Challenging Stigma and Enacting Citizenship Through Liberatory-Relational Songwriting with People Living with Dementia

by

Taylor Kurta

A thesis

presented to the University of Waterloo

in fulfilment of the

thesis requirement for the degree of

Doctor of Philosophy

in

Recreation and Leisure Studies - Aging, Health and Well-Being

Waterloo, Ontario, Canada, 2026

© Taylor Kurta 2026

EXAMINING COMMITTEE MEMBERSHIP

The following served on the Examining Committee for this thesis. The decision of the Examining Committee is by majority vote.

External Examiner	ALISON PHINNEY Professor School of Nursing University of British Columbia
Supervisor	SHERRY L. DUPUIS Professor Emerita Department of Recreation and Leisure Studies University of Waterloo
Internal Member	BRYAN GRIMWOOD Professor Department of Recreation and Leisure Studies University of Waterloo
Internal-external Member	ELENA NEITERMAN Professor School of Public Health Sciences University of Waterloo
Other Member(s)	PIA KONTOS Senior Scientist KITE Research Institute, University Health Network
	ELIZABETH MITCHELL Assistant Professor Faculty of Music Wilfrid Laurier University

AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

ABSTRACT

People living with dementia (PLwD) frequently experience stigma, social exclusion, and limited opportunities to participate in creative and collaborative processes that centre their voices and lived experiences. Dominant biomedical and tragedy narratives of dementia often emphasize decline, dependency and the total loss of self, overlooking the relational and creative capacities of PLwD. This is especially true for PLwD later in the disease progression who are written off and denied their social citizenship rights, including opportunities to contribute to their own and others' lives. In response to these limitations, this dissertation explores how collaborative songwriting rooted in liberatory and relational processes supports the enactment of relational citizenship and challenges stigmatizing discourses of dementia.

Grounded in relational and critical theoretical perspectives, including relational caring philosophy, relational citizenship, and community and music-centred approaches to music therapy, this research employed liberatory/activist arts and critical arts-based inquiry to facilitate a collaborative songwriting project with nine PLwD in a residential care home in Ontario, Canada. Over nine weeks, the songwriters engaged in a series of songwriting sessions culminating in the public release of an original song, Wisdom and Respect, and an accompanying short film.

Analysis of the songwriting sessions illustrated how the liberatory, relational process created opportunities for songwriters to share their personal histories and experiences, attend to one another, negotiate creative decisions, and engage in critical dialogue, reflection, and collective meaning-making through music. Through this analysis, the Liberatory-Relational Dementia Songwriting Framework was developed, identifying key relational literacies (i.e., processes and ways of being and relating in the world that support embodied capacities and

cultivate opportunities for relational connections to flourish) that supported the songwriting process. These relational literacies include relational knowledging, relational attuning, and relational decision-making. The research also demonstrated how the song and film functioned as a counter-narrative to dominant discourses of dementia by highlighting the relational, creative, and expressive capacities of the songwriters. Preliminary feedback from audience members at the community release party indicated shifts in perceptions of the capacities and personhood of PLwD, with some participants expressing intentions to change how they interact and engage with PLwD in their own lives.

This research contributes theoretical, methodological, and practical insights to dementia studies, music therapy, and leisure studies. It challenges dominant biomedical conceptualizations of leisure, and specifically music in the dementia context, and instead offers a liberatory approach that recognizes and supports the continued and evolving capacities of PLwD later in the disease progression to engage in social justice projects. As both a theory and a relational practice, relational citizenship involves knowing and being known, belonging and solidarity, attunement and recognition, and the agency to act together. The Liberatory-Relational Dementia Songwriting Framework created opportunities for these dimensions to be expressed and sustained within the group. By documenting a collaborative songwriting methodology grounded in relational and liberatory arts-based approaches, this dissertation offers a framework for researchers, practitioners, and communities seeking to use participatory arts to challenge stigma and support the enactment of relational citizenship with PLwD, including those later in the disease progression.

ACKNOWLEDGEMENTS

I would like to acknowledge everyone who supported me throughout this journey. Doing a PhD, it turns out, is really hard. It is not something I would have wanted (or have been able) to do without all of you behind me. First, thank you to my supportive committee, who stood by me throughout this long journey. Your kindness, understanding, and adaptability over the years have meant more than you know. Sherry, thank you for not retiring before we had the chance to work together. I could not have done this without you as my supervisor. To my family and friends, thank you for cheering me on. It is not easy to be around someone who spends most of their days writing alone. Thank you for sticking it out with me. I think I will be better company now. To my incredible Buby, thank you for being the best grandmother anyone could ask for and for always checking in to make sure I was writing. I love you more than I can describe here. More than anyone, thank you to my husband, Daniel. There really should be support groups for spouses of people doing a PhD. When I say I would not have finished this degree without your support, I mean it. Lastly, to everyone reading this who I do not know, thank you for being here and for thinking deeply about how we can improve the lives of people living with dementia in our communities.

DEDICATION

Dedicated to Anne

TABLE OF CONTENTS

EXAMINING COMMITTEE MEMBERSHIP ii

AUTHOR'S DECLARATION iii

ABSTRACT iv

ACKNOWLEDGEMENTS vi

DEDICATION vii

LIST OF FIGURES xi

CHAPTER 1: INTRODUCTION 1

- **Why Dementia? A Personal Narrative** 1
- **The Problem** 5
- **Research Objectives and Questions** 10

CHAPTER 2: THEORETICAL POSITIONALITY 12

- **Ontological and Epistemological Alignment** 12
  - **Ontological Alignment** 12
  - **Epistemological Alignment: Social Constructionism** 15
- **Theoretical Alignment: Critical and Relational Theories** 18
  - **Tenets of Critical Theory** 19
  - **Freire's Critical Pedagogy** 22
  - **A Critique of Critical Theory: Drawing on Foucault** 24
  - **Relational Conceptualizations in Critical Disability Studies** 26
  - **Relational Cultural Theory: A Historical Overview** 29
  - **A Historical Context Towards a Relational Citizenship** 33
  - **Relational Citizenship** 36
    - ***Relationship Centred-Care*** *37*
    - ***A Case for Citizenship: The Passive Model of Citizenship in the Dementia Context*** *38*
    - ***Embodied Selfhood: Merleau-Ponty, Bourdieu, and the Musical Self*** *40*
  - **Relational Caring** 45

CHAPTER 3: A REVIEW OF DEMENTIA, MUSIC, AND MUSIC THERAPY 49

- **Music in the Dementia Context** 49
  - **Music Therapy and Its Approach in the Dementia Context** 50
    - ***Definition and history of the profession*** *50*
    - ***Biomedical Approaches to Music Therapy with PLwD*** *53*
    - ***Music-Centred Perspectives in Music Therapy*** *56*
    - ***Music-Centred Music Therapy in the Dementia Context*** *64*
  - **Musical Engagement with PLwD Outside of Music Therapy** 67
    - ***Music as Life Enrichment*** *67*
    - ***Music to Challenge Stigma Associated with Dementia*** *70*
- **Songwriting** 74

Therapeutic Songwriting 75
Therapeutic Songwriting with PLwD *76*

CHAPTER 4: METHODOLOGY AND METHODS 81

Liberatory/Activist and Critical Arts-based Methodologies 81
Liberatory/Activist Arts 84
Critical Arts-based Inquiry 85

Creative Research Plan 87
Preparation 88
Setting *89*
Recruitment of Songwriters and Inclusion Criteria *90*
Gaining Consent *93*
Establishing and Building Relationships *96*
Meet the Songwriters *98*
Implementation 101
Collaborative Songwriting Sessions *102*
Documenting and Reflecting on the Creative Research Process *111*
Exhibition 113
Reflecting on and Analyzing the Entire Creative Research Process *115*

CHAPTER 5: LIBERATORY-RELATIONAL DEMENTIA SONGWRITING FRAMEWORK 121

Relational Literacies Supporting the Songwriting Process 121
Relational Knowledging 123
Drawing on Previous Relational Knowledge *125*
Sharing Parts of Myself with the Songwriters *128*
Sharing Cultural Knowledge *131*
Relational Knowledging Through Knowledge Transfer *138*
Relational Attuning 141
Attuning Through Recognition, Validation, and Encouragement *143*
Attuning to and Weaving Storylines Together *149*
Musical Attuning *151*
Relational Decision-Making 157
Summarizing and Revisiting Emerging Ideas *159*
Embracing Evolving Negotiations *162*
Playing with Sound to Create a Shared Aesthetic Vision *165*
Creating Space for Inclusive Critical Dialogue and Reflection *171*

CHAPTER 6: DISRUPTING DISCOURSE – CRITICAL CONTRIBUTIONS FROM THE LIBERATORY-RELATIONAL SONGWRITING PROCESS 180

Wisdom and Respect: A Song Co-Created by People Living with Dementia 181

Returning to Citizenship as a Theoretical Lens 181

Enacting Relational Citizenship: Assertions of Knowledge, Care, and Social Roles 184
PLwD as Embodied Knowers 184
Asserting Knowledge Through Testimony *185*
Asserting Worth through Continued Learning, Growth, and Teaching *190*
Resistance of the "Welfare Recipient" 200

PLwD as Relational Carers ... 201
Decentring Dementia: The Songwriters Chosen and Embodied Identities ... 206

The Transformative Potential of Liberatory-Relational Songwriting ... 210

Relational Deepenings: From Inclusion to Belonging and Relational Solidarity ... 219
Posthumanist Conceptualizations of Citizenship ... 220

Theoretical, Methodological and Practical Implications ... 228
Theoretical Implications ... 229
Methodological Implications ... 231
Practical Implications ... 235

Limitations and Directions for Future Research ... 237

And in the End… ... 240

References ... **242**

Appendix A: Staff Recruitment Script for Residents ... **276**

Appendix B: Staff Recruitment Script for SDM ... **277**

Appendix C: Researcher Recruitment Script for SDM ... **278**

Appendix D: SDM Information and Consent Form ... **281**

Appendix E: Resident Information and Consent Form ... **288**

Appendix F: Verbal Assent Script ... **293**

Appendix G: Getting to Know the Songwriters Interview Questions ... **295**

Appendix H: Weekly Session Plans ... **296**

Appendix I: Songwriting Reflection Worksheet ... **304**

Appendix J: Information Form and Questionnaire for Event ... **306**

LIST OF FIGURES

Figure 1: Overview of the Creative Research Process 88

CHAPTER 1: INTRODUCTION

Why Dementia? A Personal Narrative

I come to this work first and foremost as a granddaughter to six grandparents (divorce runs in the family). From a young age, I witnessed how the medicalization of aging, illness, and disability controlled and dictated the lives of these six individuals.[1] For example, my Zaidy (grandfather), Jerry, who was diagnosed with Parkinson's disease at the age of 45, moved into a long-term care (LTC) home in Toronto when he turned 58 after experiencing challenges from Lewy body dementia.[2] I remember going to visit and listening to him speak as he shared how much he missed his home, my grandmother, and his freedom. Despite this, he would always tell me stories about his work as a photographer and about his experiences photographing famous boxers. We would spend our time together singing and watching Johnny Carson reruns. One night, he yelled for a nurse to come to his room because he was in pain. No one came. The next day, he died of sepsis. When we asked the home why no one came to help him, they told us that many residents yell, and it is usually not a sign of concern. His 'yelling' was only understood as a symptom of dementia (Boyle, 2014).

My grandpa Richard was a WWII veteran who fought in the British army as an engineer specializing in mine detection. My grandpa played a part in liberating Sicily and then Naples in

---

[1] By "medicalization," I am referring to dominant framings of aging, illness, and disability understood primarily through a biomedical lens, where individuals are viewed as needing to be fixed or cured, often leading to practices that prioritize intervention, surveillance, and functional outcomes (Zaks, 2024).

[2] Dementia is a broad term that encompasses several diseases (e.g., Alzheimer's disease, vascular dementia, Lewy-body dementia, etc.) that are identified by a set of symptoms that may include memory loss, changes in mood, and difficulties with thinking, problem-solving and language (Alzheimer Society of Canada, n.d.).

1943. Though he ate four servings of French fries a day and never ate a vegetable during the time that I knew him, he lived until he was 98. In his early 90's, he developed dementia and was moved into a LTC facility. The first time I went to visit him, he told me, "It's a really nice prison."

After my grandpa (Richard) died, my grandmother's (his wife) cognitive and physical health started to decline. One day, I rushed to my grandmother's apartment after receiving a call from EMS that she had fallen earlier in the day and that they had to wait with her until a family member arrived. Upon arrival, a paramedic began to speak to me as if my grandmother wasn't in the room - "Old people are wonderful…but you know…they put a strain on the system."

Lastly, my Zaidy Willie, a Holocaust survivor, embodied resilience, strength, and courage, despite his parents and seven siblings being murdered in a concentration camp. In the early part of the war, he was shot while escaping a train bound for a death camp. He was eventually caught and confined to a cell where he and many others were abused and tortured. He once told me that whichever person was found sleeping closest to the cell door would be shot and killed in the middle of the night.

In the summer of 2019, I received a call saying that my Zaidy Willie had had a stroke. I raced into the emergency room to witness my grandfather in restraints with a blank look in his eyes. The doctor informed me that he was agitated and was "antagonizing" hospital staff. After being given antipsychotic medication, he calmed down enough so that the restraints could be removed. However, as the medication wore off, he became agitated again. This time, I witnessed what happened when they tried to restrain him. He screamed in a way that has been forever etched into my memory. It was a scream that caused me to cry out for him. The next day when I

was sitting beside him in the hospital room, he apologized to me. He explained that hospitals made him feel like he was back in a concentration camp.

In April of 2020, after a year of cognitive decline, my Zaidy Willie had another stroke. Because of a COVID-19 outbreak in the hospital, none of us could be with him. Again, we were told that because he was agitated, they had to restrain him. Every day since he died, I think about the image of my grandfather who endured the unimaginable, dying alone, thinking he was in a concentration camp.

My grandparents' experiences within a system and society that marginalize and oppress older adults, and specifically PLwD, have shaped my life and the way I come to this work. I have carried their stories with me throughout my work as a music therapist in long-term care and into this research, where they continue to inspire my commitment to building a better future for our grandparents, parents, and ultimately, our future selves.

I also believe we are at a pivotal moment in our history to change the way we treat PLwD in our communities. During the COVID-19 pandemic, over 80% of COVID-related deaths in Canada happened in LTC settings, with the majority being PLwD (Grigorovich & Kontos, 2020; Haslam-Larmer et al., 2023).[3] As someone working in LTC during this time, I saw PLwD locked

[3] Throughout this dissertation, I use the terms LTC and residential care interchangeably to describe settings that provide continuous, around-the-clock support for older adults with significant care needs. In Canada, these homes may be operated by municipal, non-profit, or private for-profit organizations. Funding for long-term care is shared between governments and residents: provincial governments subsidize nursing and personal care services, while residents are responsible for accommodation costs, although financial assistance is available for those who meet eligibility criteria. Another common form of seniors' housing in Canada is the retirement home. Unlike LTC, retirement homes are privately owned, with residents paying the full cost of both accommodation and care services they receive. The range of supports varies across retirement homes. Some provide independent living with limited assistance, while others offer assisted living services that support older adults in maintaining independence. Some

and confined to their rooms for months at a time, unable to see or visit with their family and friends. I also saw people (like my Zaidy Willie) who were forced to die without loved ones by their side. Unfortunately, I was not alone in what I was seeing. In Ontario's Long-Term Care COVID-19 Commission Final Report (2021), many residents living in LTC settings experienced "confinement syndrome," a condition prevalent among individuals put in solitary confinement (p. 19). For example, one resident living in LTC shared:

> I have been in what I call a pandemic prison and solitary since April of 2020. The solitary happens when anyone tests positive in the entire home, and every single one of us must stay in our rooms without being allowed a shower; and even same goes for when we return from a hospital stay. Fourteen days isolation, no shower. (p. 30)

The report also shared accounts from staff members who tried their best to connect residents with their family members before they died and the emotional toll of witnessing the separation of loved ones. For example, one staff member stated:

> For one resident, I sat at bedside after he died with the iPad because the family wanted to see him one more time. So I watched and listened as his wife and adult children spoke of their love and silently wept under my mask and face shield. (p. 19)

Though PLwD living in LTC facilities were mistreated and stigmatized long before the start of the pandemic, it was the horror which ensued at the start of March 2020 which forced

---

retirement homes in Canada have expanded their services to provide levels of care comparable to those found in LTC. The home where this research was conducted is one such example. Although it is formally classified as a retirement home, the intensity and scope of care provided closely resemble that of LTC. For this reason, I refer to it throughout this dissertation as both LTC and residential care reflecting its functional similarities to LTC.

society to pay collective attention to the abuse and neglect PLwD face in our healthcare system. I worry that our window is closing - that as our society begins to adapt to a new 'normal,' PLwD will once again be forgotten. It is vital that we seize this moment to amplify the voices of PLwD so their stories are heard. We must use our collective grief and outrage to change the narrative of dementia and the culture of care provided to them to ensure our grandparents, parents, and future generations are not exposed to the same suffering society has caused PLwD thus far.

The Problem

PLwD are highly stigmatized in their communities through the language and images used in academic literature, policy documents, and media that depict them as "doomed" or "socially dead" (Dupuis et al., 2016a, p. 358; Mitchell et al., 2011). Stigma related to dementia has profound consequences for PLwD and their family members, shaping how people think about PLwD, their relationships with others, and the structures and experiences of care (Dupuis & Kontos, 2026). These experiences lead to fear, isolation and exclusion, and the silencing of PLwD, decreasing their quality of life and denying them their human rights (Dupuis & Kontos, 2026; Kontos et al., 2018). As I have also described, these experiences also lead to abuse, neglect, premature death, and even suicide (Kontos et al., 2018; Mitchell et al., 2013).

The biomedical model, its practices, and related discourse have had a particularly devastating effect on the way PLwD are viewed and treated in society (Mitchell et al., 2013). For example, Kontos et al. (2016) argued that by focusing largely on individual deficits, the medical model often ignores or minimizes the capabilities and diverse ways PLwD live in and navigate the world. Additionally, by focusing on "fixing" or "curing" PLwD, the biomedical model contributes to a culture where illness and disability are seen as a fault and problem of the individual rather than something embedded in broader social, cultural, political, and institutional

systems and structures (Dupuis & Kontos, 2026). According to Kontos et al. (2018), biomedical discourse also perpetuates language that depicts PLwD as unable to foster meaningful relationships or engage in purposeful activities and depicts PLwD as "irrational, disruptive, and uncontrolled" (Mitchell et al., 2013, p. 4). These harmful labels contribute to PLwD being stripped of their autonomy, social citizenship, and human rights (Dupuis et al., 2012a; Nolan et al., 2002; Kontos & Miller, 2017). These experiences are exacerbated for PLwD living in LTC settings and especially for PLwD in later phases of the dementia journey.[4]

In the dementia context, the biomedical model is often taken up through prescribing medication and therapeutic interventions to treat symptoms of dementia, including anxiety, agitation, memory loss, and wandering behaviours (Mitchell et al., 2013). Though psychotropic medications have been used heavily to manage these symptoms, studies indicating the dangerous side effects of such medications have called for non-pharmacological approaches to symptom management (Kontos & Grigorovich, 2018). As such, creative arts therapies, specifically music therapy, have been widely embraced as an effective non-pharmacological approach to reducing symptoms of dementia (Ijaopo, 2017; Kontos & Grigorovich, 2018). While dementia advocates, critical scholars, and music therapists have advocated for more humanizing approaches to the arts and music with PLwD (Basting, 2018; Bellass et al., 2019; Jonas-Simpson et al., 2022; Young, in press), the biomedical model still influences much of the research, literature, and public discourse on music, and specifically music therapy, in the dementia context (Beard, 2011; Clements-Cortes, 2020; Jonas-Simpson et al., 2020; Kontos & Grigorovich, 2018).

[4] As dementia progresses, many require increasing support with activities of daily living and, in the later stages, may need around-the-clock assistance.

Though the academic literature seems to lean toward more biomedical approaches to music-making and music therapy with PLwD, I argue that the biomedical model does not align with a significant portion of music therapy theory, practice, and research outside the dementia context. For example, many music therapists do not practice within a biomedical framework (Aigen, 2014a), choosing instead to align with approaches to practice which center relationships/relationality, reciprocity, community, and social justice (Baker, 2015; Rolvsjord, 2010; Stige & Aarø, 2012). Music therapists who take a relational and critical approach to practice are particularly well-suited to challenging stigma associated with dementia. I will describe this more in Chapter 3 of this dissertation.

A growing body of literature also supports the use of the arts as an effective way to challenge stigma surrounding dementia (Dupuis et al., 2016a; Dupuis & Kontos, 2026; Jonas-Simpson et al., 2020; Kontos et al., 2020). For example, Dupuis, Kontos and colleagues (see Dupuis et al., 2021a, 2025; Kontos et al., 2020) used critical participatory research methodologies to develop a research-informed drama called *Cracked: New light on dementia*. The creation of *Cracked* was a collaborative process between academic researchers, actors, PLwD, family members, and professionals. Through fostering a dialogical space (i.e., an environment where understandings can be challenged and new learning and unlearning can be supported through open discussion, openness to difference of opinions, mutuality, and respect) (Boyd & Sherry, 2024), PLwD, their family members, and healthcare professionals working in LTC and other healthcare settings shared stories about the harmful impacts of the dominant discourse on PLwD. The researchers and actors then used these stories to create a performance highlighting the lives of two PLwD and their care partners. The play's performance created a space where audience members could reflect critically and aesthetically on their assumptions and

biases regarding PLwD (Gray et al., 2020). In another study, Dupuis et al. (2016a) used visual arts to challenge preconceived notions surrounding the limitations of PLwD. However, despite the demonstrative capacity of the arts to challenge stigma associated with dementia, the use of music as a liberatory art in this context is much less understood.

Though the use of music for social justice/liberatory purposes is underutilized in dementia spaces, music, and specifically song, has been shown to be a powerful tool for resisting oppression and marginalization, raising awareness, and exposing oppressive and dehumanizing policies and practices. When I think of songs that challenge social structures, I think of protest songs that raised awareness of issues such as war, women's rights, and the civil rights movement. For example, *Strange Fruit* recorded by Billie Holiday (1939), a song protesting the lynching of Black Americans in beginning of the 20th century, was seen as "the first significant protest in words and music, the first unmuted cry against racism" by jazz composer Leonard Feather and "a declaration of war… the beginning of the Civil Rights movement" by producer Ahmet Ertegun (Margolick, 1999, p. 92). Another example can be seen in the protest songs of Phil Ochs (1940 – 1976), who brought attention to labour issues, the civil rights movement, and the Vietnam War in the 1960's and 70's.

It is from examples like these, my experience writing songs with PLwD in both community and LTC settings, and my career as a singer/songwriter that I have come to believe songwriting can support PLwD in asserting their personhood and relationality, and in resisting social stigmatization and the injustices it causes. Changing the discourse around dementia is an important first step in transforming how we think about and care for PLwD. Yet, even within research grounded in liberatory and participatory approaches, opportunities for PLwD to engage in collaborative songwriting, and in stigma-reduction research more broadly, remain limited,

with those in later phases of dementia rarely, if ever, included (as exceptions see Dupuis et al., 2012a; Fortune et al., 2015; McKeown et al., 2016). With the number of PLwD expected to increase by 75.6 million by 2030 and triple by the year 2050 (Boscart et al., 2019), and the current social climate where society is paying closer attention to the treatment of PLwD, it is imperative that we advocate for more inclusive and liberatory approaches to music-making which celebrate the capacities, creativity, relationality, personhood, and relational citizenship of PLwD, including PLwD in later phases of the dementia journey.

Recognizing and supporting the social and relational citizenship of PLwD has been advocated as an essential counter approach to the dominance of the biomedical model of dementia (Bartlett & O'Connor, 2010; Kontos et al., 2017; O'Connor et al., 2022; Phinney et al., 2016). I describe social and relational citizenship more deeply in the next chapter, but for me, they hold promise in their recognition of the socio-political contexts that can limit and support access and opportunities for PLwD, especially PLwD living in LTC settings. Relational citizenship also introduces the importance of embodied selfhood for PLwD, and the multiple ways PLwD express valued aspects of themselves through embodied expression (Kontos et al., 2017). Although some research has explored the ways leisure and the arts can support the social and relational citizenship of PLwD (Dupuis et al., 2022; Jonas-Simpson et al., 2022; MacTavish, 2025; Phinney et al., 2016), much of this research focuses on PLwD in the early phases of dementia and living in the community (for exceptions, see Kontos et al., 2017; MacTavish, 2025; Miller & Kontos, 2016). Very little research explores the possibilities of collaborative songwriting in supporting the social and relational citizenship of PLwD in LTC and residential care settings, including PLwD in later phases of dementia.

Research Objectives and Questions

My primary objectives in this study were to challenge the stigma of dementia for PLwD by providing an alternative narrative through music co-created with PLwD, and to document and explore the possibilities of a collaborative, liberatory songwriting process for challenging dominant stigmatizing discourses. Specifically, guided by humanist relational theories, critical and liberatory arts, and community and relational models of music therapy, this research supported PLwD in a collaborative songwriting project aimed at:

1) highlighting the continued relational and creative capacities of PLwD in LTC settings,
2) amplifying the voices of PLwD in LTC settings and supporting them in asserting their personhood and relational citizenship,
3) providing a collaboratively created counter-narrative of dementia using music,
4) documenting and sharing a collaborative, liberatory songwriting methodological process with PLwD and examining how such processes support the relational citizenship of PLwD, and
5) exploring the possibilities of collaborative, liberatory songwriting in challenging the stigma associated with dementia.

Research questions that informed the process were:

1) How do PLwD living in LTC settings experience a collaborative, liberatory songwriting project?
2) How does collaborative liberatory songwriting support the relational and creative capacities and relational citizenship of PLwD in LTC settings?
3) What relational processes support collaborative songwriting with PLwD, including PLwD later in the disease progression?

4) How might a collaborative, liberatory songwriting process and the resulting song/film challenge stigma associated with dementia? What are the transformative possibilities?

In the next chapter, I describe my positionality as a critical and relational scholar and the theories that guided my research. Chapter 3 provides a literature review and critique of the current landscape of music and music therapy in the dementia context, including the music therapy theories and models I drew on to guide my collaborative, liberatory songwriting process. In Chapter 4, I outline the methodology, methods, and procedures used throughout the research process. In the last chapters of this dissertation, I turn to addressing my research objectives. Chapter 5 primarily focuses on Objective 4 and presents the results of an analysis of the collaborative songwriting process. In this chapter, I present the Liberatory-Relational Dementia Songwriting Framework and describe the relational literacies and processes that supported the relational and creative capacities, personhood and relational citizenship of the songwriters (i.e., Objectives 1 and 2). It is my hope that this process might inspire and inform other collaborative and liberatory music-making processes with PLwD and other stigmatized populations. Lastly, Chapter 6 addresses Objectives 3 and 5 and explores how the collaborative songwriting process and the resulting film challenge dominant discourse and public perceptions of dementia.

CHAPTER 2: THEORETICAL POSITIONALITY

Although I continue to reflect on my theoretical positionality, I primarily see myself as a critical and relational researcher embedded in constructionism. In this chapter, I describe my ontological and epistemological alignment, as well as the theories that guided the research process.

Ontological and Epistemological Alignment

Ontological Alignment

Schwandt (2015) described ontology as "the philosophical study of the nature of existence, being, or reality" (p. 221). I primarily subscribe to the ontology of humanism which places human knowledge at the forefront of understanding the universe and posits that humans are "endowed with the capacities of reason, consciousness and agency" (Barker, 2004, p. 88). However, while I align with humanism, it has also been critiqued for perpetuating ways of living and being which prioritize the independent self over others (Jordan, 2017; St Pierre, 2000), and, as I discuss later in this chapter, aligns with Enlightenment philosophy which places notions of selfhood and knowing in brain processes (ideas that contribute to discourse which strips PLwD of their personhood as their cognition declines) (Kontos et al., 2017). To address these critiques, particularly the limited attention given to relational mechanisms in the construction of reality, I turn to Gergen's (2009) conceptualization of a relational ontology.

Drawing on the work of Heidegger (1962) and Dewey and Bentley (1949), Gergen (2009) posits that there is no separation between subject and object, as they can only exist in relation to each other, a concept referred to as "relational being" (p. 36). For example, consciousness exists only if it is perceived by another being or object. If there is no perceiver, there is no consciousness, and if there is no consciousness, there is no perceiver (Gergen, 2009).

It is through this mutually dependent relationship that Dewey and Bentley (1949) advocated for a shift in how we view the relationship between subject and object (as a one-way causal relationship) to a transaction (existing as a co-dependent relationship) (Gergen, 2009). The process of transacting with another relational being is referred to as "co-action" (Gergen, 2009, p. 68). It is also important to recognize that co-action extends beyond human-to-human interaction and encompasses our relationships with all things. For example, Gergen (2009) stated that even isolated activities, such as brushing our teeth or reading, are relational processes through the collective meaning society has given to them. Therefore, Gergen (2009) argued that "we cannot specify what exists before there is co-action, because the moment we try to enumerate these fundamentals we are indulging in the fruits of co-action" (p. 37). What I take this ontological perspective to mean is that we exist in an interrelated web of connections with each other and the things around us (e.g., nature, structures, systems, and communities), and our experiences in these relationships shape our lived realities. It should also be noted that a relational ontology, as Gergen (2009) defined it, differs from poststructural conceptualizations of relational ontology. Poststructural perspectives typically argue that ontological priority is granted to neither subject nor object, such that humans are not privileged as the primary center of knowledge but rather are understood as entangled with both living and non-living entities (Barker, 2004). In contrast, the relational ontology informing this research continues to center human beings and human meaning-making, while explicitly challenging the primacy of individuality by emphasizing relational processes as foundational to experience and understanding.

As a critical researcher, I align with this ontological perspective for many reasons. First, relationality forces us to break from the traditional hierarchy of subject vs. object (in this case, I

am referring to a person in a position of power in relation to a marginalized person or group) and replace it with an ethic of care, which gives ontological priority to neither. For example, drawing on Levinas (1985), Gergen (2009) stated that, because we live in a world composed of relations, we are responsible for caring for these relationships. To me, caring for relationships means attending to the relational processes that make up these relationships. For example, as a researcher, I have an ethical obligation to care for the relationship between myself and the people who choose to participate in the research. Because PLwD are so often left out of the research that informs policies and decisions made about their lives (Dupuis et al., 2012a), this means working with PLwD as equal collaborators in the research process.[5] Additionally, adopting a relational ontology means attending not only to relationships between people but also to those between structures, systems, and policies that shape lived experience. For example, as a researcher, I am not only in relationship with PLwD, but must also attune to how structures, systems, and policies function in relation to PLwD, either supporting or oppressing them.

Another component of a relational ontology that resonates with me is the notion of change and transformation. For example, Santos (2015) stated that in the interconnections between relations and relata, "new types of relations, relata, and relational systems are continuously generated, destroyed and transformed" (p. 440). A similar viewpoint is held by Gergen (2009), who argued that because the concept of individualism is a "collective construction" (p. 16), this construction can be collectively undone to create more just and equitable ways of being and living in the world. The idea of relational transformation is

[5] More detail on the ways participatory methodologies will be utilized in the context of this research will be explored in Chapter 4.

particularly relevant to this research, as the stigmatization and oppression experienced by PLwD are not fixed but can be undone and transformed to create a better future. It is the recognition of and commitment to relational ethics and transformation that will drive this research.

Epistemological Alignment: Social Constructionism

If ontology answers the question of "what is," epistemology is concerned with answering the question of how we know what we know (Crotty, 1998). Social constructionism argues that knowledge is contingent on the social meanings we assign to our material world (Crotty, 1998). For example, Crotty (1998) argued that, while things in our natural world exist despite our knowing them (e.g., the mountains or the sun), it is only through engaging with these objects that they take on meaning. Additionally, it is not enough to say that individuals give objects subjective meaning; rather, this meaning is embedded in the broader culture's social fabric. Therefore, while objects exist on a material level, the meanings ascribed to them are entirely socially constructed (Crotty, 1998; Fish, 1990).

Social constructionists believe that human beings are born into a world embedded with meaning. This meaning is created through human interaction with one another and with the world around them. When we are born, our understandings of knowledge and reality are filtered through a cultural and political lens at a particular time in history. Furthermore, our culture brings certain ideas into focus while overlooking others (Crotty, 1998). Subjects construct the meaning of objects depending on their constructed reality (Burr, 1995; Crotty, 1998). Various subjects then construct different meanings of the same object or phenomenon based on the historical, cultural and political lens through which they are viewing it at the time (Crotty, 1998). As a critical researcher, then, I am interested in how historical, cultural, political, and social processes construct certain understandings of the world while ignoring, silencing or excluding

other understandings. The ways we view the world and the nature of reality shape how we operate in and navigate it.

In trying to decipher how social constructionism views the production of knowledge, I found it helpful to draw on Burr's (1995) four tenets of social constructionism and how it draws on the relationship between the social, historical, and cultural components of meaning-making. These four tenets are:

1) **Knowledge is produced and sustained through social processes** (p. 3)

   Like Crotty's (1998) definition of social constructionism, Burr (1995) argued that knowledge is constructed between people through language and social interactions, which shape our understandings of the world. Knowledge is therefore not based on an objective 'truth', but rather on the ongoing ways cultures construct and sustain meaning through social and relational processes (Burr, 1995). Additionally, social constructionism holds that we are born into a world already embedded with meaning and that we interpret our world through the lens of the culture we are born into (Fish, 1990).

2) **Knowledge is both historically and culturally specific**

   Burr (1995) also argued that knowledge is not only socially produced but also contingent upon its relationship with the culture and historical context in which it exists. For example, Foucault's (1965) genealogy of illness and disability revealed that people with disabilities were once considered to possess godly qualities and that it was not until society deemed these individuals as "mad" that they were institutionalized in an attempt to "normalize" them. A similar viewpoint can be taken with the treatment of PLwD. For example, the concept of sending older adults and

PLwD into LTC settings is a Global North phenomenon rooted in ageism and fears of death and dying, meant to hide the frailties that come with aging and realities of our mortality from the rest of humanity. When individuals are seen as a "burden" on society, they are removed (Hazan, 2002; Minkler & Estes, 1999; Mitchell et al., 2020). This view of older adults and PLwD is also historically and culturally rooted in capitalism, which views a "good citizen" solely based on their productive value (Minkler & Estes, 1999).

3) **Knowledge and social action go together** (p. 3)

   Because knowledge is culturally and historically dependent, there is no one objective truth. Instead, there are many possible ways to socially construct our lived realities. Barr (1995) argued that in each social construction lies the potential for people to construct new meanings or ways of doing. In this way, social constructionism invites an undoing or redoing of the ways we produce knowledge.

4) **Social constructionism calls for a critical stance towards our taken-for-granted knowledge** (p.3)

Lastly, and perhaps most important for the purposes of this research, social constructionism calls for a critical stance towards the ways culture produces and reproduces knowledge, privileging some and oppressing others (Crotty, 1998). Because we are born into a world of already-constructed knowledge (Fish, 1990), it is important to recognize how our culture prioritizes certain discourses or realities over others. For example, as someone who was born into a culture that views PLwD as "incompetent" and in need of "curing" or "managing" (Mitchell et al., 2013), it is important not to take this knowledge as an objective truth but rather a product of social–relational processes and

norms. According to Burr (1995), social constructionism requires us to critically examine the ways our taken-for-granted assumptions shape our perceptions and actions in the world. It is by taking a critical stance towards seemingly static knowledge claims that we can expose false consciousness and work to undo or create new cultural understandings that aim to build a more just and unified world.

In summary, social constructionism encourages transformation by thinking critically about the ways power, language/discourse, ideologies, and intersections of social conditions in the world function in relational processes, in our relationships with others, within our community, cultures, institutions, and broader society. By challenging dominant ways of constructing the world and providing alternative discourses, new ways of being and acting can be imagined and realized.

Theoretical Alignment: Critical and Relational Theories

If ontology relates to what is and the nature of reality, and epistemology is concerned with "how we know what is", then theory is how we take that knowledge and apply it to the world around us (Schwandt, 2015). Additionally, the theoretical perspectives we align with are often influenced by our ontological and epistemological beliefs (Gray, 2013). In relation to a social constructionist epistemology, I embed myself within a critical theoretical framework that challenges the notion that the way the world functions is static and unchangeable and instead seeks to make actionable changes for a more just future (Crotty, 1998). Critical theory is not only the driving force behind this research but has also fundamentally changed the way I view and act in the world, both in my personal life and in my work as a music therapist and researcher. It is a theoretical lens which has made me a better, more aware, more reflective, and more empathetic person and has influenced the way I view and engage with PLwD.

Tenets of Critical Theory

Although there are many critical theories, critical theory can be broadly defined as a "way of submitting the very givenness or taken-for-granted character of the social world (its concepts, understandings, cultural categories, etc.) to critical reconsideration" (Schwandt, 2015, p. 51) for the purposes of liberation (Crotty, 1998). Rooted in social constructionism, I take this to mean that the ways we assume the world functions (e.g., the systems, structures, concepts, etc.) are not a given, but a product of our social landscapes, which have been socially constructed. I also take this to mean that through critical thinking and critical research, we can undo these systems and structures to create better futures. For example, Crotty (1998) stated that research rooted in critical theory "is a contrast between research that seeks merely to understand and research that challenges" (p. 113).

In critical research, researchers are primarily concerned with issues of power and their role in harmful hegemonic discourses, oppression, and injustice (Crotty, 1998). It is through critical research that the way power functions is uncovered and challenged, making way for a more socially just world (Crotty, 1998). Upon reading more about critical theory, I came to understand that it is a broad philosophical framework adopted by many theorists in various ways. For example, my positionality as a critical scholar began to take shape when I was introduced to the critical theory movement emerging from the Frankfurt School. The Frankfurt School was a social research institute established in 1923 by a group of post-Marxist philosophers who sought to adapt Marxist ideology to expose how dominant narratives promoting capitalism led to inequity and oppression (Crotty, 1998; Horkheimer & Adorno, 1972; Schwandt, 2015). In an essay written by Horkheimer (1995) (a member of the Frankfurt School) as cited in Brookfield (2014), critical theory postulates the following: (a) western democracy functions by producing

and reproducing ideologies which contribute to economic, racial, and class inequality; (b) this way of life is normalized and accepted as a natural state of being; and (c) the role of critical theory is to expose and understand the way power and oppression functions in society and seek to challenge/change it.

