had a long-standing relationship with music therapy. In her time receiving home-based palliative care, Jo had worked with a colleague of mine, and decided to continue music therapy sessions when she was admitted to the residential hospice where I work. One particular song became her point of focus, and she requested it multiple times over the course of her admission. She guided me through the songs she wanted to have at her memorial service and shared her deeply rooted connections to each one.

“I want it to be serious at first…and fun at the end of the church service. And the first one is ‘I hear the wind of God today,’ which nobody knows, but it’s a beautiful hymn. And the second hymn is ‘All things Bright and Beautiful, All Creatures Great and Small.’”

Jo’s daughter came into the room. “I have your straw, Mom.”
“Ok. Good. Leave it there,” Jo motioned to her tray table. “SarahRose is going to play the one I love.”

“Perfect,” her daughter said, sitting down. “I’m going to close my eyes…”

“Yes,” said Jo nodding. “And I’m going to close my eyes too. You’ll play it twice, and I’m going to close my eyes because I love it. It’s perfect.” Jo and her daughter held hands. The room was still. I began to play.

“I feel the winds of God today, today my sail I lift;

Though heavy, oft with drenching spray, and torn with many a rift;

If hope but light the water’s crest, and Christ my bark will use,

I’ll seek the seas at His behest and brave another cruise.

It is the wind of God that dries my vain regretful tears,

until with braver thoughts shall rise the purer, brighter years;

If cast on shores of selfish ease or pleasure I should be;

Lord, let me feel Thy freshening breeze, and I’ll put back to sea.

If ever I forget Thy love and how that love was shown,

Lift high the blood red flag above; it bears Thy name alone.

Great pilot of my onward way, Thou wilt not let me drift;
I feel the winds of God today, today my sail I lift.”

I paused. Silence. I wondered if Jo had fallen asleep. I waited.

“Did you do that twice?” Jo asked without opening her eyes.

“I did, would you like me to do it again?”

Jo’s daughter, who had begun to cry as soon as the song began, nodded. I played it again. And again. Jo’s face appeared calm and relaxed. Her daughter looked up at me quietly and nodded. I continued to play, transitioning to several other hymns that I knew Jo found meaningful. I sang “All Through the Night” and “Abide with Me.” I intertwined “Come Thou Fount of Ev’ry Blessing” with Erik Satie’s Gymnopedie No. 1, pulling in thematic material from a waltz by Johannes Brahms. Jo had drifted off into a deep sleep. Her daughter smiled at me. “That’s perfect,” she whispered.

I quietly made my way out of the room.

Exit Music Playlist

The following is a list of songs that I sang/played during Jo’s music therapy session. I also incorporated improvisations with keyboard and voice.

- R.V. Williams/Jessie Adams: I feel the winds of God today
- Welsh Air: All Through the Night
- Satie: Gymnopedie No. 1
- Robert Robinson: Come Thou Fount of Ev’ry Blessing
- Ian Flynn/Traditional: Be Thou my Vision
- L. Bourgeois: All Creatures that on Earth Do Dwell
- Cat Stevens: Morning Has Broken
Patient Information Overview

Jo was an 86-year-old woman with metastatic lung cancer, initially diagnosed in August of 2018. Jo was admitted to residential hospice care in January of 2019 and requested MAiD shortly after her admission. She was supported by her three adult children (two daughters and one son). Jo had a total of one music therapy session which lasted approximately 30 minutes and died via MAiD in residential hospice care (KH) after being transferred there from a retirement home.

Analysis: Patient (Jo)

The following themes resulted from a hermeneutic phenomenological analysis of Josephine’s single session.

Wholistic Reading Overview

From a wholistic perspective, themes that emerged in the patient participant’s session were primarily an aesthetic enjoyment of the music (the melody, harmony, and lyrical content) amidst an anticipation of the end of life, in tandem with finding comfort and meaning in specific lyrics of specifically chosen songs. Jo fell asleep during the session, and her daughter was present at her side throughout. She appeared calm and relaxed as she listened to the music that she specifically indicated as a source of meaning and significance. She acknowledged that the lyrics of her chosen hymn (“I Feel the Winds of God Today”) paralleled her experience of facing her own death, and she noted that she anticipated experiencing an opportunity to reflect on these sentiments during music therapy, during which I played and sang this song, among others.

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect Jo’s experiences of music therapy throughout her single session.

Statement. “Tomorrow I’ll be … pulling the plug, so to speak, so you can go ahead.”
*Interpretive-descriptive reflection.* Jo indicated that she was anticipating the events of the following day and sought out the music in the moment as an opportunity to connect to meaningful sentiments. Jo had shared the sentiments in an early (not recorded) session and made it clear that she wanted to listen to this particular favourite and significant hymn several times before she died (though not at the time of death). It was also important for Jo to listen to it in the presence of her daughter, and for her daughter to listen to the lyrics, so as to experience part of what Jo was experiencing.

*Statement.* (To daughter): “Close your eyes. I’m going to close my eyes too. (To therapist/researcher): “You’ll play it twice, and I’m going to close my eyes because I love it. It’s perfect.”

*Interpretive-descriptive reflection.* Jo was directive in this moment, indicated exactly how she wanted to experience the requested hymn (“I Feel the Winds of God Today”). Jo and her daughter were holding each other’s hands and her daughter began to cry as soon as I started playing and singing. The direction Jo was giving felt significant as she appeared to be in control of how she wanted to experience her chosen hymn, and more broadly, how she wanted to experience music therapy. It is possible that this sense of control was a significant aspect of her care, given that she could in fact control the style and structure of the music therapy session, as well as the assisted death timing itself (to some degree). There were and always are many other factors out of one’s control in life and in death, so I noted the significance of the direction given to me and to her daughter.

*Action.* I sang the hymn twice and Jo asked me to sing it a third time.

*Interpretive-descriptive reflection.* Jo continued to direct how she wanted the music therapy session to unfold. We exchanged few words in this session, but when Jo did speak, she
was clear in what she wanted. Of note, her cognitive status was fluctuating slightly, and she shared with me that she was aware of a potential increasing confusion. Her desire to be clear direct in our music therapy session felt significant, as she was able to indicate exactly what she sought. Jo fell asleep after the third singing of the hymn (after which I transitioned musically into several other hymns at her daughter’s request).

**Detailed reading examples.** The following examples are direct lines from the patient participant session transcript, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “I love it!” (stated repeatedly throughout the session)
  - Phenomenological response: Few words were spoken in this session, but Jo stated many times that she “loved” the music. This may have indicated her experience of aesthetic enjoyment and feeling connected to the specific music that she directed and chose.

- “Could you play that one more time please?”
  - Phenomenological response: An experience of finding something in the music that merited revisiting; Jo requested the hymn three times, perhaps to sit with the sentiments the hymn evoked, or perhaps to revisit the lyrics several times in the midst of what may have been a cognitive fluctuation. In either case, there was a palpable sense of comfort in the repetition of the same melody and lyrics several times.
Analysis: Caregiver

The following themes resulted from a hermeneutic phenomenological analysis of the follow-up caregiver interview with Jo’s daughter four months after Jo’s death. The interview was conducted over the phone and lasted approximately 30 minutes.

Wholistic Reading Overview

In revisiting the experience of music therapy within assisted dying with Jo’s daughter, notable themes that emerged included her own witnessing of her mother’s experiences, including new insights about who her mother was, specifically because the lyrics of the music chosen paralleled Jo’s life narrative (as explicitly stated and shared by her daughter). She acknowledged the importance Jo placed on her daughter’s understanding of the role of that hymn, and on taking control of the environment through choosing specific music. Jo’s daughter also reflected on the logistical challenges and wondered when the optimal time would have been to have music therapy (NB: Jo had a private music therapist through another hospice organization, who met with her regularly before her admission to hospice; Jo’s daughter felt this was, in some ways, more or differently beneficial because Jo did not have the strain of multiple hospice workers and numerous MAiD-related requirements to fulfill). Jo’s daughter shared that she felt the most critical component of music therapy was that it was context-dependent, and timing, logistics, and appropriate moments for music were difficult to determine for Jo and her daughter.

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect Jo’s daughter’s (caregiver) experiences of music therapy throughout Jo’s session.
**Statement.** “Mom’s a bit of a control freak and she wanted a sense of order with everything, and I think at that point the music had a duality of purpose. One was she really wanted me to hear it, she wanted me to know what it was, why it was important to her, why she loved it, that I was aware of it, that I knew what the words were and why she chose it. I think for the two of us, it was a shared activity, which was really lovely to kind of bond and connect, and I think she purely, and this is probably what I should have said first, is about the joy of just hearing something familiar that she just loved so much and she felt so comforted in it. She fell asleep, and I know that she had a lot of joy and calmness from it.”

**Interpretive-descriptive reflection.** Jo’s daughter reflected on the multiplicity of meanings within the one music therapy session she participated in and articulated her perceptions of the purpose(s) of the music. She highlighted the role of the lyrics and the importance of those lyrics being share between mother and daughter, but beyond the sharing, she acknowledged the interconnectedness and “bonding” experienced in the co-listening of the songs. She perceived a sense of calm and a sense of joy, linking the act of falling asleep to a feeling of comfort and familiarity.

**Statement.** “Because I think she both loved it, and well, I thought she would have enjoyed just having music, but the music, my observation was the music had a purpose for her at that time. It was about what she wanted to do for her end of life, and I thought she would just enjoy listening to music, you know. We tried to set up an iPad, we tried to set up a CD player, but the technology part of it just didn’t work out for whatever reason. So, it surprised me, the role music played for her in hospice was sorting out her funeral. It kind of had a purpose as opposed to just pleasure. And I thought it would be both. I mean, she enjoyed it and I could tell that she loved hearing it. I mean, the number of times she said, “Please play that again…” I could see that she
was at peace and, it was as much about control for her, which I think is the issue for people, from what I understand, for people who choose end of life — they’re people who really want to have control over their lives. So, there’s some correlation there in personality types and maybe what role music plays when you’re making such major decisions in your life, maybe it’s different than what role music plays for my 23-year-old.”

*Interpretive-descriptive reflection.* Jo’s daughter reflected on the specific role(s) music played for her Mom and shared her surprise that the roles she had presumed were different than what her mother actually requested and sought out. It is possible that Jo’s perceptions and her daughter’s reality had a great deal of crossover, but it is difficult to fully know whether Jo wanted the music for one specific purpose, or if she felt the music was multi-purposed (e.g., funeral planning as well as aesthetic pleasure). It is perhaps not possible to separate the two experiences as the aesthetic of the music is ever present, however perhaps there is a truth in Jo’s daughter’s interpretation of her mother’s need to plan through the music. Perhaps Jo was able to envision her own funeral, perhaps she was able to reflect on her life. This highly personal process is never fully revealed in Jo’s case.

*Statement.* “When the physicians asked the questions, like what music do you want, what food do want…that was overwhelming! Like, what music do I want? It gives a finality to it that’s terrifying. Like, that needs to be re-looked at. That wasn’t done well. I remember her saying to me, ‘Why are they asking me that?’ And the reality is, you don’t have to have music.”

*Interpretive-descriptive reflection.* This statement represented a critical component of MAiD in that choice is paramount, and that music does not necessarily need to play a role or may play a role at certain times and not others. It was notable that when the physicians (assessors, specifically) asked Jo about music, she found it overwhelming. Perhaps the question
was situated amongst a number of other questions, detracting from the importance or the profundity of the questions, or perhaps the assumption regarding the use of music was disconcerting. This caregiver statement leads me to wonder about the role of the assessors in asking about the specific intervention structure, and whether conversations around music require a certain sensitivity, and whether assessors and providers could be trained by music and health specialists on how to ask about music in an optimally supportive way.

**Detailed reading examples.** The following examples are direct lines from the caregiver interview transcript, followed by an interpretive response to the phenomenological question, “what does this sentence say about the experience of music therapy within medical assistance in dying?”

- “Sometimes I just couldn’t handle it, and then sometimes it was incredibly joyous for her, so it all, it was so contextual.”
  - Phenomenological response: Jo’s daughter experienced music as highly contextual in her mother’s care; her comment about being unable to “handle it” may perhaps be indicative of the emotionally loaded content that music often brings into a care space, or perhaps the comment is an acknowledgement of the fluctuations in abilities to emotionally tolerate the wide range of emotion that music may evoke (a very common experience for participants in music therapy). Jo’s daughter stressed the contextual nature of the experience, later elaborating that timing was critical within music therapy and MAiD, and perhaps not ideally optimized close to end of life, at least for Jo.
- “I think the song served as a kind of therapy or closure. It was her story within that song: the good, the bad, the ugly. And her strength. Her strength and resilience. It also was
contextual in a sense of where she grew up. She grew up on Lake Erie, which at times could be a wild lake. The power of water and respecting that … it was environmentally related to where she grew up and it had that context, and that was kind of neat.”

- Phenomenological response: Jo’s daughter once again commented on context, but this time she experienced her mother’s music therapy process as one of closure, narrative, or personality traits, and of life history and identity. She noted the connection of the lyrics in Jo’s requested hymn to her “story.”

- “It would actually be better if it could be sooner, like when people are starting to die, and people can start to make sense of it. By hospice, there’s a lot of stuff going on.”

- Phenomenological response: Jo’s daughter shared that she felt the timing was not optimal, as she felt that the music therapy her mother experienced earlier in her trajectory (by another music therapist) served a more functional purpose.

**Analysis: Therapist/Researcher**

The following themes resulted from a hermeneutic phenomenological analysis of the researcher reflections written immediately after Jo’s single session.

**Wholistic Reading Overview**

Looking broadly at the overall themes emerging out of the therapist’s experiences in this case, the most prominent themes included a sense of intentionality experienced by the therapist as directed by the patient. A non-verbal relationship developed as Jo said little but directed exactly that which she needed when she needed it. The sensation within the room during our session felt as though Jo was navigating an intentional journey and using the music as a vehicle to experience the varying emotions she felt.
Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect my experiences of music therapy as therapist/researcher throughout Jo’s session.

Statement. “Jo was quiet but inviting. I felt an intentionality in her decisions, a control, a sense of intention.”

Interpretive-descriptive reflection. I sensed a quiet determination in Jo, a sense of intentionality, which was confirmed in the follow up caregiver interview with her daughter, who shared that she felt Jo was very purposeful in her use of music at the end of her life. The control I reference in this reflection may have stemmed from her guidance around exactly what I was to play and how I was to play it; this was done kindly but exactly.

Statement. “When Jo fell asleep, it felt like a gentle escape.”

Interpretive-descriptive reflection. Because of Jo’s intentional directives in the session, I sensed and experienced Jo’s physical response to the music as a form of escape, in a gentle fashion. Jo situated herself within the music and appeared to allow her body to ease into it and let go within in. She did rouse slightly at the end of the second iteration of the song (as it was played and sung three times in total), which perhaps indicated an experience of ease but not total escapism: she was still present and did not fall into a deep sleep. I experienced this as gentle, in my role as provider of the music.

Statement. “The power of simplicity: two songs, oscillating back and forth. The suggestion of handholding: holding on, letting go. Timing is crucial within MAiD. Advocates are crucial with MAiD.”

Interpretive-descriptive reflection. In this statement, I noted a reflection on the simplicity of the musical component of the session (I played and sang “I Feel the Winds of God Today”
three times, then transitioned into “Abide with Me,” then came back instrumentally and vocally to “I Feel the Winds of God Today”). This A-B-A format/structure of a session provided the container and backdrop for the connection between Jo and her daughter. Jo asked/suggested that they hold hands while listening to the music, and I felt I experienced holding on as well as letting go. Jo and her daughter were bonded in that moment, but with the knowledge and understanding that Jo would die the following day. I also reflected on the role of timing. I was aware that timing was vital because of the necessary legal steps that had to be taken (Jo had to maintain cognitive capacity in order to consent to MAiD), and I was acutely aware that Jo’s cognition was shifting at times. She had a number of advocates within the process, including our hospice team, as well as her own family, particularly her daughter. I felt the role of power, of suggestion, of timing, as well as advocacy to be topical, palpable and immediate, all within this session.

**Detailed reading examples.** The following examples are direct lines from the researcher reflections, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “There is always so much going on below the surface. We as clinicians (music therapists in my case) are invited to witness the tip of the iceberg. If we are lucky.”
  - Phenomenological response: I sensed a feeling of privilege in that we as clinical team members are invited into the life world of the patient/family/friend circle, however I felt acutely aware that what we are exposed to is minimal. In a time of dying, people who enter into a health care space or facility bring with them an enormous amount of life that they have lived. I felt invited to witness their dying, however acknowledged the depth of what may have been occurring below the surface. There is so much we do not know.
• “Surprise, gratitude, concern. Anxiety, nervousness, interest. Connected, unsure, hyperaware.”

  o Phenomenological response: These were some of the feelings I witnessed, and I also experienced, and this reflective journal entry points to a parallel and to intersections between experiences of the patient, caregiver, and clinician. There were times when I felt surprise, and there were times when I felt Jo was surprised. These feelings were fluid at times, clear and articulated at other times. The experience is one of context (as Jo’s daughter spoke about) and fluidity of a spectrum of emotion.

• “She linked the themes in the lyrics to her own life: themes of pilgrimage, faith, departure, navigation.”

  o Phenomenological response: I sensed and experienced a parallel in the experience of the hymn’s lyrics to the experience of Jo’s life and end of life. She (and later her daughter) spoke about these parallels, and how intensely and intimately these lyrics spoke to her experiences. I felt I was bearing witness in these moments, specifically witnessing the connection between music and life experience, as music told part of Jo’s life narrative.
Participant 10: Linda

You should go
from place to place
recovering the poems
that have been written for you
to which you can affix your signature.
Don't discuss these matters
with anyone.
Retrieve. Retrieve.
When the basket is full
someone will appear
to whom you can present it.

- Leonard Cohen, Book of Longing

Linda: A Narrative

I was admittedly a little nervous when I stepped into Linda’s room, but her warm smile
welcomed me.

“Oh! I was looking forward to speaking with you,” she said, her eyes bright with anticipation.
Her MAiD procedure was scheduled for the following day at 10 a.m.

“It’s lovely to meet you, Linda,” I said. I had seen Linda’s family milling about the hospice over
the past few days. I had heard her case reviewed in rounds and had spoken with our hospice team
about the various symptoms she had been experiencing. I knew she was adamant about MAiD, but I had no idea whether music would be something she would want as part of her MAiD process. I explained my role.

“You know, music was such a big part of my life. And I worked in the arts, so it just makes sense, you see,” she said matter-of-factly. “And I know exactly what I want. “Hallelujah.” Leonard Cohen. You know it, right?”