Although critical theory has been contextualized in a myriad of ways, Kincheloe and McLaren (2011, pp. 288 - 291) outlined the following tenets of critical theory as it has developed and evolved towards the end of and post-20th century that I find particularly relevant to my work:

1) **Critical enlightenment:** Critical theory examines power relations and structures and how they function. These power relations and structures are formed through social and historical contexts (i.e., socially constructed). For example, the treatment of PLwD, especially in LTC settings, is historically rooted in a biomedical and institutional model of care which seeks to "fix", "treat", or "manage" people with disabilities (Dupuis, 2012b). Additionally, some groups of people are privileged over others, resulting in oppression of the non-privileged group. Oppression continues through the oppressed group, seeing their position as a given. Critical theorists challenge ideologies that view social inequity as a given and instead view social inequities as produced and maintained by power relations and structures. For example, the biomedical model silences PLwD by seeing medical and other healthcare practitioners as the experts. In this model, practitioners are viewed as knowing what is best, and PLwD are expected to comply (Kontos et al., 2018).
2) **Critical emancipation:** Critical research seeks to challenge and transform the systems and structures that silence marginalized groups and limit their ability to inform decisions that shape their lives. This is particularly relevant to the present

study, as PLwD are frequently excluded from public, professional, and policy-related conversations about care, citizenship, and social participation (Dupuis et al., 2012a). Rather than speaking for PLwD, this research aims to cultivate conditions through which they can articulate how they wish to be understood and treated in the world. In doing so, this study seeks to contribute to shifts in how dementia is perceived by those involved in shaping care practices, institutional responses, and policy discourse.

3) **The rejection of economic determinism:** Critical theorists reject the Marxist notion that economic conditions influence all issues related to the human condition. Instead, they recognize that there are many facets of oppression that are often interconnected, and it is important not to prioritize one type of oppression over another (Crenshaw, 1991). Instead, we must be aware of all forms of oppression and their intersections. For example, ageism, ableism, and gendered ideologies often intersect in ways which contribute to the experiences of PLwD (i.e., an individual who has dementia and identifies as transgender will have a different experience than someone with dementia who identifies as cis gender). Oppression also manifests itself in different ways, in what Young (1990) referred to as the 'faces' of oppression, including exploitation, marginalization, powerlessness, cultural imperialism, and violence. We must be aware of and attend to all forms of oppression in the dementia experience.
4) **Linguistic/discursive power:** Critical theorists do not see language as an "objective conduit of description of the real world" (p. 291) but as a means of constructing our social landscapes, and these constructed landscapes serve to elicit power/control over certain groups. For example, discriminatory language used to describe PLwD,

> reinforced through public and academic discourse, is used to construct a particular understanding of dementia that can then be used to justify responses through social policies, regulations and laws (Mitchell et al., 2013). Labelling PLwD as "aggressive," for instance, is perpetuated through how PLwD are depicted in the media and in much research on "behaviours," resulting in social policies and practices that seek to restrain and sedate PLwD in LTC and other settings.

It is in these central tenets of the Frankfurt School and critical theory more broadly that I have been able to contextualize and make sense of the ways PLwD have been oppressed and discriminated against in society. It has also encouraged me to engage in research which critiques traditional postpositivist conceptualizations of knowledge and acknowledges the importance of research which seeks to change social landscapes. Using these tenets as an anchor, critical theorists engage in research aimed at addressing social inequalities and liberating oppressed groups through a process called praxis (Crotty, 1998; Schwandt, 2015). To gain a fuller understanding of praxis and its relationship to liberation, I draw on the work of the critical philosopher and activist Paulo Freire.

Freire's Critical Pedagogy

Paulo Freire (1921–1997), a Brazilian educator who developed literacy education programs for oppressed groups in Brazil, is best known for his creation of critical pedagogy and his book Pedagogy of the Oppressed (1972). In this book, Freire (1972) argued that only the oppressed can liberate themselves. As an educator, Freire (1972) believed in the power of education and knowledge to support oppressed groups in their fight for liberation. However, unlike traditional models of education, what Freire calls banking education, where the teacher imposes knowledge onto students as they passively take in information (i.e., an approach to

teaching which places the teacher in a position of power), Freire advocated for a dialogical approach to teaching he called "problem-posing education" (p. 79). Problem-posing education aims to disrupt the teacher-student power differential by "reconciling the poles of the contradiction so that both are simultaneously teachers *and* students" (p. 72). It is in this relational process that students resist the role of passive learners, and teachers embrace being moved by and taught by their students. At the core of problem-posing education is the act of critical dialogue whereby students are empowered to reflect on the ways their lived reality and the power structures around them have contributed to oppression and "come to see the world not as a static reality, but as a reality in process, in transformation" (p. 83). Freire (1972) referred to this process as praxis, or "the action and reflection of [human beings] upon their world in order to transform it" (p. 79).

Freire's concept of problem-posing education resonates with me for two reasons. First, problem-posing education demands a breakdown in hierarchy between student and teacher. In the disruption of the student/teacher relationship, Freire (1972) disrupts the notion of the relationship between subject and object. This is important in the context of this research, as much of the existing research in the dementia context is conducted on, rather than with, PLwD (Dupuis et al., 2012b). By adopting a problem-posing approach to this research, I can disrupt traditional notions of what it means to be a "researcher" and work alongside PLwD as "critical co-investigators" (Freire, 1972, p. 81).[6] Problem-posing education also excites me for the ways it brings learning outside of the classroom and into our everyday lives. As a critical researcher, it is

[6] Similar disruptions of power hierarchies can be found in many of the music therapy theories that will be used to guide this research, which I describe further in Chapter 3.

essential that research leaves the confines of the academic space and literature to make change in our communities. For example, this research aimed to challenge societal perceptions of dementia through both the collaborative songwriting process and by sharing the co-created song/film with PLwD at a community event. By sharing the song/film with the broader community, I was able to explore how it might challenge attendees' perspectives on the capabilities of PLwD and how these changed perspectives might shift the ways attendees interact with PLwD.[7] Although the concepts explored in critical theory (e.g., liberation, praxis, power) provide the theoretical basis for this research, I must reconcile several points of contention. I turn to this discussion next.

A Critique of Critical Theory: Drawing on Foucault

While I align with many critical theoretical stances on agency, I struggle with how they seem to lack a relational understanding of how the world functions. For example, while critical theory offers a lens with which we can challenge and actively change taken-for-granted narratives and binaries, it is argued that using language embedded in humanism reinforces these binary structures (St. Pierre, 2000). Because critical theory places equal value on subject and object, it adheres to the humanist notion that our world is comprised of totalizing categories, meta-narratives, and binaries (Johnson & Parry, 2015). For example, St. Pierre (2000) argued that the use of language like "oppressor/oppressed," "abled/disabled," and "free/enslaved" used so often in critical theory perpetuates these binaries by placing them into categories that privilege one over another, failing to recognize the complexities of power relations. It is this essentializing language which limits the role of power in acts of liberation. For example, post-structural

[7] I provide a discussion of the specific ways attendees' conceptualizations of dementia were challenged and the possibilities for personal and social transformation in Chapter 6.

scholars argue that within the realm of humanist binaries, power is perceived as something one either has or does not have (Gutting, 1995; St. Pierre, 2000). However, according to Foucault (1978; cited in St. Pierre, 2000), power cannot be "acquired, seized, or shared, something that one holds on to or allows to slip away" (p. 94). Instead, Foucault (1978) described power as being without binaries and much more relational than the constraints placed on it by humanist theories (St. Pierre, 2000). For example, Foucault (1978) stated that power is not a single institution nor something humans are born with, but something that flows between us (i.e., a relational process). Additionally, power is not innately negative. For example, Foucault (1991) argued that: "We must cease once and for all to describe the effects of power in negative terms: it 'excludes', it 'represses', it 'censors', it 'abstracts', it 'masks', it 'conceals'. In fact, power produces; it produces reality; it produces domains of objects and rituals of truth" (p. 194). In this, Foucault also saw the possibilities of knowledge as a form of power. In a society which strips PLwD of their human rights and excludes PLwD from participating in research that impacts their daily lives, this conceptualization of power-knowledge recognizes that by virtue of having dementia, PLwD can be supported in sharing what they know about living with dementia, contributing to understandings of those experiences, and in advocating for how they want to be viewed and treated.

It is through viewing power beyond the confines of either/or and towards a more relational lens that we can push against the systems and structures which oppress and marginalize PLwD by using power as a form of resistance. For example, by understanding power as relational, we can resist harmful policies and practices which strip PLwD of their power. We can do this by shifting our view of PLwD as a group who are powerless, to one that sees power

as embedded in all relations, as a relational process, and by attending differently to how power is taken up in the context of this research.

Drawing on relational understandings of power (and sitting with these tensions) has also provided a useful lens for understanding the complexities of critical perspectives in disability studies and their relationship to the dementia experience. In the following section, I explore how relational developments in critical disability studies have encouraged me to think beyond essentializing concepts and towards a more relational approach to research and practice.

Relational Conceptualizations in Critical Disability Studies

Through engaging with the literature on social and relational models of disability, I have come to understand the importance of shifting our focus from the biomedical model to these more nuanced models. In doing this, I see how our relationships with all things (bodies, people, structures, systems, ideologies, laws, physical space, etc.) shape the experiences of PLwD and recognize the value of attuning to both sociopolitical impacts of disability and personal experiences of illness in supporting PLwD in sharing their stories.

Unlike the biomedical model which places the "problem" of disability on the individual and focuses on "fixing", "rehabilitating', or "curing" disability (Oliver & Barnes, 2012; Thomas, 2004; Titchkosky & Michalko, 2009), the social model of disability states that our understanding and experiences of disability are informed by the cultural systems and structures we are embedded in (Conrad & Barker, 2010). For example, Davis (1997) argued that "We live in a world of norms, and both medical and welfare definitions of disability define people in their relation to the norm" and that the "the idea of a norm is less a condition of human nature than it is a feature of a certain kind of society" (p. 9). Therefore, the social model of disability reframes disability from something located within the individual to a product of how our social world

produces and gives meaning to it. For example, in describing the social construction of disability, Davis (2000) stated:

> Disability is not so much the lack of a sense or the presence of a physical or mental impairment as it is the reception and construction of that difference. An impairment is a physical fact, but a disability is a social construction. For example, lack of mobility is an impairment, but an environment without ramps turns that impairment into a disability. A disability must be socially constructed; there must be an analysis of what it means to have or lack certain functions, appearance and so on. (p. 56)

Through taking up the social model of disability in my music therapy practice, I have both shifted the way I use and see the value of music in the dementia context and how I understand the role of the music therapist. While an exploration on these shifts will be described more thoroughly in Chapters 3 and 4, it is important to note that the social model of disability has drastically changed my perspective of practice, moving me from a music therapist who aimed to "fix," "slow-down" or "prevent" symptoms or so-called "behaviours" of dementia, to a therapist who sees how this way of practice perpetuates the stigmatization and oppression of PLwD. For example, when we think of "behaviours" of dementia as being a symptom of the disease itself, what might we be missing? Are these "behaviours" a symptom of the disease or a reaction to oppressive institutions which keep PLwD on a locked unit in a LTC setting? What are the implications of this (Dupuis et al., 2012b)? It is through the social model of disability that we can ask these questions, reshape our understandings of dementia as being an "individual problem," and reimagine the laws, practices, discourses, social and physical spaces, and systems in the world that oppress and marginalize PLwD.

Though the social model of disability has provided me with a critical lens for reflecting on how biomedical models of care harm PLwD, as a critical and relational researcher, I also wonder about the potential implications of placing disability solely within a social context. In only seeing the dementia experience as a product of societal forces, I worry that we risk diminishing the very real challenges PLwD face outside of social oppression and stigmatization. While I agree that much of the suffering PLwD experience is largely rooted in societal discourse and treatment, it seems ethically irresponsible to ignore the very real challenges PLwD face in the context of the illness itself. For example, is it possible that even if society did not stigmatize or institutionalize PLwD, it might be distressing to potentially not recognize someone you love? What about the frustration of having difficulty swallowing your favourite foods? And while I recognize that the discomfort accompanying these situations might be alleviated through non-medical models of care, I argue that there is something inherently unsettling about potentially not knowing who someone is or the changes that come with the progression of the disease itself. Therefore, I argue that engaging in this research solely with the understanding that the dementia experience is influenced by societal barriers is not only essentializing and un-relational but also risks silencing the voices and full experiences of PLwD.

Similar concerns have been discussed in the disability literature, critiquing the social model of disability for separating impairment from disability, thus perpetuating similar modernist binaries inherent in the biomedical model (see, for example, Shakespeare & Watson, 2001; Thomas, 2004). By taking illness/impairment out of the discussion, Shakespeare and Watson (2001) have argued that we fail to account for the fact that impairment and disability are intrinsically related to one another through "biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision" (p. 22). By not attending to

the ways impairment impacts the experience of disability, we fundamentally silence disabled people in their potential experiences of physical or mental discomfort, thus not recognizing the oppression impairment can play in the disability experience (Williams, 2001). Thomas (2004) advocated for the adoption of a social relational model of disability, arguing that ignoring impairments in social models of disability is problematic, while also emphasizing that "disability *only* comes into play when the restrictions of activity experienced by people with impairment are *socially imposed*" (p. 580). By adopting a relational framework in this research, I believe that the theories I employ must truly embody relationality. This means attuning to *all* parts of the dementia experience (not just the social or societal, but also the physical, emotional, and individual experiences). A social-relational model of disability supports me in recognizing impairment and how it might shape individual experiences of dementia and the way ableism and social structures that reproduce ableism, dis-able PLwD.

Critical theory and critical disability studies offer a lens with which to challenge, resist, and change harmful discourse and practices which oppress PLwD. However, when considering the dementia experience from a relational standpoint, it is essential to draw on relational theories that highlight specific relational processes and how they materialize in practice. The remainder of this chapter will explore the relational theories underpinning this research. Specifically, I will draw on the central tenets and concepts of relational cultural theory, relational citizenship, and relational caring, and discuss how they will inform this research.

Relational Cultural Theory: A Historical Overview

Critical feminist researchers at the Stone Centre in the US were among the first to advocate for relational understandings and approaches in research and practice. Relational Cultural Theory (RCT) emphasizes the interdependencies and reciprocities that underpin caring

relationships and makes explicit the importance of relationships to quality care, growth, and overall quality of life. Although embedded in humanism, like Gergen's (2009) conceptualization of relational ontology, RCT challenges the dominance of individualism in psychological theories and advocates a shift towards relational processes (Jordan, 2017). Specifically, these scholars argued for more accurate representations of women's experiences in traditional psychological theories (Jordan, 2008) by challenging the notion that the ways behaviours attributed to women (such as empathy and the need for relationships) pathologized women as being too needy or emotional (Jordan, 2017; Jordan et al., 2004). For example, relational ways of being exhibited by women were often viewed as "fluff, add-ons, or signs of weakness and inadequacy," not only in psychology but in society as a whole (Jordan, 2017, p. 237).

RCT disrupts traditional psychological theories and the ways they have discriminated against women by reframing them as strengths. For example, RCT argues that all people "grow through and toward relationships throughout the life span" and that relationships built upon "mutual empathy, creativity, and worth" contribute to a better and more just society (Jordan, 2017, p. 228). While RCT initially focused on advocating for women's rights specifically, it now extends to encompass all people, particularly marginalized groups (Jordan, 2017).

RCT also states that in a society that values independence and competition as markers for success, people who meet these markers are afforded power, while those who do not are viewed as failures and subjected to cultural violence (Jordan, 2017; Jordan et al., 2004). When dominant groups hold onto power and deny others the opportunity to share in this power, disconnections occur (Jordan, 2017). Jordan (2008) described this disconnection as the silencing and isolation of non-dominant groups as a tactic to weaken "the representation of their reality in dominant discourse" (p. 3). For example, in a society that equates success with independence and

autonomy, individuals viewed as dependent or "incompetent" are made to believe that they, and not societal structures, are responsible for their oppression (Jordan, 2017). This sentiment is also supported by Gergen (2015), who argued that societal values on independence and autonomy have led to the belief that disease or disability (i.e., "conditions" that require assistance) are an individual's fault. Therefore, we disregard the socio-cultural conditions that contribute to a person's situation, leaving the societal structures which uphold these discriminatory discourses untouched (Gergen, 2015). In the dementia context, we see this played out in the ways society views PLwD as "irrational, disruptive, and uncontrolled" (Mitchell et al., 2013, p. 4) without acknowledging how social structures and public discourse strip PLwD of their personhood and citizenship status (Kontos et al., 2017) (i.e., use of psychotropic medications to manage misunderstood expressions of PLwD, confinement in locked units in LTC settings, the lack of inclusion of PLwD in decision-making processes in practice and in research that informs policies about their lives, etc.).

RCT also recognizes how socio-cultural contexts have created a culture that privileges power over relationships and critiques the systems and structures that prioritize individualism, or what Jordan (2017) called the separate self. In a self-first world, feelings of well-being and safety stem from one's ability to set boundaries, be independent, remain autonomous, and have power over others (Jordan, 2008). According to Jordan et al. (2004), the concept of the separate self and its influence on the core beliefs of the Global North is a significant contributor to power and control over marginalized groups. For example, in my work as a music therapist, I often distanced myself from the people I worked with, ensuring I kept professional "distance" (i.e., through not sharing too much about myself, where I came from, what was important to me, etc.).

In hindsight, I wonder how, by keeping my authentic self from the people I worked with and setting those boundaries, I was placing myself in a position of power over PLwD.

RCT critiques models of care that view the therapist as the expert who imposes change through unilateral relationships (Jordan, 2004). For example, RCT states that when a relationship is based on maintaining the power dynamic between therapist and client, there is little room for authentic growth as the client is pushed further towards isolation (Jordan, 2017; Jordan et al., 2004). Additionally, Jordan et al. (2004) argued that when we limit opportunities for people to influence one another, we disempower their relational capacities. Recognizing that traditional theories of psychology uphold and perpetuate self-first ideologies, RCT strives to create an alternative approach to therapy and therapeutic relationships grounded in mutual empathy, courage, and the sharing of power to foster what Miller (1998) called a "growth-fostering relationship" (p. 5). Growth-fostering relationships are those in which both individuals honour their own sense of well-being while also being attuned to the well-being of another and open to being moved by and changed by that person (Jordan, 2017). According to Miller (1988), growth-fostering relationships consist of "zest, creativity, worth, clarity, and a desire for more connection, for both people" (p. 5).

Being in a growth-fostering relationship also requires what Jordan (2004) defined as "relational competence" (p. 15). Relational competence involves the ability to show empathy towards oneself and others (mutual empathy), regard for how our actions influence and impact others, an openness towards being changed by being in relationships with others, being curious about relationality and relational processes, seeing and experiencing vulnerability as an opportunity for growth, and not exerting power over another (p. 15). According to Miller (2004), shifting to a relational practice requires a radically different approach to therapy. For example,

instead of the therapist trying to "fix" the client, RCT requires both people to be in a growth-fostering relationship with each other. In practice, this involves both the client and therapist being open to growth, change, and learning from one another (Jordan, 2017), and moving beyond a culture of pathologizing individual behaviour by recognizing how our social conditions contribute to individual pain (Jordan, 2004).

Thus far, this chapter has explored my ontological and epistemological alignment, as well as the critical and relational theories that have influenced my perspective on my work as both a music therapist and researcher. However, in focusing this work on the dementia context, it is imperative that I draw on theories which take a critical and relational lens specifically to the dementia experience. For example, in supporting PLwD in sharing their stories to challenge stigma associated with dementia, I must have a comprehensive understanding of how PLwD came to be stigmatized in the first place, the effects of this stigmatization on the care and experiences of PLwD, and what is being done to rectify it. To fill this gap, I turn to two theories specific to dementia (relational citizenship and relational caring). Specifically, I will describe the historical context towards relational models of care with PLwD, explore the main tenets of relational citizenship and relational caring, and conclude by discussing how these relational theories will be utilized in the context of this research.

A Historical Context Towards a Relational Citizenship

The dominant discourse on dementia associates cognitive decline with a loss of self and personhood (Kontos et al., 2017). Such notions of personhood date back to the 17th century, with the rise of the 'modern self,' in which the self was equated with brain function (Vidal, 2009). When the brain is understood as the centre of one's sense of self, the body plays a subordinate role (Kontos et al., 2017; Vidal, 2009). The dominant discourse, which privileges cognition as

the self, has had detrimental effects on PLwD (Kontos et al., 2017). For example, language and images used in academic literature, policy documents, and media often depict PLwD as "doomed," "socially dead" (Mitchell et al., 2011; Dupuis et al., 2016, p. 358), or "empty shells" (Morhardt & Spira, 2013, p. 38). Additionally, PLwD, as non-persons, are stripped of their citizenship status and of their right to exercise autonomy as their cognition declines (Bartlett & O'Connor, 2007; Kontos et al., 2017). For example, Bartlett and O'Connor (2010) critiqued Global North conceptualizations of a citizen as a person who "is fully cognizant with the capacity to make judgements and decisions, assume responsibility, participate in the exercise of political power and fulfil civic obligations such as voting and working" (p. 31). Unfortunately, individuals who do not meet these criteria are deemed "non-citizens" and excluded from activities, roles, functions and human rights other 'citizens' have access to (Bartlett & O'Connor, 2010, p. 31).

Until the 1990s, traditional notions of personhood dominated the way PLwD were perceived in society (Kontos et al., 2017; Morhardt & Spira, 2013). For example, PLwD were often characterized as "passive victims" and "sufferers" of a disease that stripped them of their personhood (Morhardt & Spira, 2013, p. 38). PLwD were also seen as unable to exert autonomy and lacking the ability to perceive and be aware of their external surroundings (Kontos et al., 2017). As such, dementia care often focused on pathologization and disease management, thereby reducing PLwD to a product of their disease, ignoring their personhood (Bartlett & O'Connor, 2007; Kontos et al., 2017), and prioritizing care focused on what Gubrium (1975) called "bed-and-body work."

In response to these dehumanizing practices and social narratives, Kitwood (1997) brought person-centred care (PCC) to the dementia context to shift care from a model that

focused solely on disease to one that acknowledged the whole person (Bartlett & O'Connor, 2007; Kontos et al., 2017). PCC challenges traditional notions of self by asserting that personhood is socially constructed (Bartlett & O'Connor, 2007). For example, Kitwood (1997) challenged constructions of personhood that equated it with cognition and argued that the loss of personhood associated with dementia was not caused solely by cognitive deterioration, but also by how PLwD were treated in society. He described what he called the social malignancy of attitudes and behaviours that undermined the personhood of PLwD (e.g., infantilization, invalidation, and social isolation).

PCC also challenges the biomedical model by focusing less on diagnosis and more on one's social history and context (Kontos et al., 2017). For example, PCC acknowledges that quality of life is determined by both cognitive changes and one's history, relationships, and how they are viewed and treated in society (O'Connor et al., 2007). By displacing the location of the self from cognitive processes to social contexts (Kitwood, 1997), PCC has challenged biomedical models as the only way of viewing PLwD and inspired person-centred care practices, that at least on paper, are supposed to centre the person rather the disease (e.g., getting to know the history of the person, aligning leisure activities with past roles and activities and routines with past preferences, finding out the preferred meal and drink preferences of the individual, providing space for a person to showcase important photos or items outside their room, etc.). Although aspects of the biomedical model continue to be used in many care settings, PCC has become the most prominent model of care talked about in the dementia context (Bartlett & O'Connor, 2007).

While PCC represents the most significant shift in understanding dementia since the 1990s (Bartlett & O'Connor, 2007), it has also been critiqued for ignoring relational processes,

thereby reinforcing unilateral relationships which exert power over PLwD (Bartlett and O'Connor, 2007; Dupuis et al., 2012a; Nolan et al., 2002). For example, Bartlett and O'Connor (2007) argued that PCC has led research and practice to focus largely on the individual and their immediate surroundings. As such, PCC overlooks the political and social factors (i.e., disability, race, gender, structural violence) which impact PLwD (Cantley & Bowes, 2004; Kontos et al., 2017). By ignoring issues related to broader social and political forces, PCC remains complicit in power-related matters. Similarly, Nolan et al. (2002) stated that PCC fails to account for relational processes present in care relationships and tends to reinforce one-way relationships (Bartlett and O'Connor, 2007). According to Downs (1997), the conservation of personhood thereby becomes "the responsibility of those who are cognitively intact rather than the individual with dementia" (p. 598), reinforcing the therapist-client binary (Kontos et al., 2017). In response to critiques of this model, new theoretical frameworks, such as relational citizenship and relational caring, were developed to address the limitations related to power and relationships in the dementia context (Kontos et al., 2017).

Relational Citizenship

To address the social discrimination faced by PLwD, Kontos et al. (2017) advocated for a relational approach to citizenship which supports the inclusion of PLwD as full citizens in our communities. Relational citizenship builds on relationship-centred care and the passive model of citizenship to support PLwD in being active agents in their care and life (Bartlett & O'Connor, 2010; Dupuis et al., 2009; Kontos et al., 2017; Nolan et al., 2002). Additionally, relational citizenship disrupts the concept of the modern self by drawing on theories of embodiment that more fully support the bodily expressions of PLwD (Kontos et al. 2017). In deciphering the central tenets of relational citizenship, I found it helpful to break the theory down into its three

core components: relationship-centred care, social citizenship, and embodied selfhood. This section will examine these three theories and discuss their relevance to this research.

Relationship Centred-Care

Relationship-centred care (RCC) emphasizes the importance of relationships to the quality of life for PLwD (Kontos et al., 2017) and seeks to "fully capture the interdependencies and reciprocities that underpin caring relationships" (Nolan et al., 2002, p. 203). In RCC, the focus on individuality in PCC is replaced by mutuality and relationality. It recognizes that quality care occurs when there are strong, reciprocal, and interdependent relationships among everyone involved in care, including PLwD, family carers, and professionals (Nolan et al., 2002, 2006). It also recognizes the importance of supporting the wellness of all involved in care and identifies six senses (i.e., sense of security, belonging, continuity, purpose, achievement, and significance) that need to be addressed to support the wellness of PLwD, family members, and professionals, and, subsequently, quality care. RCC also recognizes the continued relational capacity of PLwD, further displacing traditional notions of personhood and representing a significant theoretical progression in dementia care by including PLwD as *partners in*, and not just receivers of, care (Bartlett et al., 2010; Dupuis et al., 2012a; Kontos et al., 2017).

While RCC addresses the limitations of one-way relationships in PCC, it tends to focus only on care relationships, thereby dismissing relationships related to societal and institutional forces (Kontos et al. 2017). In this way, RCC is similar to PCC in that it ignores socio-political contexts that significantly impact PLwD. By not fully accounting for how societal structures and institutions strip PLwD of their sense of self, traditional notions of personhood are upheld, PLwD are unsupported in fully expressing their personhood, and are not seen as full citizens in

our communities. A citizenship perspective addresses many limitations in both PCC and RCC (Bartlett & O'Connor, 2007; Kontos et al., 2017) and is used in relational citizenship to more fully support the rights of PLwD.

A Case for Citizenship: The Passive Model of Citizenship in the Dementia Context

A citizenship lens addresses issues related to power and advocates for the full citizenship of PLwD in our communities by supporting PLwD in challenging the dominant narratives that seek to strip them of their citizenship status (Kontos et al., 2017). It aims to further RCC by recognizing the relationships one has with social and political institutions and the impacts of these relationships on PLwD (Bartlett et al., 2010). According to Dupuis et al. (2016b), the notion of citizenship brings forward issues relating to power and control and highlights the ways societal forces exclude PLwD from participating fully in society (e.g., being excluded from decisions made about their care/lives and policy decisions that affect their livelihood) (Dupuis, 2012a).

While a citizenship lens recognizes the influence of socio-political factors on the well-being of PLwD, it has been critiqued for upholding traditional notions of personhood for its "emphasis on self-cognizance" (Bartlett & O'Connor, 2007, p. 108). By privileging cognitive intactness or the ability to engage in societal responsibilities as a marker of citizenship, individuals who do not meet this requirement are not granted full citizenship status (Bartlett & O'Connor, 2010). To address this barrier, scholars in dementia studies suggest a shift to a passive model of citizenship (Bartlett et al., 2010).

The passive model of citizenship focuses on "people getting what they are entitled to or have a right to expect as an equal citizen" (Bartlett et al., 2010, p. 108), regardless of their ability to contribute to society (Kontos et al., 2017). It is described by Bartlett et al. (2010) as:

> A relationship, practice or status in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level. (p. 37)

This conceptual shift is significant because PLwD are granted full citizenship regardless of their cognitive status. It also offers an alternative lens through which to reconceptualize the actions of PLwD from exhibiting "behaviours" viewed as symptoms of dementia to acts of agency and resistance (Kontos et al. 2017). For example, in a study on experiences of living in aged care settings, Paterniti (2003) found that refusal of certain institutional routines (i.e., showering at specific times and being rushed to finish meals) were not "a behaviour of dementia," but ways that the residents expressed their individual preferences and resisted institutional norms.

Though RCC and the passive model of citizenship provide a much-needed theoretical shift in supporting the rights of PLwD, they do not actively challenge traditional notions of self-actualization (Kontos et al., 2017; Kontos & Martin, 2013). For example, while the passive model of citizenship argues for the inclusion of PLwD as full citizens despite their cognitive capacities, it does not account for the embodied ways PLwD express their personhood and relationality (Kontos & Martin, 2013). According to Miller and Kontos (2016), incorporating theories that acknowledge the full communicative capabilities of PLwD is fundamental to PLwD receiving full citizenship status. Therefore, relational citizenship turns to the literature on embodiment and dementia, specifically the theory of embodied selfhood, to further support the human rights of PLwD (Kontos et al., 2017; Kontos & Martin, 2013; Miller & Kontos, 2016).

Embodied Selfhood: Merleau-Ponty, Bourdieu, and the Musical Self

Biomedical practices focusing on cognitive deterioration and understanding dementia as a disease rooted in brain processes have led to an approach to care that overlooks embodied expressions and theories of embodiment (Kontos & Martin, 2013). For example, experiences involving the body in dementia are most often considered in terms of their symptoms related to the disease (i.e., falling or wandering behaviours) (Kontos & Martin, 2013). The inclusion of embodiment theory over the past 20 years has continued to push the dementia discourse away from the biomedical model and traditional notions of personhood and towards approaches which acknowledge the various ways PLwD assert their citizenship and express themselves (Grigorovich et al., 2019; Kontos, 2005; Kontos et al., 2020). Specifically, the theory of embodied selfhood advances RCC and the passive model of citizenship by disrupting the 'modern self' through placing significance on the expressive capacities of the body (Kontos & Grigorovich, 2018; Miller & Kontos, 2016). For example, while RCC emphasizes the importance of relationships for the well-being of PLwD (as well as family members and professionals), relational expressions are still understood within a cognitive paradigm (i.e., singing and dancing as products of cognitive capabilities) (Kontos, 2014). Relationality in embodied selfhood, however, is not understood as a result of cognitive awareness but as a pre-reflective capability existing despite cognitive capacity (Kontos, 2014).[8] This theoretical shift allows traditional notions of self to be released from their cognitive roots and placed in corporeality, thus contributing to preserving selfhood with PLwD despite cognitive decline (Kontos, 2026; Kontos

[8] Many music-centered music theories share a similar view of relationality (described in Chapter 3).

& Martin, 2013). This section will explore the two sub-theories which comprise embodied selfhood: Merleau-Ponty's (1962) reconceptualization of perception and Bourdieu's (1997, 1990) concept of habitus.

Reconceptualizations of Perception and Habitus

Embodied selfhood draws from Merleau-Ponty's (1962) philosophy of perception, specifically the pre-reflective notion of agency and basic intentionality, to argue for the body's role in self-expression (Kontos & Martin, 2013). According to Merleau-Ponty (1962), human expression resides in the pre-reflective body. The pre-reflective body possesses a natural capacity for self-expression, which is both primordial (existing from birth) and pre-social (existing despite one's social experiences) (Kontos & Grigorovich, 2018). Because self-expression naturally exists within each person, the ability to assert agency persists despite cognitive decline (Kontos, 2014; Kontos & Grigorovich, 2018).

The location of such expressions is further explained by Merleau-Ponty's (1962) concept of basic intentionality. Basic intentionality posits that the body possesses a natural ability or "know-how," which enables it to engage in certain tasks intentionally without prior reflection (Kontos 2014, p. 114). Merleau-Ponty (1962) referred to this as the "primary-perceptual" level, which relates to the primordial capabilities of our bodies (Kontos, 2014). For example, when working in a LTC setting, I was introduced to a resident with dementia who had been a professional accordion player. One day, I brought an accordion that I kept in my office to his room and asked if he would like to play. Though he hadn't played the accordion in many years, his fingers immediately flowed across the keys in an effortless motion, producing a beautiful melody. While this philosophy radically disrupts mind/body dualism, it does not account for how our social worlds impact perceptions and experiences (Kontos, 2014; Kontos & Grigorovich,

2018). Our bodies always perceive in relation to the social, cultural, and physical world in which we are embedded. To address this gap and explain how sociocultural contexts influence self-expression, embodied selfhood draws on Bourdieu's concept of habitus (Kontos, 2014).

Bourdieu's (1977, 1990) concept of habitus refers to the ways in which embodiment and socialization interact. Kontos (2014) explained habitus by stating that our ways of being in this world are comprised of bodily know-how, which is influenced by sociocultural contexts. According to Bourdieu (1990), this type of social know-how is developed "by the childhood learning that treats the body as a living memory pad" (p. 68). Like Merleau-Ponty's (1962) pre-reflective notion of agency, habitus is enacted at the pre-reflective level rather than the cognitive level (Kontos, 2014). Therefore, agency persists separate from our cognitive capacities.

Merleau-Ponty's (1962) reconceptualization of perception and Bourdieu's (1997, 1990) theory of habitus extend the theory of relational citizenship by considering both the pre-social and natural ways people embody their worlds, the ways sociocultural contexts influence embodied ways of being, and shows how the unconscious ways in which we embody our social worlds are preserved despite cognitive decline (Kontos 2014; Kontos & Martin, 2013).

The Musical Self

In addition to relational citizenship providing a useful lens for better supporting the full relational capabilities of PLwD, it also draws on tenets of embodied selfhood and applies them to the musical capacities of PLwD. According to Bowman (2004), traditional theories of music perception are rooted in a mind/body dualism, which privileges cognition as the centre of personhood and dismisses corporeality as an agential source of expression. In recent years, researchers in the dementia space have begun challenging these traditional theories by framing musical experiences as corporeal experiences, arguing that PLwD can express musical agency

despite cognitive decline (Kontos & Martin, 2013; Kontos & Grigorovich, 2018). For example, Kontos and Grigorovich (2018) argued that core elements of music-making, such as rhythm, beat, melody, and timbre, could not be fully perceived without the body and that musical experiences are expressed as "forms of know-how that are internalized, function below the threshold of cognition, and are enacted at a pre-reflective level" (p. 45). To further challenge traditional models of music perception, Kontos and Grigorovich (2018) argued that relational citizenship offers a critical lens for advancing theoretical insights into music perception to better support the musicality of PLwD. For example, in biomedical approaches to music-making with PLwD, music is understood as a communicative tool that triggers neural stimuli (i.e., familiar music evoking memory recall) (Kontos, 2014). Relational citizenship, on the other hand, acknowledges music as a communicative tool but roots it deeply in the body's natural, pre-reflexive, and socio-cultural relationship with music (Kontos & Grigorovich, 2018; Kontos & Martin, 2013).

It should be noted that the notion of musical abilities as corporeal is not new, and music therapists have been researching this concept long before Bowman (2004). For example, the concept of the "musical child" (Nordoff & Robbins, 1977) asserts that the capacity for musical expression is innate in every individual, despite illness or disability (persisting even when comatose) (Aigen, 2015). In my work as a music therapist, I have witnessed this concept many times. The following describes the story of Mary, an 87-year-old female living with dementia whom I worked with during my time in a LTC setting:

> *Mary sat in her wheelchair with her eyes closed and her head turned into her chest. Over the last few years, she lost her ability to communicate verbally and seemed to keep mostly to herself. Mary's husband sat next to her, holding her hand, and invited me into the*

room. As I took a seat, Mary's husband sighed and said, "Every year something else seems to be taken away from us." Knowing that Mary enjoyed music, I took out my guitar and started to sing "Oh What a Beautiful Morning." As I sang, I noticed Mary beginning to tap her feet to the beat of the music. During the chorus of the song, Mary began tapping her feet in time with the music. As I continued to sing, Mary lifted up her head and kissed her husband on the cheek.

Though this example illustrates how musical embodiment persists at a pre-reflective level, it is also important to recognize the significance of cultural preferences in our musical responses. For example, tastes in music and ways of musical expression are not innate, but rather something we acquire through social experiences with music (Bourdieu, 1990; Kontos, 2014; Kontos & Grigorovich, 2018). The following example describes how musical capacities both exist at a primordial level and are influenced by our cultural experiences:

When I walked into Jim's room, his breathing was slow and irregular. His wife Carol was standing beside the bed holding his hand. Carol looked at me, smiled, and invited me to come play music at the bedside. I asked Carol if there were any songs she thought Jim would like to hear. She told me about Jim's lifelong involvement at their community synagogue and that he loved to sing Hebrew music. We smiled at each other as I began to play a Jewish prayer called "Avinu Malkeinu" (a prayer sung during the High Holidays). As I sang, Carol joined in. We sang this prayer over and over. It acted as a container - holding us in the moment as we supported and honoured Jim's life. After we finished the song, Carol told me that their daughter used to sing this prayer during the high holiday services and asked if I would sing it again. This time, as I sang, Jim began to hum along

with me. Through tears, Carol said, "His favourite thing to do is sing." Jim died four hours later.

In each of these examples, we see how musical capacities and expressions persist across levels of cognition. It is through seeing PLwD express their embodied selfhood (i.e., the love they have for their husband or the way they let their family know they still love to sing in their last hours of life) that I have recognized the role music plays in supporting relational citizenship. Through reflecting on these experiences, I have also come to recognize that my work as a music therapist with PLwD, like that of many of my colleagues, has always been rooted in honouring and supporting the musical child.

Relational Caring

The final theory introduced in this chapter is relational caring, which brings together many of the relational, ethical, and practice-based threads that I have discussed thus far. Relational caring is a philosophy of care that emerged in response to the negative impacts of the biomedical model of care and therapeutic culture on PLwD. It resists the biomedical model by prioritizing relational processes and promoting collaborative relationships that focus on strengths instead of illness (Dupuis et al., 2025a; Jonas-Simpson et al., 2022). Relational caring is informed by three theories: relationality/hermeneutic of connection (Jordan et al., 2004; Nolan et al., 2002; Olthius, 2000); embodied selfhood (Kontos, 2012); and knowing otherwise (Olthius, 1997). Relationality/hermeneutic of connection is the dedication to prioritizing quality relationships (Mitchell et al., 2021). Embodied selfhood (discussed in the previous section) seeks to disrupt the mind/body binary previously discussed by arguing that selfhood exists below the cognitive threshold and is therefore present despite cognitive decline (Kontos, 2012; Kontos &

Grigorovich, 2018; Mitchell et al., 2021). Knowing otherwise involves seeing differences among people as opportunities for growth by being curious and open to different ways of knowing (Mitchell, 2021; Olthius, 1997).

Like RCT and RCC, relational caring argues that caring, compassionate, mutual relationships lie at the core of health, well-being, and our ability to thrive (Dupuis et al., 2016a). It also recognizes how our relationships with all things (i.e., animals, nature, space, time, non-living things such as sentimental objects, and broader social systems and structures) impact and influence our lived experiences (Jonas-Simpson et al., 2022).

What I find particularly helpful about relational caring as it pertains to this research is its focus on relational processes that support caring, compassionate, interdependent relationships. Relational caring has also been translated to relational arts by embedding relational caring principles and intentionally attending to relational processes (e.g., attending to the role we play in relationships; showing empathy and curiosity by being responsive and emotionally present; being open to mutual influence and discovery and to vulnerability as a strength; sharing power and working in authentic partnership with others; and working to remove injustice and inequities that limit opportunities to flourish) in art-making spaces (Dupuis et al., 2022; Jonas-Simpson et al., 2022; Mitchell et al., 2021).[9]

The practical use of relational caring is evident in the Bitove Method, which is unique for grounding its work in a relational caring philosophy (Dupuis et al., 2022; Mitchell et al., 2021). Located in Toronto, the Bitove Method brings together PLwD, family members, care staff,

[9] Many of these principles are also present in the music therapy theories and models of practice discussed in Chapter 3.

community artists, students, volunteers, and others to experience, learn about, and engage with the arts. Specifically, the Bitove Method intentionally designed their physical space as a relational environment that fully supports the freedom to move, be, and relate differently through the arts (Dupuis et al., 2022; Jonas-Simpson et al., 2022; Mitchell et al., 2021). Additionally, they were intentional in the development, translation and nurturance of relational literacies (Dupuis et al., 2022; Mitchell et al., 2021). This involved building an understanding of relational caring philosophy and what it means to be truly relational through regular opportunities for critical reflection on taken-for-granted assumptions, the exploration and removal of constraints (such as stigmatizing attitudes, language, and practices), and mentorship and role-modelling in relational caring. Thus, the Bitove Method employs a relational caring philosophy and the arts to foster relationships, opportunities for learning and engagement, and fully supports PLwD in creatively expressing themselves and their relational citizenship (Jonas-Simpson et al., 2022; Mitchell et al., 2021). The Bitove Method resists a biomedical culture of care by rejecting the diagnosis, assessment, labelling, and segregation of PLWD, or using the arts to address clinical or functional outcomes (Mitchell et al., 2021). For example, they disrupt the client/therapist binary inherent in the biomedical model by referring to PLwD not as "clients" but as academy members who engage with community artists in developing reciprocal relationships in which both members and artists are vulnerable, attentive, and curious toward one another.

The relational theories discussed in this chapter (i.e., RCT, relational citizenship, and relational caring) were intentionally utilized in this research through my engagement with PLwD as both research partners and songwriting collaborators. Unlike traditional postpositive research, which places the researcher in a position of power above the participant, this research sought to work alongside PLwD by embedding relational processes across all aspects of the research

process. For example, the aim of this research was not to "fix" or "treat" PLwD, but to collaborate with them to support their sharing of stories, strengths, and hopes for the future. Hierarchical boundaries between "researcher" and "participant" were minimized through mutual sharing of experiences, genuine curiosity and openness, and attunement to the ways our relationships with all things influence our experiences (i.e., not only the relationship between myself and PLwD but being acutely aware of my positionality and power as both a music therapist and researcher, and to the ways societal and structural forces impact PLwD). In the next chapter, I turn to the literature on music and music therapy in the dementia context and draw on the ways non-clinical approaches to music therapy can more deeply support the relational capabilities and relational citizenship of PLwD.

CHAPTER 3: A REVIEW OF DEMENTIA, MUSIC, AND MUSIC THERAPY

This chapter summarizes the current literature on music therapy and music for well-being with PLwD more broadly, discusses the ways that biomedical approaches to practice do not accurately represent the broader field of music therapy, and describes alternative theories, models, and approaches to practice which guide the work of many music therapists outside of the dementia context and are relevant to this work. I then explore how songwriting has been used with PLwD and why it is particularly effective in challenging stigma associated with dementia. This review of relevant literature aims to contextualize my research and help situate it within the existing body of knowledge.

Music in the Dementia Context

According to Dupuis et al. (2024; Dupuis & Kontos, 2026), once someone is diagnosed with an illness or disability, such as dementia, leisure is medicalized (i.e., used to meet functional and clinical goals). The medicalization of leisure for PLwD has gained popularity from research indicating the dangerous side effects of psychotropic medication aimed at treating symptoms of dementia. As such, a push for non-pharmacological treatments, specifically creative arts therapies (e.g., music therapy, recreation therapy, art therapy), has been widely embraced as effective approaches for reducing symptoms of dementia (Ijaopo, 2017; Kontos & Grigorovich, 2018). In this approach, music is often used to awaken cognitive processes in PLwD, such as increasing memory recall (Kontos & Grigorovich, 2018; Thaut, 2014) or as a means of managing misunderstood "behaviours" associated with dementia (Dupuis et al., 2012b). This section provides an overview of the use of music with PLwD. Specifically, I will address how the use of music with PLwD is discussed in the music therapy literature, as well as in literature on music as

a means of recreation or leisure for well-being and life enrichment.[10] I start by providing a definition and brief history of music therapy, describe the ways music therapy is taken up within a biomedical paradigm in the dementia context, define and summarize non-medical approaches to music therapy and how they are used with PLwD, and discuss the ways music is used with PLwD outside of a music therapy context.

Music Therapy and Its Approach in the Dementia Context

Definition and history of the profession

The Canadian Association of Music Therapists (2020) define music therapy as:

> a discipline in which Certified Music Therapists (MTAs) 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 spiritual domains. (About Music Therapy, para 1)

According to Kenny (1982), there are two main schools of thought in music therapy: medical and nonmedical.[11] In the medical approach to practice, music therapists use music to achieve non-musical, functional, and clinical goals (Aigen, 2014a). In non-medical approaches to music therapy, the biomedical model is heavily critiqued and functional/clinical goals are replaced with a focus on mutuality, relationality, and collaborative music-making (Aigen, 2015; Rolvsjord, 2010).

---

[10] It is important to note that the way I describe the use of music with PLwD is only meant to give an overview on an otherwise very complex topic. As stated at the end of Chapter 2, I recognize that the theories I write about might not always align with practice or vice versa.

[11] While I argue that this conceptualization of music therapy is reductive, it serves to map out the profession and to understand how these schools of thought have come to dominate current research and practice.

Though the practice of music as therapy has been traced back to ancient antiquity (Gouk, 2000), music therapy as a regulated healthcare profession emerged in the West with the rise of capitalism and state-governed health and social institutions in the late 1800s (Ansdell, 2014). During this time, musicians had increasing opportunities to play music for patients in hospitals and psychiatric settings. Despite attempting to align with the treatment models employed in these institutions, professional musicians working in these spaces were criticized by both musicians for not exhibiting a high level of musicality and physicians for lacking theoretical and clinical rigour (Ansdell, 2014; Edwards, 2008). To gain professional legitimacy, musicians experimented with various designations, including "medical musician, musical aide, hospital musician, music worker, musical therapy, [and] musico-therapy" (Ansdell, 2014, p. 15).

Opportunities to further legitimize the field arose in the United States during WWII, when hospitals caring for veterans sought new rehabilitative approaches to care (Bunt & Stige, 2014). Musicians during this time used music not only for entertainment but also to support patients' psychosocial needs (Ansdell, 2014). This shift in professional purpose prompted the development of training, research, and the organization of music therapy as a designated profession (Ansdell, 2014). From the mid-1940s to the 1960s, music therapists asserted their professional identity, aligning with the biomedical model and incorporating theories rooted in clinical psychology, behaviourism, and psychoanalysis (Aigen, 2014a; Ansdell, 2014). Though much of the profession at this time was rooted in a biomedical paradigm, there were always music therapists resisting the biomedical model who advocated for approaches to practice centred on the unique characteristics of music and musical experiences (i.e., music-centred music therapy) (Aigen, 2014a; Kenny, 1987; Rolvsjord, 2010). For example, the development of Nordoff-Robbins music therapy, created by Paul Nordoff and Clive Robbins (1977), called for

music therapists to place their musicianship at the forefront of their practice and to view musical processes and experiences as the primary goal of therapy (Ansdell, 2014; Lee, 2015).

During the 1960s and 1970s, advancements in musicology, the social call for deinstitutionalization in healthcare, and critiques of healthcare professions, specifically psychotherapy, for their lack of political engagement, paved the way for the community music therapy (CoMT) movement (Aigen, 2014a). This movement advocated against biomedical approaches to practice, with scholars and practitioners increasingly interested in drawing on critical theories to challenge the institutionalization of music therapy (Stige, 2015). While music therapists had already been using CoMT in their work prior to this movement, the early 1980s to 2000s saw a rise in CoMT practices with more music therapists asserting themselves within this approach (Pavlicevic & Ansdell, 2004).

Today, music therapy practice and research in many contexts is based on music-centred approaches to practice (i.e., CoMT and NRMT). Drawing from relational, critical, and poststructural theories, these approaches inform a practice that is anti-medical, anti-oppressive, and rooted in social justice (Rolvsjord, 2014). Although approaches like CoMT have become more prominent over the last 22 years, simultaneously, the rise of the evidence-based movement and interests in music and health have inspired a new wave of music therapists interested in using music solely for functional and clinical outcomes (Aigen, 2014a; Dileo & Bradt, 2005; Rolvsjord, 2010). For example, Neurologic Music Therapy (NMT) is a model of music therapy which adheres strictly to evidence-based protocol (Thaut & Hoemberg, 2014). NMT comprises 20 standardized techniques that focus on various cognitive domains, rooted in cognitive neuroscience, to improve and maintain functional movements and behaviours (Thaut, 2005). In the NMT literature, PLwD are described as experiencing “a disturbed sense of self that disrupts

interactions with family members and other caregivers," and music is used to increase memory recall and assist in restoring a sense of self (de l'Etoile & Jones, 2025, p. 399).

While there are many approaches to music therapy that resist the biomedical model, these approaches seem largely unaccounted for in the dementia academic literature. It is the influence of the evidence-based movement in music therapy practice, coupled with the institutionalization and stigmatization of PLwD, that I believe has largely confined the literature in this area to a biomedical paradigm. Having said that, there are some examples that draw on music-centred approaches to music therapy in the dementia research literature. The following section will explore the various ways music therapy has been utilized and researched in the context of dementia.

Biomedical Approaches to Music Therapy with PLwD

Research on music therapy to achieve functional/clinical goals, often aligned with a biomedical approach, accounts for a significant portion of the literature on music therapy in the dementia context. For example, Clements-Cortes (2020) stated that music therapy with PLwD is often aimed at "reducing anxiety, reducing aggressive behaviours, stimulating reminiscence, and stimulating cognitive functioning" (p. 15) and that many studies on music therapy with PLwD have indicated a decrease in "wandering, yelling, or other disruptive vocalizations" (p. 9). Additionally, Beard (2011) stated that music therapy in the dementia literature "primarily focuses on reducing behaviours labelled problematic or enhancing those deemed desirable by care providers and clinicians" (p. 638).

Scoping reviews on music therapy/music interventions with PLwD have also focused on functional and clinical outcomes.[12] For example, in a scoping review by Elliot and Gardner (2018), much of the literature on music therapy with PLwD used structured music therapy sessions in LTC facilities to reduce agitation and anxiety and improve cognitive functioning. Additionally, out of the eighteen studies included in a review by McDermott et al. (2013) on music therapy in the dementia context, 13 studies centred on the use of music to reduce behavioural and psychological symptoms of dementia, while only five looked at social and relational components of the therapeutic process (i.e., empowerment, trust, joy). Moreover, some of the studies in this scoping review that highlighted the social and relational aspects of music therapy (e.g., Brotons & Marti, 2003) still referenced its functional benefits for cognition and behaviours and were characterized by problematic language about PLwD (e.g., wanderer, confused, agitated, easily upset), focusing primarily on deficits. Additionally, a more recent scoping review by Lam et al. (2020) only included six studies on quality of life, with the remaining 82 focusing on one or more biomedical outcomes such as cognition, memory, language, behavioural and psychological symptoms of dementia, anxiety and depression, agitation, apathy, and daily functioning (p. 6). Similarly, a systematic review by Moreno-Morales et al. (2020) included eight studies on the effects of music therapy on cognition, quality of life, and depression. It should be noted that none of the studies focused solely on quality of

[12] As stated throughout this dissertation, while the research on music therapy with PLwD is often rooted in a biomedical framework, it is important to remember that research does not always reflect practice. In fact, I would argue that many music therapists working with PLwD are much more music-centred than what is captured in the literature. For example, Young (in press), argued that "it should not be assumed that all music therapists approach their work in dementia care from a biomedical treatment perspective" and that "many music therapists situate their work in dementia care within relational, resource-oriented, person-centred, music-centred, multicultural or critical–theoretical perspectives" (p. 8).

life, instead incorporating this outcome with outcomes related to cognitive functioning and memory recall.

In many of these examples, PLwD are described as "confused," "agitated," "aggressive," and/or "disruptive." Such depictions of PLwD perpetuate stigma associated with dementia and do not account for the diverse ways PLwD assert their personhood, relationality, and citizenship. I argue that when we focus primarily on the use of music and music therapy to reduce "symptoms of dementia" or to increase "cognitive functioning," we further oppress and marginalize PLwD in our communities. For example, Young (in press) argued that viewing dementia as "a disease that must be *tackled* (even with music, as this article indicates) not only serves to demonize the condition [but also to inadvertently] demonize the person by extension" (p. 6). In reflecting on my own practice, I have never worked with someone diagnosed with dementia who said that they wanted to increase memory recall or reduce their perceived behaviours. In fact, most, if not all, the people I have worked with over the years have only expressed wanting to engage in music because, quite frankly, they enjoy it.

Though much of the literature on music therapy in the dementia context is situated within a biomedical framework, Aigen (2014a) argued that this approach does not accurately reflect the practice of many music therapists. Stige (2003), for example, stated that many music therapists do not actually "fix" or "cure" people with disabilities, making the biomedical model irrelevant to music therapy practice. Additionally, Rolvsjord (2010) argued that the medical model negatively impacts the profession, as it reinforces a practice that focuses on weaknesses instead of strengths and places the music therapist in a position of power over the client. Rolvsjord (2010) also argued that, because most music therapists do not practice based on interventions to "cure illness" and because people's reactions to music are unique and influenced by their

sociocultural context, the medical model runs counter to the profession itself. This argument is further supported by many music therapy scholars who argue that the medical model misrepresents the profession in that music therapy practice is not only much more process oriented than the biomedical model allows for, but also ignores the many music therapy models and theories that actively resist biomedical discourse (Aigen, 2005; Aigen, 2014a; Garred, 2006; Lee, 2003; Pavlicevic & Ansdell 2004; Rolvsjord, 2010; Stige 2002). Upon reading beyond the dementia literature, I have come to realize that music therapy encompasses far more than what is represented in this one area, and that many approaches to music therapy are inherently relational and attuned to social justice issues, making them well-suited to confront issues of marginalization, discrimination, and stigmatization.

The following section aims to provide a broader depiction of music therapy practice and research by discussing the theories and approaches to practice that underpin much of the work that I, as well as many other music therapists, utilize in practice. Specifically, I will explore the main epistemological and theoretical tenets of music-centred music therapy. I then discuss three models situated within a music-centred framework (Nordoff-Robbins music therapy, community music therapy, and resource-oriented music therapy) that informed this research. It is my hope that by drawing on these theories and models in this research, the gap between the broader ethos of the profession and its representation in the dementia literature will begin to shift.

Music-Centred Perspectives in Music Therapy

Aigen (2005) defined a music-centred approach to music therapy as being "more than an art form, a means for communication, or even a vehicle for therapy. It is a way of being with other people that embodies particular [music-centred] values" (p. 77). In this way, music-centred music therapy is not a specific theory or model, but a perspective music therapists hold (much

like taking a person-centred care approach to practice) (Aigen, 2014b; Lee, 2015). Unlike approaches to music therapy which use music to reach non-musical goals, the focus of a music-centred perspective is the musical experience and process within the therapeutic relationship (Carpente & Aigen, 2019). Although secondary benefits (i.e., memory recall and improved cognition) may result from engaging with music, they are not of primary concern in a music-centred approach. Rather, the goal of a music-centred music therapy session is musical expression in and of itself (Aigen, 2014b). Advocating for music-centered approaches to practice, Aigen (2014b) made the following arguments: 1) when we base music therapy practice on theories outside of music (i.e., psychology or neuroscience), our understanding of the role *music* plays in a therapeutic context diminishes; 2) many people seeking music therapy are brought to music therapy to engage with and make music (not to work non-musical goals); 3) when we ignore people's musical motivations, we devalue their preferences and motivations; and 4) the predominance of non-musical theories to explain our relationships with music contributes to a focus on disability in practice (i.e., music is viewed as a tool to reduce symptoms of illness instead of a vehicle for expression and connection).

Central to music-centred music therapy is the concept of musicing (Aigen, 2014b; Elliot, 1995).[13] Musicing disrupts the notion of music as an object (i.e., a tool for non-musical goals) by treating music and musical engagement as actions. For example, Elliot (1995) described musicing as a musical engagement activity or an "action and interaction in social and cultural contexts" that is created "through shared action in context" (Stige, 2002, pp. 99 - 100). Because

[13] I have chosen to use Elliot's (1995) spelling of "musicing" over Small's (1998) "musicking" as Elliot's spelling is more widely used in North America (Aigen, 2014) and emphasizes the role of embodied knowing in the process of musical engagement (Aigen, 2014; Stige, 2002).

musicing is created through collaboration, it is an inherently relational process. It is not something we can impose on people, but exists only in relation to who we are making music with and to our sociocultural context. For example, when I am singing a song with someone I am working with, I am engaged in a relational process. The music I play is always tailored to the person's preferences and the sociocultural context in which we live. The way I sing responds to how the person receives what I am playing and to how they convey or express their feelings in that moment. In this way, music always exists and is created in relation to something and/or someone else. Similar to Gergen's (2009) concept of co-action, music and musical engagement are fluid and emergent, molded and shaped through relational processes.

Also central to music-centred thinking is a commitment to creating spaces where musicing comes first and can flourish for all involved, "with problems, pathology, or limits always coming second" (Ansdell & Stige, 2015, p. 604). Therefore, the "clinical" component of music-centred music therapy is not how music can be used to treat symptoms of disease, but how music therapists cultivate safe and inclusive spaces where musicing can flourish (Aigen, 2014b). To create these spaces, music-centred music therapists recognize the importance of the therapeutic relationship. However, unlike traditional therapist/client relationships, a music-centred perspective sees the therapeutic space as a collaboration between musicians. Because musicing is a relational process, with each person sharing in its formation, the hierarchy between therapist and client dissolves as each person is moved by and shapes the music (Aigen, 2014b; Ansdell, 2002). Before I summarize the research on music-centred approaches with PLwD, I will describe the three music-centred approaches that I believe are most relevant to my research: Nordoff-Robbins music therapy, community music therapy, and resource-oriented music therapy.

Nordoff-Robbins Music Therapy

Nordoff-Robbins music therapy (NRMT), developed by music therapists Paul Nordoff (1909 – 1977) and Clive Robbins (1927 – 2011), is credited as the earliest approach to music-centred music therapy (Aigen, 2005). In NRMT, elements of music (e.g., tempo, timbre, melody, rhythm) are used to cultivate a collaborative music-making relationship (Guerrero et al., 2015). Unlike models of music therapy, which employ specific types of interventions to meet functional goals (e.g., neurologic music therapy, medical music therapy, behavioural music therapy), NRMT is premised on in-the-moment relational music-making and improvisation (Guerrero et al., 2015). According to Ansdell (1995), a main tenet of NRMT is the concept of a "musical meeting where both players share something of thought, feeling and intention within the purely musical" (p. 67). The relational impact of a musical meeting was described by Ansdell (1995) as:

> …the difference between being on land and being in water. Suddenly you feel different – freer, supported, you can do different things… [A relationship is] established in the improvisation from the first time a musical contact is made, and developed through the point where a true 'meeting' can come in the music (p. 68)

The relational nature of the therapeutic relationship in NRMT is further described by Guerrero et al. (2015) who stated "By joining readily in the client's spontaneous playing, movement, and vocalization, the therapist works to draw the client into increasingly reciprocal communicative interaction …What is most importantly communicated in this musical interaction is that each of them *is affected by* the presence and actions of the other" (p. 486).

Another central tenet of NRMT, which is relevant to this research, is the concept of the "musical child" (Nordoff & Robbins, 1977). As stated in Chapter 2, the "musical child" is similar to Merleau-Ponty's (1962) notion of basic intentionality (which views knowledge or

"know-how" as embodied) in that it asserts that the capacity for musicing is innate in every individual, despite illness or disability (persisting even when comatose) (Aigen, 2015). In the dementia context, these two central tenets (musical meeting and the musical child) serve to reconceptualize the role music therapy plays in the lives of PLwD. For example, viewing musical capacities as innate human capacities, NRMT displaces notions of loss in dementia and recognizes the capacities PLwD have to create and engage with music. This view also resonates with the literature on embodiment and dementia, specifically in relation to relational citizenship and the musical-self, which views music within a primordial and pre-reflexive context (Kontos & Grigorovich, 2018; Kontos & Martin, 2013).

Although NRMT provides a framework for thinking about music in the dementia context, it focuses less on the potential of music therapy as a medium for social change. To gain insight into how music therapy can support social activism, I turn to the literature on community- and resource-oriented approaches.

Community Music Therapy

Community music therapy (CoMT) is an approach to practice premised on participatory music-making, inclusion, and equity within communities (Stige & Aarø, 2012). Actively resisting biomedical and ableist discourses, it is described as "an anti-model that encourages therapists to resist one-size-fits-all-anywhere models (of any kind) and instead follow where the need of clients, contexts, and music leads" (Ansdell, 2003, p. 4). This approach to music therapy differs from more traditional approaches in that it moves away from "individualized treatment" and towards an ethic of care that recognizes the relationships among "individual, community, music, health, and therapy" (Ansdell & Stige, 2015, p. 609).

An important aspect of CoMT is its commitment to practicing music therapy differently in our communities. It does this by challenging the boundaries of what traditional music therapy practice considers to be music therapy. For example, Ansdell and Stige (2015) argued that "traditional music therapy arranges a few chosen formats in a hierarchy privileging individual work and small group work as 'proper' therapy and prescribes other musical-relational formats, such as learning instruments, workshops, music for occasions, performances, as 'not therapy'" (p. 605). CoMT rejects this notion and instead adheres to the core music-centred principle, which states that all forms of musicing can be beneficial (Stige et al., 2016). It is therefore up to the music therapist to support communities in musicing in the ways that *they* find most helpful.

CoMT also demands a critical stance towards the ways our sociocultural contexts contribute to well-being and recognizes the ways music can support social activism (Ansdell & Stige, 2015). For example, Stige and Aarø (2012, pp. 18 – 24) provided the acronym PREPARE, which contextualizes CoMT through the values that practitioners take with them into practice:

P = participatory – Music making is always a collaboration between all parties involved in the process.

R = resource-oriented – Collaborative music making is empowering and supports community building.

E = ecological – Music therapists must recognize and understand the relationships between individuals and their sociocultural contexts (including policies, groups, music, etc.).

P = performative – These sociocultural contexts can be strengthened through performance (e.g., community relationships enhanced through public performance, awareness of harmful policies, etc.).

A = activist – CoMT requires music therapists to be critically and socially conscious.

R = reflective – Continuous critical reflection and engaging in reflective dialogue is necessary for all participants (including the music therapist) to understand and shift to the changing needs of the initiative.

E = ethics-driven – Although ethical considerations must be viewed in context, universal ethical principles such as equity, respect, and solidarity must be at the core of all CoMT practice.

It is through these core values that CoMT takes a participatory, critical, and relational approach to music therapy practice. In the context of this research, CoMT offers an important framework for many reasons. First, it embodies an approach to music therapy that stands in direct opposition to the ways music therapy is traditionally practiced with PLwD (i.e., by rejecting the biomedical model and recognizing the ways our relationships with all things influence our health and well-being). Second, it rejects traditional models of music therapy, which view social justice projects and performances as "inappropriate" in a therapeutic context. Lastly, it merges the concept of music with activism, providing what I believe is missing in NRMT. Though CoMT accounts for some of these gaps, I have also been inspired by the ways feminist music therapists' development of resource-oriented music therapy explicitly centers social activism and the nourishing of strengths in their work. I turn to this discussion next.

Resource-Oriented Music Therapy

Drawing on the central tenets of feminist theory, positive psychology, Common Factors literature, and empowerment philosophy, Rolvsjord (2010) developed a strengths-based approach to music therapy known as resource-oriented music therapy (RoMT). According to Rolvsjord (2010, p. 73), RoMT includes the following four components:

1) the nurturing of strengths, resources and potentials;

2) equal collaboration rather than intervention;

3) viewing the individual within their context; and

4) seeing music as a health resource

In RoMT, nurturing strengths and resources involves rejecting deficit-focused approaches to practice (i.e., the biomedical model) and celebrating the unique strengths of each individual (Rolvsjord, 2015). In my practice as a music therapist, this looks like writing songs with PLwD which celebrate and highlight their unique qualities. For example, I once wrote a song with an individual about the advocacy work they did in their community and the ways they exhibited strength throughout their life. Like CoMT (and the relational theories discussed in Chapter 2, such as RCT and relational caring), RoMT values reciprocity between therapist and participant. For example, RoMT requires the music therapist to engage in therapeutic relationships which center mutuality, shared decision-making, and the breakdown of hierarchical power structures (Baker, 2015; Rolvsjord, 2010).

While RoMT might seem to focus more on the individual than CoMT or feminist music therapy more broadly, it does view the individual within their larger context. For example, Baker (2015) argued that RoMT sees a person as part of the larger sociocultural landscape. Additionally, RoMT is highly critical of the term "intervention" and instead advocates for relational collaboration between therapist and client, where the "client's craft" (i.e., strengths and musical abilities) is nurtured (Rolvsjord, 2015). In this way, RoMT rejects biomedical discourse, which places the "blame of disability" on the individual, and instead empowers individuals to develop resources (through musical engagement) that challenge stigmatizing discourse and practices. For example, when working as a music therapist in a LTC setting, I developed a

community concert series in which residents showcased their musical talents by collaborating with local musicians and performing for other residents and staff. Instead of using music to "fix" symptoms of illness or disability, we focused on using music and musicing to support residents in showcasing their musicality within their community. Through this concert series, residents expressed pride in their musicianship; staff and family members saw residents in terms of their continued capacities; and music was used as a resource for both empowerment and community building.

In this section, I outlined three main models of music-centred music therapy which embody relationality, social justice, and/or collaborative musical processes (i.e., NRMT, CoMT, and RoMT grounded in feminist theories). Examples of how principles and practices grounded in these approaches were integrated into this research are detailed in Chapter 4. Though music therapy as a discipline includes many models and approaches which center these values, they are underrepresented in the dementia literature. I turn to this discussion next.

Music-Centred Music Therapy in the Dementia Context

Much of the literature describing a music-centred approach in the context of dementia draws on either CoMT, RoMT, or NRMT, or uses a combination of approaches. For example, Dennis and Rickson (2014) highlighted the importance of CoMT in a hospital unit for PLwD. In this case study, PLwD staying in the hospital formed a band and performed music together. Through this experience, PLwD were supported in sharing their musicianship and in challenging notions of loss associated with dementia. A study by Rio (2018) used both RoMT and CoMT to develop a support group for PLwD and their care partners. Results from the study showed an increased sense of relationality between care partners and PLwD (through engaging in meaningful music-making together), support (through sharing health and wellness resources with

one another), and comfort. Additionally, a study by Pavlicevic et al. (2015) on the use of NRMT and CoMT in LTC settings showed how bringing music therapy outside of an individual context (i.e., where someone is referred to music therapy and "treated" via a pre-determined time and space) and into the communal spaces of the home strengthened relationships between residents, care staff, and family, and elicited feelings of empowerment and resilience for PLwD.

Though these studies were situated within a music-centred framework, I found that some still used biomedical and/or stigmatizing language rooted in a tragedy discourse to justify the use of specific music therapy techniques and/or describe the experiences of dementia. For example, when describing symptoms of Alzheimer's disease, Dennis and Rickson (2014) stated that PLwD "are confused and can become irritable, aggressive and experience mood swings…" (para. 1).[14] Additionally, though Rio (2018) used CoMT and RoMT as the theoretical frameworks with which to guide a support group for PLwD and their care partners, they also stated that "loss of memory, difficulty with language and communication, and decrease in judgment are issues that affect [PLwDs'] home life, creating behavioral and psychological symptoms of dementia (BPSD), which are accompanied by physical decline" (p. 2).[15] Lastly, a study on the use of NRMT in hospital settings with PLwD by Cheong et al. (2016) stated: "It is known that [PLwD] can be resistant to custodial care and nursing procedures and not uncommonly refuse participation in therapy. [NRMT] can be incorporated in the daily care of

[14] What I find problematic about this language is that it presents irritability, aggression, and mood fluctuations as defining features of PLwD, overlooking that these behaviours are common amongst all human beings, and failing to take into consideration the contexts of these personal expressions of experience. This reflects a broader pattern of pathologization within dementia scholarship and reproduces deficit-based narratives (Dupuis & Kontos, 2026).

[15] Similar to the previous example, describing dementia only using deficit-based language fails to consider the relational, environmental, and situational contexts in which these responses often arise and dismisses the complexities of dementia and the continued capacities of PLwD.

such patients to improve patient compliance and cooperation" (p. 273). While these studies bring a welcome change from the prominence of biomedical approaches to music therapy with PLwD, describing PLwD as "aggressive" and using music to decrease "behavioural symptoms" or cognitive function stands in stark opposition to the values and aims of music-centered music therapy. I argue that when we adopt music-centred perspectives with PLwD, we must be especially attuned to how societal discourses related to music and dementia shape our engagement with music-centred practices and ensure that all we do aligns with the values embedded in the approach. Unfortunately, I have not come across any studies in the dementia context which incorporate music therapy as a means for social justice (with the exception of one study on songwriting, which will be discussed at the end of this chapter). This is a missed opportunity, as taking a social justice approach to research offers a framework with which to support PLwD specifically in activism and liberation. Because this research not only aims to support PLwD in expressing their full personhood and relational citizenship but also to challenge the stigma associated with dementia, it is essential to incorporate theories and approaches that take a strong stance towards social activism.

While music therapy in the dementia context is most often situated within a biomedical framework, I found a few studies that entirely resist using music therapy for functional goals. For example, Dowlen et al. (2022) explored the importance of in-the-moment musical experiences in supporting PLwD in expressing creativity and engaging in relationships. Drawing on the literature by Kontos (2004, 2005) on embodiment and dementia, this study examined the experiences of PLwD participating in a community music program called Music in Mind. This program, led by a music therapist and a member of the Manchester Camerata Orchestra, provides PLwD with opportunities for community music-making. Rooted in principles such as agency and

choice, this program values the non-verbal musical contributions of each group member, thereby celebrating the embodied selfhood that is innate in all of us. Additionally, a study by McDermott et al. (2014) interviewed PLwD living in LTC settings and their care partners on the role music plays in their lives. Acknowledging the saturation of literature on the use of music therapy to reduce symptoms of dementia, this study showed how music therapy supported PLwD in self-expression and in building deeper relationships with their care partners (both familial and staff).

Musical Engagement with PLwD Outside of Music Therapy

Thus far, I have outlined the use of music therapy in the context of dementia. While music therapy theories and models of practice will inform much of this research, it is essential to examine the literature outside of a music therapy context to gain a more comprehensive understanding of how music is used with PLwD and to incorporate modes of music-making relevant to this research.

Music as Life Enrichment

Before addressing the literature on music for life enrichment with PLwD, it is important to note the complexities of broadly defining its use for this purpose. For example, when first writing this chapter, I named this section "recreational music-making". In reading more deeply on this topic, I found that Bittman et al. (2004) defined recreational music-making (RMM) as "enjoyable, accessible and fulfilling group music-based activities that unite people of all ages regardless of their challenges, backgrounds, ethnicity, culture, ability or prior experience" (p. 5). However, they also state that in "RMM sessions, utilizing music as a universal language for enhancing interpersonal bonding, are facilitated by caring, supportive guides who focus on enabling participants to achieve non-musical outcomes" (p. 5). Additionally, Young (in press) argued that many scoping and literature reviews on music and dementia do not distinguish

between music therapy and broader music engagement. These two factors make it difficult to define music for life enrichment and gain a clear understanding of the literature on this topic. Therefore, I have decided to define music for life enrichment as music-based activities which are not led by a music therapist.

According to Elliot et al. (2020), the literature on music with PLwD outside of music therapy is limited, and the research that does exist outside of a music therapy context often focuses on functional outcomes. A similar sentiment was shared by Sixsmith and Gibson (2007), who argued that there is little research exploring the role music plays in the lives of PLwD more broadly. For example, a scoping review by Fraser et al. (2015) on aging and the arts revealed how research on music with older adults is most often used as an intervention. Similar findings were reported by Dowlen et al. (2018), whose systematic review of the benefits of music for PLwD found that the majority of studies focused on using music to treat "behaviours" associated with dementia or to improve cognition.[16] While much of the research in this area is situated within a biomedical framework, Dowlen et al. (2018) noted a growing interest in the role that music plays in the relationships and quality of life of PLwD. For example, in a study by McCabe et al. (2015) on creating an opera with PLwD and their care partners, participants reported feeling more confident and seen as a person, rather than their disease. Additionally, a study by Elliot et al. (2020) exploring the meaning music has in the lives of PLwD found that music supports connection with the self, care partners, and music itself. Lastly, as described in Chapter 2, The Bitove Method (formerly known as the Dotsa Bitove Wellness Academy) has

[16] It should be noted that some studies included in this review were led by music therapists which is consistent with Young's (in press) argument that many scoping reviews on this topic do not distinguish between music therapy and non-music therapy.

intentionally created a space where the arts, including music, are primarily used for connection and life enrichment (Jonas-Simpson et al., 2022).

Though some of the literature on music for life enrichment in the dementia context demonstrates the relational and self-expressive benefits of music, I found that much of the literature used biomedical, and often stigmatizing, discourse to justify the use of music with PLwD (Daykin et al., 2018; Lee et al., 2021; Shibazaki & Marshall, 2017; Unebaum et al., 2021; Wollan, 2023). For example, in a study exploring the impact of concerts on well-being with PLwD, Shibazaki and Marshall (2017) rationalized the use of music by stating, "as dementia develops, a wide range of mental abilities gradually diminish and memory loss, inability to carry out basic tasks, changes in personality and behaviour, increased levels of agitation and sometimes aggression often become more apparent" (p. 468). A similar argument was made by Daykin et al. (2018), whose study on participatory music-making with PLwD in hospital settings aimed to improve well-being by focusing on decreasing agitation and falls in PLwD. Additionally, in a study using music activities to promote social interaction among PLwD, Unebaun et al. (2021) stated that PLwD "tend to isolate themselves from the outside world, therefore carers need to develop strategies to maintain communication with them" (p. 439). This was problematic to me as the author's focus on the reasons for isolation on the individual experiencing dementia, failing to recognize others' relational capacities, and the broader systems and structures that isolate PLwD in the first place. Lastly, a study by Wollan (2023) on the benefits of music in the dementia context refers to PLwD as "dementia sufferers" (p. 319). Such stigmatizing language, often associated with biomedical and functional models, perpetuates the tragedy discourse of dementia and places disability on the individual and does not account for the ways sociopolitical and other factors contribute to experiences of illness and disability.

In summary, though there are some examples in the literature which use music purely for enjoyment, relational, and community-building purposes (Dowlen et al., 2018; Elliot et al., 2020; McCabe et al., 2015), most of the research in this area justifies the use of music with PLwD based on the functional benefits it provides, even outside of music therapy (Elliot et al., 2020; Fraser et al., 2015; Sixsmith & Gibson, 2007). In response to the stigmatizing effects of the biomedical model and functional focus on the lives of PLwD, critical dementia scholars and advocates have turned to the arts, and specifically music, to challenge harmful discourses, practices, and policies in the dementia context.

Music to Challenge Stigma Associated with Dementia

More recently, music has been used to challenge the profound stigma associated with dementia. To highlight and draw awareness to the potential of relational arts in supporting the creativity, freedom, and expression of PLwD, researchers involved in developing The Dotsa Bitove Wellness Academy (now known as The Bitove Method) created a research-informed documentary called *Music is Life*. The purpose of this documentary was to challenge and disrupt dominant discourses that stigmatize and oppress PLwD by showcasing the possibilities for a model of relating that promotes the humanity, citizenship, relational capacities, and personhood of PLwD (Kontos et al., 2017). The documentary was also used to describe the meaning of music in the lives of PLwD from their perspectives. The documentary features a collaborative song written by The Bitove Method members and artists about the importance of music in their lives and includes interviews with members and artists on the Academy's role in supporting the full capacities of PLwD. Research on the meanings and experiences of music, conducted to support the development of the documentary, demonstrated the foundational nature of music in being and relating for all involved in the academy (Jonas-Simpson, 2022; see also the film Music is Life:

https://www.youtube.com/channel/UC84ZIctVED6a_9eP95KHJlw). Preliminary research on the film's impacts suggests that it is effective in challenging the stigma associated with dementia, prompting critical reflection, and inspiring new ways of being and relating to PLwD (Jonas-Simpson et al., 2020).