“Hallelujah.” Leonard Cohen. I smiled, reflecting on the dozens of people I knew who had requested Leonard Cohen’s iconic, poetic song for their significant life moment: a wedding or funeral, a memorial or MAiD procedure. The number one requested song for MAiD deaths in my clinical practice. Top of the MAiD charts, almost three years at number one. I will always wonder why “Hallelujah” has such an intense hold on so many people, and I imagine I will never have an answer to that question.

“Yes, I would be very glad to play that for you,” I told her. We went through the specifics of her requests, and I sat with her as she asked me questions about what to expect the following day.

“I’ve spoken with the doctors, and you know, everyone has been so wonderful, but I am wondering, from your perspective, what’s it like in the room? You’ve done this many times, I imagine, so what’s it like?”

What is it like? I’d asked myself a thousand times. Shouldn’t I know something about it? Didn’t I craft an entire doctoral degree around this question?

What’s it like to witness a planned death, sonically surrounded by the music that holds the most significance in that moment?
What’s it like to be the vehicle for that music, to embody the vibrations that form the words, the melodies, the harmonies?

My body becomes a vessel for the transmission of sound, in time, in synchrony, in tandem with the end of another human being’s corporeal existence.

Heart has stopped.

Brain activity not detected.

Time of death stated.

Coroner’s office called.

Funeral home arrives.

Family left to process, to grieve, to sit with the unimaginable.

Traces of the song still linger in the air.

Well it goes like this, the fourth, the fifth, the minor fall, the major lift…

Sure, that’s how it goes. But what’s it *like*?

I looked at Linda. “It’s a little bit different every time, but it’s peaceful. Quiet. Our hope is that it is what you need it to be.”

Peaceful.

Lidocaine injected so that the rocuronium isn’t painful as it enters the veins.
Quiet.

Propofol administered to stop the heart from beating.

That first drum, that perpetual rhythmic indicator of our existence.

Full stop.

Colour changes.

Body becomes immobile.

Death certificate is filled out.

What’s that like?

As a music therapist, I hold space. It’s what I teach my students, it’s what I write about in my journals, it’s what we talk about in psychotherapy theory. Though I am not pushing the intravenous medication, I do feel a tangible and intense power over the environment. Music moves, shifts, changes and holds the room and everyone in it.

It’s like holding energy in your arms and rocking it gently until it slows and stops.

It’s like listening closer than you’ve ever listened before.

It’s like watching more carefully than you’ve ever watched before.

It’s an immense privilege.

It’s a skill to sing with a steady voice when so much about the environment around you in the room is unsteady, unstable.
It’s making eye contact with the doctor whom you trust implicitly in order to find stability, groundedness, comfort and support.

It’s like holding something so precious and so valuable that you’re not sure you’ll ever be able to sustain the act, but somehow you do. Somehow, I do.

Cohen says it’s a cold and it’s a very broken Hallelujah. Maybe that’s what it’s like.

Linda took my hands in her own, her 75-year-old body frail and riddled with metastatic disease, her veins damaged from extensive chemotherapy. “Could you possibly print out enough copies so that everyone in the room can sing along, if they choose? It’s possible no one will,” she laughed, “but I’d like to give them the option. Because I’ll be singing.”

Of course, Linda. Of course I will.

Nine-thirty in the morning. I arrived. Olivia, one of our hospice nurses, came up to me. “Linda rang the call bell at seven o’clock in the morning, and when I showed up, she said she wanted to make sure you could come today,” she said. “I told her you’d be here.”

I smiled. “Thanks Olivia, yes, I think we’re ready to go.”

I gently checked in with Linda’s husband, her daughter, her family members. I quietly set up my keyboard in the corner of her room. I spent ten minutes chatting with Dr. Taylor, who would be performing the procedure. I explained the lyric sheets, and her song choice. “Ah, that’s familiar,” he smiled. We had done this many times before.

Nine forty-five.

Family had gathered.
Intravenous access had been obtained.

Linda had a number of rituals that she had requested. Her friends and family took turns saying their goodbyes, gently touching her head, gently kissing her cheek. The doctor, kind, brilliant, and attentive, nodded at me.

“Hi everyone, I’m the music therapist, SarahRose,” I said quietly from my perch behind my keyboard in the corner of the room.

About ten people had gathered around Linda’s bed.

“Linda has asked that you each take a lyric sheet if you would like,” I said as I passed them around, “and feel free to sing along if you would like. But, you know, no pressure.”

Soft laughter.

Linda was smiling, her eyes closed, as she lay in bed with a single red rose lying delicately on her chest. Dr. Taylor placed a lyric sheet next to him. The energy of the room was palpable.

Hold the space, I told myself silently. Hold the space.

I took a breath and began to play.

“I heard there was a secret chord that David played, and it pleased the Lord, but you don’t really care for music, do ya?” I began.

Linda joined. Her family joined her. Her daughter lifted her arms in the air during the chorus. Two friends held each other, one looking away as tears streamed down her face. Linda’s husband held Linda’s hand.
“It’s not a cry you can hear at night, it’s not somebody who has seen the light, it’s a cold and it’s a broken Hallelujah!” we all sang. I saw the doctor looking at the lyric sheet. I saw Linda’s mouth moving in synchrony with the lyrics, and I watched a gentle release of her jaw, a loosening of the grip of her husband’s hand, and ease in her face. She died while singing, at the peak of the song she loved so dearly, a masterful and subtle moment which I knew was orchestrated by Dr. Taylor, conducted by me, guided by Linda.

Tears, sobs. We completed the song.

Smiles. Sighs.

“She has died, comfortably, peacefully. Thank you all for being with her today,” Dr. Taylor said softly.

No one moved for what felt like an eternity. Or possibly just a minute.

I carefully left the room, letting go of the space I held.

About half an hour later, I sat down with Dr. Taylor in the nursing station. “Jim, you were following along, weren’t you? You were timing the medication!” I said.

“Of course I was,” he laughed. “We’ve done this before, haven’t we?” he smiled. I sensed a connective, collegial bond between us. Being together helping people die is connective.

“Thanks Jim, I think that really meant a lot to Linda,” I told him.

“Least we can do,” he shrugged. “It’s a good song.” I smiled.

Top of the charts. Love is not a victory march.
I sighed. “Yeah, it is, Jim. It really is.”

**Exit Music Playlist**

The following song was the musical selection played and sung by me (and Linda’s family and friends) during her music therapy session.

- Leonard Cohen: Hallelujah

**Patient Information Overview**

Linda was a 75-year-old woman diagnosed with metastatic ovarian cancer in February of 2017. Because she was not deemed a candidate for surgical resection, she underwent chemotherapy and immunotherapy however faced a significant decline and was admitted to residential hospice at KH for palliative and end of life care in early April 2019. She died later that month via MAiD.

**Analysis: Patient (Linda)**

The following themes resulted from a hermeneutic phenomenological analysis of Linda’s single session (lasting approximately 45 minutes).

**Wholistic Reading Overview**

Linda gathered loved ones in ritual, exercising choice and control in her type of death but also in her sequence of events within the death itself. She facilitated connection and communication through her chosen ritual (asking friends and family to touch her head with oil while saying a final goodbye, lighting a candle for her deceased son, and requesting all those present to sing her chosen song). She spoke very little, but her actions embodied the participation and group experience she wanted in her dying moments.
Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect Linda’s experiences of music therapy throughout her single session.

**Statement.** (Session 1): “Now that everyone has gathered here, this is a time representing each and every one of you, all the times we have been together and everything we have been through. I love you all dearly, and you’ve enhanced my life in so many ways.”

**Interpretive-descriptive reflection.** Linda invited those close to her (family and friends) into her experience of death, choosing the events she wished to witness and partake in, including the symbolism of various rituals such as the single red rose placed on her chest, and the anointing of her head with oil by a number of her friends and family members.

**Action.** (Session 1): Linda sang along to her final song as she was dying, accompanied by numerous other family and friends singing alongside her.

**Interpretive-descriptive reflection.** As per Linda’s request, many people in the room sang along to the song, initially led by me (the therapist/researcher) and carried forward predominantly by the people in the room. Linda closed her eyes by engaged in singing until the minute she died. She had shared with me earlier that day that “Hallelujah” was a particularly significant song in her life, and that she felt music was important to have in her death because of the prominent role it played in her life. As she moved towards death, she looked back and reflected on her life not only in music but also in the words she shared about her son who had died years before. Music carried a deep associative experience.

**Detailed reading examples.** The following examples are direct lines from the patient participant session transcripts, followed by an interpretive response to the phenomenological
question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- Therapist/researcher: “Linda and I had a conversation earlier and she asked that I provide you with lyrics, so if you should want to sing you can, you don’t have to, I’m just going to pass these along- if you could take one and pass it on, you don’t have to, but, this is a specially chosen song.” (I played the song to match Linda’s breathing, to facilitate group singing, and in tandem with the intervention physician who timed Linda’s death to be at the peak of the music.)
  - Phenomenological response: Music facilitated connectedness and communication between patient and loved ones, between patient and clinicians in the room, and between clinicians.
- Doctor (after Linda died): “She died absolutely the way she intended. She was a courageous woman with a strong will.”
  - Phenomenological response: Linda exercised control in planning not only her death but also in each ritual leading up to it in the minutes prior to her last breaths.

**Analysis: Caregiver**

The following themes resulted from a hermeneutic phenomenological analysis of the follow-up caregiver interview with her husband approximately four months after Linda’s death. The interview was conducted via phone and lasted approximately one hour.

**Wholistic Reading Overview**

Linda’s husband’s interview was the final one completed in the trajectory of caregiver interviews. His reflections offered his thoughtful perspectives and insights as he reflected on the day, the hour, and the moment of Linda’s final breath. His commitment to her autonomy and
admiration of her intentionality was apparent in his comments, and his own personal connection to the music she chose held themes of reflecting and witnessing, as was evidenced as a trend throughout all caregiver interviews. As he spoke about his experiences as well as his perceptions of Linda’s experiences, he noted his own connections to the lyrics of the song, and to how the song reflected part of their relationship. He also highlighted the fact that many other people witnessed Linda’s character and values through the use of music in that moment of her death, but also in her choice of music for the funeral service, and the ongoing connections he continued to feel towards her through music. He reflected on the role that specific music played, as well as the role that specific music continues to play for him to this day (as of writing this paper).

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect Linda’s husband’s (caregiver) experiences of music therapy throughout Linda’s session.

Statement. “For Linda and all the people that felt close to her, we felt this was the right thing to do and the right way to deal with this moment in her life. And I think it accomplished it far more than anything else I could have imagined. You know, someone could have given an impassioned speech or something like that, but it wouldn’t have reflected Linda the way that music did.”

Interpretive-descriptive reflection. Linda’s husband reflected on Linda’s choices and autonomy in orchestrating her planned death and incorporating what she found meaningful. He spoke about how music reflected not only Linda’s life but her wishes for a specific type of experience at end of life. Music functioned as an opportunity for life review from her husband’s perspective, and in Linda’s case, this happened within a brief time period, with immediacy out of necessity (there was only one music therapy session). He noted that part of her was reflected in
the music and continues to be each time he hears the song (as per statements below). Linda’s husband noted that the song “accomplished” something, essentially functioning as a mechanism to “deal with the moment.” While he did not elaborate on exactly what he meant by this, he did state that the music “reflected Linda,” linking to the idea of reflection.

*Statement.* “They were all very intentional acts, and very much a reflection of her personality. This is a woman to whom the beauty of ordinary life was so important; it enriched her life. And beauty was very important to her. And the beauty of music as well. It was something that was intentional, and she found great enjoyment and enrichment in that.”

*Interpretive-descriptive reflection.* Linda’s husband elaborated on the role of choosing music as a medium of reflecting her personality, specifically the use of choosing music intentionally. He felt this act of choosing ultimately represented a part of who Linda was, and where she found meaning and importance. Many of Linda’s husband’s reflections mirrored the patient participant themes that emerged through analysis, including life reflection (the music as a form of narrating one’s life events), control over choices, and the aesthetic pleasure Linda experienced as a catalyst for memories and identity representation. As her husband explained, “Hallelujah” represented Linda’s personality, and her intention in having not only music but that specific song in her dying moments reflected the meaning she found in the beauty or aesthetics of “everyday life,” in this case in music.

*Statement.* “Well, it’s all about memory, and it was very … you know, that whole passage Linda went through? Well for me, it went on for over two years, and the last six weeks were just more and more intense. So, as we sang “Hallelujah,” it was an emotional intensity that I expect I’ll never have again for the rest of my life. It was certainly very, very important to me. So, thank you. Thank you for providing that.”
Interpretive-descriptive reflection. Linda’s husband shared the unique nature of the emotional intensity that he felt in Linda’s last moments of life, positioning the experience in the context of the difficulty of witnessing Linda’s suffering for several years prior to that last moment. He alluded to a significance and spoke of an emotional intensity for which he expressed gratitude. He specifically pointed to the singing of “Hallelujah” as the moment of emotional intensity and referred to the unique experience that he felt would never be replicated in his lifetime. He linked this poignant moment to memory in two ways: his own memories of his wife, and memories related to the past two years of caring for her. He also acknowledged gratitude for the provision of the facilitation of the moment, noting that it was “very, very important to him,” and significant in the context of Linda’s death.

Statement. “The lyrics are there on my refrigerator, I have read it many times, I’ve puzzled over it. And as I read it, I began to see things in it that I never saw before, but that’s, you know, when you hear a song being sung, one of the problems is you miss something or it passes you by, and of course Cohen was very good at that. But having it on my refrigerator, I read it as a poem, and I hum the ‘Hallelujah’ chorus to myself. It’s become a little part of some of the things I think about, and when I think about that, I think about Linda in that moment. And you know, it’s not unpleasant. It’s a way of connecting to her, I guess.”

Interpretive-descriptive reflection. On the day of Linda’s death, she requested that I print off several copies of “Hallelujah” in order to distribute them to those in attendance at her MAiD procedure in hopes that they would sing along with her. Linda’s husband shared that not only had he kept his copy, he currently has it posted somewhere visible and interacts with it on a daily basis. He shared that his regular return to the lyrics not only supports him in a deeper understanding of the words themselves, but also acts as a trigger and a way to evoke memories
and feel connected to Linda. He shared that this was in fact a connective (and “not unpleasant”) experience, in fact a very personal opportunity for reflection. He shared that he interacted with the lyrics as poetry, and engaged in a visceral, physical embodiment of the song through humming the chorus (which he described in the interview as the most powerful component of the song itself). This ever-present manifestation of the experience as well as a reminder of his wife seemed to hold deep significance for him, and though he noted he “puzzles over it” and continually returns to it, he shared that it serves as an opportunity for reflection, and perhaps continues the theme of bearing witness to the experience on an ongoing basis.

**Detailed reading examples.** The following examples are direct lines from the caregiver interview transcript, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “She knew what she wanted to do. And even at her funeral, there were songs.”
  - **Phenomenological response:** Linda’s husband was clear that Linda was certain and had clarity in her intentionality and her desire for control over choices. These choices in her dying moments were reflected in the songs she requested, and the specific moments at which the songs were performed or sung. He also noted the fact that there was music in her dying process (MAiD), but also in her death (at the funeral).

- “I went through the death of my parents, and that was more of a trauma. You know, with Linda’s passage, it was more like an art-work than trauma.”
  - **Phenomenological response:** This statement displays Linda’s husband’s reflection on his experience on Linda’s death versus his parents’ death processes. He noted
that he experienced a trauma in experiencing his parents’ deaths, but he likened his wife Linda’s death to that of an artwork (in contrast to trauma). He did not deny the existence of grief or the bereavement process; rather, he analogized the death to art, also linking back to a previously noted theme of Linda’s life being reflected in her use of music in death. As she was an arts administrator during her career, she (and her husband) found it fitting that music (or art, more broadly speaking) was embodied and reflected in the use of music in her dying process.

Analysis: Therapist/Researcher

The following themes resulted from a hermeneutic phenomenological analysis of the researcher reflections written immediately after Linda’s single session.

Wholistic Reading Overview

Linda was the final patient participant, and her single session felt emotionally intense, as I felt I was bearing witness to not only her death, but the carefully planned rituals she organized, which represented some part(s) of her identity which she wanted reflected in her dying moments. I felt uncertain, but within that uncertainty, I was able to trust the music as a co-therapist and felt deeply trusting of Linda’s guidance in fulfilling her wishes.

Selective Reading: Statements and Actions

The following statements and actions describe moments that reflect my experiences of music therapy as therapist/researcher throughout Linda’s session.

Statement. “It felt like a holding space, like a container, but that something was allowed to emerge and break forth because the space was primed, contained, and safe.”

Interpretive-descriptive reflection. In revisiting the physical and emotional experience of being present for Linda’s assisted death, I found myself considering the space, and trying to find
words to articulate what the room felt like, because within that space, I felt I was creating a holding environment. Winnicott’s (1992) concept of holding has been particularly influential in my own practice and therapeutic process, and I connect the concept of a safe and therapeutic holding space as a parallel to the holding space created for an infant by a mother; this is the type of holding environment I attempt to create at the end of life. In Linda’s situation, particularly because our session was her death, I felt a visceral sense of the concept of holding not only Linda in her requests and her musical experience, but also her family, friends, clinicians in the space and the physical room itself.

**Statement.** “I wasn’t sure what would unfold but I followed Linda and allowed her to navigate; she led all of us in that room, including Dr. Taylor, and guided us though indeed she did not know exactly what was coming.”

**Interpretive-descriptive reflection.** I felt that Linda took a chance on me as a therapist, and on the music as a process. She had not heard me play or sing but for hearing moments while I was in a session with the hospice resident who was next door to her. She had not heard me sing “Hallelujah.” She had only met me formally once before her death. And yet, she had a deep sense of trust about this process; I felt she trusted me to facilitate in a way that felt true to her wishes, and I felt she trusted the health care team, including the MAiD interventionist (Dr. Taylor in the narrative) to align with her requests. And this unfolded as she seemed to have planned. And yet, the trust continues to strike me as remarkable. There was an uncertainty on my part of what would unfold, and Linda modeled trust, whether she realized it or not. I felt I trusted the music to hold the space and trusted that Linda’s navigation would guide us all exactly where we needed to go.
Detailed reading examples. The following examples are direct lines from the researcher reflections and journal entries, followed by an interpretive response to the phenomenological question, “What does this sentence say about the experience of music therapy within medical assistance in dying?”

- “The space felt filled with stories: stories, emotion, music, life, and death.”
  - Phenomenological response: The room felt like a physical container of many complex narratives, emotions, and a fundamental human experience of life and death.