Another example of music that challenges stigma in the dementia context was demonstrated by Reynolds et al. (2017), who interviewed 109 audience members who attended a concert by the BUDI Orchestra (an orchestral group comprising PLwD and their care partners, student volunteers, and professional orchestral musicians). Results from this study indicated a shift in preconceived notions about the capabilities of PLwD. For example, one respondent called the concert "an eye opener as to what people can do rather than what they can't do" (p. 223). Like the BUDI Orchestra, community choirs have also been shown to support PLwD in asserting their strengths, building relationships, and challenging stigma. For example, a study by Mabire et al. (2023) on a community choir with PLwD, their care partners, and volunteers showed an increase in self-confidence among PLwD and a shift in negative attitudes toward dementia among volunteers. Additionally, an intergenerational choir comprising university students and PLwD in the community challenged students to rethink their conceptualizations of dementia (Harris & Caporella, 2018). For example, one student said, "The more time I spend with them, the more I realize the importance of seeing past the diagnosis and recognizing the inherent human dignity of the person with the disease" (p. 2568). Participating in the choir also provided PLwD with opportunities to develop relationships with students, which contributed to feelings of belonging. For example, a choir member stated, "When I spend time with the students, I feel energized and accepted. It is fun being around young people" (p. 2571). Lastly, a study on an intergenerational choir comprising PLwD, care partners, and high school students

called Voices in Motion, found that group singing increased social bonding among choir members and supported students in gaining a better understanding of the dementia experience (Smith et al., 2026). These studies exemplify the possibilities of music in highlighting the continued capabilities of PLwD and bridging divides in our communities.

Using the arts to challenge stigma associated with dementia has also been explored through liberatory arts. Liberatory arts is a collaborative, participatory, critical, and dialogic approach to art-making, in which artists and community members work together to critically reflect on and acknowledge systems of oppression, disrupt harmful narratives and discourses that perpetuate harm, and create space to reimagine better futures (Watkins & Shulman, 2008).[17] Using liberatory arts as a framework, a global activist group called Reimagining Dementia: A Creative Coalition for Justice (https://www.reimaginingdementia.com/) co-wrote a song to challenge stigma associated with dementia. Reimagining Dementia is an international group of dementia activists and allies, including PLwD, family members, professionals, artists, researchers, policymakers, and others, all of whom share a vision of life, care and support that promotes inclusion, relationality, creativity, joy and the possibility of growth for everyone living with dementia (Kontos et al., 2021). Recognizing the emancipatory potential of liberatory arts in inspiring culture change (Kontos et al., 2021), the coalition decided to write and record an original song called "Let's Reimagine*."* The song, written entirely online in collaboration with many of their over 700 coalition members at the time from around the world, centers the voices of PLwD in sharing what they want the world to know about living with dementia (Dupuis et al.,

[17] Liberatory arts as a research methodology will be described in greater detail in Chapter 4.

2023).[18] The final song includes a professional recording and a music video featuring PLwD, artwork made by PLwD, and messages of hope, joy, and friendship between PLwD and the broader community. Since the song's release, coalition members have been invited to speak on various media platforms to share the coalition's message more broadly. As a coalition member and songwriter on the project, I had the opportunity to participate in one of these interviews with another member living with dementia. In the interview, this member shared how they want the world to see that PLwD are more than their disease and have much to contribute to society. Since this interview, I have received numerous messages from community members about how watching the interview and listening to the song have inspired them to critically reflect on the way we treat PLwD in our communities. What is exciting for the Coalition is that other countries have created their own versions of the song, helping to address stigma in their own countries (https://www.reimaginingdementia.com/contributions/reimagining-dementia-malaysia).

These examples illustrate the potential of music to foreground the continued strengths, agency, and relational capacities of PLwD, reflecting what Dupuis and Kontos (2026) described as leisure/arts activism, where PLwD are supported in engaging with the arts not as therapy but as a means of challenging harmful stereotypes and dominant narratives about the dementia experience. Alongside my experience engaging in collaborative songwriting with PLwD in my work as a music therapist, this understanding has shaped the rationale for the present research. The final section of this chapter outlines the literature on songwriting in the context of dementia.

[18] It should be noted that while themes, ideas, and certain lyrics were written collaboratively with coalition members, the final lyrics were created by a songwriting team that did not include PLwD.

Songwriting

In reflecting on this research, I have often asked myself, "Why songs?" Despite my bias as a songwriter and my lack of talent in other artistic mediums, there is something specific about songs and songwriting that makes them so powerful in this context. Reflecting deeper, I think songs carry the weight of both words *and* music. For example, when I perform, I am always mindful of how the lyrics match the melody. There are times when I choose to belt out a phrase, and other times when I hold back and sing a word almost in a whisper to draw people in. As a singer/songwriter, I have always felt that songwriting has helped me assert my power in situations where I was once powerless. For example, from a young age, I would write songs to make sense of growing up in a chaotic household:

> *Wake up, wake up, this house is on fire, unlock the doors or we will just die here. It's not fair, it's not fair, so let me out of here.*

I have also used songwriting to express myself after a toxic relationship:

> *Cry, cry, cry, till your eyes are bone dry, I'll tie you to a track, and watch the train go by. And you will bleed a pool of lies, and I'll just watch you cry, cry, cry.*

Through writing and performing my songs, I gained the confidence to advocate for myself. It is because of these experiences that I am passionate about supporting others in doing the same.

As I mentioned earlier in this chapter, I also strongly believe in the power of song to raise social awareness and create alternative narratives that resist oppressive discourses, systems, and structures. Albergato-Muterspaw and Fenwick (2007) argued that singing is a powerful tool to "reclaim all voices to build inclusive communities and confront social concerns" and that songs "engage audiences in confronting conditions of inequity and injustice, envisioning alternate possibilities, and daring to consider their personal responsibility" (pp. 160 - 161).

Finally, as a music therapist with experience in LTC settings and a musician leading songwriting initiatives in the community, I have seen how PLwD can write original works rich with personal and interpersonal meaning, with the creative potential to challenge dominant discourses associated with dementia. However, despite these experiences, the use of songwriting within the dementia context is vastly underutilized, especially with PLwD in LTC settings and in later phases of the dementia journey. The creative potential of songs and collaborative songwriting to challenge oppressive discourses, systems and structures has inspired me to use songwriting as the method for this research. This section provides a brief overview of songwriting in music therapy practice and research and discusses how therapeutic songwriting (TSW) has been applied in the context of dementia.

Therapeutic Songwriting

Baker and Wigram (2005) defined TSW as "the process of creating, notating and/or recording lyrics and music by the client or clients and therapist within a therapeutic relationship to address psychosocial, emotional, cognitive and communication needs of the client" (p. 16). While this definition of TSW focuses on the individual rather than broader systemic or structural issues, like the landscape of music therapy, TSW approaches are informed by various theoretical frameworks, including cognitive, neuro-rehabilitative, psychosocial, and social-activist domains. For example, TSW has been used to improve cognition and memory with people with traumatic brain injuries (e.g., Baker et al., 2005), to aid in end-of-life work in palliative and cancer care

settings (e.g., Abad, 2003; Clements-Cortes, 2009), and in social justice initiatives to challenge social norms and stigma (e.g., MacDonald & Viega, 2012; O'Grady 2011; Silverman, 2020).[19]

Baker (2015) described four songwriting methods that are frequently referenced in the literature. One of these methods is original songwriting using known structures. This approach to songwriting involves the therapist and the individual (or group) working together to write a song using familiar song structures (i.e., verse, chorus, bridge). This is the method of songwriting I use most in practice and what was used in this research.

Therapeutic Songwriting with PLwD

Since the 1990s, the music therapy literature on TSW has been steadily increasing. Between 1990 and 1999, 14 studies were published on the topic, while between 2000 and 2005, 23 studies were published. In 2014, over 50 studies were published (Baker, 2015). A search of articles on TSW published between 2020 and 2024 yielded approximately 866 studies. Although the literature on TSW is extensive, it is used less frequently in the dementia context, possibly due to preconceived assumptions about the cognitive capacities of PLwD (Ahessy, 2017; Baker, 2015; Clark et al., 2021; Kelly et al., 2025).

In reviewing the literature, I found only nine studies which employed TSW with PLwD (Ahessy, 2017; Antipas & Woon, 2022; Baker & Stretton-Smith, 2018; Clark et al., 2020, 2021; Hong & Choi, 2011; Kelly et al., 2025; McMahon et al, 2021; Silber & Hes, 1995). Out of these nine studies, two focussed solely on using TSW to improve symptoms of dementia (Hong & Choi, 2011; Silber & Hes, 1995), three used TSW for expression of personhood and

[19] This section aims to give a brief overview of TSW more broadly. Specific information on the ways songwriting is used to support social justice initiatives is discussed in Chapter 4.

strengthening relationships (Baker & Stretton-Smith, 2018; Clark et al., 2021; McMahon et al., 2021), two used TSW for a combination of psychosocial and cognitive goals (Ahessy, 2017; Clark et al., 2020), and two used TSW as a tool for social activism, one that just came out as I was finalising my dissertation (Antipas & Woon, 2022; Kelly et al., 2025).

Though seven out of the nine studies did not primarily focus on using TSW for functional outcomes, many still used biomedical, psychological or functional discourses in one way or another. For example, Antipas and Woon (2022) used group TSW to inform a CoMT initiative where people with young-onset dementia and their families wrote a song about what living well with dementia looks like. The song was then shared on social media platforms and presented at conferences to disrupt ableist and normative discourses. Though this study situated itself in a CoMT and posthumanistic theoretical framework, the rationale given for beginning sessions with singing familiar songs was to "stimulate the emotional centres of the brain to maximize awareness" (p. 50). I argue that language like "stimulate" and "maximize awareness" is situated in a paradigm which roots cognition and the brain as the epicentre of being and reinforces the narrative that PLwD are in need of a "cognitive awakening." In a case study on TSW with a woman with Alzheimer's disease, Ahessy (2017) stated that goals for the session included emotional self-expression, identity formation, and increased cognitive functioning and mood. Similarly, while listing the benefits of TSW with PLwD, Baker and Stretton-Smith (2018) stated that TSW activates cognitive skills.[20]

[20] It is important to note that it is not my intent to demonize the use of music for these reasons. Rather, I question why it is often never enough to just engage in songwriting for life enrichment and social justice causes with PLwD, and that even when these are the stated aims, there is still a focus on functional and biomedical objectives and outcomes. As we will see in Chapter 4, songwriting is commonly used solely for social justice purposes outside of the dementia context. We must therefore question and critique why biomedical and functional language is embedded only when we use songwriting (and music more broadly) with PLwD.

While many studies drew on biomedical, psychological and/or functional discourses to justify the use of TSW with PLwD, many also emphasized the relational and expressive potential of TSW. For example, a study by Clark et al. (2021) on the experiences of TSW from the perspectives of PLwD indicated that the songwriting process promoted social connections, relationships, inclusion, and mutuality between PLwD and care partners. Similarly, Baker and Stretton-Smith (2018) reported that PLwD experienced feelings of empowerment and agency through group TSW. Though only two studies specifically used TSW to challenge stigma associated with dementia, three of the nine studies reported that using TSW with PLwD contributed to challenging perceptions of PLwD's capacities (Baker & Stretton-Smith, 2018; Clark et al., 2021; McMahon et al., 2021). For example, Baker and Stretton-Smith (2018), reported that healthcare practitioners shared feeling "surprised" by the capacity for PLwD to engage in TSW with one participant stating, "they could actually make a sentence out of [the ideas on the whiteboard] and then make four lines and it made sense. I think that was quite amazing knowing their capabilities…" (p. 55). Though this quote indicates stigma towards PLwD, I argue that it also shows the potential of songwriting to counter the perceived capacities of PLwD. In this study, PLwD also shared how TSW encouraged them to rethink their own capacities as songwriters. Similarly, Clark et al. (2021) stated that group TSW with PLwD and their care partners created a space where PLwD felt accepted without judgment, contributing to creating non-stigmatizing spaces and places for PLwD to flourish. Lastly, in a study by McMahon et al. (2021) on the benefits of TSW with PLwD from the perspective of music therapists, participants shared how TSW has the "potential for influencing perspectives and challenging stigma" (p. 68). For example, one participant stated:

> When you say ‘I’m going to run a songwriting group for people with dementia’, people look at you like you’ve got two heads. They say, ‘Well, what if they’ve got significant cognitive impairments?’ and ‘How will you manage destructive behaviours?’ And I don’t see those sorts of things as being an issue. I want to break down barriers. I want to say, ‘Well, actually, I disagree’ (p. 68)

Lastly, a study by Kelly et al. (2025) used TSW to highlight the continued capacities of PLwD and to better include PLwD in research processes. The resulting song, “We Will Tell Everyone,” empowered songwriters in sharing their experiences of dementia and gave them hope for a better future. Such findings are consistent with the literature on the broader use of the arts to challenge stigma associated with dementia (see Dupuis et al., 2016a; Dupuis & Kontos, 2026; Kontos et al., 2020).

To summarise, though TSW is widely represented in the music therapy literature (Aasgaard et al., 2015; Baker, 2015), it is used less often in the dementia context (Ahessy, 2017; Baker, 2015; Clark et al., 2021; Kelly et al., 2025). In the limited research that does exist on the topic, most draw on biomedical, psychological and/or functional discourses to justify the use of TSW with PLwD (Ahessy, 2017; Clark et al., 2020; Hong & Choi, 2011; Silber & Hes, 1995) and only two studies to date (one published after my research was conducted) have used TSW for social justice purposes, and to specifically challenge stigma associated with dementia (Antipas & Woon, 2022; Kelly et al., 2025). While there are examples of songwriting outside of the music therapy literature which challenge stigma associated with dementia (Dupuis et al., 2023b; Dupuis & Kontos, 2026; Kontos et al., 2017), they do not draw on music-centred music therapy principles, which can provide a context and framework to *musically* support the full relational capabilities and citizenship of PLwD. Additionally, much of the existing literature on

songwriting with PLwD has focused on community contexts and earlier phases of the dementia journey, leaving a notable gap in work exploring collaborative and liberatory songwriting with PLwD in later phases of the dementia journey, particularly in LTC or residential care settings. As a music therapist, I believe that the music-centred models and approaches outlined in this chapter, when used intentionally in songwriting processes, can expand the ways we use music, and specifically songwriting, with PLwD to advocate for social change.

In the next chapter, I outline how the theories and music therapy models from Chapters 2 and 3 were utilized to inform the methodologies and methods in this research. Using these theories and models as a framework, this research used TSW as a vehicle to support the relational capacities of PLwD and support PLwD in asserting their relational citizenship. Though the arts (and specifically songwriting) have been shown to challenge stigma associated with dementia, engaging with the arts on its own does not necessarily lead to social change. Instead, it is through intentionally engaging with the arts in the context of critical self-reflection and dialogue about issues of oppression, stigmatization, and inequity which support social transformation (Kraehe & Brown, 2011). Therefore, Chapter 4 will discuss how critical arts-based methodologies, including liberatory/activist arts, critical arts-based inquiry, and TSW methods rooted in social justice, supported the research process.

CHAPTER 4: METHODOLOGY AND METHODS

To remind the reader, my primary objectives in this study were to challenge the stigma of dementia by providing an alternative narrative co-created with PLwD, and to document and explore the possibilities of a collaborative, liberatory songwriting process in challenging these dominant stigmatizing discourses. As I moved from theorizing and towards putting this research into action, I was reminded of a quote from bell hooks (1994) who stated that “theory is not inherently healing, liberatory, or revolutionary. It fulfills this function only when we ask that it do so and direct our theorizing towards this end" (p. 61). In the dementia context, a similar sentiment is shared by Dupuis et al. (2012b), who argued that by not taking up theories that disrupt hegemonic discourses, we risk upholding the structures and systems that oppress PLwD. Therefore, it was essential that the methodologies and methods used in this research intentionally encapsulate the values of critical and relational theories as well as the music-centred and anti-oppressive approaches to music therapy discussed in the previous chapters. More specifically, aligned with these theories and approaches, I drew on liberatory/activist arts and critical arts-based inquiry as the guiding methodology and integrated these with TSW approaches rooted in music-centred music therapy, including CoMT and RoMT, to support PLwD in writing a song about what they want the world to know about them. This chapter outlines the methodology and methods influenced by these theories and approaches to practice and describes the process used to facilitate this research.

Liberatory/Activist and Critical Arts-based Methodologies

The power of the arts to create space for social dialogue, critical reflection, and transformation is widely recognized in the academic literature (Dupuis & Kontos, 2026; Foster, 2016; Greene, 2000; Kraehe & Brown, 2011; Wang, 2001; Watkins & Shulman, 2008). For

example, Foster (2016) argued that the arts are a disruptive tool that displaces "common sense understandings and act as a reminder that there are possibilities for things to be otherwise" and that the arts "enable an examination of the everyday in imaginative ways that draw attention to the cruelties and contradictions inherent in neoliberal society" (p. 1). Additionally, Greene (2000) stated that experiencing and engaging with the arts opens us up to new perspectives that often differ vastly from our own, prompting critical reflection and personal and social transformation.

The ways the arts inspire personal and social transformation can be further understood through Schutz's (1967) concept of wide-awakeness. As described by Dupuis and Kontos (2026), wide-awakeness refers to "an alternative mode of existence that transcends the passive attitude so easily assumed in relation to one's surroundings" (Williams, 2017, p. 3). Drawing on this concept, Greene (1995) viewed the arts and aesthetic experiences as providing opportunities for individuals to experience wide-awakeness (i.e., becoming more perceptive and responsive to the world around them). Similarly, Wang (2001) described the arts as an awakening experience by stating: "An aesthetic experience is always open to something other and different. It is beyond the repetitive and the uniform that an aesthetic experience plays its transformative role and leads to an essential openness to the 'moreness' and 'newness' of experiences" (p. 9). Importantly, the experience of wide-awakeness is not limited to individual transformation. As Hocoy (2005) argued, the arts can also "serve as a basis for social action" (p. 8). Recognizing this broader transformative potential, and specifically the ways in which the arts foster wide-awakeness, Dupuis et al. (2025a) suggested that the arts are particularly valuable in challenging stigma associated with dementia as they "expose things not seen before, disrupt and expand understandings, and promote consciousness-raising, social action, and social justice" (p. 584).

Given the aims of my research, I chose to draw on approaches to art-making rooted in social justice and participatory processes, specifically liberatory/activist arts (Brown, 1996; Foster, 2016; Keifer-Boyd, 2011; Kester, 2004; Watkins & Shulman, 2008) and critical arts-based inquiry (Finley, 2008, 2011; Kraehe & Brown, 2011; Osei-Kofi, 2013). These approaches also align with the concept of wide-awakeness in that they situate artmaking as a relational and participatory practice that offers opportunities for heightened awareness and critical reflection, particularly regarding social inequities and taken-for-granted assumptions (Dupuis et al., 2025a).

It is important to note that liberatory/activist arts are described using various names in the literature. For example, Watkins and Shulman's (2008) definition of liberatory arts shares many elements with Keifer-Boyd's (2011) description of feminist art activism and Foster's (2016) description of arts for social justice. Similarly, Dupuis and Kontos (2026) drew on the concept of civil leisure (Mair, 2002) and liberatory arts to describe what they call leisure/arts activism:

> discursive spaces where the things we do in our leisure (e.g., creating art or music, dancing, or theatre experiences) are used intentionally to challenge and expose the stigma associated with dementia, open up spaces for dialogue, and promote social justice for PLwD and social change in dementia care. (p. 260)

For clarity, I have grouped these related approaches under the umbrella term “liberatory/activist arts.” I also drew on critical arts-based inquiry, a research methodology that uses the arts to expose social injustices and promote personal and social change (Finley, 2008, 2011; Kraehe & Brown, 2011; Osei-Kofi, 2013). While liberatory/activist arts and critical arts-based inquiry are taken up by different groups (i.e., liberatory/activist arts are used by individuals both within and outside of a research context and critical arts-based inquiry is taken up primarily by researchers, some of whom are also artists), they both served to enrich the way the arts were utilized in this

project. For example, liberatory/activist arts highlight the participatory and collaborative processes present in advocacy projects, and critical arts-based research challenges traditional notions of how research "should" be conducted, disseminated, and evaluated, and highlights the importance of the arts for knowledge generation and mobilization. This section will outline the methodological characteristics of liberatory/activist arts and critical arts-based inquiry as they pertain to this research.

Liberatory/Activist Arts

Liberatory/activist arts are a participatory, critical, and dialogical approach to arts engagement, where the barrier between artist and spectator is challenged and replaced by a collaborative approach to artmaking. Liberatory/activist arts explore and represent aspects of oppression that have been silenced or repressed and create counter-narratives to envision a better future (Watkins & Shulman, 2008). Kester (2004) stated that the difference between liberatory/activist arts and "object-based" art projects lies in the way the process unfolds (p.10). For example, an object-based art initiative is created solely by an artist for the enjoyment of a spectator. In contrast, liberatory/activist arts are collaborative projects in which artists and community members work together to critically reflect on and acknowledge systems of oppression, disrupt harmful narratives and discourses that perpetuate harm, and create space to imagine a way forward (Brown, 1996; Watkins & Shulman, 2008).

In accordance with the relational and critical theories taken up in previous chapters, liberatory arts promote critical reflection and dialogue, are participatory, collaborative, transformative, and centred in relationships (Keifer-Boyd, 2011). Liberation/activist art projects often begin with a group of people who have a collective interest in coming together to critically examine and disrupt systems of oppression which have influenced their lived experiences

(Watkins & Shulman, 2008). Within this space, group members engage in critical reflection and dialogue about taken-for-granted narratives and discourses and discuss ways to envision a different future. For example, Watkins and Shulman (2008) stated that in liberatory arts, "people may reflect together on how limits came to be, begin to see them as a construction that can be undone, and as a situation that can be rethought and transformed" (p. 207).

Centring relational processes, liberatory/activist arts prioritize a collective 'we' in breaking down hierarchies between group members and strive to create a safe dialogic space where group members' diverse histories and perspectives are respected. For example, Watkins and Shulman (2008) stated that the helper/helped binary in liberatory/activist art projects is challenged by viewing each group member as being impacted by systems of oppression in some way. Additionally, creating the art itself is a collaborative effort where all creative decisions are made as a group (Watkins & Shulman, 2008). In a social landscape which dehumanizes, oppresses, and stigmatizes PLwD, liberatory/activist arts can serve as a framework for supporting PLwD in speaking for themselves and challenging harmful discourses.

Critical Arts-based Inquiry

Critical arts-based inquiry (CABI) is a research methodology that utilizes the arts for specific social justice purposes. CABI “exposes oppression, targets sites of resistance, and outlines possibilities for transformative praxis” (Finley, 2008, p. 71). CABI views the arts as a tool to unsettle our preconceived notions regarding commonly held values and beliefs to shape new ways of doing and being in the world (Foster, 2016). Though CABI is a mode of research inquiry, the ways in which research is created and disseminated cannot be delineated into specific methods or processes as seen in postpositivist research. Instead, CABI is more of an

overarching approach to research which sees the arts as a promising tool to disrupt issues surrounding oppression, stigmatization, and marginalization (Finely, 2008).

In positioning myself as a critical and relational researcher, I am drawn to both liberatory/activist arts and CABI for many reasons. First, these approaches disrupt traditional hierarchies between researcher and subject, requiring researchers to work with participants in equal partnership towards actionable social change (Finely, 2011). While such role disruptions in the research process are common in critical methodologies more broadly (e.g., critical participatory action research, critical ethnography), it is the way CABI brings this value into the art-making process itself that makes it especially relevant for this research.

Second, these approaches disrupt traditional knowledge systems, which have "historically dominated our understanding of what is and is not considered research" (Leavy, 2013, p. 24). Specifically, liberatory/activist arts and CABI place importance on the role of performance in creating research/art that "…engages in critical reflection, resists neoconservatism in preference of social justice, and purposefully facilitates imaginative thinking about multiple, new, and diverse ways of understanding and living in the world" (Finely, 2008, p. 80). In engaging in research aimed at challenging conceptions of dementia, it was essential that this work exist beyond the confines of academic literature and be accessible in spaces where it could reach a much broader audience. As will be discussed later in this chapter, performance (and specifically performing songs) also serves as a tool for empowerment and social resistance (Albergato-Muterspaw & Fenwick, 2007; Dupuis & Kontos, 2026).

Moreover, CABI disrupts traditional research processes, particularly in how it measures validity and reliability. For example, Foster (2016) argued that "[t]raditional positivist and post-positivist criteria of validity and reliability, rigour and value-neutrality make little sense when

applied to the creative inquiry" (p. 113). Instead, validity and reliability in CABI are based on the impact it has had on participants and the community (Foster, 2016). This is consistent with researchers rooted in constructionism who have argued for authenticity as a more relevant concept for assessing the methodological rigour of constructionist research (Lincoln & Guba, 1985; Shannon & Hambacher, 2014). Specifically, Lincoln and Guba (1985) described five components to assessing authenticity in constructionist research: fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity. Fairness refers to the extent to which participants feel supported in contributing to the research process. Ontological authenticity concerns the extent to which participants grow through their engagement in the project. Educative authenticity refers to the extent to which participants' understandings of others' experiences in the world have grown. Catalytic authenticity captures the extent to which insights and interpretations facilitate further action. Finally, tactical authenticity explores the extent to which participants were empowered to act on new insights. These approaches are important in the context of this research, not only to ensure that PLwD are supported in expressing their full relational citizenship and are not simply being used or seen as research "subjects," but also to ensure that I intentionally attend to the ways our collaborative, liberatory work might challenge dominant discourses of dementia in ways that might prompt broader social change.

Creative Research Plan

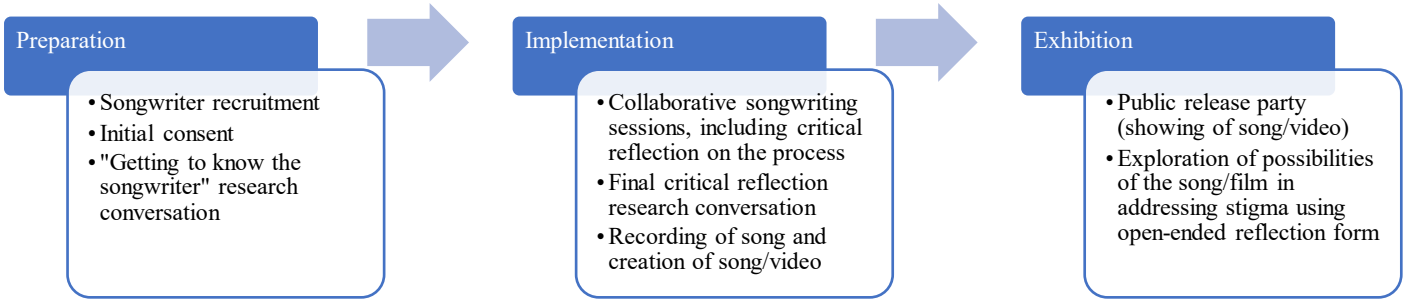
Thompson's (2015) aesthetic of care describes a three-step process for engaging in relational arts projects: preparation, execution, and exhibition. This process was used by Gray et al. (2020) to create a research-informed play called *Cracked: New Light on Dementia*. I find this use of language helpful for describing my research plan because it recognizes the relationship

between phases of the art-making process and allows for fluidity between them. However, I felt it was important to make one small change to how these phases of the process are labelled. Some of the songwriters involved in this process were Holocaust survivors, and the word "execution" felt inappropriate for describing the second phase of my process. Therefore, I refer to this part of the project as "implementation." Using this three-step process as an overarching framework, this section outlines each step as it pertains to my creative research process (see Figure 1 for an overview of the creative research process).

Preparation

Thompson (2015) described preparation as "an openness and honesty of intention, the selection of artists or participants and questions of the location of a project" (p. 437). This includes ethical considerations such as the accessibility of a space, travel costs, and time constraints for participants (Thompson, 2015). I take this to mean that preparation involves everything that goes into planning the art-making process before the actual art-making begins.

Figure 1: *Overview of the Creative Research Process*



Thompson (2015) described preparation as "an openness and honesty of intention, the selection of artists or participants and questions of the location of a project" (p. 437). This includes ethical considerations such as the accessibility of a space, travel costs, and time constraints for participants (Thompson, 2015). I take this to mean that preparation involves everything that goes into planning the art-making process before the actual art-making begins. This section will describe the steps I took in preparation, including identifying a setting for the creative research process, engaging in recruitment, obtaining consent, and intentionally building relationships throughout the recruitment and consent process. I will then introduce the songwriters who participated in this project.

Setting

Initially, I approached an LTC setting to conduct this research. While the care team expressed enthusiasm for the project, significant challenges with recruitment emerged. Recruitment of the minimum required five participants was not achieved, in part because staff expressed uncertainty about their ability to identify individuals who could provide informed consent to participate. Although this was initially disappointing, the experience prompted deeper reflection on how institutional constraints, risk-averse research cultures, and dominant assumptions about capacity may shape opportunities for PLwD to participate in relational and creative research processes. These reflections are discussed further in Chapter 6.

During this time, I was also facilitating weekly music therapy sessions at a retirement home in Southern Ontario that specifically provided 24-hour care for PLwD. Following the recruitment challenges at the first site, I approached the director of recreation and the manager of community relations at this home to explore their interest in participating in the study. They expressed immediate enthusiasm, and together we developed a recruitment plan. Reflecting on

the relative ease of approaching this site, it is important to acknowledge the role of established relationships in supporting creative research processes with PLwD. I had been working at this home for nearly a year and had developed close relationships with many residents and their family members. In addition, staff regularly attended the group music therapy sessions and were familiar with my facilitation style and approach. The trust I had built over time with various people in the home was critical to the support the home provided for this research. This home also seemed to have a higher staff-to-resident ratio than the first home, which may have afforded greater staff capacity to support research activities. With a research setting confirmed, I was ready to continue with my creative research process.

While limited information is publicly available regarding the size of the home where this research took place, the facility is located in an urban area and is home to approximately 70 residents, all of whom have a diagnosis of dementia. In addition, while the home maintains a kosher kitchen to accommodate its predominantly Jewish residents, it is open to individuals from all backgrounds and religious traditions and provides accommodations and programming designed to support diverse cultural and spiritual needs. In addition to music therapy, the home offers pet therapy, speech therapy, occupational therapy, and design recreation programs using the Montessori Method.

Recruitment of Songwriters and Inclusion Criteria

In qualitative research, it is not uncommon for sampling strategies to focus on recruiting individuals with a specific knowledge base or interest in participating in the study (Campbell et al., 2020; Miles & Huberman, 1994; Palinkas et al., 2015). For example, purposive sampling is a sampling method which selects participants "by virtue of their capacity to provide richly textured information relevant to the phenomenon under investigation" (Vasileiou et al., 2018, p. 2). This

study employed purposive sampling to recruit songwriters interested in participating in a collaborative songwriting project.

Once I had consent to conduct my creative research process by the home's leadership, I turned to recruiting potential songwriters. I was looking to recruit songwriters who fit the following criteria:

- *Diagnosis of dementia* – As this project aimed to support the relational citizenship of PLwD and support PLwD in sharing what they want the world to know about them, it was essential that PLwD were at the forefront and that their voices were heard. Though I have worked on projects where both people with and without dementia contributed to the songwriting process (i.e., "Let's Reimagine"), this project specifically centred the voices of PLwD. Given that the research setting catered specifically to PLwD, this criterion was easy to address.
- *Openness in playing and creating music in a group context and interest in the aims of the project itself* – It is important to recognize that not everyone is comfortable/interested in group music-making. To meet the aims of this project, songwriters needed to be interested in both musical engagement and songwriting. While some songwriters were very clear about their interest in creating a song aimed at challenging stigma, others just stated their interest in writing a song about what they want to share with the world more broadly. To include PLwD in the later stages of the disease process, it was only required that songwriters show general interest in the project. No prior musical experience was required to contribute to this project – just a love of music and a willingness to engage in the process.

- *Ability to communicate verbally and in English in some capacity* – There is an inherent tension in research aimed at supporting the relational capacities of PLwD that only includes PLwD who can express themselves verbally. However, because this project incorporated verbal critical reflection as a major part of the songwriting process, I wanted each songwriter to be able to contribute and feel included. Being able to communicate verbally, at least to some capacity, was important to their inclusion in the critical reflective process. Drawing on embodied selfhood, I also attended to how PLwD communicated nonverbally throughout the sessions.

I was first invited to present the project to family members of residents at a social event at the retirement home. In this presentation, I outlined the project's objectives and plan, as well as the inclusion criteria. Family members who expressed interest in their relatives participating in the project were then added to a staff list. Staff were then asked to reach out to these residents to explore whether they would be interested in participating or learning more about the project. Following this presentation, I also met with the director of recreation and the manager of community relations to identify other residents they thought might be interested in participating. As I also led weekly music therapy sessions at the home, I was familiar with many of the residents and had suggestions for who might be interested in participating, based on my observations of their interest in music during group sessions. To ensure potential songwriters did not feel pressured to participate because of our prior relationship, all initial recruitment was conducted by staff, allowing residents to consider participation without my direct influence.

To support the full relational citizenship of each songwriter and to ensure that each songwriter's voice and message were heard in the song, I told staff members that I was looking to recruit no more than six to ten songwriters. Small sample sizes are common in qualitative

research “in order to support the depth of case-oriented analysis that is fundamental to this mode of inquiry” (Vasileiou et al., 2018, p. 2).

Gaining Consent

According to Reed et al. (2004), there are challenges in adhering to the values of participatory research with PLwD while meeting the requirements of traditional research norms and regulations. For example, Grout (2004) stated that participatory processes with PLwD are often not considered in the consent process as this process is usually “based on a required minimum level of cognitive competence assessed in a way that is generally both clinical and non-situational specific” (Dewing, 2007, p. 13). To challenge exclusionary consent protocols in research with PLwD, Dewing (2002, 2007) developed what they termed process consent. Drawing from Gilligan’s (1982) feminist ethics of care, process consent “acknowledges that capacity is situational, that capacity can be present even after the usual legal threshold has been crossed and that it is often strengthened or even reinvigorated within an enabling and caring relationship” (Dewing, 2007, p. 13). Process consent contains five iterative components: background and preparation; establishing the basis for capacity, initial consent, ongoing consent monitoring, and feedback and support (p. 13):

- *Background and preparation* – In this phase, the researcher ensures that staff and/or family members have granted permission to connect with a potential participant. Although not every situation requires this permission, because this research took place in a retirement home, I needed permission to enter the home and approach potential participants who met the eligibility criteria and who agreed to hear more about the project. While it is argued that needing permission from people other than PLwD sits in opposition to an ethic of care (Bartlett & Martin, 2002), it also “acts to

remind practitioners that they do have a legal and professional duty of care towards [PLwD] in their care to act in their best interests, and should neither give researchers carte blanche permission nor deny permission" (Dewing, 2007, p. 15). As described above, I connected with family members and staff to create a list of residents who might be interested in participating in the study. Staff members then approached the residents on this list using a script provided to them (see Appendix A). Substitute decision makers (SDMs) of interested residents were emailed by staff using an email script (see Appendix B) to see if they were interested in learning more about the study. I then called the SDMs who informed staff that they would like to learn more about the study using a verbal script (see Appendix C). SDM's who were still interested after our phone call were sent an information letter and consent form (see Appendix D). Once I received consent from each SDM, I met one-to-one with each resident and began the consent process with them.

- *Establishing the basis for consent* – Before obtaining initial consent, the researcher must inquire into each person's capacity to consent. In this phase, Dewing (2007) argued that it is important for the researcher to consider the following six criteria: the person's usual self-presentation; the person's usual level of ill/well-being; how a decrease in the level of this person's well-being may be triggered; how any decreasing level of well-being can be recognized; any significant conversation or behaviour that might be indicative of a deeper psychotherapeutic need/intervention; and how the person usually 'consents' to other activities and procedures within their day-to-day life. (p. 17)

What I like about this phase of the consent process is that it challenges researchers to think creatively about how to better include PLwD in consent processes. In this process, residents who could communicate verbally and engage through body language were considered able to consent. For example, one resident who initially expressed verbal interest in the project closed her eyes and shook her head when I met with her to go over the information letter and consent form. After asking her again a few days later and receiving the same response, I interpreted this as a refusal to participate in the project (despite her SDM having signed a consent form).

- *Initial consent* – After gathering information about each person's ability to consent, the researcher is ready to request initial consent. In this phase, the researcher uses information from the previous phase to customize the consent process for each individual (Dewing, 2007). To ensure the consent process was as inclusive as possible, I found ways to be flexible and to meet the participants where they were. For example, I found that some participants could better communicate verbally at certain times of day. In these cases, I returned to meet with the participant at a time that suited them best. I also met with some participants in the presence of their SDM, as they seemed more comfortable engaging in conversation when someone familiar was with them. Further, while some participants could engage with me while I read them the entire information and consent form (see Appendix E), this was unrealistic for everyone. In these cases, I met with the participant with their SDM present and explained the project more succinctly. Lastly, in this phase, the researcher must record "the location, time, information given, props or equipment used, questions and answers" (Dewing, 2007, p. 18). I did this by filling out a

consent-tracking form that recorded each participant's information regarding the consent process.

- *Ongoing consent monitoring* – Dewing (2007) stated that process consent includes "ensuring initial consent is revisited and re-established on every occasion or even within the same occasion" (p. 19). By consistently gaining consent throughout the research process, PLwD are supported in advocating for themselves and have the opportunity to withdraw from the project if they wish. Ongoing consent for this research was obtained in a few different ways. First, I began every songwriting session by restating the project's goals and objectives and asking each songwriter to consent to participate (see Appendix F). There were also times when songwriters arrived late or decided to skip that day because they were tired. In these cases, I made sure to summarize what had happened in the group, so that each songwriter was included in each step of the process as much as possible. Regular check-ins with the songwriters were essential to the consent process.

Establishing and Building Relationships

Pyer and Ward (2024) emphasized that remaining flexible, establishing relationships with potential participants, and familiarizing oneself with the organization or setting from which participants are being recruited are key to ensuring that PLwD feel supported throughout the recruitment and consent process. Additionally, as stated earlier, Dewing (2007) stressed the importance of embedding Gilligan's (1982) feminist ethic of care into consent processes with PLwD. A feminist ethic of care involves placing "interdependence and connectedness through relationships" at the forefront of all that we do (Dewing, 2007, p. 13). I drew on Dewing's (2007) process consent approach and Gilligan's (1982) feminist ethic of care to intentionally support the establishment and development of relationships between myself and the songwriters

throughout the recruitment and consent process and as we prepared for our songwriting sessions. For example, after obtaining initial consent, I met with each songwriter for a "getting to know you" research conversation (see Appendix G). During these discussions, I learned what was important to the songwriters, what they valued, and how music had been meaningful in their lives. These conversations also gave the songwriters a chance to get to know me better, as they often asked about my background and how I came to this work. Importantly, these early relational discussions supported the songwriting process by laying the groundwork for trust and engagement.