- “Linda died as she was singing. Family and friends holding hands around her. Some sang to her, some looked away. Watching that, witnessing that, and actually maybe facilitating that felt so human and so intense. But she wanted it exactly that way.”
  - Phenomenological response: I experienced Linda’s final minutes as a controlled unfolding of her final wishes, embedded in music as a reflection of her life and death, and embodied in relationships, as I created the music that served as a the foundation to the holding of hands, the anointing of oil, the singing of song.
Table 1.4 Primary and Secondary Themes for Patients

As described in the narratives/experiences above, a number of primary and secondary themes emerged from the data analysis. The following Table (1.4) outlines all the primary and secondary themes for patients, which are described initially in Chapter Six, and in detail in Chapter Seven.

<table>
<thead>
<tr>
<th>THEME 1</th>
<th>PRIMARY</th>
<th>SECONDARY</th>
<th>SECONDARY</th>
<th>SECONDARY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Life reflection</td>
<td>In a time of moving towards death</td>
<td>As witnessed by and engaged in with caregiver and/or therapist</td>
<td>As triggered by musical choices</td>
</tr>
<tr>
<td></td>
<td>(through the immediacy of musical interaction, music as narrator and as trigger)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>THEME 2</th>
<th>Control</th>
<th>Death acceptance as a form of control</th>
<th>Control over choice of ritual and sequence of events</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(over choices: musical, ritual, physical)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>THEME 3</th>
<th>Communication and connectedness</th>
<th>Music as an invitation to connect and communicate (between loved ones, between patients and loved ones and between patients and clinicians)</th>
<th>Music as an act of exploring and understanding relationships</th>
<th>Expression of emotion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(with the self and others through music)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>THEME 4</th>
<th>Aesthetic pleasure</th>
<th>Music as a catalyst for memories and identity representation</th>
<th>Music as a visceral, physical, and associative experience of pleasure</th>
<th>Aesthetic properties of music as a source of symptom management support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(musical pleasure as a catalyst for therapeutic outcomes)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The following Table (1.5) outlines all of the primary and secondary themes for caregivers, which are described in Chapter Six and outlined in detail in Chapter Seven.

**Table 1.5 Primary and Secondary Themes for Caregivers**

<table>
<thead>
<tr>
<th>THEME 1</th>
<th>PRIMARY</th>
<th>SECONDARY</th>
<th>SECONDARY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Immediacy of Emotion</strong>&lt;br&gt;<em>(access to emotion through music)</em></td>
<td>Music creates a holding space that allows for immediate access to emotion.</td>
<td>Music connects to emotional content with immediacy.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>THEME 2</th>
<th>PRIMARY</th>
<th>SECONDARY</th>
<th>SECONDARY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reflection</strong>&lt;br&gt;<em>(on personal narratives within the music)</em></td>
<td>Music invites a retrospective reflection into the caregiver’s experiences.</td>
<td>A contextual reflection period is created (within the music).</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>THEME 3</th>
<th>PRIMARY</th>
<th>SECONDARY</th>
<th>SECONDARY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Witnessing</strong>&lt;br&gt;<em>(emotional and narrative expression)</em></td>
<td>Witnessing patient’s experiences through the lens of music;</td>
<td>Intersconnectedness between patient narratives and caregiver narratives</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>THEME 4</th>
<th>PRIMARY</th>
<th>SECONDARY</th>
<th>SECONDARY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unexpected Opportunities</strong>&lt;br&gt;<em>(for life review through music)</em></td>
<td>Opportunity to engage in life review.</td>
<td>Opportunity to express unexplored/unarticulated emotion</td>
<td></td>
</tr>
</tbody>
</table>


The following Table (1.6) outlines all of the primary and secondary themes for the therapist/researcher, which are outlined in Chapter Six and described in detail in Chapter Seven.

**Table 1.6 Primary and Secondary Themes for Therapist/Researcher**

<table>
<thead>
<tr>
<th>PRIMARY</th>
<th>SECONDARY</th>
<th>SECONDARY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>THEME 1</strong></td>
<td>Trust</td>
<td>Acknowledging and empathizing with the uncertainty of the patient; many unknowns in the MAiD process</td>
</tr>
<tr>
<td></td>
<td>(in the midst of uncertainty)</td>
<td></td>
</tr>
<tr>
<td><strong>THEME 2</strong></td>
<td>Witnessing</td>
<td>Witnessing intimacy of relationships in the patients’ and caregivers’ lives.</td>
</tr>
<tr>
<td></td>
<td>(the unfolding of narratives through music)</td>
<td></td>
</tr>
<tr>
<td><strong>THEME 3</strong></td>
<td>Therapeutic Relationship</td>
<td>Creating and maintaining the holding environment</td>
</tr>
<tr>
<td></td>
<td>Immediacy</td>
<td>(formation and development through music)</td>
</tr>
<tr>
<td><strong>THEME 4</strong></td>
<td>Navigation</td>
<td>Navigating timing of sessions within the context of MAiD.</td>
</tr>
<tr>
<td></td>
<td>(of MAiD processes, in tandem with patients, caregivers and the music)</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER SEVEN: FINDINGS AND THEMES

The purpose of art is not the release of a momentary ejection of adrenaline but rather the gradual, lifelong construction of a state of wonder and serenity.

— Glenn Gould, *A State of Wonder*

As per the hermeneutic phenomenological thematic analysis in Chapter Six, the following patient, caregiver, and therapist/researcher themes (presented initially above in Tables 1.4, 1.5, and 1.6) are described in further detail in this chapter and are presented in order of prominence within the data. Using the previous chapter’s hermeneutic phenomenological writing and analysis as a springboard for a reflective inquiry process, I now present outcomes of an analysis that employed what van Manen refers to as “the existentials of lived relation” (2014, p. 302). These “universal themes of life” (van Manen, 2014, p. 302) as philosophically outlined by Merleau-Ponty (1962; 2012) allow phenomena to be explored heuristically, using these notions to examine, explore, and gain insight into the broader themes (as uncovered in the analysis in Chapter Six). The following existentials were used as thematic guides within the analysis: lived relation (relationality), lived body (corporeality), lived time (temporality), and lived dying (death). These specific existential themes were chosen based in part on van Manen’s suggested guided existential inquiry to assist with reflection on hermeneutic phenomenological themes, and also in part due to the existential nature of the topic (2014). By virtue of the fact that assisted dying is itself an experience of life and death, the topic raises questions of life and death and its limits, boundaries, and challenges, and raises existential questions.
Patients: Cross-Case Findings and Themes

Life Reflection (Through Immediacy of Musical Interaction, Music was Narrator and Trigger)

All participants experienced a component of personal life reflection within their music therapy sessions, albeit in unique and often contrasting ways. By “life reflection” I refer to a retrospective experience of previous life events, shared verbally and/or non-verbally (e.g., through music) with the therapist and sometimes with caregivers. The offer of music within the therapy seemed to immediately (often within a matter of minutes) prompt a sharing of life events and experiences, frequently connected to loved ones, careers, travel, and rites of passage (e.g., weddings, births, deaths, transitions, etc.). In all cases, each patient participant engaged in a life reflection process with immediacy, both because the music seemed to trigger an opportunity for sharing early on in the therapeutic relationship, and because the therapy was generally brief (one to five sessions), given the nature of what patients were requesting for their end of life care (MAiD).

Music functioned as both a narrator of life events and a trigger of memories and reflections related to life events. Some patient participants used more verbal narrative retellings of their life events, often prompted by the music itself. For example, Marie (#1), John (#2), Yvette (#3), William (#4), Alice (#5), Rob (#6), Frank (#7), Michael (#8), and Linda (#10) retold several significant life events that were prompted by the patient themselves (or caregiver) suggesting a song/songs. In these cases, music served as a trigger for the sharing of stories and narratives through life events. These events included stories of migration and movement from country of origin to new land (Marie), cultural identity (John and William), times of happiness and bonds of friendship (Michael), and times of significant travels and shared familial
experiences (Frank). At times, the music itself would tell the story, and function as a narrator. For example, in Jo’s (#9) case, the lyrics of the hymn she chose to hear several times in a row the day before her assisted death paralleled what she experienced as her life path. In this way, music itself told Jo’s story and narrated her life reflection, thereby functioning as a narrator. Michael’s request of “I Will Remember You” by Sarah McLachlan was, in his words, a relatable story in that it articulated how he felt in losing many friends to HIV/AIDS during the 1980s and 1990s, and in acknowledging the ending of his own life.

All participants were notably moving towards death, all at different speeds as some had scheduled MAiD interventions while others were physically and cognitively declining; within this movement towards death, each participant had an experience of life reflection that manifested as retrospection via sharing and retelling of significant life events through and as a result of music. In many cases, the life reflection process (whether in music or words or both) was witnessed by the caregiver and/or the therapist, and in many cases, it was further prompted by the caregiver or the therapist. Rob chose several artists that held meaning in his early life, and his caregiver noted this and prompted further repertoire requests that connected to similar parts of Rob’s life, which he notably found to be comforting.

**Control (Over Physical, Musical, and Ritualistic Choices)**

Control emerged as a prominent theme, specifically with regards to control over musical choices, and over sequence of events, rituals, and manifestations of identity through music. Patient participants were often particular about their musical choices or musical interventions (occasionally requiring some prompting from the therapist if they were unsure about intervention options or styles of available music; typically, I as the therapist would take any musical request given by the patient). Patient participants sought out specific physical control regarding their
MAiD process, as patient participants often spoke about the act of requesting MAiD as an exercise of control. The request itself was a manifestation of a need for some component of control over some aspect of the end of life experience. Even within MAiD, many components were out of the patient’s control, although many sought to control what they could (e.g., the atmosphere in the room during MAiD). Musical choices were frequently carefully controlled by the patient, often for the purposes of identity representation. For example, Michael (#8) chose music that represented aspects of his life and identity and shared that certain lyrics spoke to him because they represented part of who he was. Marie (#1) chose music that reflected her experiences as a young woman in a refugee camp, and as an immigrant in a new country, identities that she spoke about at length in her music therapy sessions. John (#2) chose music that represented his cultural professional identity as a chef in an Italian restaurant who often sang Italian folk songs for his patrons and colleagues.

Control over ritual within the MAiD experience was a common theme, as patient participants often dictated exactly how and what they wanted the experience to be within the room during the intervention. Linda (#10) laid out a number of rituals that she wanted on the day of her MAiD intervention, including the specific act of having lyrics available to all her attendees, a ritual in which Frank (#7) and his family also partook. Linda was particular about not only the song and the way it was introduced and sung with her family and friends (a ritual she tasked me, the music therapist, with), but also about various other rituals such as friends saying final goodbyes while anointing her head with oil.

**Communication and Connectedness (With the Self and Others through Music)**

The music in the therapy sessions functioned as an opportunity for patient participants to experience communication and connectedness between themselves and loved ones, as well as
between themselves and clinicians (music therapist, physicians, nursing staff, etc.). Patient participants often sought out communication and connectedness within the music, in that they spoke of significant relationships with regards to the musical content (sharing life experiences that connected them to others through music). For example, Rob requested music that he used to enjoy with his friends, as did Michael, which was specifically music that they enjoyed in a celebratory, joyous way (e.g., singing folk songs as young people, and singing together in bars and clubs, respectively). Jo requested music that connected her to a personal experience of herself, her needs, her thoughts, and her feelings. Linda chose a song for her MAiD intervention that was significant in her personal and professional life (she had worked in the arts, and shared with me that she found it fitting to include music at the end of her life as it connected her with her experiences as a professional throughout her life). She noted, “I had music all the way through my life, it would make sense that I have music at the end of my life.”

Music functioned as a tool to explore and understand relationships within the context of connecting and communicating with others. This secondary theme emerged frequently throughout patient participant sessions; William’s wife connected with him by using music to sing to him during the music therapy sessions and in the last moments of his life, an act she felt she was empowered to do as a result of the connection they experienced in the music therapy session. Marie shared that she was able to explore her relationship with her daughter through the songs she requested, which she used to play when her daughters were growing up. Michael alluded to several key relationships in his life, and to his own sense of self, which he felt emerged in the lyrics of the songs he chose in his session.

Connection between patient participants and significant people in their lives manifested with and without words. Many patient participants expressed a sense of connection through non-
verbal means, such as listening to songs through which they felt a connection to others and sharing after listening that they felt connected to others through the memories elicited in the music. This happened for Alice within the songs she wrote to her daughters, her partner, and her ex-partner. Alice shared that she felt connected to them when writing and listening to the songs and shared that she took solace and comfort in knowing that her family would be connected to her long after her death through the songs themselves.

**Aesthetics (Musical Pleasure as a Catalyst for Therapeutic Outcomes)**

A prominent theme within patient participant sessions was a focus on the experience of aesthetic pleasure within the music. What emerged from the data analysis was that patient participants found the aesthetic musical pleasure they experienced functioned as a catalyst for therapeutic outcomes, such as symptom management support, as well as memory triggers, emotional processing, and identity exploration and representation. Many patient participants commented directly on the “beauty” or “enjoyment” of the music itself, stating that they found it “soothing” (Yvette) or “calming and beautiful” (Frank) or “blissful” (William). Marie shared that she felt she was “dancing on clouds” while listening, and several caregivers commented on the experience of listening to a live singing voice which they found aesthetically enjoyable. Notably, the aesthetic experiences shared by patients often led to them sharing that they felt “so relaxed” (Alice) or “perfect” (Jo) after listening. Though music is multi-layered and complex, and emotional/physical reactions are rarely elicited by one factor alone, it is notable that many patient participants shared feelings of physical comfort or ease after listening to the music, thus leading to the emergence of the theme of aesthetics as a catalyst for therapeutic outcomes. The pleasure that patients noted they experienced in the music often resulted in a form of symptom management support. For example, Frank shared that he felt he enjoyed the music itself and
wished he could “listen to it all day”; at this point in our session, his brow was unfurrowed and he appeared comfortable and relaxed. The aesthetic experience of music appeared to offer visceral and physical sensations for patient participants and offered an opportunity for ease and enjoyment.

Through the Lenses of Existentials

The thematic outcomes of the initial hermeneutic phenomenological analyses of patients who experienced music therapy within medical assistance in dying (life reflection, control, communication and connectedness, and aesthetic pleasure) can be reflected upon and further explored through the use of the existentials of lived relation (relationality), lived body (corporeality), lived time (temporality), and lived dying (death).

Lived relation (relationality). Within the existential of lived relation (relationality), the phenomenon in question (in this case, music therapy within medical assistance in dying) can be relationally explored by asking further questions about its relational quality and significance. For example, van Manen (2014) asks, “How are people or things connected?” (p. 303). I ask, how is music therapy in assisted dying experienced for patients in relationship to others, and how are individuals (i.e., patient, caregiver, and therapist) connected? In reflecting on both of these questions, I am drawn first towards the theme of communication and connectedness, as it emerged in the data as a strong indicator of a relational experience. In response to van Manen’s question regarding how people or things are connected, connection is created through music at a time of disconnection (physical ending/death). Connections are created between patient and the music itself, between patient and therapist, between patient and caregivers (as applicable), and within the patient and themselves. The music manifested through the means of music therapy (as opposed to recorded music chosen by the patient or caregiver or staff). This is relationally
significant as the development of therapeutic rapport is vital within any psychotherapeutic relationship, and plays a significant role in music psychotherapy, which was the approach of music therapy provided for all ten participants, regardless of initial clinical goals. I developed a therapeutic relationship with each of the individuals with whom I worked, and this was a fundamental point of connection as there was an access gained into patients’ lived experience, and generally in a limited number of sessions (between one and five).

**Lived body (corporeality).** Within the existential of lived body (corporeality), music therapy and assisted dying can be explored by asking further questions about the nature of corporeality and its intersections with this phenomena. Van Manen (2014) asks, “How is the phenomenon we study perceived, sensed, and touched by the body?” (p. 304). I ask, how is music therapy experienced in patients’ bodies in the context of medical assistance in dying?

There is a physical component to the experience of music in that music itself is an embodiment of sound, which is ultimately vibration. These vibrations connect with the bodies of the listeners in a physical manner, as they bounce around spaces they occupy. Sound literally strikes the pinnae, a human’s jutting outer ear, which functions to amplify sound by funnelling it into the ear canal (Jourdain, 1997). Listening to music and experiencing it as an aesthetic pleasure ultimately begins as a physical experience in that our bodies interpret sound in a physical capacity; however, these targeted questions explore how music therapy within assisted dying is perceived, sensed, and touched by the body. I suggest that there are two components to exploring these questions: first, the corporeal experience of live music within close proximity to one’s body (e.g., at bedside) and secondly, the experience of dying while hearing music. The dying may be imminent (as in the cases of Rob, Frank, and Linda), or may be days or weeks away (as in the
cases of Alice and Michael). In all cases, the body was experiencing a moving towards death, and a slowing down, a stopping, and declining of physical functionality.

When patient participants experienced music therapy, the music was always in close physical proximity to their bodies. I brought my keyboard to their bedside, or within a few feet of their hospital/hospice bed. This made the physical experience of music that much closer and more directed, and the sound was generally aimed towards them. The experience of music in close proximity changed the experience in that the music’s volume was tempered to adapt to the individual’s needs, and the therapist’s voice/playing was tempered to connect to the individual’s breathing patterns. As therapist, I used entrainment (DiMaio, 2010) as a technique to match the tempo of patient’s respirations, essentially matching the music to the speed of their breathing. This often resulted in the patient’s breathing in turn matching the tempo of the music I was playing. The patient’s body and physiological response was as much an indicator of musical and therapeutic choices as the patient’s words and actions.

Several patient participants died while listening to their chosen music, and one (Linda) was singing as she was dying, and when she died. The physical termination of bodily functioning through MAiD is final, intense, and generally very peaceful, quiet, and fast (approximately ten minutes in total). Having music directed at the patient and their body in their dying and connecting with them in a physical (vibrations intersecting with the body) and non-physical way (music creating associations, memories, thoughts) is a fundamental component of the experience of music therapy within assisted dying for the patient. Music on a recorded device may have had a different effect, in that it would be less directed than a human-to-human (therapist to patient) targeted physical musical experience.
Lived time (temporality). In exploring the phenomenon in question through the lens of temporality, van Manen (2014) asks, “How is time experienced with respect to the phenomenon that is being studied?” (p. 305). I ask, what is the experience of time in music therapy and assisted dying from the perspective of Heidegger’s notion of time? Heidegger suggests that being is time, since without time, being would not be possible, positing that time is a fundamental component of existence and experiencing human phenomena (Heidegger, 1962). Time may be experienced not only as temporal in the sense of marking the passage of minutes, hours, and days, but also as lived time, which van Manen refers to as “telos,” or the wishes, plans, and goals which we aimed for and attempted to succeed in throughout our lives.