Additionally, Pyer and Ward (2024) noted that "building rapport with participants is also about building rapport with the organizations (where relevant) and understanding the usual practice in which the [recruitment and] consent process may be slotted into" (p. 298). While consent meetings were often planned with staff in advance, there were occasions when prospective participants were engaged in other activities upon my arrival. Rather than leaving and returning later, I viewed these moments as opportunities to further embed myself in the home's culture. For example, on one Friday afternoon, I arrived to find that the residents I had planned to meet were participating in Shabbat programming.[21] I joined the program and participated alongside residents and staff. At other times, I sat with prospective songwriters during dinner, engaging in informal conversation unrelated to the project. Embedding myself in the everyday life of the home and outside my music therapy practice supported the development of relationships not only with the songwriters, but also with staff and family members, which

[21] Shabbat is a weekly Jewish observance, beginning on Friday evening, involving rituals, prayer, and communal reflection.

was critical for facilitating trust and enabling the practical and ethical conditions necessary for the research to take place.

Meet the Songwriters

Initially, eight songwriters agreed to participate. However, after the third session, an SDM who had originally stated that they did not want their loved one to participate asked whether they could join. To be inclusive of all who wanted to participate in the process, they joined in Week 4, accompanied by their SDM. During the consent process, each songwriter chose whether they wanted their full name, first name, or a chosen name to be used in the dissertation and subsequent representations of the project. Eight songwriters chose to use their first names, with one opting for a pseudonym. This section will introduce each songwriter and some of the insights they provided from the "getting to know you" research conversation.[22]

Faigie	Faigie describes her life as a miracle. It is important to Faigie that people know she is a Holocaust survivor who was just a child in the concentration camp. When asked about her relationship to music she said "Music is one of the most important things. Music saved us. We sang in the ghetto and concentration camps to keep our hope. I could have had a nicer voice, but I put in gusto!" Faigie was also a kindergarten teacher who loved to sing songs with her students. When asked about what is important to her, she said "We should try to be nice to each other because we are actually all the same."

[22] Because some songwriters were able to express themselves in more embodied ways, some of the descriptions include my interpretations of the ways they expressed themselves in the research conversation. Additionally, because one songwriter joined after the songwriting sessions began, the interview did not happen. In this case, I had their SDM fill out the questions on their behalf (we did it in this way to also accommodate the songwriter who did not communicate in full sentences).

Lily	Lily describes herself as someone who does what she sets out to do and a person who wants to help others. It is important for Lily that people know she is from Scotland and feels a lot of pride for her country. When asked about her relationship to music Lily said "I love music. I can't describe it to you. To make music that has a good message, it makes me feel good. Jewish music has a special place in my soul."
Lorraine	Family is the most important thing to Lorraine, and she is proud of her family for looking after each other. Lorraine values people and gives to people in need. When asked about her relationship with music she said "I love music. Jewish music is important to me. It made me feel connected to my family. My parents taught me how to be a mensch through Judaism and music is a part of that."[23]
Bill	A lover of Frank Sinatra, Rod Stewart, and Kenny Rogers, Bill is described as a gentle, kind, and highly intelligent person. Others often refer to him as wonderful and speak to his great sense of humour and warmth.
Milton	Milton describes himself as "a busy guy" who "likes the action." When asked what was important to him he said "Peace and quiet. A family should be well knitted. My family all wants to be together. They know what's right and they know what's wrong. It's important to be a good Jew. Zay a mensch. You never go wrong if you're helping another person. Life is not a bowl of cherries. Be friendly and be a good person."[24] Milton has a strong

[23] Mensch means a good person or a person with good character in Yiddish.

[24] Zay a mensch means be a good person in Yiddish.

	relationship with music and enjoys "soft music that tells a story" and songs that "you can imagine yourself in."
Andrew	Andrew says the number one thing that is important is "life and happiness." He is someone who treats people fairly and doesn't care if "you are rich or poor." As an elementary school teacher, Andrew has many life lessons to teach others including "If you don't like it, just walk away" and "Your stupidity, to me, might be very nice."
Helen	Escaping Poland on a boat before the Holocaust when she was a child, Helen values having a "safe life." When asked how she would describe herself she said, "If I have nothing nice to say, I don't say it. We don't have to be the same to like each other." She also described herself as someone who doesn't like "showy things." Helen is a mother who raised two sons. When speaking about her family she said, "I raised two sons. They are well educated and have good careers. I've had my life. I want them to have a good life. When talking about the aims of this project, Helen said, "People don't listen to older people. They don't care what we have to say." While Helen doesn't feel a deep connection to music, she said that she enjoys listening to music on the radio.
Avi	Avi describes himself as a fair, ethical and happy person. When asked what is important to him he said, "Life. It is important to smile. It is important to do the right thing." Avi loves engaging with music and especially singing. When asked about his relationship to music, his eyes began to water as he sang a beautiful melody. He then said "Music makes me feel good. I feel what I sing."
Robert	Robert describes himself as someone who likes helping others and who enjoys surrounding himself with people "who are authentic." Robert has always loved music

	and even worked at a record store in Toronto for many years. When asked about his relationship with music he said, “There is nothing in this world that is better than music. Can you imagine what this world would be without music? It allows you to be the best you can be.” He also feels that music “is everything around us” and “without music, everything crashes.”

Implementation

The second phase of the aesthetic of care framework is defined by Thompson (2015) as “the process of collaborative working on artistic projects which forge inter-human relationships” (p. 438). He also emphasized that a project grounded in an aesthetic of care “relies on building mutual activities of sharing, support, co-working and relational solidarity within a framework of artistry or creative endeavour” (p. 438). What I like about this framework is that it regards the creative research process as just as (if not more) important as the research product. This is important in the context of this research for many reasons. First, placing equal importance on the creative research process recognizes that transformation can occur throughout the process, not just through engagement with the finished artistic creation. Second, a focus on the process, an essential enabler of authentic partnerships with PLwD (Dupuis et al., 2012a), creates space for nourishing relational processes and the relational citizenship of all songwriters by intentionally taking time to reflect on the process, understand what is working and not working, and make changes to better support the active engagement of all PLwD. It is in nourishing these relational processes that we can better ensure that the song created was, in fact, a collaborative and participatory endeavour. Third, by sharing the relational process of this project, other researchers, music therapists, and community musicians can adopt a more relational approach to

songwriting and music making with PLwD more generally. This section will describe the implementation phase of this research, including the collaborative songwriting process and the documentation and analysis of the research process.

Collaborative Songwriting Sessions

The collaborative songwriting sessions took place over eight weeks. The first six weeks focused on the collaborative songwriting process, including five weeks of songwriting followed by one session dedicated to group reflection on the process. Each of these sessions lasted approximately 60 minutes. Following the songwriting phase, songwriters were invited to participate in the recording of the song and the creation of a short film as part of the project's knowledge mobilization component. These sessions occurred in Weeks 7 and 8. In this section, I describe the collaborative songwriting sessions in greater detail, beginning with an overview of the therapeutic songwriting (TSW) approaches that informed my facilitation. I then outline an overarching collaborative songwriting framework and describe how the songwriting and recording processes unfolded across sessions.

Collaborative and Participatory TSW Approaches Guiding the Process

In designing the collaborative songwriting process for this study, I drew on TSW approaches rooted in social justice, relational processes, and strengths-based practice. As stated in Chapter 3, while TSW is often defined in relation to individual psychosocial, emotional, cognitive, and communication goals (Baker & Wigram, 2005), the approaches that most informed this project extend beyond individual outcomes to emphasize collaboration, participation, and social transformation. Specifically, feminist group therapeutic songwriting (FGTS), resource-oriented therapeutic songwriting (RoMTS), and community music therapeutic

songwriting (CoMTS) informed the values and facilitation practices underpinning the process and my role as facilitator.

FGTS is an approach to therapeutic songwriting that embeds the core principles of feminist music therapy, including empowerment, reciprocity, and social justice, within a collaborative songwriting process (Hadley, 2013; Baker, 2015). FGTS positions songwriting as a vehicle for social transformation and has been used in projects where groups have written, recorded, and publicly shared songs to challenge structures of power and marginalization. For example, Day et al. (2009) described a project in which a group of women created and performed an album to raise public awareness about childhood abuse, including performances attended by government officials and policymakers. Similarly, O'Grady (2009) documented a group of women in the legal justice system who created and performed a musical to highlight experiences of power and oppression within prison contexts, with performances aimed at provoking critical reflection among government and healthcare workers (Baker, 2015; O'Grady, 2009).

Drawing on FGTS, the collaborative songwriting process in this research emphasized empowerment, reciprocity, and social justice, and approached songwriting as a collaborative process through which shared experiences could be reflected upon, challenged, and reimagined (Baker, 2015; Hadley, 2013). Central to this approach was the rejection of hierarchical therapist–client relationships in favour of relational engagement, where I participated alongside group members by sharing aspects of myself while supporting the songwriters in sharing aspects of

themselves within the creative process.[25] FGTS also informed the decision to extend the songwriting process beyond creation toward sharing and performance, recognizing public dissemination as an important mechanism for fostering broader social reflection and challenging taken-for-granted assumptions (Baker, 2015).

Also informed by feminist music therapy, RoMTS shaped this project's strengths-based orientation. In this approach to TSW, the focus is on existing capacities, identities, and inner resources rather than on deficits associated with a diagnosis (Rolvsjord, 2015). In practice, this meant positioning songwriters as capable creators, valuing their musical ideas, creativity, lived experiences, and self-knowledge, and engaging as equal and active participants in the songwriting process.

CoMTS further informed my approach to collaborative songwriting by emphasizing the relational value of the songwriting process itself. Rather than positioning the song alone as the primary vehicle for change, this approach highlights musicing as a way of fostering connection among participants and between participants and their broader community (Stige, 2002). Within this framework, the role of the music therapist is understood as relational and facilitative, involving the creation of safe and supportive environments, modelling collaboration and vulnerability, and attending to both interpersonal and contextual factors that shape participation (Baker, 2015; Stige, 2012). This orientation was particularly relevant in the context of this

[25] I recognize the weight that the word "therapist" holds and how this language does not align with the values of many of the theories and methodologies described in this proposal (i.e., relational caring, liberatory/activist arts, CABI, authentic partnerships). However, in using music therapy theories and approaches to practice rooted in social justice and critical theories, the language of therapist is more akin to a collaborator, which is how I am using the term. For example, Aigen (2002) stated that unlike models of music therapy where the therapist's role is more akin to a psychotherapist, in CoMT, the music therapist views their role as a musician who uses their musicianship to support the community in which their work is embedded.

research, where attention to environment, relationships, and accessibility was central to supporting the relational citizenship of the songwriters.

An Integrated Collaborative Songwriting Framework

I used a step-by-step songwriting model to facilitate the collaborative songwriting process. The development of this model was inspired by my work writing songs with PLwD, elements of the TSW models described above, the critical and relational theories outlined in Chapter 2 (i.e., relational cultural theory, relational citizenship, relational caring, and critical pedagogy), and the methodologies described at the beginning of this chapter (i.e., liberatory/activist arts and critical arts-based inquiry). Together, these influences informed an integrated, collaborative songwriting framework comprising eight interconnected phases. While the phases are presented sequentially for clarity, they were revisited iteratively across sessions.

Each songwriting session followed a similar structure, including welcome and overview, consent, musical warm-up, collaborative songwriting, closing critical reflection, summary and planning, and a closing musical activity. The songwriting sessions took place in a spacious room on the main floor of the home with large windows. Chairs were set up in a semicircle by staff before each group, and the songwriters were brought to the space by recreation staff. Detailed weekly plans outlining the specific activities undertaken in each session are provided in Appendix H.

- ***Phase 1: Cultivating the Songwriting Space*** – According to Baker (2015), it is common for individuals who have never engaged with songwriting to feel unease or anxiety about beginning the songwriting process. Therefore, it is essential to cultivate an environment where group members feel safe(r) and supported to engage in songwriting. This is similar to the connecting, committing and creating a safe space enabler of authentic partnerships

(Dupuis et al., 2012a). To support a relational and supportive space, Baker (2015) suggested not introducing songwriting in the first session but rather engaging in musical and non-musical activities to build rapport. In my work in LTC settings, I have traditionally done this by establishing relationships with people before the songwriting process, for example, by playing favourite songs, engaging in musical improvisation, and taking time to learn about individuals' lives, dreams, hopes, and aspirations. In the context of this research, I established a similar relationship before delving into songwriting. As stated earlier, during the initial consent process, I met with each songwriter and asked them to describe themselves, what they felt was important for me to know about them, and their relationships with music. This process helped build rapport and provided information that I was then able to intentionally bring into the songwriting sessions. Additionally, while we did not begin writing lyrics or melodies in a formal sense during the first session, the songwriting process was gradually introduced through relational dialogue and asking guided questions. More specifically, the initial session focused on getting to know one another through musicing together, including singing songs that were meaningful to group members. Alongside this, I asked open-ended questions that helped group members get to know one another and introduced the kinds of reflective processes that would later inform the songwriting process (discussed in more detail in Phase 2). We also discussed the aims and objectives of the project and the ways songs have been used for social justice. Because this research was rooted in relational processes and music-centred music therapy theories, cultivating the songwriting space remained important throughout. As such, each session began with a check-in and time to

sing and play music that was meaningful to the songwriters before delving into the songwriting process.

- ***Phase 2: Asking Guiding Questions*** **–** The next phase of the songwriting process involved asking open-ended guiding questions to brainstorm ideas and lyrics. These questions were intentionally designed to draw on the songwriters' strengths and personhood, while also eliciting critical discussion (in line with both RoMT and liberatory/activist arts). To learn more about the songwriters, I asked questions such as "How would you describe yourself?" "What is important to you?" and "What makes you happy?" To facilitate critical discussion aimed at challenging dominant discourses associated with dementia, I asked questions such as "What do you want the world to know about you?" How do you want to be treated in the world?" and "What wisdom do you want to share with others?" Responses from these discussions were written on chart paper for the group to see and served as the basis for the lyrics.
- ***Phase 3: Discussing Key Themes and Subthemes*** **–** Based on what songwriters shared in response to the guiding questions, we worked together to identify the central theme of the song as well as subthemes the songwriters felt were important. In my work as a music therapist, this stage of the songwriting process often includes circling main themes and underlining subthemes, which then become the chorus and verses. A similar process was used in this research. The songwriters shared that they wanted the song's main theme to focus on the wisdom they wished to share with others. As a group, we circled responses related to this theme and underlined responses connected to the remaining questions, which became the basis for each verse. By this stage, we had created the "skeleton" of the song, meaning a rough draft of the direction and lyrics of the song. Two authentic

partnership enablers were particularly important during this phase: valuing diverse perspectives and establishing and maintaining open communication (Dupuis et al., 2012a). At various points in the songwriting process, songwriters expressed differing opinions about specific phrases or lyrics. Attending to these differences required acknowledging each perspective, intentionally providing opportunities for all songwriters to contribute to the discussions, checking to ensure we were all understanding what was being shared, and engaging in dialogue to arrive at a collective decision.

- ***Phase 4: Exploring the Mood of the Song*** – After identifying themes and subthemes, we examined the mood conveyed by the lyrics. To do this, I read the rough draft of the lyrics aloud and asked group members what they felt the song should sound like. Songwriters shared that they wanted the song to sound happy, uplifting, and like "love."
- ***Phase 5: Creating the Melody and Choosing Instrumentation –*** Once we decided on the song's mood, we created the melody. Because the group seemed most excited about the chorus lyrics, we co-created that melody first. To do this, I presented four guitar chords as the basis for the melody and asked the group whether they matched their vision and the mood they had identified for the song. Because the songwriters wanted the song to sound uplifting, I chose a major-key chord progression with an upbeat tempo. I hummed a melody that fit the chord progression, and some songwriters began to sing along, contributing to the melody's development. Feedback was invited throughout, and changes were made collaboratively before repeating the process for the verses. In Week 4, a music producer joined the session to involve the songwriters more fully in decisions about melody and instrumentation. Group members requested instruments such as accordion,

violin, drums, and piano, which the producer added in real time using music recording software.

- ***Phase 6: Shaping, Learning, and Rehearsing the Song –*** Shaping the song was a fluid and iterative process. Throughout the songwriting process, time was provided for feedback on lyrics and melody, and revisions were made collaboratively. Learning and rehearsing the song occurred over several weeks, beginning once the chorus was completed in Week 3. Because the chorus was repeated throughout the song, it was easier for songwriters to learn, and rehearsals typically began with the chorus followed by the verses. A dedicated rehearsal session was held prior to recording and filming the song.
- ***Phase 7: Critical Reflection and Assessing Authenticity –*** In accordance with authentic partnerships (Dupuis et al., 2012a), CABI, and Lincoln and Guba's (1985) approach to assessing authenticity in constructionist research, critical reflection was an essential component of the collaborative songwriting process. Opportunities for critical reflection were embedded throughout the songwriting sessions and intentionally held at the end of each session. Engaging in closing critical reflection each week provided space for songwriters to express their insights from participating in the project, their hopes for the song, and what they would like to explore further in the coming weeks. Questions such as "What excites you about what we created this week?", "How might this song change someone who hears it?", and "What do you feel is still missing from the song?" supported ongoing meaning-making and informed subsequent sessions. In Week 6, I held a dedicated critical reflection session focused on assessing specific aspects of authenticity. This session aimed to engage songwriters in critical discussion about what they had learned and how they felt they had grown throughout the process (educative and

ontological authenticity), how they hoped the song would inspire others to take action (tactical authenticity), what the experience was like for them, and what they would change if they were to do it again (fairness).

- ***Phase 8: Recording and Filming the Song –*** As stated earlier, sharing the final song with public audiences served as a means of resisting oppression, connecting songwriters with the broader community, and creating opportunities for community members to see songwriters beyond a dementia diagnosis and critically reflect on personal understandings. Following the final reflection session (Week 6), I met with the songwriters to determine their interest in participating in a recording and filming process. While all participants were included in the approved REB protocol, the public-facing nature of the song/film required separate, explicit consent from both songwriters and their SMDs. Each SDM was contacted and provided with a media release form outlining two participation options: involvement in the recording of the song only, or participation in both the recording and filming of the song and the accompanying video. Eight songwriters were approached to participate in the recording and filming process, as one songwriter moved to another home prior to the start of recording. Of these eight participants, six took part in both the recording and filming of the song, while two participated only in the recording, in accordance with their SDMs' wishes. After the six-week songwriting process, songwriters who elected to participate were invited to attend a rehearsal session, during which the group practiced singing the song and discussed what to expect during the recording process. In Week 8, a sound engineer and videographer attended the home to record and film the song. The decision to include a recorded song and short film as knowledge translation tools was informed by literature highlighting the

capacity of film to inspire critical reflection and transformational change related to inequity and oppression (Burns et al., 2020; Kontos et al., 2024; Ogston-Tuck et al., 2016). Following the recording session, the sound engineer and videographer collaborated to compile a draft version of the film. This draft was shared with SDMs, and a private screening was held at the home to allow songwriters to view the film and provide feedback on any changes they wished to make. Based on this feedback, a final version of the short film was produced.

Documenting and Reflecting on the Creative Research Process

The methods used to document the creative research process were aligned with the values of liberatory/activist arts and CABI, while intentionally providing opportunities to reflect on and further embed relational processes. Two strategies were used to document the process. First, field notes were made immediately after each songwriting session using the Songwriting Reflection Worksheet (see Appendix I). Reflection prompts from this worksheet were specifically designed to have me reflect on the embodied ways songwriters expressed themselves each week, the ways relational processes were unfolding, and the ways the process enabled or hindered participatory processes. For example, the worksheet prompted me to reflect on aspects of the physical setting that influenced relational principles and collaborative music-making, on the ways songwriters were included as active participants, and on how they engaged both verbally and non-verbally. Second, I also audio-recorded each session and transcribed the recording before the next session. I then spent time critically reflecting on the process, as reflected in the Songwriting Reflection Worksheet and the transcription of the sessions, and used these to better integrate participatory and relational processes in subsequent weeks.

I used an adaptive approach to Creative Critical Hermeneutic Analysis (CCHA; Van Lieshout & Cardiff, 2011) to guide my critical reflections and analysis of the process, as well as my facilitation of the songwriting process during the sessions. CCHA is a participatory, collaborative approach to analysis that represents emergent themes in data through creative expressions. It comprises seven phases: preparation, familiarization, contemplation, expression, contestation and critique, blending, and confirmation (Van Lieshout & Cardiff, 2011). Traditionally, in the preparation phase, the data is compiled into texts (i.e., transcriptions of the recorded critical reflections). The next phase, familiarization, involves reading through the texts and recording/acknowledging the feelings, images, and bodily sensations that arise. The contemplation phase involves a creative activity designed to prepare oneself to represent the data in an innovative way. Researchers/group members are then encouraged to represent the texts they read in a creative way, which they feel captures the "essence" of the data (Van Lieshout & Cardiff, 2011, p. 228). In contestation and critique, creative expressions are critically analyzed (i.e., pointing out similarities, differences, and contradictions between creative expressions). Blending involves selecting the most significant themes from each expression and creating an updated expression that better reflects these themes. Lastly, group members review the final data set and add any missing information. The CCHA process was intentionally embedded within the songwriting itself, serving not only as an analytic framework but also as a means of shaping the song and ensuring that the final composition accurately reflected the songwriters' ideas and visions.

More specifically, each week I transcribed the songwriting session recording and drew on notes from the Songwriting Reflection Worksheet to create a summary of what had been discussed and developed during the previous session (i.e., preparation). At the beginning of the

following session, I presented my summary of the previous session to the group and asked the songwriters for their feedback on it (i.e., familiarization and contemplation). This process helped remind the songwriters of what we had accomplished during previous sessions and provided an opportunity to critically reflect on the co-creation and make changes to ensure it reflected what they felt was important to convey in the song (i.e., the expression). Together each week, we explored different perspectives on the song, what might be missing, what the songwriters liked best about what we were creating, and what was causing discomfort. Often, songwriters offered additional ideas to include. For example, when reviewing what was identified as important to the group in Week 2, one songwriter suggested adding the line "it is important to be nice to others"; this inspired the chorus of the song. All these steps supported the contestation and critique, and blending phases of CCHA. In the final collaborative songwriting session and the final reflection session, the songwriters were provided with additional opportunities to reflect on both the song and the songwriting process and ensure that the final expression (i.e., the song) captured everything the songwriters wanted to communicate and that the songwriters were supported in sharing their insights on their experiences throughout the process (i.e., confirmation). This collaborative analytical process occurred in a cyclical manner (i.e., discussing guiding questions, transcribing the data, representing the data in an updated and summarized format, presenting this updated format to the group, receiving feedback, and repeating the process), ensuring that all new information and insights were incorporated into the final lyrics of the song.

Exhibition

The final stage of Thompson's (2015) aesthetics of care framework is exhibition. According to Thompson (2015), the performance or exhibition of art provides opportunities for

relational processes between audience members and artists. For example, Thompson (2015) stated that:

> An exhibition in the mode of an aesthetics of care would involve an invitation, a dialogue and an opportunity for reciprocity, with an aesthetics built in the sensations stimulated in the particular moment, specific to the differences of each audience or spectator, and not located in the assumed pre-ordained power of the artwork itself. (p. 439)

The literature on CoMT also recognizes the significance of performance in fostering relational connections between performers and audience members (Baker, 2015; O'Grady, 2009). For example, in a study on the use of performance in a youth mental health facility, a coffee shop where clients shared their music abilities provided "audience members' new perspectives on performers" and "often sparked interactions and relational possibilities that would not have occurred otherwise" (Mitchell, 2021, p. 200). Therapeutic songwriting models, including FGTS, also emphasize the crucial role of performance in engaging critically with audience members to reflect on their taken-for-granted assumptions and create more inclusive futures (Amir, 2006; Baker, 2013, 2015; O'Grady, 2009; O'Grady & McFerran, 2006). As a main objective of this research was to support PLwD in asserting their personhood and relational citizenship and to challenge stigma associated with dementia, it was essential to bring this project to the public sphere.

The exhibition for this project was held as a release party at the retirement home on July 3rd, 2025. The manager of community relations sent invitations to all staff, family members, and volunteers at the home, who then shared them with their family and friends. Flyers were also posted in common spaces throughout the home to reach a wider audience. Approximately 30 people attended the event (not including the songwriters). The release party included time to

watch the film and an award ceremony where I presented each songwriter with a speech about their contributions to the songwriting process.

To better account for catalytic authenticity, the exhibition also included opportunities for audience members to reflect on the song/film through completing an anonymous critical reflection form. A similar approach was used by Kontos et al. (2018), who asked audience members of their play, *Cracked,* to complete a questionnaire to better understand the impact the play had on their perceptions of PLwD and how that might change their future actions. The questionnaire I used included both closed and open-ended questions and included questions inspired by the one used after performances of the theatre production of *Cracked* such as, "what key messages did you take from the song/film," "what, if anything, surprised you about what you saw in the song/film," and "what, if anything, has changed for you from engaging with the song/film" (see Appendix J for Questionnaire). In total, 19 audience members completed the questionnaire. The first question on the questionnaire asked audience members to identify their role within the home (e.g., staff member, family member, friend, person living with dementia, volunteer, or other). Of the 19 audience members who completed the questionnaire, nine identified as family members, two as staff members, three as friends, and four selected other. One participant did not respond to this question. The results from the questionnaire are presented in the final chapter of this dissertation.

Reflecting on and Analyzing the Entire Creative Research Process

The final phase of the creative research process included reflecting on and conducting a formal analysis of data from all phases of the process. This analysis was conducted in two separate phases. In the first phase, data from the songwriting sessions (i.e., verbatim transcriptions and insights from the Songwriting Reflection Worksheets) were used primarily to

address two research questions: (a) How does collaborative liberatory songwriting support the relational and creative capacities and relational citizenship of PLwD in LTC settings? and (b) What relational processes support collaborative songwriting with PLwD, including PLwD later in the disease progression? The analysis of the songwriting sessions informed a relational, collaborative songwriting framework, the Liberatory-Relational Dementia Songwriting Framework, presented in Chapter 5.

In the second phase of the analysis process, I used data from the fieldnotes and transcripts of the songwriting sessions, the lyrics of the song itself, and the data from the audience questionnaires from the exhibition phase to address the other two research questions: How do PLwD living in LTC settings experience a collaborative liberatory songwriting project?, and How might a collaborative, liberatory songwriting process and the resulting song/film challenge stigma associated with dementia? The results of this critical analysis are described in Chapter 6.

All data were analyzed using reflexive thematic analysis (RTA) (Braun & Clarke, 2021). Unlike more traditional forms of thematic analysis (TA), which often align with postpositivist epistemologies and methodologies such as some approaches to grounded theory (i.e., research that emphasizes the removal of researcher bias and the use of more rigid analytic procedures), RTA views researcher subjectivity, reflexivity, and flexibility as necessary components of the analysis process (Braun & Clarke, 2019). Additionally, while TA is often used to code and summarise data in primarily descriptive ways, RTA aims to generate richer interpretations by viewing data analysis as a process of storying (Braun & Clarke, 2019). For example, in RTA, themes are conceptualized as "key characters" in the story told about the data, rather than as categories used to describe repeating ideas from the data (Braun & Clarke 2019) In this way, RTA is not a passive or procedural approach in which coding is "a process for finding evidence

for pre-conceptualised themes," but rather a creative and reflexive practice that "involves immersion in the data, reading, reflecting, questioning, imagining, wondering, writing, retreating, [and] returning" (Braun & Clarke, 2021, p. 332; Braun & Clarke, 2019). Ho et al. (2017) described this process as "dwelling with data," in which researchers "continuously and rigorously reflect on their own taken-for-granted thinking" (p. 1760).

In situating this research within a constructionist epistemology and drawing on critical, relational, and arts-based theories and methodologies as the primary analytic framework, RTA was particularly useful in providing the flexibility needed to interpret and represent the data in ways that attended to meaning, context, and relational processes. Additionally, RTA emphasizes the use of theory as a framework for interpreting and making sense of data (Braun & Clarke, 2021). This was especially important in this study, as theory was central to both the implementation of the collaborative songwriting process and the interpretation of the relational processes through which songwriting challenged stigma associated with dementia and supported the relational citizenship of the songwriters.

Similar to CCHA, RTA comprises fluid, iterative phases including familiarization, generating codes, searching for or constructing initial themes, reviewing themes, defining and naming themes, and producing a final report (Braun & Clarke, 2013, 2019, 2021).[26] In the first phase (familiarization), the researcher reads and rereads (or listens to) all datasets (in this case, audio transcriptions, reflective notes, audience questionnaires, and song lyrics) and begins to make notes and ask questions within a critical framework (Braun & Clarke, 2013). This phase of

[26] In later iterations of RTA, Braun and Clarke (2021) problematized using the word "searching" in relation to theme development as it implies that themes emerge from the data instead of created through the theoretical framework utilized by the researcher(s). Therefore, I have decided to refer to this phase as "constructing initial themes."

the analysis process drew on the theories informing this research (i.e., relational caring, social citizenship, relational citizenship, and music-centred and community music therapy) as the lens through which to ask critical questions. For example, when initially familiarizing myself with the transcripts from the songwriting sessions, I asked myself questions like "in what ways did the songwriters support one another" and "in what ways did I support embodied expressions?" Similar questions were asked during the analysis of the questionnaire data. For example, I read responses to the questionnaire by first asking, "In what ways do these responses reflect critical transformations amongst audience members' conceptualizations of dementia?" With these questions in mind, I circled and made notes of what stood out.

Braun and Clarke (2013) described the second phase of RTA, generating initial codes, as "the individual bricks and tiles" of a house (p. 61). In this phase, the researcher writes down initial ideas from the data that address a specific research question. For example, the songwriting transcription analysis included codes such as "recognition," "validation," and "encouragement." The third phase, constructing initial themes, groups codes based on similarities and larger overlapping ideas (Braun & Clarke, 2019). This is described by Braun & Clarke (2013) as "the walls and roof" of a house (p. 61). Based on these previous codes, I clustered them to create the initial theme of "recognition, validation, and encouragement."

The fourth phase, reviewing potential themes, is the process of ensuring that the developing themes accurately depict the data. For example, Braun & Clarke (2013) suggested that researchers ask themselves the following questions while reviewing themes (p. 65):

- Is this a theme (or could it just be code)?
- If it is a theme, what is the quality of this theme (does it tell me something useful about the data set and my research question)?

- What are the boundaries of this theme (what does it include and exclude)?
- Are there enough (meaningful) data to support this theme (is the theme thin or thick)?
- Are the data too diverse and wide-ranging (does the theme lack coherence)

As I asked myself these questions while reviewing the developing themes and subthemes, it became clear that many of my initial themes were quite narrow and could be grouped together. For example, "connecting stories" and "picking up on phrases" became a larger theme called "weaving storylines together."

In the fifth phase, defining and naming themes, the researcher "state[s] what is unique and specific about each theme" and describes the "essence" of the themes and sub-themes (Braun & Clarke, 2013, p. 66). At this phase in the analysis process, I began to see the components of a relational process (i.e., relational literacies) more clearly and began to define each of these for myself. This meant exploring how each was similar to and different from other relational literacies of the relational process. Reflecting on and comparing the sub-themes of each of these relational literacies was an important part of this phase. In reviewing these initial themes and collapsing them with codes, I created the Liberatory-Relational Dementia Songwriting Framework presented in Chapter 5. For example, the theme of "recognition, validation, and encouragement" was more than just a description of the ways that the songwriters and I related to one another but represented one of the ways we relationally attuned to each other (i.e., relational attuning).

The sixth phase, producing the report, involves creating a "compelling story about your data based on your analysis" (Braun & Clarke, 2013, p. 69). Unlike quantitative research, where results are written after the analysis, the process of "storying" the data is fluid and iterative, developing and re-developing as you work through the analysis process (Braun & Clarke, 2013).

What is important here is that the story goes "beyond description to make an argument that answers your research question" (p. 69). For example, while relational attuning (i.e., the ways the songwriters relationally attuned to one another and the world around them) serves as one part of the collaborative songwriting framework presented in Chapter 5, the depths of this attuning could not have occurred without the songwriters and me learning about one another (what I refer to as relational knowledging). This process of storying was particularly compelling to me as a songwriter and researcher using songwriting as a method, given that the process itself is inherently a form of storying. In fact, many aspects of the collaborative songwriting process described earlier in this chapter align closely with the six phases of RTA.

After the development and writing of the Liberatory-Relational Dementia Songwriting Framework, I repeated all of the phases of RTA to critically explore the songwriters' experiences of the creative research process and how it supported relational citizenship as well as the possibilities of the song/film for challenging the stigma associated with dementia and supporting individual and broader change.

This chapter outlined the methodology and methods used to facilitate this creative research process. Through the intentional use of liberatory/activist arts, CABI, and the various approaches to therapeutic songwriting grounded in music-centred, community, and resource-oriented music therapy, nine PLwD worked together to create a song highlighting who they are, how they want to be treated in the world, and the lessons they want to share with others. The next two chapters present the findings from the formal analysis processes described at the end of this chapter, summarize the theoretical, methodological, and practical implications of this research, and discuss the limitations of this research and opportunities for future research.

CHAPTER 5: LIBERATORY-RELATIONAL DEMENTIA SONGWRITING FRAMEWORK

Two primary aims of this research were to document, examine, and share a collaborative songwriting methodological process with PLwD and explore how such processes support the relational citizenship of PLwD. Grounded in relational theories and practices, including relational caring philosophy, relational cultural theory (RCT), relational citizenship, and music-centred music therapy, and drawing from my analysis of reflective notes and transcriptions from the songwriting sessions, this chapter describes a relational songwriting framework I call the Liberatory-Relational Dementia Songwriting Framework. Grounded in my analysis of the songwriting process, this chapter describes the songwriting framework and the relational literacies that informed it. Chapter 6 will then explore the possibilities of this framework through the lens of social and relational citizenship.

Relational Literacies Supporting the Songwriting Process

As I revisited session transcripts and reflective notes, I noticed recurring relational patterns, particularly in how knowledge was shared and shaped, how responsiveness and trust were built, and how creative decisions were negotiated and decided on as a group. From this analysis, I created three main relational literacies: relational knowledging, relational attuning, and relational decision-making (processes essential to supporting collaborative songwriting with PLwD). I think of relational literacies as specific processes and ways of being and relating in the world that support embodied capacities and cultivate opportunities for relational connections to flourish.

Licona and Chávez (2015) defined relational literacies as both events and practices. Building on Heath's (1982) focus on events as interactions with alphabetic literacy, Licona and

Chávez described relational literacies as not only interactional occasions with a piece of writing but also with "multimodal, technological, embodied, imagined, and/or performed works" (p. 96). The event in the context of this work was the space of music-making and performing, as we interacted with the evolving piece of music we were co-creating. Licona and Chávez (2015) described relational literacies as practices in this way: "relational literacies imply the labor of making meaning, of shared knowledges, or of producing and developing new knowledges together. In other words, relational literacies are understandings and knowings in the world that are never produced singularly or in isolation but rather depend on interaction" (p. 96). What I appreciate about this definition is how it emphasizes that relational literacies are not only processes that support relational connections but also practices through which knowledge is co-created. Relational literacies have enormous potential "as they can open people to new ways of understanding, learning, imagining, and being in relation to others' stories, interests, and contexts" (Licona and Chávez, 2015, p. 96).

It is important to note that while the relational literacies comprising this framework are presented separately here, in practice, they were deeply interconnected, overlapping, and mutually reinforcing. My intention in developing this framework was not to create rigid categories, but rather to illuminate the relational literacies that supported the collaborative songwriting process. Together, these relational literacies (i.e., relational knowledging, relational attuning, and relational decision-making) describe ways of engaging in relational arts with PLwD that cultivate shared knowledge creation, opportunities for mutual support and friendship, and collective creativity. When used with intention and care, these relational literacies can support the emergence and flourishing of the full relational capacities of PLwD and those who engage with them. The sections that follow explore each relational literacy in turn and illustrate

how, together, they supported a meaningful, engaging, and deeply collaborative songwriting process.

Relational Knowledging

Throughout this research and collaborative songwriting process, I specifically drew on various forms of knowledge gathering and sharing to facilitate relational connections both between individual songwriters and me and within the larger group. Relational knowledging refers to the processes used to learn about individual songwriters, the application of that knowledge to strengthen relational bonds, and the ways the songwriters shared and developed knowledge with and about each other.

Central to relational knowledging is Olthuis's (1997) theory of knowing otherwise. Knowing otherwise views difference as a space in which wisdom and growth can emerge. Within this way of thinking, differences between people are not something to solve or change, but an opening through which new understandings develop. Mitchell et al. (2013) extended this concept to the dementia context, suggesting that what are commonly framed as "symptoms" (i.e., differences) of dementia may also be understood as alternative expressions of meaning, experience, and insight. Rather than positioning changes associated with dementia as problems to be cured, knowing otherwise requires openness to PLwD and their personal expressions as forms of knowledge and wisdom. As Mitchell et al. (2013) argued, "…if difference is the space of emergent wisdom, then persons with dementia create even more potential space and opportunity for developing wisdom and for knowing otherwise…" (p. 13). In this way, relational knowledging requires a recognition of the relational capacities of PLwD and an openness to receive the expressions of PLwD as opportunities to expand what we traditionally view as knowledge. Mitchell et al. (2013) described the importance of embodied selfhood to knowing

otherwise in the context of dementia by viewing the embodied expressions of PLwD (i.e., embodied know-how) as legitimate forms of knowledge expressions. To engage in knowledge gathering and sharing in this research, it was vital that I came to this work understanding knowledge as a relational process. It also required that I came to this work from a place of understanding PLwD as knowledge holders and gatherers, capable of sharing that knowledge in a range of ways and being attuned to the verbal and embodied ways that they expressed their knowledge. Through coming to this work from a place of knowing otherwise, I was able to support knowledge sharing in ways that facilitated relational connections necessary to create safe(r) spaces for this collaborative work.