In response to questioning the phenomenon through the lens of temporality, time as temporal and time as telos were experienced in different ways for patient participants. Time as a temporal concept came to the forefront of many conversations with patient participants as they planned their assisted death and anticipated the days, hours, and sometimes minutes leading up to the death. Some patient participants feared that time was not working in their favour, in the sense of temporality and movement, and that they did not have enough time, such as Yvette, William, Rob, Michael, and Jo. All of these participants had concerns about time robbing them of their final wish to have an assisted death, and two of them (Yvette and William) died before their assigned date for MAiD. All patient participants made reference to time in various ways. Marie noted the passage of time in its telos sense and shared how she perceived her identity and sense of bravery as a young woman in comparison to now, facing the end of her life. She commented on raising her daughters and the role reversal she was experiencing now that they were taking care of her. Though she noted that they were “all grown up” she also stated that her eldest would “always be her baby” no matter how old she was. Alice shared her hopes for the future of her
family, after her death, and spoke at length about raising her daughters over the past 30 years. All participants shared that they were thinking about time in the context of facing the end of their lives, and specifically with regards to their pending assisted deaths.

**Lived dying (death).** As van Manen notes, existentials are thematically recurrent in phenomenological literature because they are largely universal and experienced by all human beings, even if in very unique capacities. He goes on to describe existentials as helpful, in that they are themes that give us insight into common human experiences. Death is a human experience that each human being will at some point face. Death is a guarantee, though an unknown process and experience, as we can only glean as much as we are able to experience in life, before we lose the ability to physically experience anything beyond the last breath of a dying person. As a music therapist, I am often able to bear witness to people’s dying processes, particularly their final breaths, an experience that is challenging and intense, weighty and curious. It is difficult to research, write about, or describe death, as I am still removed from the patient’s experience, although I am bearing witness to its occurrence. Existentialist philosophers and writers have mused and written about death, attempting to connect to meaning or find and provide insights through philosophy (Sartre, 1989; Heidegger, 1962), but death continues to be mysterious in many ways. I ask the question, how is death experienced in the context of medically assisted dying and music therapy?

Death as an existential theme has naturally occurred throughout this study as it is a fundamental component of the phenomenon being studied. All ten patient participants requested a medically assisted death, as each participant knew their natural deaths were impending, and in the foreseeable future. Death was ever-present in conversations, and wholly present in each patient’s hospital or hospice room, as it became the primary focus of each patient’s medical
team, whether they were working towards facilitating a smooth and comfortable MAiD procedure or working towards keeping the patient comfortable for a natural death.

Many of the patient participants’ comments and responses revealed that they experienced death as inevitable yet controllable, in that the circumstances of the patients’ deaths were ideally going to be laid out and organized in a way in which the patients had some degree of control (the request for MAiD itself might be viewed as a form of control). Death through the MAiD process with music therapy accompanying the experience was experienced as an opportunity, in that patients had some options (depending on their functional status) regarding the logistics and organization of the procedure itself. Music added layers of experiences (described in more detail in the thematic analysis) within death.
Symphonic: A Reflection

There is a conductor in the room
Who manipulates and maneuvers
Masterfully directing the final minutes:
Steady hands, steady heart.
There is another conductor in the room
who makes the terminal decision
Singing a swan song
With weak pulse
yet fierce intention:
Steady mind, steady release.
There is yet another conductor in the room
Who breathes in tandem with the last breaths of the bravest
The last lullabye
A final farewell:
Steady voice, steady eyes

Somehow,
they all let go
In unison.

SarahRose Black
**Caregivers: Cross-Case Findings and Themes**

**Immediacy of Emotion (Access to Emotion through Music)**

The immediacy with which emotion was accessed for caregivers was a consistent theme throughout each caregiver case. For several participants, their caregivers were present in the room during the music therapy sessions, and often participated in some capacity. For many of these caregivers, music brought up a lot of emotion, manifesting in tears, conversation, sharing of experiences, and acknowledging of various challenges within the MAiD process. For all caregiver participants, music seemed to elicit an emotional response in an immediate way. Almost caregiver participants began to cry as soon as music was played, or shortly thereafter.

There are a number of theories as to why music might elicit immediate emotion, or may cause individuals to cry as soon as it begins, but what is notable about these seven caregiver participants is that each of them was in a unique circumstance: their loved ones were in the process of requesting (and in some cases, receiving) medically assisted deaths. The amount of time that their loved ones had left to live was significantly compressed, and each caregiver was aware that their loved one would die relatively imminently. It may be that the immediacy of the patient participants’ pending mortality triggered an immediate release of emotion in their caregivers, and the music therapy session offered a venue within which to express that emotion. It may also be that caregivers were coping with a number of logistical challenges and time constraints (as MAiD requires a great deal of logistical preparation, paperwork, etc.) and perhaps may not have had as much time as necessary to begin to process the grief they may have been experiencing. In any event, music appeared to trigger emotion with immediacy.

All seven caregivers who were interviewed spoke to the emotional response they had within the sessions themselves. Marie’s daughter noted that the music was difficult to listen to as
they knew it would be the last time they would experience live music with her mother, and
shared that it was very difficult to hold back tears despite her efforts to do so, as she did not want
to upset her mother. Frank’s daughter shared that the music allowed for a natural release of
emotion, and for her to be able to feel many feelings towards her father. Rob’s friend shared that
the songs he requested (as well as the songs she and many of their other friends requested on the
day of his MAiD procedure) held vivid and meaningful memories that represented their lengthy
and significant friendships. Listening to this music together was, she felt, a way of processing
some of the difficult feelings and releasing some of the sadness experienced in the midst of the
process. Many caregivers were very tearful during their follow-up interview when they began
talking about the music in relation to their loved ones. Though not all patient participants
consented to have their caregivers contacted as part of this study, each caregiver who was at the
bedside of their loved one before, during, and after MAiD (as applicable) displayed a virtually
immediate emotional reaction to the music once it began within the music therapy session.

Reflection (on Personal Narratives via Music)

Though each caregiver was ardently focused on and committed to their loved one’s (patient
participant’s) care, their own personal reflections emerged through the music therapy sessions in
the midst of their caregiving roles. Each caregiver was going through their own processes while
attending to their loved ones. Many were experiencing anticipatory grief, a pre-emptive grieving
that occurs prior to a loved one’s death, in anticipation of their loss and the pending
bereavement. In the midst of being part of the music therapy sessions, caregivers appeared to
have considered their own lives and stories. William’s wife shared that she reflected on their
marriage, and on her own reactions to some of the song choices, particularly because they held
meaning in life events that she shared with William, such as their wedding. Frank’s daughter
chose a number of songs for his session an hour before his assisted death, as she felt they represented elements of her own personal relationship to her father. She noted that there were thematic elements in many of the lyrics of the songs that expressed her own experience of their relationship. She also shared that some of the songs were ones that she and her father had enjoyed together throughout her life. Alice’s partner spoke to the intimacy of his emotional experiences with her, and how their representation within the song she wrote for him would always be a source of meaning and support which he could rely upon in times of need. Marie’s daughter spoke about her own memories of the songs her mother chose for her music therapy sessions. Though her mother chose them for specific reasons, Marie’s daughter had her own visceral response that brought back memories of her upbringing, childhood, and experiences in early adulthood. Jo’s daughter shared her own reflections on the way she perceived her mother’s musical choices and experiences, acknowledging the role the music (specifically the chosen hymn) played in allowing her mother to exercise her own autonomy, which Jo’s daughter recalled as a rarity in Jo’s early life. Rob’s friend told many stories about her and Rob’s experiences with music many years ago and linked the songs in music therapy session to the memories she had.

**Witnessing (of Loved Ones’ Emotional and Narrative Expression)**

A consistent theme throughout all caregiver cases was witnessing, and the role of bearing witness to emotional and narrative expressions of the caregivers’ loved ones. All caregiver participants had their own unique experiences of witnessing their loved one’s MAiD process, however the consistent finding that all caregivers specifically noted in their sessions and/or follow up interviews was that they felt a sense of bearing witness to their loved ones’ emotional and narrative expressions.
Caregivers spoke about watching their loved ones go through various emotional processes. Jo’s daughter shared that she witnessed her mother’s life reflection process through the repetitive request for her favourite hymn, indicating that she felt this was a significant narrative expression for her mother. She stated that she felt her mother was processing her own death and her own life experiences by listening to the hymn several times in a row, and also noted that she thought her mother felt it important for her to have some insight into the significance of the hymn. Marie’s daughter shared that she found herself to be witnessing her mother’s retelling of her life narratives in a unique way (through music) and emphasized the profound nature of these moments within the music therapy sessions. Marie’s daughter recorded much of her mother’s narrative expressions and sharing of life events in order to revisit them after she died. At one point in William’s session, he quietly said to his wife, “Music is here to be shared.” She returned to this notion in our follow-up interview and commented on the significance of being able to choose music for his funeral and have a lengthy discussion with him about what held meaning in his life experiences (which manifested in a playlist for the funeral service). She shared that she felt music therapy opened up a space for them to have these conversations, and for her to be able to witness his personal process of reflecting on his life through music. Rob’s friend noted that music provided an opportunity for everyone to be together in the space and be present for Rob, but without needing to actively do anything, change anything, or engage in conversation: witnessing and being present was enough. In his follow-up interview, Alice’s partner described watching Alice go through a number of challenging emotional situations as a result of her declining health, and commented on witnessing her experiences in song-writing, sharing that she felt it was important for her to express herself to her daughters through song in a way that would be long-lasting and significant.
Unexpected Opportunities (for Life Review through Music)

All caregivers shared that they were surprised by the role of music therapy in their loved ones’ care. The caregivers were generally surprised by the opportunity for a life review through music within the music therapy session and spoke to the unique role they felt that music played in giving their loved one’s a chance to explore significant life events through music. Marie’s daughter spoke about the difference in hearing her mother tell the story of her immigration to Canada through the use of music, in that she felt her mother was quite energized by the chance to hear music that was significant in those circumstances. She felt that her mother was able to relive some of the happy times she experienced while listening to the music, which allowed her to narrate her story to her daughter. Marie’s daughter also noted that she had not seen her mother have that kind of upbeat energy for quite a long time, as she had been physically declining for several months at that point. William’s wife spoke about the unexpected nature of the opportunities that music therapy provided, sharing that she and William had a chance to relive some of the most significant moments in their lives through the music that was offered in the session (which also became a catalyst for further life review after the session, when William and his wife were able to discuss funeral music, as well as when William was actively dying, and his wife sang a familiar French folk song that William used to sing to their son). Alice’s partner shared that he was not expecting a song as a legacy gift from Alice, but felt it was a profound opportunity for Alice to reflect on her own life in a positive way, and furthermore to feel like she was leaving something for her family members who could then turn to it in bereavement, an act which he felt was soothing and comforting to her. Rob’s friend shared that she was surprised by having the option to have music therapy at the hospice, and noted that it was welcome surprise,
something that she and Rob’s friends would not have thought to do on their own, but were grateful for it, as it provided a chance for them to be together and reflect within the music.

**Through the Lenses of Existentials**

The following section explores the thematic outcomes of the initial hermeneutic phenomenological analyses of caregivers of patients who experienced music therapy within medical assistance in dying (immediacy, reflection, witnessing, and unexpected opportunities) which can be reflected upon using the existentials of lived relation (relationality), lived body (corporeality), lived time (temporality), and lived dying (death).

**Lived relation (relationality).** With regards to the existential of relationality, van Manen (2014) asks, “How are people or things connected?” (p. 303). I ask, how is music therapy in assisted dying experienced for caregivers in relationship to others, and how are individuals (i.e., patient, caregiver, and therapist) connected? In response to these questions, the thematic recurrences of immediacy, reflection, witnessing, and unexpected opportunities all contain dynamics of relationality. The immediacy of emotion through the music that was experienced by caregivers happened in relationship, with curated music that was targeted to speak specifically to the experiences of the patients and caregivers. While song selections and styles were generally requested by patients and caregivers, the human element of having a music therapist produce, receive, embody, and reflect back the content within the songs is in and of itself a connective and relational process. The connective aspect of immediately feeling emotion that has a direct link to another person’s experience is profoundly relational. Caregivers’ immediate emotional reactions were triggered within the context of a situation affecting their loved ones (assisted dying) and were often contextualized in a narrative that affected both the patient and the caregiver. Marie’s song choices held meaning to her for reasons initially related to her teenage years, but also held
meaning for her daughter because she connected the songs to memories of her mother. Music itself is a relational act, as we human beings exist in relationship to songs (as they form associations and memories), and we often gravitate towards music that holds meaning related to either another person, or a life event that involves other people.

**Lived body (corporeality).** With regards to the existential of the lived body experience (corporeality), van Manen (2014) asks, “How is the phenomenon we study perceived, sensed, and touched by the body?” (p. 304). I ask, how is music therapy experienced in caregivers’ bodies in the context of medical assistance in dying? Music is, as noted above in the patient participant description of the existentials, fundamentally experienced in our bodies, as sound is experienced as vibration and physically interacts with our physiological mechanisms (e.g., pinnae, ear drums). Most caregivers were present in the room during various music therapy sessions, and physically experienced the music alongside their loved ones, sometimes in very close proximity, and sometimes at a relative distance. Frank’s family initially sat around his bed before his procedure, and then proceeded to sit directly next to him (some family members sat on his bed), and physically held his hands as he received the medication. Music was playing throughout all of this. Marie’s daughter sat beside Marie during the first music therapy session, but in her second music therapy session, two of Marie’s daughters were lying in bed with her and had curled up closely to her. William’s wife had sat very close to William and at one point was about to crawl into his hospital bed with him while they were listening to songs that held meaning from their wedding day. It was at that point in the session that a nurse came in to administer medications and he asked to be repositioned due to pain and discomfort, so his wife stayed in her chair. Jo asked her daughter to hold her hand while listening to her requested hymn. Rob’s friend was ever attentive, at bedside through each session and facilitating any kind of care
that she could provide: helping him have a drink of water or holding his hand when he was in pain. There was a physical closeness that manifested in the sessions and typically during the actual provision of the music, perhaps suggestive of the manifestation of music within the bodies of the caregivers. Perhaps they felt a physical need to be close to their loved ones in a shared emotional process of witnessing their loved one’s experience. Of note, when the music began for Frank’s assisted death, his daughter-in-law physically moved closer to her husband (Frank’s son), saying, “I just feel like I need to be close to you right now”.

**Lived time (temporality).** In exploring the phenomenon in question through the lens of temporality, van Manen (2014) asks, “how is time experienced with respect to the phenomenon that is being studied?” (p. 305). I ask, what is the experience of time for a caregiver in music therapy and assisted dying from the perspective of Heidegger’s notion of time (being as time)? In reflecting upon emergent caregiver themes, time as temporal (tracking minutes, hours, and days) seemed to be experienced by caregivers as retrospective and prospective. In witnessing their loved ones’ music therapy process within their assisted dying, caregivers often looked back at days past and memories of years gone by, and also were able to look ahead and anticipate what was to come. Caregivers often shared stories and memories from their pasts, as related to the musical choices in sessions, however after their loved one died, most caregivers spoke in their follow up interview about what life might be like going forward. Many shared ways in which life was emerging and unfolding and spoke about what they felt lay ahead for them, and the role of music in their ongoing bereavement. Marie’s daughter spoke during the sessions and in the follow up interview about her childhood memories, and also spoke about how she was coping with her mother’s death, and how she intended to move forward in her grieving. William’s wife shared memories of life events in the session and spoke at length about various memories of
events that occurred well before William’s illness in our follow up interview. She also spoke about strategies she had developed regarding using music in her own bereavement, and literally carrying a part of William with her by carrying his iPod and listening to his music.

With regards to time as telos, or the wishes, plans, and goals which we aimed for and attempted to succeed in throughout our lives, these sentiments and reflections were often shared by caregivers in session, and also in the follow up interview with regards to their loved ones’ experiences. Alice’s partner reflected on some of Alice’s accomplishments, and wondered about her legacy and how her daughters would cope with her death in years to come. Frank’s daughter reflected on special moments with her father in her earlier life, as it related to music, speaking about the songs they used to listen to when they would spend time together. She also spoke about other individuals having access to music therapy as a part of MAiD, commenting that she would like to know that music therapy could be more widely accessible to other families whose loved ones were at the end of life.

**Lived dying (death).** Based on the data and subsequent analysis, caregivers had their own unique experiences of lived dying. Although they were not experiencing the physical death firsthand, they were bearing witness to it and experiencing lived dying in their own ways. All caregivers who were interviewed as part of this study were present beside their loved one during the moment of their death, and had their own physical, emotional, cognitive, and spiritual responses to the experiences. In the style of using the existentials to further explore the research themes, I ask the question, how is death experienced for caregivers in the context of medically assisted dying and music therapy?

As an existential, death is a universal human experience, and death affects the lives and futures of the people connected to a dying person. In the multiple caregiver interviews that were
conducted, death was noted to be experienced as deeply painful though generally expected as it was mostly planned, however death was also experienced in a unique way through music therapy. Caregivers spoke of music therapy shifting the experience of death in that it provided a different form of care than was expected with assisted dying. The additional style of care targeted aspects of the experience that the patient and caregivers did not necessarily realize they needed or wanted, as multiple caregivers explained; however, once it became a part of the death experience, the music itself carried on and held meaning and significance beyond the moment of death and into bereavement and moments of remembrance after the person died.
Lullabye: A Reflection

Today I will arrive and I will escort you to the edge of death

I will arrive and I will attend,

and wait while you let go

I will watch your colour fade while you unhinge

I will sing as your breath ends

Sing you into a place

that no one but you could ever really know

Today I have arrived to accompany you to that edge

(as close as I can before I feel myself fall)

Today I have arrived to keep vigil

Today you will exit

But you will be held and you will be rocked

I have arrived to hold you and rock you

until you arrive

Here. Hear, your final lullabye

Goodbye…

Goodbye…

Goodbye.

SarahRose Black
Researcher: Findings and Themes across Ten Cases

Trusting (in the Midst of Uncertainty)

Throughout each of the ten experiences into which I entered during this research, I noted the thematic trend of trust. In reviewing, analyzing, and reflecting on my personal written reflections, at the end of either a patient interaction or a caregiver interview, trust emerged as a prominent theme. I noticed trust developing between the patient participant and me, between the caregiver and me, between the patient (and caregiver as applicable) and the music therapy process. There was often, though not always, a sense of uncertainty before the initiation of music therapy when patient and caregiver participants were unsure of the role music therapy might play in the context of assisted dying. I always felt it took a great deal of courage to trust a process that was inevitably unknown and unfamiliar, particularly in a time of such uncertainty. So many of the patient participants did not know whether they would be approved for MAiD, and, if they were approved, whether they would live long enough to reach the intervention date. There was also a great deal of uncertainty as to the specific outcomes of music therapy. Patients and caregivers who invited me into the room did so with what I sensed was courage and trust: trust that I as therapist would provide something potentially therapeutic, trust that I would be clinically sensitive to their needs, and trust that as a researcher, I would respect their experiences.

In a reflection following a session with Alice, I wrote, “I admire her courage to share her feelings and trust in me to support her in doing so.”

Patient participants would initially want to hear about the role of music therapy and would seem to want to process the idea in a logical and practical way. However once I actually began to play the piano or sing, I noticed they would almost immediately let go: they would almost always close their eyes, lie back in their bed or chair, and often ask me to continue
playing or repeat a song, or perhaps play until they fell asleep. A similar outcome was notable in
caregiver experiences. Patients and caregivers often began to cry as soon as the music began, and
even reached out to have me hold their hands after a piece of music stopped. It is difficult to
decipher whether patient and caregiver participants felt a deeper sense of trust after the initial
music was provided, but the trend in the physical and emotional shift once the music began was
remarkably consistent throughout almost all participants and sessions.

In my researcher reflections, I wrote extensively about feeling trusted by patient and
caregiver participants and feeling as though I was able to trust the music to accomplish goals and
go to emotional places that I would not have been able to go through words alone. I noted a
theme of trusting the patient as the navigator of their preferences within their experiences. As I
followed their lead, I might point out possible directions and ideas, but always trusted the patient
as the navigator of their own needs. I wrote that I was often anxious entering a space, particularly
because of the dual role I was playing as clinician and researcher, but I felt remarkably supported
by having the clinical tool of music at my beck and call, and felt that it allowed for a deeper trust
to build between myself and the people with whom I interacted. In my researcher reflection on
one of the sessions with Michael, I wrote,

“I was nervous to go into the room, and Michael’s no-bullshit attitude really intimidated
me at first, but I allowed myself to lean into it, be honest, and be brave. And I felt like
Michael was honest and brave too. He was initially guarded but even just talking about
music made him cry. That was so moving.” (Participant #8, Researcher Reflection)

These feelings of anxiety were not unique to Michael’s first session, as I often felt trepidation
entering the room, unsure of what patients and caregivers would say and expect, or how they
would react. The trust that I felt I had to embrace manifested in my trust of the music, which I
noted may have been a reflection of the patients’ and caregivers’ need to trust me as therapist and researcher.

**Witnessing (the Unfolding of Narratives through Music)**

Being invited into a patient’s room at any stage in their care trajectory is always a privilege and a unique experience. I was invited into ten patient participants’ rooms, experiences, and stories and was given the opportunity to bear witness to their own life and death narratives unfolding through music. In analyzing and reflecting on the writing I had done after all sessions, I noted a thematic trend of witnessing. I commented regularly on the role of being a witness. I was watching so much unfold in front of me, sometimes as a result of the music that was provided, and sometimes due to the circumstances and situations outside of the musical experiences. I witnessed a wide range of emotional expression, everything from tears to laughter, joy to intense grieving. I was also able to bear witness to the last weeks, days, hours, and sometimes minutes of life, as well as the shift from life to death, and the moments after death as a body lies still and a heart stops. I witnessed as a present human being in the room, but also bore witness in my musical offerings, in that I supported patients and caregivers in sharing their narratives through music. My witnessing took place in the performative nature of telling patient stories through song. In many of my reflections, I write statements that indicate my sense of feeling like a witness, as I watch stories unfold through song. For example, in a researcher reflection following the session with Jo, I wrote, “There is always so much under the surface. We are invited to witness the tip of the iceberg, if we are lucky, and that’s where I find myself. Witnessing.” (Participant #9, Researcher Reflection). In a researcher reflection following the session when Frank died, I wrote, “It felt like both a privilege and a heavy burden to carry, to witness and sing this man’s musical autobiography as scripted by him and his family” (Researcher reflection,
Participant #7). In a researcher reflection following the session with William, I wrote, “I felt like I was witnessing something very honest, very true.” (Researcher reflection, Participant #4).

I witnessed Marie and John sharing their identity with their daughters through the soundtracks of her youth. I witnessed Michael process his fears around losing control and his self-expression through songs that represented his feelings. I witnessed Linda’s dying, surrounded by her loved ones and the music that represented how she wanted to be remembered and what she wanted to feel in her last moment of life. I witnessed each patient and caregiver participant experience assisted dying in their own unique ways, with their own unique musical choices.

**Therapeutic Relationship Immediacy (Formation and Development through Music)**

Though there was no control group in this study, and no way of assessing the difference between having a music therapist provide music versus a recording (e.g., iPod, other music-playing device), I wrote at length in my researcher reflections about the therapeutic rapport that I strove for and that I hoped was evolving through the use of music. I noted a consistent trend in patient and caregiver participants sharing intimate details about their lives, their emotional states, fears, challenges, concerns, and thoughts around death and particularly MAiD. While this is not necessarily unique to a music psychotherapy relationship, what was unique and notable was the timing of when participants shared these details with me. Generally, the therapeutic relationship seemed to reach a deeper level of intimacy and connection after music was provided/shared/experienced together, and this was usually very soon after the first moments of our meeting. In a researcher reflection following a session with Michael, I wrote, “The way in which he invited me in and how quickly and immediately he shared so much about himself … I felt immediately connected” (Researcher reflection, Participant #8).
In other reflections, I wrote that I felt the music brought emotion to the surface and exposed vulnerability on the part of both the patient and the therapist. As a result, I noted I felt a sense of rapport develop in a rich way, particularly as a result of some of the musical interactions. Often, people begin to cry in a music therapy session as soon as the music begins, and these MAiD/music therapy sessions were no exception. Within my reflections, I wondered about the role music played in forming and developing therapeutic rapport and commented many times on the immediacy of the therapeutic relationship development within the context of the music itself. For example, in one of the reflections I wrote after a session with Frank, I said,

“Frank shared a lot within the context of the music; music seems to provide an intimacy in a very quiet and direct way. His physical reaction was remarkable as well — ease was apparent within the music and memories appeared to be quite comforting.” (Researcher reflection, Participant #7)

The music seemed to open up a space and draw us both in with relative immediacy and ease, as well as a sense of therapeutic rapport. The development of rapport may also have been because of the choices of music, as they were personally catered to the individual, and would shift, ebb, and flow depending on the needs of the individuals at any given moment. So, although there was no control group to compare those who would listen to recorded versus live music, there were many themes within the researcher reflective writing pieces that pointed to the role of the live music as a catalyst for the development of therapeutic rapport with immediacy within music.

**Navigation (of Processes, in Tandem with Patients, Caregivers, and the Music)**

Each patient and caregiver participant was in a process of navigating their own experiences in their own ways. Within my researcher reflections, I noted that I was often part of the navigation process. Patients and caregivers alike would ask me for my thoughts, advice, support, and
reassurance around the steps of the process of applying for MAiD, asking questions to clinicians around MAiD, and planning the event. Sometimes, patients would ask direct questions and request my advice on how best to move forward with a specific component of the MAiD process. For example, Michael asked what I thought he should focus on in preparation for the final assessment/interview prior to the intervention. Jo asked if I thought her health care providers would be able to help her manage her medication in order to remain alert, oriented, and fully present for her assessments. Linda asked me what the MAiD experience was like, based on my experience with other patients and families. In reflecting on this, I wrote that I wondered whether patients felt safe with me, and willing to ask questions because I was not clinically implicated in their approval for MAiD. I would have no say as to whether they would be approved, but I did have experience with the process so was able to empathize or provide support in a unique way. In a researcher reflection following a session with Alice, I wrote, “As she shares so much with me, I am curious about the nature of this MAiD request: she is wanting so much to be here to support her family however also wants to have control over her own death. There is what seems to be inner conflict but a need to express this in a safe way.” Because the experience of requesting and receiving MAiD has so many layers and components, it seemed that part of my role as music therapist was to provide a safe space for patients and caregivers to share the complexities of their experiences.

Through the Lenses of Existentials

The thematic outcomes of the initial hermeneutic phenomenological analyses of a music therapist who cared for patients who experienced music therapy within medical assistance in dying (trust, witnessing, therapeutic relationship immediacy, and navigation) can be reflected
upon using the existentials of lived relation (relationality), lived body (corporeality), lived time (temporality), and lived dying (death).

**Lived relation (relationality).** With regards to the existential of relationality, van Manen (2014) asks, “How are people or things connected?” (p. 303). I ask, how is music therapy in assisted dying experienced for the therapist in relationship to others, and how are individuals (i.e., patient, caregiver, and therapist) connected? As I was both the researcher/writer and the analyst of the writing, I acknowledged the bias of my reflections (see Chapter Eight), but also highlighted the intimacy with which I have come to know my personal experiences in relationship to others. After every session and interview and experience, I reflected at length on my own sense of what had occurred, and often began by describing the relationships that existed between individuals in each context, with further reflections delving into my own relationship with my experience (specifically examining counter-transference experiences, noticing my reactions to patients, caregivers, and situations within the therapy). The themes that arose (trust, witnessing, therapeutic relationship immediacy, and navigation) are fundamentally connected to concepts of relationality, as each was experienced in the context of relationship. Trust was experienced between therapist and patient, as well as therapist and caregiver, and between the therapist and her relationship to music itself. I noted a trust of the actual music and felt that in the midst of my own insecurities and anxieties, the relationship I had to music was a factor that allowed me to take chances within the therapeutic relationship. Further to this, the relationality that was present within the witnessing of the patient and caregiver participants’ experiences was palpable: I as music therapist was witnessing the intimacy of the experiences of patient and caregiver participants because I was in relationship with them, and not exclusively an observer. The witnessing took place in the context of relationship.
The development of therapeutic rapport is, in essence, a relational process, as individuals must become familiar with one another and develop a dynamic that allows for a therapeutic process to unfold. In the case of music therapy and MAiD, the thematic finding was that the therapeutic relationship developed with immediacy within the music, and notably, the music was created in relationship. A human being (therapist) was engaging in music with other human beings (patients/caregivers), as opposed to a technological relationship or an individual choosing music for themselves. Lastly, the theme of navigation emerged because of a sense of patient and caregiver participants seeking out support in navigating the MAiD process from the music therapist. This experience was fundamentally a relational one, as there were many concerns, fears, challenges, and questions that arose; human beings (patients and caregivers) inherently sought out another human being’s (music therapist’s) perspective(s).

**Lived body (corporeality).** Van Manen (2014) asks, “How is the phenomenon we study perceived, sensed, and touched by the body?” (p. 304). I ask, how is music therapy experienced in the therapist’s body in the context of medical assistance in dying? In my experience as therapist/researcher, I often considered my bodily experience in terms of the space I felt I was holding. Throughout analysis of the reflective writing, I noted a consistent pattern of acknowledging the holding of space. This holding of space took place in the sense of the therapist/researcher feeling that the sonic environment was manipulated and contained through the live music provided in the room during sessions. I was providing music with a purpose that felt containing, and within this containment, my body felt like a vehicle for the provision of the medium (music). I played and sang and used my physical self to attend to the atmosphere, the situation, the patient and caregiver participants, and the dynamics present in the room.
This notion of holding is linked to all four of the prominent emergent themes (trust, witnessing, therapeutic relationship immediacy, and navigation) in that the provision of the therapy (and thus the holding and containment) was provided by my physical being: I physically played the music and sang the songs, which were catalysts for the therapeutic outcomes, but especially for the development of the trust and the immediate development of the therapeutic relationship. The witnessing I felt I was experiencing was a result of my physical and corporeal being in the environment alongside the patient and caregiver participants. The notion of navigation and the role I perceived having in supporting patients and caregivers navigating their MAiD processes was a physical experience of being present to the different steps of their MAiD process and being with them as they moved through the different stages of their request and intervention (as applicable). Indeed, there is a physical embodiment of these themes, and a sense in the data that my physical presence contributed to the emergence of these outcomes and trends.

**Lived time (temporality).** Van Manen (2014) asks, “How is time experienced with respect to the phenomenon that is being studied?” (p. 305). I ask, what is the experience of time for the therapist in music therapy and assisted dying from the perspective of Heidegger’s notion of time (being as time)? The notion of time was ever-present in that it was almost always at the forefront of all patient and caregiver participants’ thought processes. They were often worried about running out of time, and not having enough time (prognostically) to go through the MAiD process. Caregiver participants often had similar worries and continued to comment on the temporal nature of their experiences in the post-death follow-up interviews, many noting the passage of time since their loved ones’ death.

As therapist/researcher, I noted time as a factor in the development of therapeutic rapport, as time was generally quite limited. In fact, upon reflection, I was constantly navigating and
interacting with time as a factor in every interaction. I was mindful of the time I took with patient participants as they had such limited time left to live, and aware of the immediacy of the development of therapeutic rapport through music, which felt like an effective use of limited time. Patient participants regularly asked for my support and reassurance about the process of MAiD. This acknowledgement of an ending of time (death) and an anticipation of running out of time (e.g., patient participants fearing a loss of cognitive capacity), highlighted the temporal nature and experience of the role of the music therapist in this situation.

With respect to time as “telos,” or the wishes, plans, and goals we aimed for throughout our lives, this sense of temporality felt very present in the witnessing I experienced. As therapist/researcher, I was witnessing the unfolding of patient and caregiver participant narratives through music, and often these narratives would be intimately connected to a sense of reflection on life accomplishments, memories, regrets, achievements, hopes for the future, and thoughts about the past. These reflections came to the forefront of many conversations, generally prompted by music, and witnessed by the therapist/researcher.

**Lived dying (death).** The existential of lived dying manifested in varying ways through the researcher reflections that were analyzed, and within the themes of trust, witnessing, therapeutic relationship immediacy, and navigation, the existential of lived dying (death) is thematically relevant. As therapist/researcher in a context of supporting my patient participants’ experiences of music therapy and assisted dying, lived dying is at the forefront of most if not all of our therapeutic interactions, and my own personal reflections. In my previous experiences as a therapist working in palliative and end of life care, there is an ever-present reminder throughout each encounter with patients and families that each human being will experience death in their own unique way. One comes face to face with one’s own mortality when faced with a fellow
human being’s suffering and dying. As a therapist/researcher in the context of music therapy and assisted dying, my reflections revealed a constant acknowledgement of bearing witness to the participants’ experiences, which were underscored perpetually by an understanding of impending death. Death was essentially ever-present, and sometimes more openly discussed, but overall there was a constant feeling of being aware of the dying process. Within assisted dying, the moment of death is planned and essentially prescribed, however there is still a process leading up to the event. Patient participants were “dying” in the days, weeks, and months leading up to their assisted death, and in my therapeutic encounters, I was able to bear witness to this process, and often bear witness to the actual death event.
CHAPTER EIGHT: DISCUSSION, CHALLENGES, FUTURE DIRECTIONS

“Mom then thanked the nurse and Mr. Habegger for helping her have a medically assisted death. ‘You have been completely kind to us all, and I thank you very much,’ she said. Leaning close to her right ear, I started singing the Brahms Lullaby that Mom often sang to me when I was young.

‘Lullaby, and goodnight in the soft evening light/ Like a rose in its bed/ Lay down your sweet head.’

Mom sang along with me, enthusiastically and in tune. It astounded me that she sang with such gusto in her final moments. Once more, I was awestruck by her courage. She showed no remorse. No fear. No hesitation. The fact that she loved me, and all the others in our family, didn’t alter the simple fact that she wanted to die.”

— Lawrence Hill, Act of Love: The Life and Death of Donna Mae Hill

Unique Experiences, Common Themes

Each music therapy session, caregiver interview, and researcher reflection was unique. As noted throughout the data presentation and analysis, thematic trends were present, and have been elaborated upon in this dissertation, but each individual (patient, caregiver, and therapist) told their stories and shared their phenomenological experiences with slight (and occasionally significant) variation. This very much parallels the notion that not only are human beings themselves highly unique (amidst our similarities), our musical choices, preferences, and needs are unique, highly contextual, and deeply personal. This is a significant point to acknowledge, as it is this unique and personal relationship we each have to music that ultimately merits the
presence of a music therapist who can personalize therapeutic interventions and care for each individual. Yet, although each participant had unique needs, the trends in the themes were remarkable and notable.

Patient participants shared their life reflections through the avenue of aesthetic pleasure, evidently exerting a form of control over their musical and ritualistic choices. Caregiver participants were able to access emotion in an immediate way, while bearing witness to the narratives of their loved ones through music, all the while connecting their own personal narratives to the process and the music. Therapist reflections revealed an experience of trusting, reflecting, witnessing, and navigating the music, the patient and caregiver experiences, and the MAiD processes alongside the families. Notably, the trends observed in patient participant data were often supported in caregiver interview data, and likewise in the researcher reflective data. These thematic trends were positioned in the midst of unique musical requests, unique patient backgrounds, histories, cultural identities, ages, life experiences, and MAiD trajectories. Though each overarching theme that was revealed in the research data had slight variations between participants, there was indeed an overall sense of a trend, pointing to the outcome of music therapy being an ultimately positive therapeutic and supportive intervention during the process of medical assistance in dying (with the caveat that a heightened sensitivity to individual needs must be observed at all times).

Implications for the Role of Music Therapy in MAiD

Medical assistance in dying has been a legalized intervention available to patients who meet the criteria for several years (at this point), but it is still a relatively new option. Each request, intervention, and experience sheds new light on the needs of the individuals going through the process. This study, the first of its kind, has offered a glimpse into the experiences and lifeworlds
of ten patients, seven caregivers, and one therapist, ultimately indicating that music therapy in the context of medical assistance in dying is a supportive and therapeutic option that offers personalized interventions in the face of what is a highly personal and intimate experience. The profession of music therapy has experienced a number of changes in its relatively short lifespan in Canada (approximately 50 years). As music therapists, we must adapt to changing health care practices and engage in rigorous research (both qualitative and quantitative) in order to more deeply understand how to best offer music (a deeply human phenomenon) at any and all stages of life and death. The findings of this research may support the development of music therapy practices in the context of MAiD in participating health care institutions or private music therapy practices. The overwhelmingly positive associations that patients and caregivers had with music therapy and MAiD may provide incentives for institutions and all levels of government to increase funding for the arts in health care. Furthermore, these initial results offer the groundwork for further research in this previously unexplored area, leading to potentially optimizing patient care both now and in future.