Relational knowledging also views collaborative arts as an important mechanism for mutual learning and shared knowledge production. For example, when articulating the benefits of collaborative arts engagement, Barndt (2008) argued that

> When people are given the opportunity to tell their own stories—whether through oral traditions, theatre, visual arts, music, or other media—they bring their bodies, minds, and spirits into a process of communicating and sharing their experiences; they affirm their lives as sources of knowledge, and they stimulate each other in a synergistic process of collective knowledge production (p. 354)

The process of coming together as a group and sharing our life stories, values, ideas, and feelings laid the foundation for the collaborative songwriting process. By drawing on our collective knowledge and remaining open to multiple forms of knowledge sharing, relational knowledging was put into practice. The mutual exchange of stories and experiences, alongside embodied expressions of knowledge, formed the relational ground that fostered connection among the songwriters and created the conditions for the songwriting process to take shape. I now turn to

describing how relational knowledging unfolded and was supported throughout the collaborative songwriting process.

Drawing on Previous Relational Knowledge

In a study on how artists at The Bitove Method translated relational arts for PLwD into a virtual space during the COVID-19 pandemic, Dupuis et al. (2025) found that the artists used various relational caring practices, specifically incorporating prior knowledge about the participants, to facilitate their online arts classes. As stated in Chapter 4, the initial "getting to know you" research conversations were incredibly helpful in weaving relational knowledge about the songwriters into the sessions. For example, in the first session, I asked the group questions similar to those I asked during these initial research conversations (e.g., how would you describe yourself, what is important to you) to support the group in learning more about one another. In one instance, I drew on what a songwriter who had difficulty expressing herself in full sentences had shared in her initial research conversation to help create space for her to describe herself to the group.

> *Taylor: Lorraine, how would you describe yourself? (long pause) Would you say that you're a caring person?*
>
> *Lorraine: Yes, of course.*
>
> *Taylor: Yeah. You were telling me that before. And you care a lot about your family.*
>
> *Lorraine: Yes.*
>
> *Taylor: Yes. (To the group) Lorraine has very deep connections to her family.*
>
> *Lorraine: That's right.*

I also used what I knew about the individual songwriters to facilitate group discussion. For example, during our initial research conversation, Andrew stated that he was a "go-getter." I

used this information during a group discussion on what was important to the songwriters, weaving in knowledge about him into the broader conversation.

> *Andrew: Anyway, that was it, is that it was these things that we've got it there, and there's nobody there too much, and then you go after that person so um…(long pause).*
>
> *Taylor: So would you say going after what you want is important?*
>
> *Andrew: Yeah.*
>
> *Taylor: Going after what you want. I'm going to write that down.*

In another week, weaving in knowledge from a prior songwriting session helped bridge the songwriter's shared values.

> *Taylor: Exactly. How do we hope people treat people like yourself after they hear this song?*
>
> *Lily: Well, it depends on how you listen to the song.*
>
> *Taylor: Oh, interesting. That's a good point. Yeah. Yeah.*
>
> *Lily: With respect.*
>
> *Faigie: With kindness.*
>
> *Taylor: Yes. With kindness.*
>
> *Faigie: All the time. Not only with the song, but with kindness all the time.*
>
> *Taylor: With kindness all the time. To treat people with kindness all the time. Milton mentioned this at the beginning of the songwriting process where he said, Zay a mensch*[27].
>
> *Group: Zay a mensch.*

[27] Zay a mensch means "be a good person" in Yiddish.

Drawing on knowledge developed during the initial research conversations also helped the songwriters come to know one another and build meaningful connections. For example, in one session, I used my knowledge of Avi to help other songwriters discover something important about him.

Taylor: Avi, I wanted to add this into the song because you did something very important for work.

Avi: Yeah.

Faigie: What did he do? Can we hear?

Taylor: You were in IT, right?

Avi: Yeah.

Faigie: Oh!

Taylor: And Avi was telling me that he was a mentor.

Avi: Yes.

Taylor: Yeah. You were a mentor to a lot of people you worked with.

Avi: Right.

Faigie: Can he be a mentor to us too? We are very nice. (Group laughs)

Taylor: Would you like to...And do you still want to be a mentor?

Avi: Yeah.

Taylor: Yeah. That never goes away.

Avi: Absolutely.

Not only did the songwriters learn something new about Avi, but they also saw how Avi might serve an important role in the group as a mentor. A similar example occurred with Robert.

During the initial research conversations, he shared that his experience working at a record store had significantly shaped his relationship with music.

> *Taylor: Robert lived here his whole life. And he's had many, many experiences in the music world. He worked, where did you work?*
>
> *Robert: At (name of record store).*
>
> *Faigie: Ooo!*
>
> *Taylor: At (name of record store). It was this very famous record store.*
>
> *Faigie: It's too bad we didn't know you then!*

Understanding this aspect of his history provided important context for Robert's participation in the songwriting sessions. Robert would often approach me after the songwriting sessions to let me know how he thought it was going and how we might "get the song out there" after it was finished. In our sessions, when asked about the importance of music in his life, he would say, "It soothes the soul." The group resonated deeply with this, and we decided to include it as a lyric in one of the verses. Taken together, these examples demonstrate how drawing on previous knowledge was essential to the relational knowledging process, creating opportunities for the songwriters to learn more about one another.

Sharing Parts of Myself with the Songwriters

As stated in Chapter 2, RCT critiques models of care that impose unilateral relationships and argues that these models exert power and control over marginalized groups (Jordan, 2004). Instead, it advocates for what it calls growth-fostering relationships or relationships which prioritize "zest, creativity, worth, clarity, and a desire for more connection, for both people" (Miller, 1998, p. 5). Attending to how power functions in relationships and minimizing the hierarchy between facilitator and participant is also a core concept in RoMT, where the therapist

engages in therapeutic relationships that centre mutuality, shared decision-making, and the breaking down of hierarchical power structures (Baker, 2015; Rolvsjord, 2010). Adhering to these principles throughout the process not only deepened our relationships but also supported the songwriters in developing their relational knowledge of me.

This project required the songwriters to share deeply personal parts of themselves, including their stories, life histories, experiences of aging, and hopes for the future. As our relationships developed, they entrusted me with increasingly personal aspects of their lives. To cultivate relationships that were truly growth-fostering and reciprocal, I also needed to share aspects of myself with them. For example, every week the songwriters wanted to know how Daniel (my husband) and I were doing.

> *Faigie: Now can you tell us if everything is okay? You're wearing a ring on your left hand.*
>
> *Taylor: Everything is amazing. I love being married (Group laughs).*
>
> *Lily: Mazel Tov!*
>
> *Taylor: Thank you!*
>
> *Faigie: You know what I mean? We wanted to know!*

In this example, Faigie used her relational capacities and observational skills, observing the ring on my finger, to further her relational knowledging and learn more about me.

Another aspect of my life that I shared with the songwriters was my relationship with my grandparents. As so much of why I come to this work stems from my experiences caring for my grandparents, it was important for me to share this with the group. Sharing my grandparents' experiences as they aged also facilitated relational and critical dialogue among the songwriters about how older adults are treated in society.

Taylor: And sometimes I think that, and I saw this with my grandparents as they got older, they weren't given so much of a chance anymore, right?

Lily: Really?

Taylor: Yeah.

Robert: But that happens all around the world.

Taylor: Why do you think that is?

Robert: People get old. They feel they're useless. But they're not.

Faigie: And people don't think how much they know, how much older people know, the knowledge that they are hiding or that they know.

Taylor: Yes. Yes, exactly. Do you feel that too? (to Helen)

Staff: (says Helen didn't hear)

Taylor: That's okay. That sometimes as we get older, people don't think we have the same amount of knowledge, but that we do.

Lily: We do!

Taylor: We have knowledge.

Lily: They do.

Helen: You don't always speak about it though.

Taylor: No, you don't always speak about it, but you have it.

Helen: You have it.

Sharing parts of myself with the songwriters proved invaluable in cultivating relationships among us. Though conventional research paradigms often privilege objectivity over mutuality, taking up relational theories that prioritize connection over detachment enabled me to participate as a relational being rather than a neutral facilitator. Sharing aspects of myself opened space for the songwriters to further demonstrate their relational capacities as they participated in

the relational knowledging process (e.g., expressing curiosity about my experiences, asking questions, and critically reflecting on what it means to grow older).

Sharing Cultural Knowledge

All songwriters in this research (including myself) identified as Jewish. Sharing our knowledge of and experience with our ethnic, cultural, and religious backgrounds played a significant role in shaping the songwriting process and the song's lyrics. Sharing cultural knowledge also supported relational knowledging within the group. In this group of songwriters, experiences of antisemitism and connections with language and cultural music cultivated relational knowledging in very personal ways, further nurturing the relational connections among the group. For instance, the songwriters all grew up during or in the wake of the Holocaust, with some being Holocaust survivors themselves, and had experienced antisemitism in one form or another. It was in sharing these experiences with a group of people who had a common cultural understanding that our relationships grew deeper.

I first became aware of the importance of shared cultural understandings during the initial consent process. During this process, I noticed one of the songwriters seemed upset. When I asked what was wrong, they apprehensively looked around the room and whispered to me that they were Jewish. I was no stranger to what this person was feeling. Many times, I have been told to keep my identity as a Jew to myself and thought that it was unsafe to be openly Jewish. In that moment with this songwriter, I felt that sharing that I was also Jewish might ease some of their worry. I whispered back that I was Jewish too (I knew saying this too loudly would only make them worried that someone had heard us). Taking a breath, the songwriter looked at me and asked if I had any tattoos. Normative Jewish practice prohibits tattooing generally, and there is a strong cultural aversion even amongst some non-observant Jews, given the Nazi practice of

tattooing numbers on the arms of prisoners in Auschwitz as a method of identification and erasure of personhood. As my Zaidy was one of these people, it was important to him that I would never get a tattoo, and I explained this to the songwriter. In that moment, bonded by mutual understanding and shared experiences of antisemitism, the songwriter teared up and held my hand. Relational knowledging, grounded in my personal experiences of antisemitism and my understanding of its manifestations, was critical to cultivating a space of safety throughout the process.

Relationships with, and experiences of, antisemitism were also present in the songwriting process itself. With two Holocaust survivors in the group, the theme of being a survivor and sharing their stories frequently emerged throughout the songwriting process. Other songwriters had family members killed in the Holocaust, and none of us were untouched by the horrors that it left in its wake. This shared experience played a significant role in many group discussions.

> *Faigie: A lot of people, we were called greeners, you have to understand.*
>
> *Taylor: Yes.*
>
> *Faigie: It means people who came to Canada.*
>
> *Taylor: Yes.*
>
> *Faigie: Okay? We were called greeners. Green horns. We weren't completely baked (Group nodding).*

Faigie is referring to a term used for immigrants from Europe in the 20th century. Though not a specific antisemitic term in and of itself, it is viewed in our community as a derogatory term that many Holocaust survivors (including my grandfather) were called when they came to Canada. When Faigie says “we weren’t completely baked,” she is referring to experiences of antisemitism where people would say that Holocaust survivors should have been “fully baked” like their

families who were put to death in the gas chambers and then burned in ovens. It is common to hear from Jewish people that they have had someone make a joke about the gas chambers to them at one point or another. What I find particularly interesting about this example is the way others in the group validated Faigie's experience (nodding along as she was speaking). Instead of being shocked or surprised by what Faigie was saying, there seemed to be a collective understanding of her experience. Relational knowledging, including the sharing of experiences of oppression and discrimination, helps in furthering connections; it was in this moment that this shared experience of antisemitism bonded us.

I also found that sharing my grandfather's experiences of antisemitism and post-war trauma facilitated opportunities for the songwriters to show care towards me and for me to validate their experiences and show care and understanding towards them; this is something that is challenging without relational knowledging processes and requires being open to vulnerability both as a facilitator and as songwriters. These findings are consistent with relational caring philosophy and RCT, which view vulnerability as a strength rather than a weakness and an opportunity for growth and the deepening of relationships (Dupuis et al., 2022; Jordan, 2004). In one instance, sharing a vulnerable experience with the songwriters related to my grandfather connected with the experiences of the songwriters.

> *Taylor: And like I shared before, the reason I came up with this project is because I really saw how my grandparents weren't treated well.*
>
> *Lily: They weren't?*
>
> *Taylor: No. Not as they got older. And so my question is, how do you want to be treated?*
>
> *Lily: Just a minute. Who was mistreating them?*
>
> *Taylor: Great question. It depends. Like I found that, you know, sometimes when they were in hospitals, my Zaidy was a Holocaust survivor…*

Lily: Oh yes.

Taylor: …and sometimes they didn't know how to handle it because they didn't understand his fear.

Faigie: You have to understand.

Taylor: You have to understand.

Faigie: You have to understand. That is rooted in who you are, if you try to even act, it's still in you.

Taylor: Yes.

Faigie: I was one of the youngest ones that survived from Lithuania.

Taylor: Yes. And it never leaves you.

In this example, being vulnerable and sharing an experience that was difficult for both my grandfather and me created an opportunity for the songwriters to show care towards me (Lily stopping me from just going on by asking a follow-up question, Faigie validating my experience) and opened space for them to share their own experiences of being a survivor. In fact, the theme of survivorship and experiencing antisemitism was so prominent in our discussions that we decided to include that some of the songwriters were survivors in the song lyrics.

Songwriters also shared cultural knowledge through their lived and relational connections to language and to the music that carried cultural meaning in their lives. As an example, many of the songwriters spoke Yiddish fluently, and we all had some familiarity with the language. Throughout many of our group discussions, the songwriters would use a Yiddish phrase or analogy to express how they were feeling or even to describe themselves; language in this sense was important to relational knowledging and demonstrating valued aspects of self.

Taylor: Milton, how would you describe yourself?

Milton: A poshiter man.

Taylor: What does that mean?

Milton: It's an average joe.

Taylor: Oh! in Yiddish!

Yiddish was also used to describe the relationships people had with their values. In Week 1, for instance, I facilitated a discussion around the things that were important to the songwriters:

Taylor: Doing the right thing. Milton, I think we've talked about this before, that doing the right thing is also important for you.

Milton: Oh, absolutely.

Taylor: Yeah.

Milton: You don't want to be a shlekhter man, you want to be a guter man.[28]

Taylor: A guter man. Doing the right thing, and I think you said to me last time, zay a mensch.

Lily: Zay a mensch.[29]

Milton: Zay a mensch. Zay a mensch, yes.

Faigie: Zay a mensch, be a person.

Milton: You can never, never go wrong if you're being a guter man.

Songwriters who had difficulty accessing their use of Yiddish expressed their connection to and knowledge of the language in both verbal and embodied ways.

Faigie: A guter mensch. A good person. A good mensch! He's a good person (group laughs).

---

[28] A shlekhter man translates to "a bad man" and "a guter man" translates to "a good man."

[29] Zay a mensch translates to "be a good person."

Andrew: I know it! It's just the words that she used.

Taylor: Yes. The Yiddish. I love Yiddish. It's such an amazing language.

Faigie: Yiddish has an awful lot of thoughts. You think about it. And you say it and it makes you feel good and it makes the people feel good.

Taylor: Yes, definitely.

Faigie: Because even I'll give you an example. Even during the war in the ghetto we sang Yiddish songs. And it made you feel good. You didn't know tomorrow you could be killed. But we sang.

Taylor: Yes. And what's amazing about Yiddish I find is that every word that you say has like a feeling behind it, right?

Faigie and Lily: Yes.

Taylor: What's a Yiddish song? I don't know many Yiddish songs.

Lily: Well, is it if you go right and you can get it done?

Faigie: (starts singing in Yiddish).

Avi: (Starts to sing to the melody) la la la la.

In this example, Andrew showed his knowledge of and deep connection to the language by visibly sharing his excitement with the group when Faigie was speaking Yiddish: "I know it! It's just the words that she used." Additionally, Avi, who did not often express himself verbally and would sometimes sit with his head down or eyes closed during sessions, would sit up straight and reach his arms outward when he heard music associated with Judaism. In this example, when he heard Faigie singing a familiar Yiddish song, he immediately began to hum the melody along with her.

My own relational knowledging made it clear early on the significance of cultural music throughout our songwriting process. Because all the songwriters identified as Jewish and frequently spoke about the importance of Judaism in their lives, it was essential to incorporate

music that reflected their ethnic, religious, and cultural identities. To support this, I drew on my knowledge of Hebrew and Hebrew songs as a relational resource, creating opportunities for participants to connect with culturally meaningful music and with one another through shared musical experience. Bringing culturally relevant music into the space aligns with Aesthetic Music Therapy (AeMT), which critiques music therapy practices that privilege Western repertoire without attending to the cultural contexts of participants (Lee, 2015). AeMT emphasizes the importance of therapists developing musical competence across styles and genres to facilitate musical encounters that resonate with participants lived experiences.

Most sessions included time to sing Hebrew songs. Beginning each session with a culturally meaningful song functioned as both a vocal warm-up and a ritual of gathering. These moments were a way of inviting the songwriters' full selves to the session, not only to sing, but also to speak to the music's meanings, supporting their relational knowledging capacities and processes.

Taylor: Are we feeling a fast song or a slow song? Let's start there.

Faigie: A slow song. Because we're happy to be together.

Taylor: Because we're happy to be together.

Faigie: No matter what.

Taylor: Well then, let's sing a song about being happy to be together. It goes like this. (starts playing "Henei Ma Tov")

Group sings together and claps at the end of song.

Faigie: Thank you. That was beautiful.

Taylor: It's such a beautiful song, isn't it?

Faigie: Yes.

Taylor: What does it mean?

Faigie: Henei ma tov, it's wonderful to be here.

Lily: Yes.

Faigie: We are like a group together. Gamyachad. Together.

Taylor: Yes.

Faigie: Together.

Lily: Yes.

In this example, singing a song with cultural significance strengthened the group's sense of togetherness and supported the songwriters in sharing their cultural knowledge with one another. Language and music were important in facilitating the sharing of cultural and relational knowledge among all songwriters.

Relational Knowledging Through Knowledge Transfer

Thus far, I have described relational knowledging as the process of learning from and sharing information with those involved in the collaborative songwriting process to deepen relationships and foster relational connections within the group. However, throughout this process, the songwriters also expressed a desire to impart knowledge to others in the form of wisdom, a capacity that aligns with Tornstam's (1989) theory of gerotranscendence. The theory of gerotranscendence was developed to challenge theories of aging that positioned the aging process as "a time period marked by illness, burden, decline, and loss" (Dupuis et al., 2016b, p. 327), instead offering a conceptualization in which "ageing becomes a positive, qualitative development towards a more profound and satisfied state of mind and being" (Jönson & Magnusson, 2001, p. 326). In the context of relational knowledging, gerotranscendence is particularly relevant because it emphasizes that older adults' perspectives continue to shift, grow, and deepen in later life (Tornstam, 1989). For example, in a study examining themes of

gerotranscendence in a LTC home in Sweden, Wadensten (2005) found that participants described "everyday wisdom" as something they had gained throughout life and through experience (p. 385).What I find particularly useful about this theory is that it challenges societal discourse that frames older adults as passive or diminished and instead emphasizes their capacity for continued growth, reflection, and meaning-making. Building on the theory of gerotranscendence, relational knowledging not only supports the recognition of this wisdom but also provides a framework through which participants can share it more broadly. In practice, this meant intentionally inviting the songwriters to reflect on the lessons, values, and insights they wished to pass on. By asking questions that centred the songwriters' life experiences and perspectives, we created space for their wisdom to be expressed. Lyric creation served as a particularly important medium for these exchanges. Much of our discussion around ideas and lyrics centred on the lessons the songwriters wanted to convey, and these insights directly informed the development of the chorus.

Taylor: What knowledge do we carry? What do we know?

Lily: Well, whatever you do, living.

Taylor: Living.

Faigie: How to treat people.

Taylor: Yeah. And it seems like all of you have a really good handle on how to treat people well.

Lily: Yes.

Taylor: We could all take a lesson from that.

Robert: Sure.

Taylor: What other lessons do we hold?

Lily: Well, you can go to someone and you can do a test with them and you can give them an idea what they want, what it is.

Taylor: Yes. Yeah, exactly. What other lessons do we hold? What do we want to teach others?

Faigie: To be a good listener.

Taylor: To be a good listener. Yes. Yeah.

Faigie: Very important.

Lily: Very.

Robert: To be a good person.

Taylor: To be a good person. Yeah. Helen, what do you want to teach other people? If you could teach someone something, what would it be?

Helen: Not to criticize in public.

Taylor: Not to criticize in public. Beautiful.

Faigie: Mhm. That's a very big thing.

Robert: Yup.

Having the opportunity to co-create a song supported the songwriters in sharing their knowledge developed over a lifetime of different experiences with a broader audience, an opportunity not often provided to PLwD, especially in the later stages of dementia (Bartlett & O'Connor, 2010). This dimension of relational knowledging extends beyond in-group connection and requires opportunities to share co-created knowledge more broadly. In this project, public knowledge sharing materialized through the public launch of the song/film. I return to a fuller discussion of this broader sharing and its impact in Chapter 6.

In this section, I described relational knowledging as an essential relational literacy needed to support the collaborative songwriting process and the relational capacities of all

involved. Through weaving in prior relational knowledge about the songwriters, being open to vulnerability and sharing information about myself, engaging with shared cultural knowledge and experiences, and recognizing and supporting the sharing of a lifetime of knowledge with others outside the group through the creation of song lyrics, relational knowledging served to deepen and strengthen our relationships and connections, not only with one another but with valued aspects of ourselves. I now turn to the ways relational attuning was used to foster relational connections throughout the songwriting process.

Relational Attuning

In addition to relational knowledging, collaborative songwriting works best when relational attuning is intentionally practiced throughout the process. In fact, relational knowledging requires relational attuning (i.e., one must be aware of and attuned to the ways PLwD share their knowledge to better support these expressions and sharing of wisdom). The Oxford English Dictionary (2025) defines "attune" as an "agreement or accordance between or among various things; harmony." While this definition captures the meaning of attuning in a basic sense, attuning in this project extended beyond simply agreeing or experiencing harmony. It involved an ongoing and responsive process of noticing, interpreting, and adjusting to one another in ways that supported connection, creativity, and relationships.

Dall'Alba (2024) expands the concept of attuning through the notion of "responsive attunement," which they define as "responding to the particularities and complexities of a situation on the basis of tuning in to others and things in the social and natural worlds, with reflexivity" (p. 308). This conceptualization moves the process of attuning beyond interpersonal harmony toward a reflexive and relational practice. It also emphasizes the importance of self-awareness and being responsive not only to individuals but also to the broader relational contexts

in which interactions unfold. This understanding aligns closely with relational caring philosophy, which highlights empathy, responsiveness, and attentiveness to relationships of all kinds (Dupuis et al., 2016b; Jonas-Simpson et al., 2022). In this sense, attuning is not simply agreeing with another, but a relational responsibility. It involves a willingness to "tune in" to what may be unfolding for another person within their lived context and to respond thoughtfully and appropriately.

To better support the relational citizenship of PLwD, the capacity to attune must also be understood as embodied and having nonverbal awareness. Research suggests that a significant portion of human communication occurs through nonverbal means (Burgoon et al., 2010). As discussed throughout this dissertation, relational citizenship emphasizes the importance of recognizing the embodied expressions of PLwD as meaningful demonstrations of personhood and relational know-how (Kontos et al., 2017). Conceptualizing relational attuning as also embodied allows us to recognize responsiveness expressed not only through words but also through gesture, touch, posture, and presence. For example, earlier in this chapter, I shared the story of a songwriter who was hesitant to have others know they were Jewish. When I spoke about my grandfather, they reached for my hand, and tears came to their eyes. In that moment, they did not simply acknowledge what I had said but responded in an embodied and relational way. This gesture served as an act of relational attuning, signalling emotional presence. In the sections that follow, I explore how relational attuning developed as a foundational relational literacy in our collaborative songwriting process, how the songwriters and I used it to respond to one another, and how this attuning strengthened our relationships.

Attuning Through Recognition, Validation, and Encouragement

Throughout the songwriting process, some songwriters shared difficult experiences from their lives (i.e., surviving the Holocaust, being treated differently as they got older). They also expressed frustration and grief when experiencing challenges with their memory and memory loss. When these experiences were shared, it was important to recognize and validate them rather than gloss over or minimize them. Dupuis et al. (2025b) identified this recognition and validation as an important aspect of relational arts. Further, from a relational perspective, disability is understood as emerging from both social barriers and the lived experience of illness or impairment (Thomas, 2004). This means acknowledging the very real challenges that dementia itself can create, rather than interpreting all difficulties solely through a social lens. For example, Helen often expressed frustration about not remembering things as well as she used to. Her frustration reflected the impact of her cognitive changes, highlighting the importance of acknowledging and recognizing the real, lived physical challenges of dementia within the songwriting process.

> *Helen: You don't remember doing things and I wasn't like that when I was younger.*
>
> *Taylor: Yeah. And that can be hard.*
>
> *Helen: It bothers me.*
>
> *Taylor: Of course. That can be really hard (kneels down to make eye contact).*
>
> *Helen: I can't remember whether I said something if I didn't hear them before. I don't think I would say something to her that was bad.*
>
> *Taylor: I don't think so. Helen was saying that sometimes it bothers her when she can't remember (to the group, after asking if I could share what Helen had said to me).*
>
> *Faigie: I think it bothers everybody.*
>
> *Taylor: It bothers everybody. Yeah. Thank you for sharing that.*

Helen: I had a good memory before. And I'm losing it. I mean, I'm accepting it and I realize that I forgot certain things.

Taylor: Yeah. Yeah. And that can be hard when we can't remember all the time.

Helen: Yeah.

In this example, Helen's frustration is acknowledged not only by me but also by one of the other songwriters. Later in the same session, when Helen brought up that forgetting was difficult for her, more songwriters stepped in to offer support, again demonstrating their relational capacities.

Taylor: Helen's saying that it can be hard sometimes.

Avi: Yes.

Faigie: Oh yes.

Taylor: And we want to thank you for sharing that with us. And we hope that our time together, I hope that our time together, even though it can be hard, that we have moments where we can share how we feel.

Helen: Yes.

Lily: Oh yes.

Taylor: So thank you.

Faigie: And to make other people feel like that too.

Helen: I don't remember certain things I forgot or I haven't said. It bothers me because I had a good memory…

Taylor: Helen's saying that it's important to accept this. To accept how things sometimes change as we get older.

Faigie: That's right.

Taylor: But what I'm seeing is that even though that might be happening, you are still sharing so much. So I want to thank you.

Faigie: Because we have love.

Taylor: Because you have love.

Faigie: Love is very important. In good times and in bad times.

These examples highlight the ways the songwriters and I attuned to what Helen was sharing with us, listening attentively, being truly present, supporting her through recognition of her and her experience, and validating her feelings of frustration.

Songwriters also attuned to one another when they needed help finding the words to describe what they were trying to say. This required paying attention to what others in the group were sharing and engaging with them, for example, by asking questions and trying to fill in the missing information.

Andrew: But I thought, well, Ed wrote this, which you made very close with India, not India, what is it, a lot of Hungarians, not Hungarians, that's a lot of them, but the ones, I'm forgetting, I get to forget at the end of the day, it was…

Robert: Was it what I said to you?

Andrew: Well, that too, but not too, but I expected to hear something coming from the middle of this country, what's the name of this?

Taylor: Canada.

Robert: Yeah.

Andrew: No.

Faigie: North America?

Andrew: No.

Faigie: No?

Andrew: No, this isn't in Hungary, it's not that, it's where there were a lot of Jews in the middle of, in the middle of there.

Faigie: In Hebrew it says Galut (meaning in exile).

Andrew: No.

Faigie: No?

Andrew: No, it was a country then, they turned themselves into a, when I first went there for, just for fun at the entrance.

Though we did not get to the root of what Andrew was trying to share with us in this instance, the songwriters showed genuine care and support (i.e., relational attuning) in trying to assist him in telling his story.

On another occasion, a songwriter listened intently as another songwriter shared a story about her mother initially not being supportive of her career path. When finished, he offered encouragement for her life choices.

Faigie: I was known as Mora Faigie, teacher Faigie.

Taylor: That's right.

Faigie: And I think she agreed afterwards. I don't know.

Robert: The point is you're here and you do good things.

Some songwriters also shared that they were not musically inclined. For example, Helen expressed unease about engaging musically with the group as she was told not to sing by adults when she was younger. Rather than dismissing or ignoring her feelings, built over many years of being told she could not sing, in these moments, it was important for me to validate Helen's experience so she knew that she was not the only person who felt this way.

Helen: I'm not good at anything, but I'm trying to say I'm good at listening to other people and I enjoy them.

Taylor: Yeah, okay.

Helen: Because I don't have the voice. I don't have that. My parents didn't encourage me. I could never learn, but I could listen.

Taylor: And do you enjoy listening?

Helen: And I enjoy that.

Taylor: That's a real gift. It is.

Helen: I felt ashamed, so they said, so keep quiet. Because I didn't have the voice for it and they didn't want me to be ashamed because other people said – so I tried, but I was so bad at it. They said, just listen.

Taylor: That is a very common experience. A lot of people when they're very young are told not to sing, to mouth the words.

Faigie: Yeah!

Taylor: This is a very common thing that we see in the world.

Helen: Yeah.

Validating Helen's experience was especially important, given that it is not uncommon for adults to internalize negative perceptions of their musical abilities, often due to discouraging encounters with music educators (Palkki, 2022). By sharing that this is a common experience, I aimed not only to validate Helen but also to ease potential discomfort among other songwriters who may have had similar experiences.

In addition to supporting songwriters through verbal validation, relational attuning requires attending to the embodied expressions of PLwD and supporting them in embodied ways (i.e., kneeling to make eye contact, changing tone of voice, and providing space for sharing feelings). For example, during a discussion about how the songwriters wanted to be treated, I noticed Andrew's body language change as he began looking down and frowning. In the excerpt below, though his answer did not seem to fit precisely with the question, it was the way he expressed himself within the context of the question and the broader group discussion that indicated to me that he needed support.

Taylor: Andrew, how do you want to be treated?

Andrew: When?

Taylor: In general. How do you want to be treated?

Andrew: I don't have that. I don't have that. Yeah. (look down, sighs).

Taylor: That's hard.

Andrew: It's every recent site time.

Taylor: Yeah.

Andrew: Today?

Taylor: Yeah. (I kneel down to meet Andrew eye to eye).

Faigie: Can we hear what they're saying?

Taylor: Yeah. Do you want to be treated nicely in the world? Is that important?

Andrew: That's hard. It's going to be very hard for my parents. Yeah. That's it.

Taylor: Yeah. Sometimes we think that it's really easy to treat people nicely and with respect and that doesn't always happen.

Faigie: Yeah. And not to forget love.

Taylor: Yes. And that can be hard. Thank you for sharing (to Andrew).

Andrew: Yeah. Thank you. (He has tears in his eyes and shakes my hand. I pause before moving forward with the session).

In this example, attuning to Andrew's embodied expressions in the moment required noticing that something had shifted for him and required responding in an embodied, compassionate, and understanding way. Often, emotional distress can be recognized through tone, gesture, posture, or facial expression. Although Andrew's verbal expressions were difficult to follow, his embodied communication, within the context of our conversation, conveyed clear meaning. Attending to Andrew's experience in this moment communicated to him that he was

being seen and that I understood. Relationally attuning to him in this way supported his relational capacities by recognizing his embodied expressions as meaningful demonstrations of selfhood and experiences (Kontos et al., 2017). By expanding attuning to include embodiment through the concept of relational citizenship, and specifically embodied selfhood, relational attuning seeks to support all forms of expression.

Attuning to and Weaving Storylines Together

At times, songwriters would contribute responses that did not align neatly with the current topic of discussion. Rather than redirecting or moving on, I would actively meet the songwriters where they were and integrate their contributions into the broader conversation. This required listening carefully for key words or phrases, noticing underlying connections, and linking their ideas back to the topic in ways that honoured their input and maintained the flow of the discussion. For instance, in Week 1, the group discussed what made them happy and the importance of making others happy. To support Andrew in contributing to this storyline with the group, I repeated specific words related to the question we were discussing.

> *Andrew: My father, there was a kid in a smile and more than that, more than that, that's nothing because he liked laughter.*
>
> *Taylor: Yeah, laughter.*
>
> *Andrew: And you can spread that out.*
>
> *Taylor: Ah! Spreading out laughter and joy*

The simple repeating of the words Andrew shared helped me highlight what Andrew was saying as examples or representations of being happy.

Weaving ideas and storylines together also helped the songwriters connect with one another and develop deeper relational connections. In one instance, I used information shared earlier in the session to help connect two of the songwriters.

Andrew: What am I?

Taylor: What makes you happy?

Andrew: When was I not happy? Well, recently. Nobody.

Taylor: Oye. Right.

Andrew: But recently it's just like that….

Taylor: You agreed before with Milton that a good joke makes you happy.

Andrew: Oh, sure.

Taylor: A good joke.

Milton: Can't go wrong with a good joke.

Andrew: A joke! (Leans over and shakes hands with Milton).

Taylor: Andrew agrees. A good joke makes us happy.

Milton: Exactly.

By attuning to what Andrew had shared earlier in the session and weaving it with Milton's contributions in the moment, I was able to highlight commonalities between the two songwriters and support relational connections within the group. What is particularly meaningful about this example is the way that relational connections were deepened through embodied gesture. When Andrew leaned over to shake Milton's hand after recognizing their shared appreciation for humour, he showed an embodied acknowledgement of their connection. Such moments illustrate how weaving ideas and storylines together can support participants in

recognizing shared experiences and values, while also creating opportunities for relational connections to be expressed both conversationally and physically within the songwriting space.

Musical Attuning

Relational attuning in collaborative music-making also requires musically attuning and using music intentionally to support relational capacities and connections. In this research, two primary forms of musical attuning emerged: musical matching and musical pacing.

Musical Matching

As discussed in Chapter 2, NRMT draws on elements of music (i.e., tempo, timbre, melody, and rhythm) to support musical relationships (Guerrero et al., 2015), or, as Ansdell (1995) called it, a musical meeting. Musical meetings in NRMT are fostered through a shared musical dialogue where the therapist joins in and responds to the "spontaneous playing, movement, and vocalization" of the participant(s) (Guerrero et al., 2015, p. 486). There are many NRMT techniques that a music therapist can use to support musical dialogue. To musically attune to the songwriters involved in this project, I utilized the NRMT technique called matching to foster musical meetings with the songwriters. Matching is a technique in which the therapist plays or improvises using similar musical motifs to the participant(s) to demonstrate that they are heard and seen (Wigram, 2004). This technique was used many times throughout the songwriting process to foster a relational musical dialogue between the songwriters and me, especially with those who had difficulty expressing themselves in words. For example, Avi would often sing spontaneously during group discussions. In these moments, I attuned to what Avi was singing and matched his musical expression to facilitate musical dialogue and foster connection.

Avi: (Starts to sing to the tune of Side by Side) La, la, la, la, la, la, la.

Taylor: What else? How else?

Avi: (sings) La, la, la, la, la, la.

Taylor: Da, da, da, da, da (matching Avi's melody).

Avi: la la la la.

Taylor: Da, da, da, da, da (holds Avi's hand as we sing together).

As Avi felt more comfortable singing on "la," I would also use matching when singing familiar music with the group to ensure he felt included in group music-making.

Taylor: And so this is how it goes. If you have a tone bar, could you go like this so I can hear it? Beautiful. (Starts singing) I see trees of green. Red roses too, I see them bloom….

Avi: la la la la (to the tune of What a Wonderful World)

Taylor: la la la (matching Avi's melody).

There were also instances where the songwriters matched one another, creating a musical meeting. One example of this was when Lily heard Avi singing "la" and started singing with him.

Group: (Singing "On the Sunny Side of the Street") Life can be so sweet on the sunny side of the street. I used to walk in the shade, with the blues on my parade. But now I'm not afraid. This rover has crossed over.

Avi: (joins in singing) la la la

Taylor: Beautiful! (while playing guitar)

Lily: (sings the last note on "la" last note)

Taylor: Beautiful!

Avi: Yes!

In another example, Robert heard Bill whistling and joined in, prompting others in the group to join in.

Bill: (Starts whistling)

Taylor: Bill, whistle away! There you go!

Robert: (Whistles with Bill)

Taylor: Robert! I didn't know you could whistle!

Robert: (Continues to whistle)

Faigie: Oh! Robert!

Taylor: Look at this! Well, we'll add some whistling on the song.

Faigie: They're whistling!

Musical attuning through matching recognized all songwriters, regardless of how they communicated, and ensured that each person was actively included in the music-making process. Attuning to the ways the songwriters expressed themselves musically required careful listening and sustained awareness of what was unfolding in the music moment by moment. Musical matching involved closely attending to tempo, rhythm, and melody, and bringing those elements forward in my own musical response (something that is difficult to convey in written transcripts). These examples also demonstrate the songwriters' own capacity for musical attuning, supporting and attending to one another through music. When one person's melody or vocalization was taken up and matched by another songwriter, it invited relational exchange. Matching in this way was not simply an imitation, but a relational process of noticing, responding, and co-creating.

Musical Pacing

As stated earlier, throughout the process, it was important to remain attuned to the range of ways the songwriters engaged in the sessions. An important part of this included noting when engagement was subsiding. For example, I found that when group discussions lasted a long time, some songwriters who participated less verbally would start to close their eyes. In these

moments, it was important to attune to both verbal and embodied cues to help guide the flow of the session. If I noticed that some people seemed less engaged during a discussion, I would shift to group music-making to support the songwriters in expressing themselves in ways that might feel more accessible. At the end of the first session, for example, I had noticed that some songwriters seemed disengaged (i.e., eyes closed or heads down). By documenting what we did in that session and taking time to reflect critically on it, I became aware of how much verbal discussion dominated the session and how some songwriters who struggled with verbal communication were left out. By attuning to this experience and reflecting on what some of the songwriters needed moving forward, I adjusted the pacing of the sessions by intentionally incorporating more opportunities for musicing each week. I did this by using the group discussion as a jumping point for a song based on that topic. For example, in Week 2, after a conversation about the importance of caring for others, we sang a song that we felt represented this theme.

> *Taylor: Yes. Beautiful. I'm trying to think of a song that's about caring for other people. What were you going to say, Faigie?*
>
> *Avi: Okay!*
>
> *Taylor: Let's think of one.*
>
> *Faigie: I love you?*
>
> *Taylor: (Starts singing and playing guitar) I love you a bushel and a peck…. (Group joins in singing and claps at the end of the song).*

This initial reflection also helped me attend more intentionally to how all songwriters were included in subsequent sessions. Later in Week 2, after we had finished responding to one guiding question, we began transitioning to the next. Right before we began the discussion, I took a pause to see how each songwriter was doing. I noticed that some of the songwriters had

started to close their eyes, which I took as a cue to break up our discussions and shift into group music-making.