The unique nature of the experience of music therapy within MAiD is largely related to the role of autonomy, agency, and control that the individual (patient requesting MAiD) is enacting, and the sense of acuity and temporality manifested in the (generally) predictable dying process. Patients displayed a sense of urgency and entered into the therapeutic relationship quickly, sharing personal and meaningful narratives and themes related to their psychotherapeutic process. This was notable as all of them were working against a timeline related to their dying; the therapy felt acute and imminent for this reason, and further speaks to the role music therapy can play moving forward as a standard of care in MAiD.
Implications for the Field of Palliative Care

Fundamentally, palliative care strives to offer an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness (World Health Organization [WHO], 2017). The initial clinical goals that contextualized each patient participant’s music therapy session essentially aligned with this broad definition of the goal of palliative care. It is vital to note that individuals requesting MAiD still have the right to receive high quality palliative care, whether they follow through with their MAiD request, or die naturally, or have an alternative outcome. Any individual with a terminal diagnosis facing end of life care decisions can ultimately benefit from the clinical goals of palliative care and should be able to access these goals through the option of music therapy. Ideally, palliative care goals of care can and should apply to any type of foreseeable death. The results of this study may open up possibilities for expansion of music therapy within palliative care practice, as in my personal experience, MAiD and high-quality palliative care often went hand-in-hand by necessity. Individuals requesting MAiD but dying naturally (e.g., Participants #3 and #4, Yvette and William) received excellent palliative care, and also had access to music therapy in their dying process. Ultimately, music therapy is a style of care that can have supportive therapeutic outcomes at any age and stage of palliative and end of life care, regardless of whether MAiD occurs.

Implications for the Field of MAiD

Because MAiD is relatively new, my personal experience of the procedure and process is that it has been highly misunderstood and somewhat stigmatized in certain health care settings. Many clinicians have incorrect assumptions about the people who request MAiD (e.g., their pain is not
well-managed or they are suicidal) and about the process (e.g., it only happens on palliative care units). Many faith-based health care facilities in Canada will not provide the service, despite the fact that it is a patient’s legal right to access the service. Clinicians who support patients who request MAiD (e.g., intervention physicians) do so voluntarily, and physicians who receive requests but conscientiously object can defer to another health care provider. The politics are complex, and the assumptions are many. Research (particularly qualitative) such as this specific study may offer a window into the worlds of the participants, allowing for the nuances of their experiences to come forth and inform future care practice. This research and future studies of this nature may in fact destigmatize MAiD, offer first-person experiences and perspectives that allow a deeper understanding of the complexity of the issues and needs involved in the care of someone requesting MAiD, and support other professions in continuing to define and refine their own best practices for providing medical assistance in dying. This study is a preliminary step, but hopefully the first of many that encourages the broader field of creative arts therapies to step forward and ask difficult questions, and hear answers directly from the primary sources, specifically the patients, caregivers, and families that we serve, and the colleagues with whom we work.

**Challenges of Researching MAiD**

Though MAiD has been legalized for a number of years, there is no nation-wide mandated protocol in place for the specific processes involved in requesting and receiving MAiD. Although assessments are mandatory (Ontario Ministry of Health and Long-Term Care, 2018), each institution has been responsible for creating their own individual processes related to the implementation of MAiD (Li et al, 2017). Different institutions navigate MAiD logistics in different ways, and what one institution might deem as acceptable might be frowned upon by
another. Attitudes and approaches varied between the various sites from which research participants for this study were recruited, even though each site fell under the same health care network umbrella. Providers had somewhat different styles when it came to discussing assisted dying with the patients and families. Sound environments and clinical settings were hugely diverse, and so many outcomes depended the ability of patients to express their wishes. Some patients were too sick to direct care as per their hopes and wishes, whereas others were well enough to order specific items for breakfast on their last day (e.g., at hospice, where meals were personally prepared). Some patients were able to meet with the MAiD team (including me as music therapist) multiple times before their intervention, whereas others were too unwell to have multiple meetings, and kept interactions to a minimum in order to conserve energy.

MAiD assessors and providers offer their clinical care voluntarily, and no clinical team member is required to provide care directly related to MAiD. However, if a clinician chooses to conscientiously object to the provision of MAiD, they are required to ensure that an appropriate referral is made to a health care provider who can provide clinical services. Because protocol is not yet standardized in all facilities, and many facilities have opted out of providing MAiD care altogether because of religious beliefs or organized religion affiliations (St. Michael’s Hospital, 2019)

Researching MAiD, a topic and a process that is still under development in many health care facilities can pose challenges, especially as each individual MAiD case comes with its own trajectory. I was extremely fortunate to be able to conduct research in a health network with clinician-scientist colleagues who had been working to establish policies and procedures around MAiD since its legalization. Despite the work done to establish processes at UHN, MAiD continues to have its own ongoing challenges. For example, the time of the request differs
between patients, as some request MAiD earlier in their illness, and some request it closer to the end of their life. This variance in timeline poses challenges for the patient, family/caregivers, as well as the clinical team, because there is a heavy administrative burden when a request is initially made. Beyond this, the patient is required to have two witnesses involved in their request and must sign their request form on the same day as the patient. These witnesses cannot be family members or members of the patient’s health care team. All of these administrative tasks must happen within a time frame that supports a patient’s ability to be cognitively alert, oriented, and able to take part in the assessor’s interviews.

The patient and family/caregivers may face stress with regards to timing of MAiD, and having a researcher enter into the process amidst all of these steps can be taxing, as it involves yet another person requiring the patient’s/family/caregivers’ attention. Although the intervention I was offering did not require verbal participation on the part of the patient, the research consent process did require considerable interaction. As a researcher, my study process arrived with additional paperwork, protocol, new faces and team members, and a request that the patient partake in a process with me. The patient and caregiver participants in this study were extremely gracious and generous in their willingness to participate, although I was deeply mindful of the intense pressures that some were facing. Michael spoke often of anxiety related to being approved, or “passing” the assessments. Yvette shared that she was scared she “wouldn’t make it” to her MAiD procedure, and in fact she did not. Jo’s clinical team worked tirelessly to ensure that Jo would be able to have the assessments she needed at the times she needed them, which included adapting sedating medicines while finding alternate routes to pain management. Each case held its own challenges, and each patient participant had unique experiences, but there was an undercurrent of anxiety related to timing and eligibility. This made the collection of data a
tricky component to navigate; I was aware of not wanting to interfere with the MAiD process, while also acknowledging that the anxieties and concerns that patients had about MAiD were part of what might be addressed in the music therapy sessions. Additionally, I was hopeful and hypothetical about the role of music in actually attending to and perhaps alleviating some of these physical, emotional, and psychosocial challenges.

**Challenges in Recruitment**

As noted above, patients are sometimes faced with a tight timeline within which to request and receive MAiD, particularly if they are facing an imminent cognitive decline due to disease progression, because they need to be able to consent at the moment of the intervention itself. Beyond this study, some of the MAiD cases with which I have been involved have been less restrictive with timing as the patients have been functionally well, though still coping with a terminal illness. Even within the study, timelines for each patient varied. Some requested MAiD and never received it, while others requested it and received it shortly thereafter, depending on the length of their reflection period.

A referral made to music therapy by a clinician often merits a further explanation of what exactly music therapy entails. The clinicians with whom I work generally do a remarkable job of describing music therapy to patients and families/caregivers. However, patients often request a more detailed explanation, and this process holds its own set of challenges. If patients are unsure, or family members are tentative, the process of gently introducing music therapy as a modality takes time. Introducing a new modality amidst all of the additional stresses during a MAiD request made recruitment challenging. In addition, patients were often unwell throughout these days and weeks and had limited energy to expend. Energy conservation was often of critical importance, and things that took away from energy conservation were often not welcome.
Fortunately, all ten of the patient participants in this study welcomed music therapy as a modality, even though only two of the ten had experienced music therapy before.

**Personal Challenges**

On the day that I learned of the Supreme Court of Canada’s ruling about the Criminal Code and its pending changes, I remember feeling a shift in myself, a kind of curiosity, and also a sense of fear. What might this mean for the practices that had, to date, been so embedded in caring for the dying? What would hospice and palliative care look like, now that assisted dying was on the verge of legalization and implementation? I felt conflicted. What would I say if someone asked me what I thought or how I felt? Surely, I thought, excellent palliative care and expertise in symptom management will prevail, and assisted dying will not happen in the places where I work. I remember thinking of the word “grey.” I felt grey about it. There’s so much grey area, I told myself. I said the same thing to my family when they asked what I thought about it. I felt consistently committed to patient choice and knew that if a patient asked me to be involved, I would not hesitate to attend to their care needs. My feelings of inner conflict arose primarily when I was publicly asked about my opinions or thoughts on MAiD. Family and friends would ask questions, and many would make assumptions. I told them it was not for me to have an opinion on someone else’s end of life care decisions. Patient-centered, I told them. That’s how I was trained, and that’s how I intend to practice.

When the first patient request came through, I remember feeling nervous, not because I had an opinion one way or another, but because I wanted to be sure I could offer all I was able to offer to this patient. When she chose her MAiD song, or her “Exit Music” (as I have affectionately dubbed it), I was so moved and had so many questions. Why music at end of life, and why music during MAiD? What function did it serve? What purpose was there in having
significant music during a planned medically assisted death? And what was that experience like for the patient, her family, and her care team? This sparked a seed of an idea that was nurtured by one of my co-supervisors, who saw the potential in the idea, and knew that there were many questions to be asked.

In my time providing clinical care and researching alongside people receiving MAiD and their caregivers/families, I have been moved by their stories, experiences, musical choices, needs, and courage. I have also been faced with various challenges, some of which were expected and others that came as surprises, some pleasant and some unpleasant. Many people have an innate curiosity about the logistics of MAiD, while others have a strong aversion. Within my own familial and social circles, I have come across a huge range of emotional responses to the concept of MAiD, and to the notion that I might be providing care during MAiD. Some people have berated me and cut off contact with me, while others have attempted to publicly attack and shame me in academic settings. Differing religious beliefs have been the catalysts behind extremely challenging interpersonal dynamics. Some individuals have refused to work alongside me, and some have had such remarkably positive and supportive responses that I have been moved to tears. The topic is controversial. However, Bill C-14, the legislation on medical assistance in dying, received royal assent on June 17, 2016. It is a person’s legal right to request assisted dying in Canada. While there continue to be various necessary restrictions and safeguards in place, the legalization of assisted dying in Canada has demanded a massive set of changes in Canadian health care, many of which clinicians, researchers, and policy makers are still grappling with and trying to understand. As a MAiD researcher, it is my sincere hope that Canadian health care teams will continue to grow and learn from the people who request and receive assisted dying in order to implement the best possible policies, guidelines, and practices.
Limitations of the Study

Dual Role of Therapist/Researcher

Bias is unavoidable in any type of research, although this is considered inevitable in qualitative research, and must be acknowledged, rather than eliminated. The goal is to attempt to be transparent and honest about the reality of its presence. The qualitative researcher acknowledges that the research experiences are ultimately seen through the researcher’s eyes, and therefore share the researcher’s voice (Wheeler & Kenny, 2005). This study is no exception, and biases exist in a number of ways. Firstly, the design of this hermeneutic phenomenological study was intentionally created to have the therapist play both the part of the clinician providing the therapy and the researcher analyzing the data. This dual role comes with its own limitations in that there is a natural and obvious bias in having the same person take on both perspectives and roles. The therapist may have a natural vested interest in seeing positive and effective therapeutic outcomes, and if also playing the role of researcher, the therapist arrives to the collected data with a bias towards seeing what they want to see in the results. Because the therapist was also collecting the interview data, this design may have opened up to the possibilities of interviewer bias (wherein the interviewer, who in this case was also the therapist and researcher, may subconsciously give subtle hints and clues as to how they want the interviewee to respond, thus skewing the results) as well as response bias (wherein the research participants give answers that they think the researcher would like to hear). Since the inception of this study, there was consistent potential for the results to be skewed as the same person who was collecting data was subsequently analyzing it, as well as curating the music therapy interventions. Furthermore, the same person (SRB: therapist/researcher) had also written the only document that provides guidelines as to how to approach music therapy in the context of medical assistance in dying.
Much of these biases were inevitable and inherently embedded in the study design, primarily for methodological reasons. Though my role as therapist/researcher had inherent biases, a strength of the study was that I would also have insights into the experiences of the patient and caregiver participants, as I was experiencing the therapeutic relationship from a first-person perspective, in an intimate and direct way. My own front-line experiences allowed a window into the world of music therapy and MAiD that would be closed off to a secondary researcher conducting interviews with patient and caregiver participants. Furthermore, the triadic perspective of patient, caregiver, and therapist allowed for my perspective to be fundamentally connected to the other two as I was in the room (or on the phone, in the case of the caregiver interviews) for every session, interview, and experience. This position allowed me to be intimately connected to the processes and experiences of the participants, as well as to have a raw, first-hand sense of what it would be like for a music therapist supporting patients and families through MAiD. The nuance of hermeneutic phenomenological data collection, and the seeking out of lived experience merited as close a connection as possible to the data, so positioning myself as both therapist and researcher allowed a deeply close relationship to the data. Ultimately, this benefit outweighed the hindrance of the embedded bias.

The steps to both acknowledge the bias and allow for other perspectives to emerge and to triangulate the data analysis included the support of a research assistant (TK) whose roles included transcribing many of the audio recorded sessions, as well as conducting a subsequent analysis of the data in order to allow for thematic emergence, which was then compared, contrasted, and integrated into the results. In addition, the research assistant (TK) participated in the primary therapist/researcher’s (SRB) own data analysis in order to offer critical feedback and insight into the thematic emergence. Raw data was shared with the co-supervisory team (Drs.
Bartel and Rodin) for their critical feedback and expertise, as they have qualitative and medical psychiatric/psychotherapeutic knowledge, respectively, and both have a wealth of research experience. Additionally, the questions that were used as prompts within the patient participant music therapy sessions as well as the follow up caregiver interviews were carefully reviewed by a number of qualitative research experts as well as the study’s research team (co-supervisors Drs. Bartel and Rodin, as well as research assistant TK). The questions themselves did not enquire about the relationship between the therapist and the patient/caregiver participants, but these themes emerged through other means, although not specifically prompted.

Multiple sources of data were used, including audio recordings of the sessions that involved both verbal exchanges/conversations as well as musical exchanges/conversations. The researcher data included researcher reflections (described in Chapter Five, Study Design) and various other writings such as poetry, reflective narrative phenomenological writing, and reflective journal writing, some of which is included in this dissertation in both the main body and appendices.

**Participant Sample Demographic**

Although the ten research patient participants and their caregiver counterparts represented a wide range of experiences in some respects (a relatively equal distribution of men and women patient participants with slightly varying diagnoses and prognoses at time of recruitment, as well as differing socioeconomic statuses and family structures), there were only middle-aged to older adult patient participants. Although cancer can occur at any age, it tends to primarily affect Canadians aged fifty and older (Canadian Cancer Society, 2017). There were no AYA (adolescent and young adult) patient participants, primarily because there were no MAiD requests from any AYA individuals during the recruitment period. Had the recruitment period
been lengthened, or under different circumstances (e.g., in another health care facility), it is possible that a wider age range would have been available. I have personally worked with AYA patients who have requested MAiD though not in a research context, so would be curious to know if there are any significant differences between older and younger adults, as has been shown in other areas of oncology and palliative care between older adults and younger adults (Mitchell, Tam & Gupta, 2018). Another variance in the patient sample was that of timing. Timing of music therapy sessions fluctuated significantly between various participants, as two (Alice and Jo) had a history of experience with music therapy while others experienced only one session. This variance in temporal connection may or may not have made a difference in the outcomes of the music therapy itself but may be a topic for a further future study.

Paucity of MAiD Research

As noted above in Chapter Three (Literature Review), there is a lack of research on medically assisted dying in Canada, and although there is some pre-existing research on various facets of the experiences of euthanasia and assisted suicide, and variations on MAiD in other parts of the world, the literature on MAiD in Canada is scarce. There was no research whatsoever on the role of music therapy in medically assisted dying. Beginning with a blank slate came with pros and cons. It was a privilege to begin the process of research in music therapy and MAiD and to lay the groundwork for future studies but was challenging to not have any research context or background in this particular area upon which my study could be based. Although the interventions and clinical goals that I used in my approach to patients were based on best practice in the fields of music therapy, palliative care, and evidence-based practice in research on these subjects, it was at times challenging to pull together resources in an area where there were no
pre-existing research findings. Hopefully, this study will serve as the groundwork for future researchers and music therapists.

Next Steps and Future Research Questions

“Words can never reach far enough into music to touch her essence. However, with the trying, our words will become more musical, our respect and wonder more absorbing, our understanding of music deeper.”

– Carolyn Kenny, *The Mythic Artery*

In order to understand more deeply the impact of music therapy of music therapy in the context of medical assistance in dying, future research is merited and necessary. While this initial study provided groundwork for entering into the lifeworld of patient, caregiver, and therapist participants, much is left to learn and understand. The relatively small sample size (patients n = 10, caregiver n = 7, therapist n = 1) was only able to capture a fraction of the data that may have come of a study that recruited for much longer with a wider scope (e.g., a multi-centre study) and additional therapists. Continuing to recruit and explore lived experience in similar contexts would add to this initial existing data.

The study raised the question of what the experience of music therapy might be like in the context of assisted dying. Future research questions may ask what the experience is for staff and clinicians involved in similar circumstances. An exploration of more music therapists’ experiences would enrich the sole music therapist perspective provided in this study. Further research objectives may include exploring patients’ perceptions and experiences, and if or how music therapy might affect physical symptoms prior to assisted death. Several of the patient participants in this study were symptomatic (some to greater or lesser degrees depending on a
number of variables), and symptom experiences were not specifically examined. A quantitative component might be particularly effective in capturing that data. Another avenue to explore in future research would be to better understand when and how to offer music therapy: currently, there are no guidelines as to when music therapy should be offered in the context of MAiD. It may be the case that if music therapy was offered earlier in some patients’ care trajectories, outcomes (physical/emotional reactions, psychosocial outcomes) may have varied. Alternatively, if music therapy was offered later, outcomes may have varied. As yet, there is no research to support either claim. Yet another direction for future research might involve conducting bereavement music therapy support groups for bereaved family members of patients who had an assisted death. The qualitative and quantitative outcomes of these potential future studies would likely offer a deeper understanding of these experiences and potential effects and would serve to underscore the need to make music therapy a more standardized offering in health care settings.