> *Taylor: I'm having a lot of fun. Okay. I'm going to put this up. Hold on here [attuning to songwriters closing their eyes]. Actually, before we answer this question, I want to sing a song with all of you and I'm going to hand out these instruments. They're really beautiful. They're called tone bars. They sound like this (plays three tone bars comprising C major). Isn't that nice?*
>
> *Group: Yes.*
>
> *Taylor: Would anyone like to play one?*
>
> *Faigie: I think we'd all like to. So maybe we'll take turns.*
>
> *Taylor: For sure. Who would like to play one?*
>
> *Lily: la da di da da (sings the triad of the tone bars)*
>
> *Taylor: Yes. Beautiful!*
>
> *Avi: (starts singing) la da di la da*
>
> *Taylor: Avi - we always say how beautiful Avi's voice is!*
>
> *Avi: (singing) la la la la la la la la la*
>
> *Faigie: (joins in singing on la)*
>
> *Taylor: Beautiful!*
>
> *Avi: (singing) la da di la da*
>
> *Faigie: Suzuki! Oye!*
>
> *Avi: (singing) la la la la la la la la la*
>
> *Faigie: (joins in singing on la)*
>
> *Taylor: Beautiful! (Group claps). You could have been a cantor!*
>
> *Avi: Yes. (group laughs)*
>
> *Taylor: Seriously!*
>
> *Avi: (smiling) I am. I am. I am. I am! I don't know!*

Taylor: It's within you!

Attuning to changing experiences during the songwriting sessions provided opportunities to pause and shift direction, keeping all songwriters engaged. Musical pacing was an especially effective technique for doing so. Further, musical attuning, through both musical matching and musical pacing, not only supported songwriters in engaging and expressing themselves nonverbally but also created opportunities for relationship building through group musicing. These moments played an important role in fostering relational connections within the group, connections that would not have been possible through verbal discussion alone.

Musical pacing also required openness to fluidity during the songwriting sessions. Dupuis et al. (2025b) emphasized the importance of "embracing emergence, spontaneity, and improvisation" when facilitating relational arts programs with PLwD (p. 7). Openness and fluidity are also core tenets of NRMT. As discussed in Chapter 3, what Ansdell (1995) described as a "musical meeting" requires openness to the emergence of spontaneous musicing (Guerrero et al., 2015). Although I entered each songwriting session with a general plan, it was essential to remain attentive to where the songwriters wanted to go. Attuning to the group's energy, mood, and engagement required flexibility in pacing. Often, this commitment to emergence manifested musically. One of the first instances of this occurred in Week 2, when, while discussing what makes us happy, the group broke out into spontaneous singing.

Taylor: We said a good smile, a smile on a rainy day.

Lily: Yes.

Faigie: And there was a song. (Starts singing) Let a smile be your umbrella on a rainy, rainy day.

Avi: (Starts singing with Faigie) La, la, la, la, la, la, la, la.

Group: (Sings the song together)

Taylor: I don't know this song. No, I have to learn it.

Faigie: You don't know let a smile be your umbrella on a rainy rainy day?

Taylor: No!

Robert: You've already sung it.

Taylor: Have I? I don't remember. Could you sing it again?

Faigie: (Sings) "Let a smile be your umbrella on a rainy, rainy day." I need help. (Group laughs)

Taylor: Oh yes, this one!

Faigie: (Sings) When you're smiling…

Group: (Joins in singing) When you're smiling, the whole world smiles with you. When you're laughing, when you're laughing, the sun comes shining through. When you're crying, be happy again. When you're smiling, when you're smiling, the whole world smiles with you. (Group claps).

By remaining open to these musical "detours," relational possibilities unfolded that might not have occurred within a more rigid structure. In this way, musical pacing requires not only attuning to the group's energy but also remaining open to in-the-moment relational expressions. It was through this openness to spontaneous moments of singing, whistling, and playing that relational bonds deepened and shared musical experiences took shape.

Relational Decision-Making

Relational knowledging and relational attuning supported each other in this relational collaborative songwriting process. These relational literacies were also important in supporting the third relational literacy of the Liberatory-Relational Dementia Songwriting Framework, relational decision-making. Dupuis et al. (2012a) advocated for the inclusion of PLwD in decision-making and demonstrated how this was not only necessary but critical to making

decisions relevant to PLwD. In doing so, they developed an authentic partnership approach which:

- recognizes how persons with dementia have been silenced, excluded and oppressed, while at the same time recognizing the collective capacity they have to empower themselves and others (Foley, 2001; Freire, 1972, 1976);
- seeks to work in partnership with persons with dementia, their families and others to promote equality and social justice for all persons with dementia (Adams & Clarke, 1999; Foley, 2001; Freire, 1972); and
- incorporates a systematic process of critical reflection and dialogue in community with others, as all partners work collectively towards the realization of new possibilities (Freire, 1972; Habermas, 1984). (Dupuis et al., 2012a, p. 432)

Further, both liberatory/activist arts and CoMT require arts creation to be participatory and collaborative processes (Stige & Aarø, 2012; Watkin & Shulman, 2008). Drawing on authentic partnerships, liberatory/activist arts, and CoMT as guiding frameworks, relational decision-making in this research involved making all decisions about the song (i.e., lyrics, melody, instrumentation) as a group, with time for reflection. This section will describe how relational techniques and processes were utilized to support relational decision-making.

As stated in Chapter 4, the collaborative songwriting process began with group discussions that served as the basis for the song's lyrics (i.e., discussions exploring what was important to us, our values, how we wanted to be treated in the world, etc.). Importantly, the relational and dialogic ways these discussions were facilitated and supported shaped how ideas were shared, how decisions were negotiated and renegotiated, and how the song evolved through collaborative emergence. To ensure these discussions were both collaborative and inclusive, I

intentionally used various techniques, including summarizing and revisiting emerging ideas, embracing evolving negotiations, developing a shared aesthetic vision, and creating space for inclusive dialogue and reflection, to ensure all songwriters were actively included in decision-making throughout the process. This section will describe these techniques and discuss how they supported relational decision-making processes.

Summarizing and Revisiting Emerging Ideas

Summarizing and revisiting ideas shared throughout the songwriting sessions were used regularly to involve each songwriter more fully in the process. For example, each session began with a summary of the previous session to provide the songwriters with context for what we had discussed and what we would do in that session. I provided this information verbally, referring to key ideas identified in point form, written in large letters on flipchart paper, so songwriters could see what we had discussed with a visual cue. In this way, each session built on the previous session(s) and supported the songwriters in connecting the information we had collected with the new information we would be discussing.

I also used summarizing throughout each session to emphasize what the songwriters had shared, which helped them connect and relate to each other's ideas. For example, after a discussion about what was important to us in Week 1, I summarized the key ideas and tried to connect them to some of the songwriters.

> *Taylor: And then when we said what's important to us, we said doing the right thing. Zay a mensch. Everything is important to us. Going after what you want is important to us. Our family, learning and discovering is important to us. Giving us a chance, being healthy, happy, creating a good society. And then lastly, what makes us happy? A smile on a rainy day (group laughs), listening to others, our family, not being so critical.*
>
> *Faigie: That's a big one.*

Taylor: That's a big one. Respecting people. Andrew and Milton said a good joke makes us happy. Beautiful.

Milton: Yeah.

Faigie: Maybe we can finish it off with a joke.

Taylor: We could put a joke in the song. For sure. We'll think of one! And Andrew said, he said it's important to spread joy and laughter.

Lily: Yes, it is

Identifying ideas with songwriters was not just a way to remind the songwriters about what had been discussed earlier, but also another way to recognize the contributions the songwriters were making to the process and the development of the song. Demonstrating that people have been heard and that their contributions are being recognized and included is an important component of supporting authentic partnerships with PLwD (Dupuis et al., 2012a). In another session, I used summarizing to connect the songwriters' ideas during a discussion of the lessons they wanted to share with others.

Taylor: Try to smile on a rainy day. That was a big piece of advice. I think Robert said, go after what you want. Milton said, try to make the world a better place. Andrew, you said it's important to spread joy and laughter wherever you go. Yeah.

Additionally, I often repeated what a songwriter shared with the group to ensure everyone could hear them (some songwriters had hearing impairments, so it was especially important to repeat phrases to include them more fully in the process). In doing so, the songwriters also built on one another during group discussions, an important guiding principle of authentic partnerships (Dupuis et al., 2012a).

Taylor: Singing makes us happy. Spreading laughter and joy. Ice cream. Robert said ice cream makes him happy. (group laughs). Family and friends, and friends who become family. Yes. Are we missing anything?

Faigie: Very important.

Taylor: Helen, what makes you happy?

Helen: Being around people who are friendly.

Taylor: Being around people who are friendly. I'm going to add that. Hold on. Being around people who are friendly.

Faigie: And smiling.

Taylor: Yes. Being around people who are friendly. Smiling.

Faigie: Smiling. Very important.

At times, staff members involved in the songwriting process reminded me that some of the songwriters might be having difficulty hearing, prompting me to repeat and clarify more frequently. This reflects what The Bitove Method describes as a "first follower" (Dupuis et al., 2025b). First followers support facilitators in attending to all participant artists and help ensure the group is guided in ways that are as inclusive as possible. They remain attentive to what is unfolding in the moment, noticing where support may be needed and drawing the facilitator's attention to things that might otherwise be missed (Dupuis et al., 2025b). At other points in the process, the songwriters themselves took up this role, indicating when they were unable to hear what others had shared and prompting adjustments to support more inclusive participation.

Taylor: Exactly. Lorainne, how do you hope, how do you hope people feel after singing this song?

Lorainne: I hope that they are very proud.

Taylor: Ah. Yeah, that's really beautiful.

Faigie: What did she say? We couldn't hear.

Taylor: Lorraine said that she hopes people feel proud after hearing this song.

Lily: Yes.

Faigie: Thank you, Lorainne!

By letting me know when they needed something repeated, the songwriters also asserted their relational capacities by actively demonstrating curiosity about others' ideas and perspectives and ensuring they were included in our discussions.

Embracing Evolving Negotiations

A central tenet of both authentic partnerships and liberatory/activist arts is the creation of a safe, dialogic space where group members' diverse histories and perspectives are respected (Dupuis et al., 2012a; Watkins & Shulman, 2008). Relational decision-making also recognizes decision-making as an evolving process of exploration, negotiation, and re-negotiation. Embracing the evolving nature of collaborative negotiation processes supports the development of a final product that reflects shared contributions and fosters collective ownership and pride. While many of the decisions made about the song were unanimous, there were times when opinions differed about what the song should say and how it should sound. In these moments, it was essential to enter the space with genuine curiosity and respect for diverse perspectives. To facilitate these negotiations, I guided discussions that supported each songwriter in voicing their concerns and working toward a shared resolution. As an example of this, at the end of one session, there were different opinions on one of the lines for the chorus of the song. To ensure that we reached a resolution, I returned to this discussion in the next session.

Taylor: This is my question, because last week, a few of you said it doesn't need to be a rainy day to smile. You can smile every day.

Faigie: Definitely.

Taylor: I want, I wanted to ask, did you want to change it to don't criticize and don't undermine and try to smile every day?

Lily: No, no.

Faigie: No.

Taylor: Do we want to keep it with rainy day?

Faigie: I think so.

Lily: We think so.

Taylor: We think so. (Helen shakes her head) Helen doesn't think so. Tell me more.

Helen: Well, every day.

Taylor: Hmm, okay, so let's…

Faigie: So you mean smile every day?

Taylor: Smile every day instead of a rainy day. Let me sing it again, and you'll tell me how you feel. Watch this because I did it weird the first time. (Starts singing) "Don't criticize and don't undermine and smile every day." How does that sound?

Lily: Well, it doesn't sound as good.

Taylor: So this is, Lily said she liked it better how we did it before. This is, this is part of the songwriting process. You see is that some people think one way, some people think another. So let me sing it one more time. Lily, you tell me how you feel. (Sings) "Don't criticize and don't undermine and smile every day."

Lily: Well, it's good because you've got it every day.

Taylor: Okay. So, yeah, so why don't we try it like that? Okay, I'm gonna, I'm going to say smile every day.

Faigie: Because if the sun is shining you are smiling anyways.

Helen's concerns about the lyrics were revisited again during Week 8 when we were rehearsing for the recording session. During the rehearsal, Helen shared that it is unfair to ask people to smile every day, since some days they may not feel like smiling. As a group, we brainstormed a replacement lyric that better reflected our values. Using the tools discussed in this section (i.e., summarizing, repetition, creating space for inclusive dialogue), we decided collaboratively to change "smile every day" to "bring smiles along the way." A similar negotiation process occurred when deciding on the title of the song.

Taylor: How does that feel for the song title? Smile every day. Lorainne how does that feel smile every day?

Helen: You can't smile every day.

Faigie: But we can try. And we can encourage others, other people to smile.

Milton: That's a good quality title.

Taylor: Milton said that that's a good quality title.

Helen: What do you want? (said to me)

Taylor: I was thinking because the end of the chorus says smile every day not as something you can actually do, but as advice.

Helen: But we can't ask them to smile every day.

Taylor: That's true.

Faigie: But we can treat people with love and respect.

Taylor: Do we want that to be the title love and respect?

Faigie: I think so.

Taylor: Does that feel better? Love and respect for the title of the song?

Helen: I think so.

Lily: Yes.

Taylor: Love and respect. Oh, I love it! Okay well it's a strong title. Milton how do you feel about that, love and respect for the title of the song?

Milton: It will go a long way.

In another relational negotiation during the rehearsal for the song's recording, the group revisited the title and decided that "Wisdom and Respect" more accurately reflected the song's message. By being open to the evolving nature of decision-making and engaging in and revisiting

relational negotiation processes that emerged over time, we created lyrics and a title for the song that represented the aims and wishes of the entire group.

Playing with Sound to Create a Shared Aesthetic Vision

In accordance with liberatory and activist arts approaches (Watkins & Shulman, 2008), all aesthetic decisions about the musical components of the song were made collaboratively. To support musical decision-making, it was important to provide songwriters with accessible ways to explore different sounds and musical elements. Because the songwriters did not play instruments themselves, we explored ways to make musical decisions that did not rely on tuned instruments. For example, when developing the initial melody for the song, I asked the songwriters how they felt the song should sound, inviting them to describe the "mood" of the lyrics. In Week 3, after we had the basis for the song's lyrics, we began forming the melody for the chorus.

> *Taylor: Okay, so we're going to start with the chorus. And my question is, when I read this out to you, what does this sound like? What do we want our song to sound like? What mood?*
>
> *Faigie: Happy.*
>
> *Taylor: Happy. What other mood do we want the song to be?*
>
> *Lily: Happy.*
>
> *Faigie: Happy and grateful.*
>
> *Taylor: Happy and grateful. What else, Robert? What's the mood of this song?*
>
> *Lily: They're all different.*
>
> *Robert: Ya, it depends on what you're talking about. The one that I can most imagine is love.*
>
> *Taylor: It's going to sound like love, happy.*

Based on this description (happy, grateful, and loving), I used an NRMT technique called grounding to support the songwriters in developing an initial chorus melody. Bruscia (1987) described grounding as "providing a tonal centre, scale, or harmonic ground" (p. 535). The purpose of this technique is to create a safe and supportive musical space for exploration. Grounding is also a core concept of Aesthetic Music Therapy (AeMT), which describes this tonal centre as the architectural tonic (Lee, 2003). Through the architectural tonic, compositions can be created between therapist and participant(s) that provide structure and stability (Lee & Houde, 2011). Because the songwriters expressed a desire for the song to sound happy, I used this as a guide when selecting initial chords (e.g., major-key chords).

> *Taylor: We're gonna start with the chorus. And the chorus is the part of the song that repeats itself.*
>
> *Faigie: That's right.*
>
> *Taylor: So this is how we're gonna do it. I am gonna play a little something based on what you told me, and we're gonna start to - I call this part of the songwriting process, molding the clay, because it's a process.*
>
> *Robert: Oh!*
>
> *Faigie: Molding the clay.*
>
> *Taylor: (Starts to play C, F, C, G, C on the guitar – group clapping to the beat of the tempo).*
>
> *Taylor: How does that feel?*
>
> *Robert: Good.*
>
> *Lily: Good. It feels right.*
>
> *Faigie: Good. But you, when you clap with your feet, a little less noise. (group laughs) Because some of us don't sing loud enough.*
>
> *Taylor: Okay yes. So a little less on the stomp there. No problem. I can do that. Helen, how did that feel? I'm gonna play it again (Plays the chords again).*

Faigie: It can be a little more with your foot (Group laughs).

Taylor: Helen, how did that feel for you?

Helen: There is something that made you think more.

Taylor: Okay so you want it to be more?

Helen: No I don't want it to be more, but there was a part where it came out louder and you understood.

Taylor: Okay, so when I play it, to play with confidence.

Helen: Yes.

Taylor: Okay. So now we have the chords for the chorus, and it goes like this, I'm gonna play it one more time (plays chords again).

Lily: Wonderful.

Taylor: Thank you. It's all you telling me what you want. Okay, so that's, that's the…

Robert: Love.

Taylor: Yeah. That's love, yeah.

Lily: Exactly. That felt great.

Once we had the initial chord progression for the chorus, we began to shape the melody. To do this, I handed out small percussion instruments and tone bars using the C triad.

Taylor: And now I'm going to tell you the next part of how I think about songwriting. So once I have that basis, I think of a melody for the chorus. Here we go. Let's think – (plays C, F, C, G, C and starts to hum) How does that sound? (sings again)

Lily: That's wonderful.

Taylor: Okay, how else do we feel? I'm gonna sing it again. Can we try it together?

Group: (Sings melody together on "la")

Taylor: Do we like this?

Robert: Yes.

Lily: Definitely.

In my experience, songwriting with PLwD often involves a careful balancing act between offering meaningful opportunities for choice while avoiding potential overwhelm. In a process that already required the group to make multiple decisions, I often tried to keep the experience manageable and supportive by not offering too many options. At the same time, reflecting on this session, I found myself questioning why I did not offer more opportunities for choice in that moment. This reflection prompted me to consider the demands of decision-making within the process and the need to be attentive not only to moments of choice but also to their overall frequency and intensity. Looking back, I might have come up with a different melody in the moment, so the group could compare which one they felt suited the lyrics better.

In Week 4, a music producer joined the group to support the songwriters in adding various instrumentation to the song. By having the producer share different musical instruments on his computer, the songwriters were able to explore and shape the song's instrumentation.

Taylor: So now what's really exciting is (producer name) here is going to add any instruments. So when we think of this chorus, what do we hear? What kind of instruments do you hear on top?

Lily: I love the music.

Taylor: I know, yes, and we're going to make this music even more full! So what kind of instruments do you want to hear on this song?

Faigie: Um, a violin?

Taylor: A violin, why not? (Producer uses iPad to play a violin sound)

Faigie: A violin is very romantic.

Taylor: (Strums the chords of the chorus over the violin sound) How does that sound? Do we like that? Do we like the violin?

Faigie: Yeah, a violin is very romantic.

Group Yes.

Taylor: Okay, let's try. Let's try the chorus together with the violin. (Looks to producer) Can we do that? Do you know the chorus? (Producer nods).

Group: (Group sings and plays tone bars and tambourines to the chorus).

Taylor: Isn't that beautiful?

Lily: It is!

Faigie: I like the violin.

Taylor: Faigie, likes the violin.

Taylor: Lorraine, how do you feel about the violin?

Lorraine: I like the violin.

Taylor: You like the violin.

Lorraine: Oh yes.

Taylor: Andrew, how are you feeling about the violin?

Lily: I like the violin.

Andrew: Yes.

Taylor: You do. Helen, how do you feel?

Helen: (Nods in agreement)

Taylor: Yeah, I think it adds something to it, right? Robert, how do you feel?

Faigie: It's like a little sweetness.

Taylor: Oh, a little sweetness. I love that.

Faigie: You know what I mean? (Starts to conduct)

Taylor: Beautiful. What other instruments do we want on our song?

Lily: You want something?

Taylor: Yeah, like, what else?

Lily: I just - that something's coming on.

Taylor: Yes, okay, so a little bit of like, like, you want attention to be brought maybe like a drum, I don't know. What do you think?

Faigie: Yeah, it could be! Bum ba (says it in the beat of a drum).

Producer: (Plays a drum sound)

Taylor: Interesting.

Producer: It's a lot of drums. One second.

Lily: What does he think? (looking at the producer)

Taylor: We're gonna ask him, he's just fixing it.

Producer: (Plays a softer drum sound)

Taylor: Yeah, that could work. Bill, how do you like it? How do you like the music?

Bill: Nice.

Taylor: (To the group) How do we feel about this drum?

Producer: (Adds a tambourine and triangle to the drums)

Taylor: Oo! (Group laughs). Yeah. Can we try the chorus with all those things?

Producer: Yeah. I can slow it down.

Taylor: Yeah, we're gonna do it a bit slower. (Producer name) is a music producer, so he does this all the time, yeah, okay, you let us know when you're ready.

Faigie: Maybe he'll recommend us for a concert!

Group: (Sings chorus).

Inviting all songwriters into the discussion reminded them that they had a role in shaping how the song would sound. Additionally, hearing different versions of the song and experimenting with different sounds also supported the songwriters in their decision-making.

Creating Space for Inclusive Critical Dialogue and Reflection

As discussed in Chapters 3 and 4, critical pedagogy and liberatory/activist arts engage groups of people with a shared interest in critically examining and disrupting systems of oppression that have shaped their lived experiences (Freire, 1972; Kester, 2004; Watkins & Shulman, 2008). Dialogue and reflection are central to critical pedagogy and liberatory/activist arts because they create opportunities for participants to share their life experiences, question assumptions, and collectively shape the direction of a process (Dupuis & Gillies, 2014; Freire, 1972). In collaborative creative work, this dialogical approach supports more equitable decision-making by recognizing that knowledge is produced through interaction rather than held by a single authority. This perspective is particularly important in the context of dementia, where the literature has rarely recognized the decision-making capacities of PLwD, and especially those in the later stages of the condition (Bartlett & O'Connor, 2007; Dupuis et al., 2012a; Dupuis & Gillies, 2014). This lack of recognition is unsurprising, as stigma surrounding dementia often assumes that PLwD are unable to communicate their preferences and experiences, lack the capacity to learn and grow, and therefore cannot shape or influence their own lives or the lives of those around them (Dupuis & Gillies, 2014). However, approaching this collaborative songwriting process from a position of knowing otherwise (Mitchell, 2013; Olthuis, 1997) involved assuming that the songwriters did have the capacity for learning, growth, and the sharing of their stories and experiences. Through attuning to relational processes, and particularly to the diverse ways PLwD shared their experiences (i.e., through both verbal and

embodied expression), it became evident that they had much to contribute to the collaborative process. While Chapter 6 critically examines these reflective dialogues through the lens of relational citizenship, emphasizing the capacity of PLwD to assert their perspectives and agency, this chapter focuses on describing how these discussions unfolded as part of the collaborative songwriting process.

It should also be noted that embedding critical dialogue and reflection can be a complex process when working with PLwD later in the disease process. For instance, some PLwD in the later stages of the disease progression might not know or remember that they have dementia. I argue that in these cases, reminding them could cause unnecessary distress. Therefore, approaching critical reflection in this project meant taking much care in how it was approached. I decided the best way to approach this was to raise issues and ask guiding questions about how older adults are understood and treated in society, in hopes of eliciting critical dialogue and reflection. For example, in Week 2, when discussing the importance of learning, I asked the songwriters whether this is still important to them.

Taylor: And would you say as you get older, you still have a zest for learning?

Lily: Yes.

Faigie: Mhm.

Robert: Of course.

Taylor: Yeah. That never really goes away. But some people think that when you get to a certain age, you don't want to learn anymore.

Faigie: That's not true.

Lily: No.

Robert: The thing is, as you get older, maybe you should know more.

Taylor: As you get older, you should know more.

Robert: Yeah.

Taylor: Yeah, I agree with you. And sometimes I think we forget that older adults hold a lot of wisdom.

Robert: Yeah.

Lily: Yes.

These reflective discussions, particularly around the knowledge that the songwriters still had, continued throughout the songwriting process.

Taylor: …Last week, we talked about just because we're older doesn't mean we don't have knowledge and wisdom.

Lily: That's true.

Taylor: It is true.

Faigie: We have a lot of…

Robert: In fact it's more, the older ones.

Taylor: Have more wisdom.

Faigie: We have a lot more wisdom. And we know to be nice.

It was through reflecting on the knowledge the songwriters had, despite their age and dementia diagnosis, that the title and ethos of the song took shape.

As stated earlier in this chapter, I shared my grandparents' experiences of oppression to elicit critical reflection on the ways people are treated as they get older. Drawing from these experiences, the songwriters were also supported in reflecting on how they wanted to be treated in the world.

Taylor: … Is there anything we're missing about how we want to be treated? This is what we said. To be loved no matter what. To be treated considerately.

Lily: Yes. Nicely, caring.

Faigie: Very important.

Taylor: Yes. We want to be listened to and treated with respect and we want to be treated the way or how would I say it? Treat people the way you would want to be treated.

Lily: Right.

Faigie: Do unto others as you want them to do unto you.

In another example, a care partner who attended the sessions each week also contributed to a discussion on how they felt PLwD should be treated.

Faigie: The first word that comes to my mind is love.

Lily: Ooo!

Faigie: To be loved.

Taylor: Yeah. Beautiful. To be loved. To be loved. Yeah. Beautiful. How else?

Faigie: No matter what.

Taylor: No matter what. How else? How else do we want to be treated?

Lily: Nicely.

Taylor: Nicely. How else?

Robert: Caring.

Helen: With respect.

Care partner: You want people to listen to you rather than disregard what you're saying.

Taylor: Yes. So you want to be treated with respect and to be listened to. Helen actually told me this a while ago. You told me that sometimes as we get older, people don't listen to us.

Faigie: That's right.

As the sessions went on, the songwriters also reflected on how they hope people like them would be treated after hearing the song.

Taylor: How do we hope people treat people like yourself after they hear this song?

Lily: Well, it depends on how you listen to the song.

Taylor: Oh, interesting. That's a good point.

Lily: With respect.

Faigie: With kindness.

Taylor: Yes. With kindness.

Faigie: All the time.

Taylor: And respect.

Faigie: Not only with the song, but with kindness all the time.

Taylor: With kindness all the time. To treat people with kindness all the time. Milton mentioned this at the beginning of the songwriting process where he said, Zaya mensch.

Group: (says together) Zaya mensch.

In addition to providing space for reflection about our lived experiences in the world, liberatory/activist arts, authentic partnerships, and CoMT require group members to engage in continuous reflection and dialogue on the process to ensure that the project is achieving its intended goals (Dupuis et al., 2012a; Stige and Aarø, 2012). To ensure the group felt the project was meeting its intended purpose, at the end of each session, I would ask how they were feeling about what we were creating together. For example, in Week 3, we discussed how we felt about the process after we finished writing the song's lyrics.

Taylor: But before we go, I have a question, how are we feeling about what we're creating?

Lily: I'm feeling good.

Taylor: Great. How else are we feeling? Robert, how are you feeling with the song we're creating?

Robert: It's my phrase. It soothes the soul.

Taylor: It soothes the soul. Yes. Faigie, how are you feeling with the song we're creating?

Faigie: I love singing.

Taylor: You love singing. Yeah.

Faigie: So this is in good times, even during the war in the concentration camps. We always sang, Since I was a little kid.

Taylor: Yeah. Exactly.

Faigie: Mhm!

Taylor: Yeah. Lorraine, how do you feel with the song we wrote?

Lorraine: I thought it was great so far.

Taylor: You thought it was great so far. Great. Helen, how are you feeling?

Helen: Satisfied.

Taylor: Satisfied.

Faigie: That's good. That's very good.

These reflections opened space for the songwriters to recognize the broader impacts of what they had created together for others. While at the beginning of our process, the songwriters had hoped that people who heard the song would be happy and like it, by the end, they were seeing a larger purpose and the importance of their role in inspiring others to live their lives.

Faigie: That is the thing. Singing makes you happy. In bad times, in the ghetto, in the concentration camp, we sang.

Taylor: yes. and Robert, exactly. And Robert was telling us last week that, you know, just because somebody is older doesn't mean that they don't…

Lily: he didn't like it.

Taylor: Well, he was, Robert said last week that just because somebody is older doesn't mean that they don't have wisdom to share. And in fact, you said, What did you say?

Faigie: The opposite.

Robert: And I was saying it soothes the soul.

Taylor: It soothes the soul. And what I'm hoping is, with this chorus (sings) "care for one another, listen to each other, treat people with love and respect"

Faigie: Terrific

Taylor: (sings) "don't criticize and don't undermine and smile on a rainy day." It's going to teach people something.

Group: Yes.

Faigie: And you know what? This is good for living.

Taylor: This is good for living.

Faigie: Not only for singing. We should all take an example from this.

I returned to this discussion in our last session together and asked the group to reflect on what the process was like for them as a whole. Again, the songwriters were opened to what the process brought to their own lives and the possibilities of the song for others.

Taylor: So before we end our songwriting process, I wanted to ask you how was your experience writing this song as a group? Tell me about your experience.

Faigie: We liked it!

Taylor: You liked it! What did you like about it?

Faigie: The words! That it gives hope!

Taylor: That it gives hope. Robert, how was this experience for you writing the song with the group about what you want the world to know?

Robert: It's important to have everyone together – at all times. There are people out there and they need to know what to do, they don't have help. And we need to have those people.

Taylor: That's really beautiful I'm just going to repeat what you said. Robert was saying that firstly, it's important to all be together and that some people in the world don't have the help that they need and it's important to help them. Yeah, and hopefully this song can help other people get the support that they deserve. Yeah, thank you for sharing that.

Faigie: That's very nice, Robert.

Robert: That's why I always say, it soothes the soul. Without that, without having a soul, where would we be.

Faigie: In any time.

Taylor: Without having a soul and without music where would we be.

By intentionally embedding opportunities for dialogue and reflection throughout the songwriting process, the group was able to share experiences, question and explore assumptions about aging, and collectively shape both the message of the song and the collaborative process. These ongoing reflections also created space for songwriters to recognize the knowledge they held and to reflect on the personal and relational growth that emerged through participating in the project. In this way, embedding these reflections throughout the songwriting process supported ontological authenticity (the extent to which participants grow from their engagement in the project) and educative authenticity (the extent to which participants' understandings of others' experiences in the world have grown) (Lincoln & Guba,1985) and will be explored further in Chapter 6.

This chapter described the relational framework used to facilitate this collaborative songwriting project. Through relational knowledging, relational attuning, and relational decision-making, the songwriters and I developed deep and meaningful connections with one another, relationships that continue to this day. Writing a collaborative song about the ways the

songwriters wanted to be treated in the world created a relational space in which traditional "researcher" and "participant" roles were transformed into those of collaborators, songwriters, and friends. By listening to and mutually supporting one another's stories, experiences, and musical ideas, we developed a deep sense of respect and care that shaped both the song and the overall songwriting experience. The development and deepening of these relationships lie at the heart of this project and lead me to believe that songwriting is not only a research method but a relational practice that supports belonging, shared meaning-making, and the full relational capacities of PLwD. While the deepening of relationships and the nurturing of relational processes were essential to this research, they are not sufficient on their own. Bartlett and O'Connor (2010) argued that while PLwD have the capacity to connect with others, they also have the capacity to engage with political issues and contribute to social change. The next and final chapter explores how the relational processes described here, along with the resulting song and film, supported the songwriters in speaking for themselves, challenged stigmatizing discourses about dementia, and invited audiences to reconsider what it means to live with dementia.

CHAPTER 6: DISRUPTING DISCOURSE – CRITICAL CONTRIBUTIONS FROM THE LIBERATORY-RELATIONAL SONGWRITING PROCESS

Chapter 5 introduced the Liberatory-Relational Dementia Songwriting Framework and explored how it supported the relational capacities of the songwriters and facilitated meaningful connections. Within this relational space, the group co-created "Wisdom and Respect," a song that embodies the themes, values, and stories that emerged across the sessions. The song was then recorded and developed into a short film, which was shared with a broader audience at a community release party in the setting where this research took place. The release party served as an opportunity to explore the possibilities of liberatory songwriting in challenging the stigma associated with dementia. This chapter examines how the songwriters, the collaborative songwriting process, and audience responses to the film gathered at the release party disrupt dominant deficit-based and tragedy narratives that frame dementia through loss and decline. Specifically, this chapter will explore how the songwriting process served as a space for people in the later phases of dementia to enact relational citizenship, through the songwriters' embodied expressions of knowledge and identity, as well as their ongoing capacities for creativity, learning, growth, and care. In this enactment, they create a counter-narrative of dementia and people living with it that exposes limitations in the dominant master narrative of dementia. I also consider how this study expands current conceptualizations of music and leisure in the dementia context, as well as the role of participatory research with PLwD, particularly those in later stages of the disease process. Lastly, this chapter concludes with reflections on impediments and supports to enacting relational citizenship, as well as considerations for future liberatory-relational arts-based projects with PLwD. Before I turn to that discussion, I introduce the film

Wisdom and Respect. The film is available for public viewing here:

https://www.youtube.com/watch?v=GHKXNw-0iTM.

Wisdom and Respect: A Song Co-Created by People Living with Dementia

Verse 1: *We have wisdom that we would like to share*
We are here to spread hope and joy everywhere
Though people might say that we do not know
We have been here awhile and have something to show

Chorus: *Care for one another, listen to each other*
Treat people with love and respect
Don't criticize, and don't undermine, and
Bring smiles alone the way

Verse 2: *We are teachers, mentors, survivors and friends*
We are listeners and learners, and that never ends
We want to be treated with love and care
We want you to listen to these words we share

Chorus

Verse 3: *We know how to make the best out of life*
We love a good joke and can smile in strife
Singing and laughing is always the goal
Just remember that music soothes the soul

Chorus

Returning to Citizenship as a Theoretical Lens

As described earlier in this dissertation, citizenship, in its most basic sense, refers to the "membership of a community, of which members are eligible to control their own life and influence their society" (Lotherington & Obstfelder, 2024, p. 2686). Traditionally, to be viewed as a citizen, one had to be "fully cognizant with the capacity to make judgements and decisions, assume responsibility, participate in the exercise of political power and fulfil civic obligations such as voting and working" (Bartlett & O'Connor, 2010, p. 31). Unfortunately, such conceptualizations, rooted in notions of cognition and brain function as the sources of agency

and personhood (Vidal, 2009), deny PLwD, who are often defined by cognitive loss, the right to participate fully in social and civic life (Kontos et al., 2017).

Expanding on what it means to be a citizen, and the dominant care frameworks in the dementia context that tend to ignore the socio-political factors that stigmatize and oppress PLwD, dementia scholars aimed to broaden what citizenship looks like and the ways it can be integrated into care to better support the dignity and personhood of PLwD (Bartlett & O'Connor, 2010; Dupuis et al., 2025a; O'Connor et al., 2022; Kontos et al., 2017; Phinney et al., 2016). By situating citizenship within a relational and social justice framework, Bartlett and O'Connor (2010) argued that citizenship extends beyond support for individual preferences or even relationships between PLwD and care partners and must also recognize PLwD as "active agents with rights, history and competencies" (p. 39). Building on this, relational citizenship emphasizes that full citizenship for PLwD also requires recognizing and supporting their full communicative capacities, including those expressed in embodied ways (Miller & Kontos, 2016). Drawing from the literature on embodiment, this perspective attends to how personhood is expressed through embodied, relational, and often nonverbal ways of being in the world. As demonstrated in Chapter 5, the songwriters expressed their embodied relational capacities through tone of voice, gesture, facial expression, and shared musical engagement.

Feminist scholars have also contributed substantially to how citizenship is understood, particularly by theorizing power and agency in relation to citizenship. Lotherington and Obstefelder (2024) summarize these contributions:

> Examples are Lister (2003) in her distinction between citizenship as status, or being a citizen, and citizenship as a process, or acting as a citizen; Nussbaum (2011) with her capabilities approach; Fraser (2000) with recognition, redistribution and representation;

> and Young (2000) with belonging and inclusion, attending to social difference and civic organizing. (p. 2686)

Feminist theorizing on citizenship emphasizes the concepts of belonging, recognition and agency in the *process* (i.e., the doing) of citizenship (Lotherington & Obstfelder, 2024). Lotherington and Obstfelder, further argue:

> With these concepts, the legal aspect of citizenship, and the nation-state, are no longer central. The concern is who belongs to, are included in, a certain community, who are recognised as equal participants and whose agency is influential. Citizenship as process, or to act as a citizen (Lister, 2003), require all: belonging, recognition and agency are all necessary conditions for citizenship, but they are not sufficient in and of themselves, individually. They must operate together. (p. 2698)

This chapter examines how the liberatory-relational songwriting process and the resulting song/film served as a space for the enactment of relational citizenship by supporting the songwriters' embodied knowledge, identities, and contributions. In the collective effort of co-creating a song meaningful to all the songwriters, where they could share important aspects of themselves with others, a sense of belonging (to each other, to their community, and to something bigger) was nurtured. Through the liberatory-relational songwriting process and the sharing of the song/film with others, the songwriters were reminded of, and reminded others of, their continued capacities, and were recognized, by one another and by others, for the knowledge they held and for the active contributing citizens they are. The song/film, as an important product of the liberatory-relational songwriting process, is the very enactment of agency, providing a powerful counter-narrative to deficit and tragic portrayals of PLwD. It is my hope that both the Liberatory-Relational Dementia Songwriting Framework and the song/film itself will contribute

to the transformation so needed in the dementia movement. The chapter begins with a discussion of how the songwriters expressed their relational citizenship. It then turns to a discussion of what is required to support the enactment of relational citizenship. Finally, I describe how these expressions can reverberate beyond the songwriting context and into our communities as a change-making tool for individual and systematic change.

Enacting Relational Citizenship: Assertions of Knowledge, Care, and Social Roles

As outlined throughout this dissertation, academic literature, policy documents, and media representations often position PLwD as "sufferers, totally impaired, and lacking insight" (Bartlett & O'Connor, 2010, p. 20). Additionally, PLwD are frequently viewed as incapable of engaging in meaningful relationships or maintaining a sense of self (Mitchell et al., 2013; 2020). These harmful perceptions and labels contribute to what Bartlett and Lid (2025) refer to as a social death, in which PLwD are viewed as incapable of participating meaningfully in social and civic life, thereby being stripped of their citizenship status (Kontos et al., 2017). This section describes how the songwriters expressed and asserted their embodied knowledge and embodied identities that extend beyond dementia. These expressions and assertions challenge dominant understandings of dementia as a social death, instead highlighting the ongoing capacities of PLwD to contribute, connect, and engage meaningfully in the world as full citizens.