**Enhancing Current Guidelines**

At present, guidelines co-authored by three Canadian music therapists (myself, Adrienne Pringle and Karie Rippin-Bilger), a psychiatrist (Dr. Madeline Li) have been published via the Canadian Association of Music Therapists (CAMT) (Black, Rippin-Bilger, Pringle & Li, 2017). These guidelines originated as a position statement, emphasizing the patient-centered approach and stance that the CAMT took towards assisted dying in Canada. The title was later changed to “CAMT MAiD Guidelines” from “CAMT MAiD Position Statement” in order to more broadly encompass the content of the document, which provided a number of different intervention styles, options, and strategies for providing music therapy before, during, and after MAiD. Since the completion of this current study, a team of MAiD and music therapy specialists have set plans to revisit the guidelines and rework the content based on the evidence of this study, and the
experience gained in the two years since its publication. A Special Interest Group headed by me and comprised of a number of music therapists, MAiD assessors and providers, psychiatrists with MAiD experience, and other clinical experts in the area of MAiD and/or music therapy will be rewriting clinical guidelines for MAiD and music therapy, which will culminate in an international conference to be held in May of 2020, followed by a subsequent paper on the topic.

Disseminating Information

In order for this data to be practically useful in the clinical practice of music therapy, the dissemination of information in this area is essential. The data will be presented at future conferences, as well as locally at hospital-wide events. The findings from the study will ideally be published in upcoming issues of journals in related topics (e.g., palliative medicine, music therapy, end of life care) and potentially in other forms (e.g. a book, or a personal reflective account). As an educator, I have a strong passion for sharing information and resources with upcoming generations of music therapists and health care professionals. I intend to seek out opportunities to disseminate this information in educational settings such as classroom environments, online publications, and other educational platforms as appropriate and applicable.

Looking Ahead

“In the best of all possible worlds, art would be unnecessary. Its offer of restorative, placative therapy would go begging a patient. The professional specialization involved in its making would be presumption. The generalities of its applicability would be an affront. The audience would be the artist and their life would be art.”

— Glenn Gould
Though the profession of music therapy was established in Canada over 45 years ago, there is still much to learn, and there will always be room to grow. As a novice within the profession, though one who is becoming increasingly focused on music therapy in the context of psychosocial oncology and palliative care/end of life, I am continually learning where the strengths and gaps lie within the field. As with so many other groups of individuals working to promote music therapy as a health activity and a supportive therapeutic standard of care in the lives of Canadians across the life span, we are all working towards a common goal of providing optimal evidence-based care through music. The profession offers so many opportunities in so many different areas, be it clinical, research-oriented, academic, or educational. Music therapists in all fields will ultimately push the profession forward if we connect to one another, learn from one another, and embrace the best that each of us, with our own areas of expertise, has to offer.

Though qualitative research is my passion as an academic, I fully embrace the power of quantitative data and analysis and am drawn to mixed methods research and the impact of blending styles. There are some questions that require a qualitative lens in order to be explored, such as the experience of music therapy within assisted dying, and there are some questions that by nature merit numbers and figures in order to manifest answers (and more questions). Within this study and others in which I have been involved, I have had the great fortune to have learned from multiple professionals who carry expertise in various areas and encourage the same of my fellow music therapy colleagues. Within the profession itself, I advocate for collaboration, seeking out methods and ideas that are novel and unique, and when merited, following one’s intuition when it comes to asking research questions and choosing appropriate methodology. There is room in the field for all of us, and we are stronger together than we are apart.
There is a crack in everything...that’s how the light gets in.

- Leonard Cohen, “Anthem”
REFERENCES


Conference. Oral paper presentation conducted at the meeting of HPCO, Richmond Hill, ON.


Georges, J., Onwuteaka-Philipsen, B., Muller, M., Van Der Wal, G., Van Der Heide, A., & Van Der Maas, P. (2007). Relatives’ perspective on the terminally ill patients who died after


http://doi.org/myaccess.library.utoronto.ca/10.1089/jpm.2018.0519
APPENDICES

Appendix A: A Comprehensive Exit Music Playlist

Since my first experience with assisted death, I have developed an interest in the songs people choose or might consider choosing as their final songs. What might that sonic landscape look like, when it is knowingly your last? I began asking friends and family members what song(s) they would choose if they had a choice. Naturally, some folks shuddered at my question while others took pause and reflected deeply. Answers were varied, surprising, moving, and touching. I continue to be fascinated by this question and continue to ask it. The following is a list of many of the songs I have heard people tell me would be their last. This list does not include songs that individuals have written with me, or improvisations I have played during people’s last breaths.

- The Rolling Stones: Wild Horses
- J.S. Bach: Prelude No. 1 in G Major for Cello
- Van Morrison: Madam George
- Van Morrison: Astral Weekes
- Ed Sheeran: Perfect
- The Tragically Hip: Wheat Kings
- The Beatles: Here Comes the Sun
- Earth, Wind, & Fire: That’s The Way of the World
- Josh Groban: You Raise Me Up
- Louis Armstrong: What a Wonderful World
- Leonard Cohen: Anthem
- Leonard Cohen: Hallelujah
- J. Pachelbel: Canon in D Major
- Barry Manilow: Can’t Smile Without You
- Yes: Awaken
- The Beatles: In My Life
- David Bowie: Starman
- Simon and Garfunkel: The Boxer
- Rodgers and Hammerstein: If I Love You, from Carousel
- Traditional Hymn: Once in Royal David’s City
- Traditional Hymn: Amazing Grace
- The Mamas and the Papas: Dream a Little Dream of Me
- Bob Dylan: Blowin’ in the Wind
- Monty Python: Always Look on the Bright Side of Life
- Nina Simone: Feelin’ Good
- Nina Simone: My Baby Just Cares for Me
- Jacob Jacobs and Sholom Secunda: Bay Mir Bistu Sheyn (To me, you are beautiful)
- Vivaldi: The Four Seasons
- Beethoven: Symphony No. 6
- Frank Sinatra: Fly Me to the Moon
- George Gershwin: Someone to Watch Over Me
- Jay Ungar: Ashokan Farewell
- R.E.M.: Man on the Moon
- The Beach Boys: God Only Knows
- West Side Story: Somewhere
- Sufjan Stevens: Come Thou Fount
- Oliver Schroer: Field of Stars
- The Beatles: Let it Be
- The Beatles: Ob-la-di, Ob-la-da
- F. Chopin: Raindrop Prelude (Op. 28) in D Flat Major
- Alan Jackson: The Older I Get
- Joni Mitchell: The Circle Games
- Harold Arlen: Somewhere Over the Rainbow
- Stephen Sondheim: Being Alive, from Company
- Jerome Kern: The Way You Look Tonight
- Nirvana: Come as you are
- Bob Marley: Redemption Song
- Tegan and Sara: Don’t Confess
- The Beach Boys: Feel Flows
- Strauss: Four Last Songs
- Bill Withers: Lean on Me
- Laura Mvula: Phenomenal Woman
- Linda Sandell: Day by Day
Appendix B: Phenomenological Interview Question Guide: Patients and Caregivers

Study Title: A Study of the Experience of Music in Medically Assisted Dying

Investigator/Study Doctor: Dr. Gary Rodin, MD gary.rodin@uhn.ca

Study Coordinator: SarahRose Black, RP, MTA, MMT, PhD Candidate Sarahrose.black@uhn.ca

List of Potential Questions for Patient Participants

- Can you describe your potential musical choices in the context of your current experience?
- Why have you chosen this particular music?
- Tell me about the role of this particular music in your life.
- What is your relationship to the lyrics/melody/orchestration/instrumentation/band/artist/performance (as applicable)?
- Can you describe your relationship with music?
- What role does music play in your life?
- What role do you hope music will do for/add to the intervention?
- What role do you want music to play on the day of the intervention?
- What are your expectations for music in dying?
- How does this music relate to you and your life (psychologically, spiritually, physically)?
- How might the music you’ve chosen reflect your identity? Personality? Life experiences?
- Who are you planning on having in the room?
- How do you anticipate the music affecting the environment?

List of Potential Questions for Caregiver Participants

- What role did music play for your loved one in the context of MAiD?
- Did your loved one have music playing in the room during their procedure? If so, what music/song/band/artist did your loved one have playing in the room during the intervention?
- Why was this music chosen?
- Who chose the music for your loved one’s MAiD intervention (e.g., patient preference, family, friends, music therapist, etc.)?
- Who was in the room during the intervention?
- Did the music reflect your loved one’s identity? Personality? Life experiences? If so, how?
- How did the music affect you during the intervention?
- Have you heard the music since the intervention took place? If so, how did it affect you?
Appendix C: Reflective Piece: Who really chooses the music? (November 2018)

It is difficult to fully understand who chooses the music. There are, of course, the obvious answers. The patient may request a song or may guide the therapist towards a genre or style that most closely matches their current mood, state, or headspace. The therapist may make suggestions based on a patient’s verbal or non-verbal indications, such as their body language, items of significance in their hospital room, or suggestions from family members, friends, or care providers. But what of the moments when the therapist is solely reliant on the patient’s breathing patterns? Or if shared language communication is not an option? What about when I, the therapist, take risks and make necessary assumptions in the hopes that some musical moment will land? How do I choose and is it fair that I have the power to make these choices on behalf of the patient? I am never really sure. But maybe this is an important space to occupy. Maybe my hesitancy is vital, maybe it is a constant reminder of the not knowing that reminds us to be alert, aware, hyper-vigilant to feedback (verbal and non-verbal), and humble in the face of the intense power of music. Maybe the not knowing, the uncertainty, the questions are all gifts that remind me as therapist to be open to whatever comes, to listen to that which is not said aloud, and to allow intuition and careful, deep listening to guide and navigate uncharted waters. So who really chooses the music? It’s all of us and no one. It’s intuition and trust. It’s blatant and yet subtle and difficult to decipher. And perhaps that’s what makes it connective, intense, and therapeutic.

(SarahRose Black)
Invitation to Participate in a Research Study

We would like to inform you of a music therapy research study taking place at The University Health Network. This study is being conducted by Dr. Gary Rodin, Head of Psychosocial Oncology and Palliative Care, and SarahRose Black, accredited music therapist and registered psychotherapist. It is open to English-speaking adults (≥18 years of age) who have formally requested medical assistance in dying (MAiD), as well as their caregivers.

There has been no research done on the role of music therapy in the context of medical assistance in dying. The purpose of this study is to gain an understanding of the role of music therapy within the context of MAiD. If you agree to participate, you may receive individual and personalized music therapy sessions, followed by brief interviews after each session, during your assessment period for MAiD, up until the time you receive the intervention as you choose. We are also recruiting caregivers of patients requesting MAiD for brief interviews about the role of music in their loved one’s (the patient’s) life, in the context of MAiD.

In the coming days, a member of our team may contact you to ask you if you would like to hear more about this study. Please feel free to refuse to talk to her if you do not wish to hear more about the study: this will not affect in any way your care at the University Health Network.

If you have any questions, or if you wish not to be approached about this study, please call the following number: 416-946-4501 (ext. 2494).

Thank you for considering participation in this study.

Dr. Gary Rodin
Principal Investigator
Appendix E: Canadian Association of Music Therapists’ (CAMT’s) Practice Guidelines: MAiD

CAMT Practice Guidelines: Medical Assistance in Dying March 2017
SarahRose Black, MA, MMT, RP, MTA
Adrienne Pringle, MMT, RP, MTA
Karie Rippin Bilger, BMT, MSW, RP, MTA
Madeline Li, MD, FRCPC

Introduction

This document has been prepared by the Canadian Association of Music Therapists (CAMT) in response to the case of Carter v. Canada, within which the Supreme Court of Canada considered whether the criminal prohibition of physician-assisted death (currently referred to as “medical assistance in dying” or MAiD) violated the Canadian Charter of Rights and Freedoms of competent adults with grievous and irremediable suffering, seeking assistance to end their lives. The Supreme Court of Canada unanimously decided that an absolute ban on medical assistance in dying is in fact a violation of the rights of these individuals; as a result, the federal government enacted legislation in order to establish a framework for medical assistance in dying in Canada. Music therapists across Canada commonly work with individuals who have life-threatening illnesses, both in community settings as well as in institutional facilities. Within these contexts, MAiD is currently being administered for patients who request it and meet the criteria.

Because music therapists may be asked to be involved in an individual’s care (and/or the family of the individual, or the staff caring for the individual) in the context of this intervention, the Canadian Association of Music Therapists has created this document to offer guidelines to support its members who are working within these contexts.

This document was created in order to support Canadian music therapists (board certified, accredited, as well as in-training) who care for individuals requesting and/or receiving MAiD.

Definition of Medical Assistance in Dying

In accordance with federal legislation, medical assistance in dying includes circumstances where a medical practitioner or nurse practitioner, at an individual’s request: (a) administers a substance that causes an individual’s death; or (b) prescribes a substance for an individual to self-administer to cause their own death (CPSO, 2016).
**Ethical Stance**

In accordance with the CAMT’s Code of Ethics, CAMT advocates adherence to the principles of Respect for the Dignity and Rights of Persons, Responsible Practice, Integrity in Relationships, Extended Responsibility, and Responsible Leadership (CAMT, 2002). This position holds our profession to a high standard of responsibility and respect both for the individuals with whom we work, as well as the communities within which we work. With particular reference to Section I.2 of the Code of Ethics, we “acknowledge clients’ rights to self-determination and autonomy, and the right to participate in decisions that affect them” (p. 6). This stance demands our consistent valuing of an individual’s right to make decisions affecting their health and well-being, whether these be decisions around active medical management, or a request to be assessed regarding eligibility for MAiD. Music therapists in Canada are bound by our Code of Ethics to maintain respect for our client’s/patient’s decisions.

**Conscientious Objection**

Although as CAMT members, we position ourselves as consistently respecting the dignity and rights of persons, conscientious objection to providing care within the context of MAiD is respected by the CAMT. As a governing body, the CAMT respects and values the beliefs and opinions of its members, and understands that each member comes to the profession with their own set of beliefs, values, and personal experiences. If a music therapist declines to provide music therapy before or during medical assistance in dying for reasons related to conscience or religion, the music therapist must maintain respect for the client’s/patient’s dignity, autonomy and personhood. Further to this, music therapists must not impede access to medical assistance in dying, either through coercion or offering their own personal beliefs/opinions to clients/patients.

In following the Code of Ethics’ mandate for Responsible Practice (CAMT, 2002), section II.10 regarding Self Knowledge and Care mandates that music therapists “Evaluate how their experiences, attitudes, culture, beliefs, values, social context, individual differences, and stresses influence their interactions with others, and integrate this awareness into all efforts to benefit and not harm others” (p. 9). In following this principle, music therapists must take great care to recognize their own reactions, feelings, opinions, and ideas regarding medical assistance in dying. If the music therapist conscientiously objects to providing care to an individual who requests music therapy before, during and/or after MAiD, the music therapist must offer alternative approaches to fulfilling this request (see section below for further information).

**Potential Role(s)**

Should a music therapist be asked to participate in the care of an individual receiving MAiD, the music therapist may be asked to engage in any number of the following ways listed below, and additional options for participation may be agreed upon between client/individual and music therapist, within reason, depending on both parties’ mutual consent and level of comfort.

If the music therapist is asked to engage, and conscientiously objects, the music therapist may offer the involvement of another music therapist if possible, or offer alternatives (e.g., another staff member may be able to support the client/patient through providing recorded music, or may be able to offer psychosocial support to the client/patient, family, and/or staff).
If a client/patient asks the music therapist to engage in a conversation around the process of MAiD (assessment, intervention, etc.), the music therapist may choose to engage in these conversations depending on his or her comfort level, however is not required to do so, and has the option to redirect and defer to another health care professional. Many health care facilities/organizations currently have a MAiD assessment and intervention team in place, which music therapists may defer to if needed. If the music therapist is asked about his or her moral stance or personal opinion about MAiD, the CAMT advises the music therapist to redirect the question(s) back to the client/patient, exploring these questions in a similar way to any other questions addressed to the therapist about their personal stances/opinions. If these conversations present challenging situations for the music therapist, the music therapist is welcome to contact another health care professional or the Ethics chair of the CAMT.

The following is a list of several possible options (though others not listed here may arise) for involvement of the music therapist within the MAiD process:

**Music therapy sessions**

- The music therapist may engage in music therapy interventions in days/weeks leading up to MAiD (e.g., receptive, active, psychodynamic, song-writing, etc.).

- The music therapist may be following the client/patient for music therapy in days/weeks before the client/patient requests a MAiD assessment; the music therapist may engage in a psychodynamic role of supporting the client/patient in processing emotion before the assessment, or during the reflection period between assessments.

- The music therapist may engage the client/patient and/or family in legacy work through song-writing, life review, reminiscence, etc. (e.g., creation of a playlist or song-writing for legacy work).

**Music therapy during intervention**

- The music therapist may provide music (live or recorded) at bedside before, during, and/or after MAiD. This may involve being present during the administration of the intervention, alongside the client/patient and interventionist, and other requested individuals.

- The music therapist may be asked to set up the audio required if the client/patient requests particular recordings of music to be played during the intervention.

**Music therapy for family support**

- The client/patient may request music therapy support for their family, therefore the music therapist may be asked to provide a playlist, for example, for the family to be able to use based on the client’s/patient’s request (e.g., before intervention, during or after intervention, or within a funeral/memorial context, or as a legacy piece).
Music therapy for staff support

- The clinical team may require support before, during and/or after the MAiD intervention takes place.

- The music therapist may be asked to engage the staff in a ritual at bedside after MAiD, or at a separate de-briefing session, or in extended staff support through psychodynamic processing (e.g., group improvisation or song-writing).

Considerations

As noted by the Canadian Association of Social Workers in their 2016 discussion paper, Bill C-14 (An Act to amend the Criminal Code and make related amendments to other Acts (medical assistance in dying) provides exemptions for medical practitioners, nurse practitioners, and pharmacists in order to protect them from culpability under the criminal code. The CASW recommends furthering these protections so that other professions that “may reasonably take part in PAD be named explicitly- as opposed to naming only ‘health care providers’” for protection under the Criminal Code of Canada” (CASW, 2016). The CAMT endorses this as music therapists could and should be considered alongside all other health professionals who may reasonably take part in MAiD. In the interim, in order to support its members, the CAMT stresses the need for professional self-care for all therapists practicing within this context, and encourages seeking out professional support through each individual therapist’s organization, place of work, or peer/professional supervision.

The CAMT is aware of the potential psychosocial impact of involvement of MAiD for music therapists, and as per the Code of Ethics, the CAMT strongly encourages its members to “Engage in self-care activities which help to avoid and alleviate conditions (e.g., burnout, addictions) that could result in impaired judgement and interfere with their ability to benefit and not harm others” (p. 10). Further to this, if music therapists have further questions or issues that arise, please connect with the CAMT Ethics Co-Chairs and/or Provincial/Regional Ethics Chairs for additional support. If music therapists find themselves dealing with issues of transference/counter-transference related to MAiD, the CAMT strongly encourages its members to notice and be aware of these feelings, which may manifest themselves as not wanting to be at work, not wanting to engage with clients/patients, feeling angry, tired or resistant, etc. If you would like more information on transference and counter-transference, please contact the CAMT Professional Supervision committee to be connected and consult with a professional supervisor. Because of the new and unfamiliar territory that all health care professionals are navigating since the passing of the new legislation by the Supreme Court of Canada, the CAMT recognizes that there may be unexpected and unique challenges that arise. The CAMT encourages all members to take stock of their own reactions and feelings as professional practitioners, and take the necessary steps in order to decide how they are choosing to approach working with individuals requesting/receiving MAiD.
Appendix F: Consent Form (Patients)

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY: PATIENTS

Study Title: A Study of the Experience of Music in Medically Assisted Dying

Investigator/Study Doctor: Dr. Gary Rodin, MD

Study Coordinator: SarahRose Black, RP, MTA, MMT, PhD Candidate

Contact Information:

610 University Avenue, Toronto, ON
416 946 4501 x2494

Introduction:

You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on the study’s risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

Background/Purpose:

Within the vast scope of clinical music therapy, accredited music therapists commonly work with individuals who have life-threatening illnesses, both in community settings as well as institutional facilities. Within these contexts, medical assistance in dying (MAiD) is currently available for and being administered to patients who request it and meet the eligibility criteria (College of Physicians and Surgeons of Ontario, 2016). Music therapists are frequently called to the bedside to provide care for individuals at end of life, and this professional role now extends to caring for those choosing to end their lives through receiving Medical Assistance in Dying (MAiD). Music may play numerous roles in both settings, such as pain management, anxiety reduction, and emotional support. Although the availability of MAiD in Canada is relatively recent, numerous patients have received this intervention, and music is often requested for the planned time of death.
Because music is being requested by patients undergoing MAiD, evidence is needed regarding its benefit, potential usage and outcomes, and how it can best be applied in order to establish practice guidelines, and improve its delivery.

The purpose of this study is to gain insight into the experience of music for an individual requesting and receiving MAiD, to better understand the role of music during this specific clinical intervention, and to ensure that it is delivered in the most therapeutic way.

**Study Design:**

We are recruiting patients (aiming for twelve participants) who are requesting MAiD and are considering the use of music before and/or alongside the intervention, as well as their caregivers.

Eligible and willing participants (patients and their caregivers) will have an experience with music therapy as part of MAiD at least once prior to the intervention (e.g. live music or playlists/songs at bedside for pain and symptom management or emotional support) and/or an experience with music during the procedure. Participants will be interviewed about their experiences of music in the context of medically assisted dying.

This approach will involve qualitative (i.e. open-ended) interviews of patients and caregivers with questions or prompts conducted by the therapist/researcher prior to the intervention, and interviews with the caregivers following the intervention. There can be flexibility in the timing of the interviews, since there the time period between initial assessment and MAiD intervention is up to ten days. The qualitative interviews will involve a series of semi-structured, open-ended questions. Those with the patient will enquire why the patient has chosen to have music as part of their MAiD intervention, what motivated their song choices, what role music plays in their lives, and what role they anticipate it will play during their procedure, if applicable. Those with the caregiver will enquire about the caregiver’s perception of the experience of music in the context of their loved one’s MAiD intervention. These interviews will be audio recorded for later transcription. These recordings will be stored securely and will only be accessed by the study team; these recordings will be destroyed ten years after study completion.

For patients referred to the study who are planning on receiving MAiD, music therapy interventions will be offered prior to and on the day of the intervention. The music therapist will then follow up as requested. This may include discussing musical tastes/preferences for the MAiD intervention in the days following the initial session, continuing with music therapy, meeting with the participant on the day of the intervention in order to provide the music (either live or recorded), or meeting with family or caregivers who will be responsible for ensuring that recordings are provided on the day of the procedure if this is requested by the patient.

Patients will also be invited to participate in the study if they are planning to use music exclusively as part of their assisted dying procedure, and not beforehand.
**Study Visits and Procedures:**

You will receive music therapy sessions (at least one individualized music therapy session with the therapist/researcher and as many sessions as feasible up to your assisted dying intervention, depending on your needs and requests, as discussed with the therapist/researcher. You will take part in a brief semi-structured interview (approximately 10-20 minutes) following each session, during which the music therapist/researcher will enquire about the role of music in MAiD. If you are requesting MAiD and are considering the use of music during the intervention, you will be offered the option of live music (please see study visits and procedures) and follow up sessions leading to the intervention as appropriate.

**Risks:**

Taking part in this study has risks. Some of these risks we know about. There is also a possibility of risks that we do not know about and have not been seen in humans to date. Please call the study doctor if you have any side effects even if you do not think it has anything to do with this study.

The risks we know of are:
- Music may trigger unpleasant or uncomfortable emotions
- Discussion of assisted dying or the end of life may cause emotional distress in patients and/or their caregivers.

**Benefits:**

You may experience direct benefits from being in this study, including an opportunity to share your own processes and experiences of assisted dying. Information gained from this study may contribute to the future use of music in health care, specifically in assisted dying, which may support other patients and caregivers in this circumstance.

**Confidentiality:**

Your data will be shared as described in this consent form or as required by law. All personal information such as your name, address, phone number, OHIP number, and family physician's name will be removed from the data and will be replaced with a number. A list linking the number with your name will be kept by the study doctor in a secure place, separate from your file.

**Personal Health Information**

If you agree to join this study, the study team will look at your personal health information and collect only the information they need for the study. Personal health information is any information that could identify you and includes your:
• name,
• address,
• date of birth (Year only)
• new or existing medical records, that includes types, dates and results of medical tests or procedures.

The following people may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study is following proper laws and guidelines:
  • Representatives of the University Health Network (UHN) including the UHN Research Ethics Board

The study doctor will keep any personal health information about you in a secure and confidential location for 10 years.

Your participation in this study will also be recorded in your medical record at this hospital. This is for clinical safety purposes.

Research Information in Shared Clinical Records:

If you participate in this study, information about you from this research project may be stored in your hospital file and in the UHN computer system. The UHN shares the patient information stored on its computers with other hospitals and health care providers in Ontario so they can access the information if it is needed for your clinical care. The study team can tell you what information about you will be stored electronically and may be shared outside of the UHN. If you have any concerns about this, or have any questions, please contact the UHN Privacy Office at 416-340-4800, x6937 (or by email at privacy@uhn.ca).

Study Information that Does Not Identify You

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

Voluntary Participation:

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later. You may leave the study at any time without affecting your care. We will give you new information that is learned during the study that might affect your decision to stay in the study.

You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.
Withdrawal from Study:

You can withdraw from this study at any time. If you decide to leave the study, you have the right to request withdrawal of information collected about you. Let your study doctor know.

If you leave the study, the information that was collected before you left the study will still be used in order to help answer the research question. No new information will be collected without your permission.

Costs and Reimbursement:

You will not have to pay for any of the procedures (music therapy) involved with this study. No expenses will be incurred as a result of participation in this study. The cost of the intervention is covered.

Rights as a Participant:

If you are harmed as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form, you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

Rights as a Participant:

If you are harmed as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form, you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

Conflict of Interest:

Researchers have an interest in completing this study. Their interests should not influence your decision to participate in this study. Because the therapist/researcher plays two roles (providing the intervention as well as asking the follow up questions after the session(s), there may be a perceived conflict of interest. This will be discussed at the first session; you are encouraged to share concerns or feedback at any time. The
questions following each session will be related directly to your experience of music and the role that music plays in the context of your assisted dying request/intervention, and will not be related to your specific interactions with the therapist. To further prevent from conflicts of interest, your interviews (once transcribed) will be devoid of any identification (personal health information or personal identifiers) and will be reviewed by the study team, not only the therapist/researcher.

**Questions about the Study:**

If you have any questions, concerns or would like to speak to the study team for any reason, please call: Principal Investigator Dr. Gary Rodin at or Study Coordinator at 416 946 4501 x2494.

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

You will be given a signed copy of this consent form.

**Consent:**

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to the use of my information as described in this form. I agree to take part in this study.

Print Study Participant’s Name  ____________________________  Signature  ____________________________  Date  ____________________________

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining Consent  ____________________________  Signature  ____________________________  Date  ____________________________

(continue if applicable)

**Was the participant assisted during the consent process? □ YES □ NO**

If YES, please check the relevant box and complete the signature space below:

□ The person signing below acted as an interpreter, and attests that the study as set out in the consent form was accurately sight translated and/or interpreted, and that
interpretation was provided on questions, responses and additional discussion arising from this process.

Print Name of Interpreter       Signature       Date

Relationship to Participant       Language

☐ The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

Print Name of Witness       Signature       Date

Relationship to Participant
Appendix G: Consent Form (Caregivers)

CONSENT TO PARTICIPATE IN A RESEARCH STUDY: CAREGIVERS

**Study Title:** A Study of the Experience of Music in Medically Assisted Dying

**Investigator/Study Doctor:** Dr. Gary Rodin, MD

**Study Coordinator:** SarahRose Black, RP, MTA, MMT, PhD Candidate

**Contact Information:**
610 University Avenue, Toronto, ON
416 946 4501 x2494

**Introduction:**
You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on study’s risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

**Background/Purpose:**
Within the vast scope of clinical music therapy, accredited music therapists commonly work with individuals who have life-threatening illnesses, both in community settings as well as institutional facilities. Within these contexts, medical assistance in dying (MAiD) is currently available for and being administered to patients who request it and meet the eligibility criteria. Music therapists are frequently called to the bedside to provide care for individuals at end of life, and this professional role now extends to caring for those choosing to end their lives through receiving MAiD. Music plays numerous roles in both settings, such as pain management, anxiety reduction, and emotional support. Although the decriminalization of MAiD is relatively recent, numerous patients have received this intervention, and music is often requested for the planned time of death. Because there is a clear trend that music is being requested by patients undergoing MAiD, evidence is needed regarding its benefit, potential usage and outcomes, and how it can best be applied in order to establish practice guidelines, and improve its delivery.
The purpose of this qualitative study is to gain insight into the experience of music for an individual requesting and receiving MAiD, in order to further understand the role of music during this specific clinical intervention, and to be able to have an evidence-based approach to offering music during MAiD in future cases. This study will also examine the role of music as an empathic support at end of life in the context of MAiD.

**Study Design:**

We are recruiting patients as well as caregivers of patients (aiming for twelve caregiver participants) who are requesting MAiD and are considering the use of music alongside the intervention. Caregiver participants will take part in an interview (approximately 45-60 minutes) during which the music therapist/researcher will be interviewing regarding the role of music in MAiD.

Patient participants will receive music therapy sessions before their MAiD intervention, and will also have the option of live or recorded music being provided during the MAiD procedure. Patient participants will also take part in semi-structured interviews following each music therapy session. Caregiver participants are invited to stay for the music therapy sessions if the patient participant consents to this.

The interviews of caregiver participants will also be a series of semi-structured, open-ended questions regarding the caregivers’ perspective on the role of music for the patient who is requesting MAiD. Additionally, some interview questions will invite caregivers to reflect on if and how music may or may not have functioned as empathic for the MAiD recipient. The therapist/researcher will conduct these interviews, either in person or by phone (depending on caregiver participant’s preferences), and will audio record the data for later transcription. These interviews will be structured in order to obtain knowledge about the caregivers’ understanding of the patient’s experience of music before and possibly during the MAiD procedure, if the patient participant requests music during the MAiD procedure. Because these is no way to understand the patient’s experience following the intervention due to the permanence of the intervention, interviewing the caregivers (family and/or friends) may provide valuable insights into the patient’s experience, and into the role of music.

If music is requested for the MAiD intervention, the caregiver may be contacted four to six weeks following the intervention for a follow up interview re: the role of music during MAiD. This is optional for the caregiver.

Eligible and willing patient participants (patients and their caregivers) may have either an experience with music as part of MAiD at least once prior to the intervention (e.g. for music therapy for pain/symptom management or emotional support, or patients choosing their playlists/songs for MAiD) or an experience with music during the procedure. Patient and caregiver participants will be interviewed about their experiences of music in medically assisted dying.
This approach will involve qualitative interviews (conducted by the therapist/researcher) of patient participants prior to the intervention, and the caregivers following music therapy sessions, up to the MAiD intervention, and following the intervention if the patient has music during the intervention. This time frame will allow for flexibility in data collection, keeping in mind that the typical assessment period between initial assessment and MAiD intervention is up to ten days. Many logistical and practical tasks have to be addressed and completed prior to the intervention, therefore allowing for flexibility for the time frame of these interviews will be essential. The qualitative interviews will involve a series of semi-structured, open-ended questions regarding why the patient participant has chosen to music as part of their MAiD intervention, what motivated their song choices, what role music plays in their lives, and what role they anticipate it will play during their procedure. These interviews will be audio recorded for later transcription.

For patients referred to the study who are planning on receiving MAiD, live or recorded music on the day of the intervention will be offered. The music therapist will then follow up as requested (e.g. if the participant wants to continue discussing musical tastes/preferences for the MAiD intervention in the days following the initial session, or if the participant wants to continue with therapy) or meet with the participant on the day of the intervention in order to provide the music (either live or recorded) or connect with family or caregivers who will be responsible for ensuring the music is provided on the day of the procedure (e.g. a recording).

Patients who have not had a formal music therapy session will also be invited to participate in the study if they are planning to use music as part of their assisted dying procedure.

**Study Visits and Procedures:**

You will be asked to take part in interviews (one after each music therapy session provided to your loved one/the patient participant), conducted separately from the patient participant, with the initial interview lasting approximately 20-30 minutes. Follow up interviews may be shorter depending on how much information you would like to share that has not already been covered in the initial interview (e.g. regarding the changing role of music in the context of your loved one’s assisted dying request/intervention). These interviews may happen in person with the therapist/researcher at your convenience, or over the phone with the therapist/researcher at your convenience. These interviews will be geared towards gaining an understanding of the role of music in assisted dying for your loved one.

**Risks:**

Taking part in this study has risks. Some of these risks we know about. There is also a possibility of risks that we do not know about and have not been seen in humans to date. Please call the study doctor if you have any side effects even if you do not think it has anything to do with this study.
The risks we know of are:
- Music may trigger unpleasant or uncomfortable emotions
- For patients discussing pending assisted dying, for caregivers discussing their loved one’s assisted dying, these conversations may elicit difficult or challenging emotions that may cause discomfort or emotional distress.

Benefits:

You may experience direct benefits from being in this study, including an opportunity to share your own processes and experiences of assisted dying, which may be emotionally cathartic and potentially helpful in your own life. Information learned from this study may contribute to the future of the use of music in health care, specifically in assisted dying, which may support other patients and caregivers in their experiences. Your data will be shared as described in this consent form or as required by law. All personal information such as your name, address, phone number, OHIP number, and family physician’s name will be removed from the data and will be replaced with a number. A list linking the number with your name will be kept by the study doctor in a secure place, separate from your file.

Personal Health Information

If you agree to join this study, the study team will collect personal health information, however will only collect the information they need for the study. Personal health information is any information that could identify you and includes your:
- name,
- address,
- date of birth (Year only)

The following people may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study is following proper laws and guidelines:
- Representatives of the University Health Network (UHN) including the UHN Research Ethics Board

The study doctor will keep any personal health information about you in a secure and confidential location for 10 years.

Research Information in Shared Clinical Records:

If you participate in this study, information about you from this research project may be stored in your hospital file and in the UHN computer system. The UHN shares the patient information stored on its computers with other hospitals and health care providers in Ontario so they can access the information if it is needed for your clinical care. The study team can tell you what information about you will be stored electronically and may be shared outside of the UHN. If you have any concerns about
this, or have any questions, please contact the UHN Privacy Office at 416-340-4800, x6937 (or by email at privacy@uhn.ca).

Study Information that Does Not Identify You

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

Voluntary Participation:

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later. You may leave the study at any time without affecting your loved one’s/patient participant’s care. We will give you new information that is learned during the study that might affect your decision to stay in the study.

You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

Withdrawal from Study:

You can withdraw from this study at any time. If you decide to leave the study, you have the right to request withdrawal of information collected about you. Let your study doctor know.

If you leave the study, the information that was collected before you left the study will still be used in order to help answer the research question. No new information will be collected without your permission.

Costs and Reimbursement:

You will not have to pay for any of the procedures (music therapy) involved with this study. No expenses will be incurred as a result of participation in this study. The cost of the intervention is covered.

Rights as a Participant:

If you are harmed as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the
investigators, sponsor or involved institutions of their legal and professional responsibilities.

**Rights as a Participant:**

If you are harmed as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

**Conflict of Interest:**

Researchers have an interest in completing this study. Their interests should not influence your decision to participate in this study. Because the therapist/researcher plays two roles (providing the intervention as well as asking the follow up questions after the session(s), there may be perceived conflict of interest. However, this will be addressed at the first session; you are encouraged to share concerns or feedback at any time. The questions following each session will be related directly to your experience of music and the role that music plays in the context of your assisted dying request/intervention, and will not be related to your specific interactions with the therapist. To further prevent from conflicts of interest, your interviews (once transcribed) will be devoid of any identification (personal health information or personal identifiers) and will be reviewed by the study team, not only the therapist/researcher.

**Questions about the Study:**

If you have any questions, concerns or would like to speak to the study team for any reason, please call: SarahRose Black, MMT, RP, MTA, PhD Candidate (Accredited Music Therapist & Study Investigator) at 416 946 4501 x2494.

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

You will be given a signed copy of this consent form.

**Consent:**

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to the use of my information as described in this form. I agree to take part in this study.
My signature means that I have explained the study to the participant named above. I have answered all questions.

(continue if applicable)

Was the participant assisted during the consent process? ☐ YES ☐ NO

If YES, please check the relevant box and complete the signature space below:

☐ The person signing below acted as an interpreter, and attests that the study as set out in the consent form was accurately sight translated and/or interpreted, and that interpretation was provided on questions, responses and additional discussion arising from this process.

☐ The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.