PLwD as Embodied Knowers

Though PLwD are often framed as "stupid, crazy, or not all there" (Spencer, 2023, p. 67), the findings from Chapter 5 disrupt this discourse by demonstrating how the songwriters engaged in relational knowledging, musical expression, and creative decision-making. While Chapter 5 examined these processes through a relational and process-oriented lens, the songwriters also disrupted this harmful dominant discourse by asserting themselves as embodied

knowers. I understand embodied knowing as one dimension of embodied selfhood. Embodied selfhood refers to the ways PLwD express important aspects of themselves through the body (Kontos, 2014). Embodied knowing refers to how PLwD share, communicate, and specifically assert their knowledge and experiences, in relational and embodied ways. It is by recognizing and supporting these expressions of knowledge that we can more fully support embodied selfhood. The songwriters in this study expressed and asserted their embodied knowledge through providing their testimonies, demonstrating their capacity and desire for learning and growth, and taking on social roles as teachers and knowledge sharers.

Asserting Knowledge Through Testimony

One way the songwriters asserted themselves as embodied knowers was through providing their testimonies in multiple ways, including conveying desires, wishes, and life experiences and lessons. Testimony is defined as the "human practices of telling and accepting (or not) what we are told" (Fricker, 2012, p. 4) and is often described in terms of providing facts or statements in regard to evidence (Oxford English Dictionary, n.d., p. 1475). While this definition describes testimony in a basic sense, I think of testimony as something deeper and more relational. A definition I came across by Hamilton (1860) defined testimony as the "communication of an experience, or…the report of an observed phenomenon, made to those whose own experience or observation has not reached so far" (p. 178). Though a dated definition, it offers a lens through which to view testimony as more than just an assertion of facts, but as the communication of lived experience and the learnings from those experiences.

Spencer (2023) argued that the testimonies of PLwD are often dismissed or rejected because they are no longer recognized as reliable "knowers" (p. 63). Additionally, when we ignore the ways that PLwD express their stories and experiences, we commit what Spencer

(2023) identified as testimonial injustice. The stigma of dementia intersecting with ageism exacerbates testimonial injustice, and the songwriters were very aware of this. In Chapter 5, for example, Robert shared his experience of testimonial injustice when speaking about how older adults are viewed as "useless."

Despite PLwD being rejected in their capacity as reliable "knowers", there were many instances throughout this process where the songwriters resisted this, actively expressing their testimonies in nuanced and meaningful ways. For example, as described in Chapter 5, throughout the songwriting process, the songwriters would often reflect on how they wanted to be treated in the world, to be loved without judgment, to be respected and cared for. The song itself reflects a collective testimony asserting the wisdom PLwD continue to have from lives long lived.

Testimony was also given through the telling of life histories. In Chapter 5, for example, Faigie repeatedly emphasized the importance of music to her survival during the Holocaust. In the film, Faigie speaks on this at 4:57.

> *Faigie: "It's important to sing in good times and bad times."*
>
> *Taylor: "When did singing help you the most?"*
>
> *Faigie: "In the concentration camp, in the ghetto. Anytime. I was a little kid. Singing was very, very important."*

I draw attention to this moment in the film for a few reasons. First, Faigie's testimony is especially significant given that Holocaust survivors, and particularly survivors living with dementia, are often depicted as paranoid, depressed, angry, aggressive, distressed, and lonely (Craftman, 2020; Farber et al., 2023; Joffe et al., 2003; Kellermann, 2001). While a large body of scholarly literature explores the experiences of Holocaust survivors as they age (Craftman, 2020; Grodin, 2011; Morgan, 2023; Teshuva & Wells, 2014), many studies focus on the hardships and

symptoms experienced by survivors as a result of their trauma (David, 2002; Morgan et al., 2023). Much less research focuses on their strengths (David, 2002; Morgan et al., 2023) and, especially, the strengths of survivors living with dementia. In this example, Faigie's testimony disrupts these dominant narratives on multiple levels. Not only does she reflect her resilience and strength as a young child, but she also counters depictions of survivors living with dementia through the way she expresses her experiences with clarity, authority, and strength. Second, while the arts (i.e., poetry and quilting) have been used with older survivors to process experiences of trauma (David, 1995/2003), there is little to no research on the use of songwriting with PLwD who are survivors of genocide, political violence, or severe trauma. In this way, Faigie's testimonies in the context of collaborative songwriting offer a lens with which to reconceptualize the common discourse of survivors living with dementia and highlight the importance of the arts, particularly music in this case, to resilience. Lastly, Faigie's testimony in the film provides evidence of how testimony is given in both verbal and embodied forms. What I find particularly moving about Faigie's testimony is the way she conveys it through tone of voice and gesture (e.g., placing strong emphasis on specific words and raising her hand to her heart). In this example, it is not only the words she shares but also how she shares them which leave a lasting impression and show the importance of embodied expression in sharing testimony.

In the dementia context, understanding how testimony can be expressed in embodied ways is especially important for PLwD who have limited use of language. Spencer (2023) argued that PLwD who experience such difficulties are at greater risk of testimonial injustice as their expressions are often "ignored or regarded as meaningless" (p. 68). The dismissal of non-verbal testimonies is referred to by Spencer (2023) as non-verbal testimonial injustice and can be mitigated through the concept of embodied testimony. Embodied testimony refers to how PLwD

express their ideas, feelings, and experiences through embodied means. For example, in Chapter 5, I discussed the ways Andrew expressed emotion through his tone of voice and body language. In this example, Andrew experienced difficulty with language, and by sharing what he was experiencing in that moment (e.g., through body language, tone of voice, and embodied actions like a handshake), he provided embodied testimony. It was also through the way Andrew expressed how he was feeling that he disrupted views of giving testimony that are rooted primarily in cognitive status and language. Andrew's expressions in this moment were anything but meaningless; in fact, some of the most meaningful connections I have experienced in my career emerged through my time with him. Had I instead moved past or ignored Andrew's embodied testimony, I would not only have perpetuated non-verbal testimonial injustice but also missed a profound opportunity to recognize him and his expression of experience in the world, connect with him, and to learn from the knowledge he was offering through his embodied ways of expressing his testimony.

To reinstate non-verbal testimonial justice, Spencer (2023) argued that we must view embodied testimony on a similar plane to other types of testimony. Recognizing and supporting embodied testimony is crucial to supporting the full relational citizenship of PLwD. However, doing so requires disrupting dominant assumptions about who is capable of giving testimony and what constitutes legitimate testimony. Ignoring, overlooking, or dismissing the communicative testimonies of PLwD as "meaningless" (Spencer, 2023, p. 67) not only strips PLwD of full citizenship but also risks having their testimonies go unheard altogether.

Embodied selfhood provides a particularly useful lens to support embodied testimony. By locating knowledge and expressive capacity within the body (Kontos & Grigorovich, 2018), embodied selfhood challenges cognition-centred models of testimony, which dismiss PLwD as

reliable “knowers” (Spencer, 2023, p. 63). From the lens of embodied selfhood, the ability to give testimony persists despite cognitive decline. However, to fully acknowledge, support, and legitimize embodied testimony, we must recognize that embodied expression is a fundamental aspect of how we *all* communicate.

As stated in Chapter 5, approximately 60–65% of human communication occurs through non-verbal means (Burgoon et al., 2010). Despite this, we continue to privilege verbal communication as the most reliable or legitimate form of expression (a bias no doubt tied to dominant notions of agency and personhood that position cognition and the brain at the centre) (Kontos et al., 2017; Vidal, 2009). Yet the very fact that so much of human communication is non-verbal also opens new possibilities. It suggests that embodied expression and knowing are not unique to PLwD. Rather, it is a central part of how *all* of us know, relate, communicate, and share our experiences. As an example, think of a time when you reacted to a stressful situation in an embodied way. Did your heart rate rise? Did you cry or stomp your feet? All these embodied responses are ways that we assert and express our experiences (i.e., embodied testimony). Would verbally stating one is crying be considered a more valid form of testimony than embodying that experience through crying itself? By attuning more intentionally to embodied forms of expression, not only in our work with PLwD but in our interactions with everyone, we can shift how testimony is understood, valued, and supported. In doing so, we can recognize embodied testimony as equally meaningful and legitimate as other forms of testimony and better support the full relational citizenship of PLwD.

Through this lens, what are often labelled as “behaviours” associated with dementia can be reconceptualized as assertions of embodied testimony. For example, as discussed in Chapter 2, Paterniti (2003) found that PLwD who refused institutional routines, such as showering at

prescribed times or being rushed through meals, were not simply exhibiting "behaviours of dementia," but were expressing individual preferences and resisting institutional norms. Pushing this beyond the expression of individual preference, viewed through the lens of embodied testimony and grounded in the concept of embodied selfhood, such responses can be understood as meaningful communicative acts through which PLwD convey their experiences, values, and desires and even agency through resistance. In this sense, these actions function as legitimate forms of testimony (i.e., the communication of experience) expressed through embodied rather than primarily verbal means. Reconceptualizing these actions as testimony not only challenges the focus on behaviours in the dementia context but also repositions PLwD as having the capacity to assert their testimonies in relation to their day-to-day experiences.

Asserting Worth through Continued Learning, Growth, and Teaching

Bartlett and O'Connor (2010) argued that "[p]eople with dementia do not stop growing, developing and wanting to experiment just because they are diagnosed with dementia" (P. 74). However, the predominant focus on memory loss and cognitive decline in dementia discourse contributes to a narrative that depicts PLwD as being unable and/or uninterested in learning new skills (Ingebrand et al., 2022; Sabat & Warren, 2023). Despite these deficit-based discourses, the songwriters asserted themselves as embodied knowers in a continued process of becoming, through their desire and capacity for learning, growth, and teaching others (Dupuis et al., 2024).

Desire and Capacity for Learning

Throughout the songwriting process and in the song/film, the songwriters asserted their desire and capacity to learn in many ways. For example, in Chapter 5, the songwriters shared how they still have a "zest for learning." Helen and Faigie also shared their desire and openness to learn in a songwriting session during a reflection on how we were feeling about the process.

Helen: I just feel, content with all these people, what they say and what they do, I feel like I'm gonna learn.

Taylor: You're going to learn something. Yes. Thank you for sharing that with us. Helen is saying that she's feeling really content being here with all of you, and that no matter what she feels, she's gonna learn something.

Lily: Yes.

Faigie: And be open to learn something.

The importance of ongoing learning was also reflected in the song lyrics: "We are listeners and learners, and that never ends." Not only did the songwriters express a desire to learn, but they also demonstrated the capacity to acquire new skills. In fact, they openly resisted assumptions that they were no longer interested in or had the capacity to learn new things. I remember during one of the sessions, I tried to ask whether the songwriters knew a particular song that connected with our discussion that day.

Taylor: There's another song about it. I think it's called, keep on the sunny side, always on the sunny side. Does anyone know that? It's beautiful.

Faigie: You can teach us.

Further, the songwriters learned to create and perform an entirely new song. This is especially significant given the common assumption that PLwD are unable to learn new skills due to cognitive loss (Sabat & Warren, 2023) and the oversaturation of the literature on the use of familiar music to enhance memory recall (Clements-Cortes, 2020; Elliot & Gardner, 2018; Lam et al., 2020). In this research, the songwriters demonstrated not only their willingness and interest in embarking on a new endeavour together (i.e., collective songwriting) but also their capacity to learn and engage with new music by experimenting with and asserting their preferences for different chord progressions and melodies, writing lyrics, choosing instrumentation, and practicing and rehearsing the song. In creating and learning the song, the

songwriters also exhibited curiosity, adaptability, and a willingness to take risks within the creative process, challenging assumptions in music-and-dementia discourse by demonstrating that PLwD are not limited to engaging with the past, but can also participate actively in new, emergent, creative processes. This is particularly significant given that much of the literature depicts PLwD as being unable or significantly limited in their ability to engage in future-oriented thinking and doing (El Haj et al., 2024).

It is also important to note that while the songwriters all engaged in the songwriting process, from creation to performance, they did so in different ways. Some were able to learn each lyric and follow along on the lyric sheet each week, some sang along by humming or vocalizing on a syllable such as "la," others whistled, and some participated in more embodied ways, such as tapping their toes or fingers. Avi, for example, expressed himself musically in the film when he is seen conducting along with the music. As he sang, he sat up in his chair and conducted with intention and presence. Although Avi seldom communicated through words, aside from the notable moment in the film when he says, "we are a unit," his strength, confidence, and assertiveness in the music-making process are unmistakable. These expressions reflect not only his embodied selfhood (i.e., embodied relational capacities) but also his embodied knowing, demonstrated through his active engagement with and interpretation of unfolding musical processes, and his contribution to these processes through conducting and singing. Through his gestures, timing, and responsiveness, Avi shows that he is not passively engaging but actively interpreting and contributing to the musical process in real time. Bill also asserted his embodied selfhood, and particularly, embodied knowing, through music. We see examples of this in Chapter 5, when Bill begins to whistle, bringing a musical skill developed earlier in his life into a new musical environment that reflects his responsiveness and adaptability

to new music. In the song/film, Bill is also seen and heard whistling, pointing, smiling, and moving his body in time with the music, demonstrating his engagement with the song and his sense of belonging to the group. These moments were particularly meaningful, as his personality, humour, and sense of playfulness became immediately visible without the need for speech.

These examples align with concepts such as the "musical child" (Nordoff & Robbins, 1977) and Merleau-Ponty's (1962) understanding of pre-reflexive bodily engagement, both of which emphasize that musical know-how exists at a primordial, embodied level. However, not only do these examples suggest that PLwD can engage with new music, but they also illustrate *how* engagement occurs (i.e., through embodied know-how that is not affected by cognitive decline). This also aligns with Sabat and Warren's (2023) argument that the term "memory loss" to describe the dementia experience is itself misleading, as it discounts the ways PLwD continue to draw from preserved memory systems (specifically embodied and emotional forms of memory) to express their personhood. In this way, the songwriters' embodied knowledge extends beyond individual expression to shape the collective creative process itself. Whether through whistling, vocalizing, lyrical contributions, or gesture, each form of embodied musical knowledge served to contribute to relational music-making processes. These examples also broaden our understanding of what engagement with new or unfamiliar music can look like for PLwD and affirm that creative, future-oriented participation remains accessible, relational, and meaningful across a range of capacities. I return to the implications of this later in the chapter.

Becoming and Growing

In addition to demonstrating the capacity to learn new skills, the songwriters also exhibited their capacity and desire for becoming and growing throughout the songwriting process. The critical reflections embedded in the songwriting sessions provided inspiring

examples of how the songwriters evolved and grew over time, particularly in their understanding of the impact their song/film might have on others. For example, in the first week, songwriters hoped that both they and the people who heard the song would be satisfied and happy.

Taylor: … And what do you hope, what do we all hope comes from this song …?

Faigie: First of all, to make people happy.

Taylor: To make people happy.

Faigie: Yes. It's a very big thing.

Taylor: Yes. Yes. I'm hoping that once we have this song done, we're gonna be able to share it with the larger community.

Lily: Yes. Yes.

Taylor: And what do you hope comes from it? Robert, what do you hope comes from the song?

Robert: Family and friends.

Taylor: Family and friends, beautiful. Wonderful. Anything else? What's one word you would describe about how you're feeling now?

Faigie: Happy.

Taylor: Happy.

Milton: (in Yiddish for happy)

Taylor: What does that mean?

Milton: We're happy. Satisfied.

As the process continued, the songwriters saw a larger role they could play and the hope that the song would, in addition to making them feel happy, also change perspectives. In Week 5, I asked a question similar to the one I had asked in the first week, and it was moving to hear how the songwriters' perspectives had evolved over our time together.

Taylor: And what do we hope people take from the song when they listen to it? What do we hope people feel?

Faigie: Hope.

Taylor: Hope.

Lily: To listen to us.

Taylor: To listen to you. Yeah. Wonderful. Yeah. What else do we hope people take from the song? Lorraine, what do you hope somebody takes from the song?

Lorraine: (Speaks quietly, directly to me)

Taylor: Ah yes. I see what you're saying, like acceptance.

Lorraine: Mhm.

Taylor: Lorraine said that she hopes that this song makes people feel accepted. Yeah, that's really beautiful. Thank you for sharing. ....

Taylor: .... Faigie, what do you hope

Faigie: That they will really listen to the words.

Taylor: That they will really listen to the words. Yes.

Taylor: Robert, what about you?

Faigie: To like each other.

Taylor: To like each other. Yes.

Faigie: And we're all good.

Taylor: And we're all good. Yeah, definitely. Robert, what about you?

Robert: It's what I've always said. It soothes the soul.

Taylor: It soothes the soul.

Helen: That people would sing it anytime, anywhere.

Another meaningful moment of growth occurred in our last session together when Helen, who described herself as shy and non-musical in week one, had this to say:

Taylor: Helen, what was writing this song like for you?

Helen: It was exciting for me because I don't do things like this. I hadn't had maybe the desire and I wanted to do it with my heart. Other things weren't that important to me. To use it in my heart. But when I like something I want to remember it. I don't want it to be, to come and go because it's natural. That I want it to linger in my heart.

Taylor: That is so beautiful.

Despite accounts from PLwD and examples from the songwriters in this study demonstrating their desire and capacity to learn and grow, this desire is seldom valued within the dementia literature or in practice. Barlett and O'Connor (2010) suggested that this dismissal is partly rooted in a dominant focus on "maintaining or preserving personhood" (p. 74), leaving development, growth, and learning as unimportant or irrelevant with PLwD. Yet, PLwD have identified opportunities to continue learning and growing as essential for flourishing and living life to the fullest with dementia (Dupuis et al., 2024). Unfortunately, because of the stigma associated with dementia, PLwD, particularly in later phases of the dementia journey, are rarely provided with opportunities to engage in the world in these ways. It is yet another example of how PLwD are dismissed in their capacity as embodied knowers, and how their capacities for curiosity, growth, and engagement are so often overlooked.

In their critique of person-centred care, Bartlett and O'Connor (2010) argued that a social citizenship approach moves from comfort and sense of security to providing opportunities for PLwD to grow and develop (similar to Dupuis et al., 2024). Moving from comfort to growth relates to the ways PLwD are supported not only in experiencing caring relationships (Kitwood, 1997) and physical/emotional safety (Ryan et al., 2008) but also the ways PLwD "seek to develop, experiment and grow as citizens" (Bartlett & O'Connor, 2010, p. 40). The liberatory-relational songwriting process contributed to this aspect of social citizenship by recognizing the

capacities for learning and growth (i.e., becoming) amongst the songwriters and providing a space for this growth to flourish. In doing so, the process provided opportunities for active engagement in their own lives and the lives of others. This, in turn, brought meaning and purpose to their lives (Lotherington & Obstfelder, 2024), challenging dominant discourses that frame dementia solely in terms of decline and loss. Through the songwriting process, the songwriters continued to evolve and discover new things about themselves and others. Similarly, Jonas-Simpson et al. (2022) emphasized the importance of relational arts spaces for discovery. Recognizing and supporting the evolving selfhood of PLwD through these relational processes is essential to supporting their relational citizenship.

Asserting Knowledge Through Teaching and Mentoring

The songwriters also asserted themselves as embodied knowers through acts of teaching and mentoring. As discussed in Chapter 5, part of relational knowledging involves the sharing of knowledge with others. This was evident in the songwriters expressed desire to communicate their experiences, values, and advice to younger generations. For example, Milton shared a life lesson when he stated, “We should all be healthy. And we should all be friendly. And help make a good society.” The importance of sharing knowledge also extended beyond individual contributions, becoming embedded in the song itself. The chorus, in particular, served as a collective testimony to the lessons the songwriters wanted to share with the world in the hope of making the world a better place for all: “Care for one another, listen to each other. Treat people with love and respect. Don’t criticize and don’t undermine and bring smiles along the way.”

Another instance of the songwriters teaching others occurred in the film when Faigie and Helen offered advice on writing a song. For example, Helen stated, “You need certain words that are meaningful. Not many, but every word should mean something,” followed by Faigie, who

added, “People should not be afraid to write, because we can always fix it.” In these moments, both songwriters position themselves as mentors and teachers, drawing on their experience of the songwriting process to guide others. These expressions not only demonstrate that PLwD are embodied knowers but also reflect their desire to contribute to shared learning and support others in their creative processes.

As another example, the songwriters often initiated opportunities to teach me new songs that I was unfamiliar with.

Faigie: There is a song. Let the smile be your umbrella. On a rainy, rainy day.

Taylor: I don't know that one. How does it go?

Faigie, Lily, and Robert: (singing) “Let the smile be your umbrella on a rainy, rainy day.”

Throughout the songwriting process, the songwriters also taught me Yiddish. In this particular example, the songwriters actively work together to not only correct my Yiddish pronunciation but also to correct my phrasing.

Faigie: Zaya Mench!

Taylor: Zaya Mench. A survivor, caring about our family, a plain man. How do you say that in Yiddish?

Milton: A poshete mon.

Faigie: A mensch!

Taylor: A poshete mon.

Faigie: (correcting my pronunciation) A poshete mensch.

Taylor: Aha.

Milton: A mon! (also correcting my pronunciation)

Taylor: A mon!

Milton: Yes.

Faigie: A Mensch or mon! A man, mensch. Mensch is a woman. Women are also mensch.

These examples are particularly significant in that PLwD are rarely included or viewed as having the capacity to be 'teachers' or mentors to others (Dupuis & Gillies, 2014). In an analysis of a forum designed by and for PLwD called *A Changing Melody*, where PLwD shared their learnings about living with dementia, Dupuis and Gillies (2014) demonstrated the growth and transformation possible for all involved (i.e., PLwD, family members, professionals) by learning with and from PLwD themselves. Specifically, attendees viewed PLwD "as being more believable because they were living the experience" (p. 121). Such findings illustrate that when PLwD are recognized not just for their individual identities but also for the different social roles/positions they can play in the world, and when they are supported in these roles (e.g., as teachers and mentors), they are also supported as embodied knowers, and their testimonies are heard. As such, disregarding the capacity for PLwD to share their knowledge and teach us constitutes a form of testimonial injustice, an act of failing to hear or value the lessons and insights they have to share. Additionally, disregarding the social positions of PLwD threatens their social and relational citizenship (Bartlett & O'Connor, 2010).

Thus far, I have argued that PLwD continue to assert themselves as embodied knowers. As demonstrated through the songwriters' testimonies, verbal and nonverbal creative expressions, desire and capacity for learning and growth, and social positions as teachers and mentors, embodied knowing is not limited to verbal or cognitive functioning. However, to be open to learning from PLwD, we must come from a place of "knowing otherwise" (i.e., being receptive to the diverse and embodied ways PLwD share their embodied knowledge and

therefore, selfhood) (Kontos & Miller, 2013; Olthius, 2000). By recognizing and supporting all forms of expression, we create conditions in which PLwD can meaningfully assert their knowledge and participate as contributors to shared social and creative life. Building on the argument that PLwD continue to assert themselves as embodied knowers, I now move to embodied selfhood more broadly, exploring how the songwriters enacted their embodied identities through caring relationships and other social positions.

Resistance of the "Welfare Recipient"

Bartlett and O'Connor (2010) argued that PLwD are often positioned as "welfare recipients" (p. 4), understood primarily as needing and being dependent on care. This framing carries significant consequences, including reducing PLwD to non-agentic, passive recipients of care and erasing the multiple, intersecting social identities through which PLwD identify with and embody (Bartlett, 2016; Bartlett & O'Connor, 2010). These dominant discourses of dementia exclude PLwD from being viewed as "active citizens" (Brannelly, 2016, p. 305) and leave little room to recognize and support the ways PLwD continue to contribute to social life and their communities. Within the citizenship and dementia literature, there is a call to move beyond positioning PLwD as care recipients or defining them primarily through cognitive impairment. Specifically, Lotherington and Obstfelder (2024) argued that PLwD must be recognized as a "diverse group of [people], and, drawing on Lister (2003), include their ability to *be* as well as *act* as citizens" (Lotherington & Obstfelder, 2024, p. 2687, italics in the original). This section examines how the songwriters actively resisted these deficit-based narratives, demonstrating their capacity to be and to act as citizens through the caring roles they embodied and through the ways they de-centred dementia by asserting their social positions.

PLwD as Relational Carers

Within the dementia literature, and society more broadly, care is often understood through a caregiver/care receiver binary, with PLwD almost exclusively positioned as the latter (Dupuis et al., 2012a). Like Foucault's (1978) critique of power as relational, discussed in Chapter 2, Bartlett and O'Connor (2010) challenged this binary by arguing that care is not something one solely gives or receives. Rather, care is relational and dynamic, flowing between people (albeit in different ways and not always equally). When PLwD are positioned solely as recipients of care, their contributions within relationships are dismissed, reinforcing stigma and positioning them as passive, non-contributing members of society (Brannelly, 2016). Advancements in dementia studies, and specifically in authentic partnerships, recognize that PLwD are partners in, not merely recipients of, care (Dupuis et al., 2012a). Similarly, relational citizenship and relational caring philosophy emphasize that care can be enacted in embodied ways and does not rely solely on cognitive or functional capacity (Dupuis et al., 2025a; Jonas-Simpson et al., 2022; Kontos et al., 2017).

It is also important to clarify what is meant by "care" within the context of this research. Jonas-Simpson et al. (2022) "intentionally use relational caring, the verb, rather than relational care as a noun, to reflect a mutual process of caring rather than the dominant unilinear one where persons living with dementia are treated as passive recipients of care" (p. 3). They also "recognize that relationships go beyond person-to-person relationships and exist within complex, dynamic, nested webs of connections among individuals and broader social, cultural, political, and environmental forces (e.g., stigma, policies) at multiple levels (e.g., family, organization, community, and culture), and that these forces play a critical role in supporting or denying the citizenship of people living with dementia" (p. 3). Similar to the way Spencer (2023) argues that,

for the testimonies of PLwD to be taken seriously, we must broaden what counts as testimony, I argue that we must see caring in a much broader and embodied sense than is often defined in the dementia literature. For example, caring goes far beyond the physical caregiving and involves intentionally attending to relational processes and the role we play in relationships (e.g., showing empathy and curiosity by being responsive and emotionally present, being open to mutual influence and discovery and to vulnerability as a strength) (Jonas-Simpson et al., 2022). In practice, this might include a warm embrace from a loved one, a look of endearment, reaching for someone's hand when they are upset, and sharing advice (i.e., all the relational subtleties that make individuals feel heard and seen in relationships). Understanding caring roles in broader and embodied ways opens space to recognize all the ways PLwD show relational caring towards others, as they did throughout the songwriting sessions.

Caring, in this project, was expressed and embodied through participants' attentiveness, responsiveness, and emotional presence with one another. In Chapter 5, for example, the songwriters used relational attuning to support one another in finding the words to describe what they were trying to say and to validate each other's concerns and difficulties with having dementia. In Chapter 5, I also described how the songwriters demonstrated relational capacities through engaging in relational knowledging by showing genuine curiosity. For example, Faigie asking me how my marriage was going (in fact, she still asks me this every time I see her). This curiosity also translated to concern for one another. For example, Lily wanting to know more about how my grandparents were mistreated.

Throughout the songwriting process, the songwriters also showed caring by expressing their gratitude for what we were creating together. This feeling of gratitude was mutual, and we

would often share this with one another. As an example, in Week 4, we ended the session by thanking each other.

> *Taylor: Firstly, I want to thank you all so much for being here.*
>
> *Faigie: We want to thank you.*
>
> *Taylor: Really, thank you. I have been learning…*
>
> *Lily: We want to thank you! You gave us a lot.*
>
> *Taylor: Oh, Likewise, likewise. You all give me a lot too, and I'm learning, like Helen said, we always learn from each other, yeah. So thank you all, and I'll see you next week.*

Some songwriters expressed their gratitude through tone of voice and body language (i.e., in embodied ways) as well as through language. In Week 1, for example, Lily expressed her gratitude through her tone of voice and body language.

> *Taylor: How are you feeling about this project? What are some feelings that are coming up?*
>
> *Lily: Oh I'm feeling glad! (said enthusiastically)*
>
> *Taylor: You're feeling glad! Wonderful.*
>
> *Lily: It's a help! To do, with you (reaches towards me). With me actually. To see, well, you can do the garden of and you can do something else of because you have that to do.*
>
> *Taylor: Yeah. Thank you!*
>
> *Lily: And it's very, very good.*

In this example, Lily expressed gratitude and, in reaching for me, communicated connection, appreciation, and relational presence in both verbal and embodied ways.

The songwriters also demonstrated their capacity for relational caring by acknowledging the group's musical strengths.

> *Taylor: …now that we've sung the song that we've wrote a few times, how are we feeling about it?*

Robert: Terrific.

Faigie: Good.

Taylor: What feels good about it? What feels good about the song?

Lily: Well I liked it.

Faigie: And that we're singing it together, it's already good.

Lily: Yes.

Taylor: It's already good that we're singing it together.

Lily: Yes, yes.

Faigie: Because not everybody is a singer. And together we sound very good.

What I like about this example is that it emphasizes the importance of belonging regardless of musical ability. By framing the song's value as emerging from singing together rather than from individual vocal ability, the songwriters created an inclusive musical space that supported participants who might not have identified as singers (for example, Helen often shared that she had no musical background and felt nervous about singing). A similar sentiment was shared by Avi in the film when, after singing the song, he said, “We’re like a unit.” Such moments enact relational caring and citizenship through a commitment to and awareness of caring for one another and the sense of belonging that is nurtured through that relational process.

Another example of the songwriters as relational carers was described in Chapter 5 when the songwriters attuned to Helen’s concern about not being able to remember as she used to. In this moment, the songwriter’s united with Helen, bonded by a shared experience, and offered support. I also argue that the ways the songwriters welcomed me into the songwriting space constituted acts of caring, grounded in relational attuning. For example, I remember feeling

nervous about how the filming would unfold. Walking into the room that day and seeing the lights and equipment set up, I was unsure of how everything would play out. However, as soon as the songwriters entered the space, I immediately felt at ease. One moment that stands out occurred when Helen looked at me just before we began recording and winked. She then sat up straight in her chair and began singing with the rest of the group. This gesture was particularly meaningful given that Helen had described herself as shy. In this moment, I understood her wink as an embodied act of relational attuning, as she appeared to sense and respond to my uncertainty, offering reassurance and signalling a shared readiness to begin. The ways the songwriters expressed relational caring also extended beyond the boundaries of the songwriting sessions themselves. A few months after the release party, I was informed that one of the songwriters had become seriously ill and was receiving palliative care. After going to say goodbye, I joined several of the songwriters who were eating dinner. Attempting to conceal my tears, I sat beside Lily, who immediately sensed that something was wrong. Without hesitation, she reached for my face, gently holding my cheeks in her hands. Looking at me, she tilted her head and said, "Do not worry. It is all going to be okay." While Lily did not know the specific reason for my distress, she recognized it and responded with care. In that moment, her actions (both embodied and verbal) demonstrated relational attuning to my emotional state and a readiness to offer comfort.

These examples challenge unidirectional conceptualizations of care and dominant assumptions about PLwD and illustrate how the songwriters asserted themselves as relational carers through their attentiveness, curiosity, encouragement, and gratitude towards me and one another. Additionally, these examples reveal the very intentional ways the songwriters took up caring roles within the group. When caring is understood as a relational process encompassing a

broad range of relational literacies (rather than solely functional roles), the relational and embodied caring capacities of PLwD become evident, disrupting dominant narratives that frame them solely as passive recipients of care. Bellass et al. (2019) argued that the "person-centred paradigm, while enacting a welcome shift in emphasis from the biomedical features of dementia to the person living with the condition, has arguably concretized an individual, rather than a relational focus" (p. 2802). To support PLwD as relational carers, a relational focus is needed, one that recognizes the capacities PLwD have for embodied knowledge, selfhood, and specifically relational knowledging, relational attuning and relational decision-making.

Decentring Dementia: The Songwriters Chosen and Embodied Identities

In addition to the songwriters showing their capacity for caring through their relational caring roles, they also asserted their embodied selfhood through their social identities, further resisting dominant narratives that position PLwD solely by their dementia and the decline associated with it. Drawing on embodied selfhood, and specifically, Bourdieu's (1977, 1990) concept of habitus, embodiment and the social world are intertwined, shaping how we come to act, relate, and make meaning in the world. As Kontos (2014) explained, habitus reflects a form of bodily know-how informed by sociocultural contexts (i.e., ways of being that come to be through lived experience). From this perspective, social roles such as caregiver, teacher, mentor, parent, or friend are shaped over a lifetime of relational experiences and become embodied dispositions. Additionally, these embodied roles and identities do not diminish with cognitive decline but continue to inform how PLwD engage with others and the world around them (Bartlett & O'Connor, 2010; Kontos, 2014). As an example, my husband's grandmother was diagnosed with dementia and lost the ability to speak before we met. Though we never had verbal discussions, like Lily, she would often hold my face in her hands and smile. The night

before she died, my husband and I sat on either side of her hospital bed, each holding one of her hands. As we stood to leave, she gently took our hands and brought them together over her heart. In this moment, she was not just a person with dementia or a dying 'patient', but a grandmother, actively asserting her role as the matriarch of the family, offering recognition, approval, and care in the way she always had. I share this story to underscore the importance of social roles in the embodied expression of caring and identity, and to demonstrate how these ways of being often remain at the forefront of self-conceptualization even when dominant discourse defines people otherwise.

As discussed in Chapter 5, the songwriters identified with a range of social roles and life histories that extended well beyond a dementia diagnosis. In the following examples, I share how these social roles and identities were not merely named but expressed in embodied ways. For example, Faigie frequently drew on her valued identity and social role as a kindergarten teacher, often speaking and interacting in ways that reflected her longstanding role as an educator.

> *Taylor: So let's sing a few songs to end today. And then I have a few more questions and that's it. Let's sing one more. What should we sing?*
>
> *Faigie: (sings) If you're happy and you know it, clap your hands (group joins in and finishes singing with Faigie). You know, in school. I was a schoolteacher. That was the first song.*
>
> *Taylor: How about we sing about being together?*
>
> *Faigie: (starts singing) Oh, here we are together (group joins in) together, together. Oh, here we are together, sitting on a chair (group laughs).*

In guiding the group in songs that she would with her kindergarten students, Faigie's discussion about being a teacher became an embodied way to assert her social position as a teacher. Throughout the songwriting process, Faigie embodied her position and identity as a teacher so strongly that other songwriters would refer to her as a teacher, essentially validating an important

aspect of Faigie's selfhood and life. For example, during a conversation in Week 1 about the importance of learning, Robert said this:

Faigie: Very important. That's very important. To learn, it doesn't matter.

Robert: She knows. She's a teacher.

Embodied social roles and positions were also expressed in ways which directly intersected with the songwriters' enactment of relational caring. For example, in the film, Bill is observed holding his wife's hand and smiling at her. In this example, Bill is not only expressing caring but also embodying his social role as a loving husband. I observed a similar situation one day after the group songwriting session when Avi's wife got up to get something from her purse. As soon as she got up from her chair, Avi did the same and followed her. As his wife was looking through her purse, Avi said, "Don't worry, I'm right here."

While these examples show how valued social positions were embodied and expressed in moment-to-moment interactions, the song lyrics themselves offer an additional, collective expression of social identity. In the first few weeks of the songwriting process, I asked the songwriters to describe themselves, to which they responded: caring, thoughtful, teacher, learner, listener, kind, mentor, survivor, shy, connected to family, and friend. I also asked what was important to them, and they emphasized listening to others, pursuing what you want, friends and family, friends who become family, believing in the good in people, and giving people a chance. These identities and values became the focal point of the second verse, which states, "We are teachers, mentors, survivors and friends. We are listeners and learners, and that never ends."

The importance of embodying and recognizing the multiplicity of identities and social roles and positions people take on in their lives was explicitly articulated by Faigie.

Faigie: Because other people, you can be two things. You can be a teacher and a survivor. You can be a teacher and a mentor.

Taylor: Exactly.

Faigie: You don't have to be only one thing.

Taylor: Exactly! We can do many things.

In contrast to dominant narratives that position PLwD through a single, deficit-based framework (Dupuis & Kontos, 2026; O'Connor et al., 2022), these expressions assert a plurality of roles, experiences, and ways of being that continue despite dementia. These findings further support Bartlett and O'Connor's (2010) argument that supporting social citizenship involves moving from identity to social positions. Specifically, they argued that dominant conceptualizations of identity in dementia fail to account for how identity can shift over time. In response, Bartlett and O'Connor (2010) proposed that social citizenship involves a shift from an "implicit focus on maintenance of status" toward the "growth, development and proliferation of statuses" (p. 22).

As we have seen in this chapter, the songwriters not only embodied a wide range of social statuses but also developed new ones. I argue that writing and sharing this song constituted an enactment of citizenship, as the songwriters positioned themselves as social activists, artists, creatives, and storytellers. Drawing on Isin (2008), White (2008) reconceptualized citizenship "not as a status that is bestowed, but as moments in which individuals and groups claim and assert their place through relational ways of being with others" (p. 44). What the songwriters and I engaged in constitutes one such enactment in practice. It also aligns with what Dupuis and Kontos (2026) describe as leisure/arts activism: "discursive spaces where the things we do in our leisure (e.g., creating art or music, dancing, or theatre experiences) are used intentionally to

challenge and expose the stigma associated with dementia, open up spaces for dialogue, and promote social justice for PLwD and social change in dementia care" (p. 260). In this way, leisure/arts activism provides a space for enacting these moments of citizenship, as the songwriters, through the identification and embodiment of their social positions and the collective sharing of their stories and creative expressions, actively participate in shaping social discourse.

Lastly, it is important to note that none of the identities or social roles/positions discussed or embodied in the songwriting process or reflected in the lyrics referenced dementia, and for the songwriters, it did not appear to form part of their self-conceptualization. While it could be argued that the songwriters may not have known or remembered that they had dementia, I argue that this is less significant than the ways they actively embodied their social roles and articulated what mattered to them about their identities and life experiences. Additionally, privileging diagnosis over these enactments of selfhood dismisses the songwriters' accounts of the social positions they identify with, perpetuating testimonial injustice and limiting recognition of PLwD as knowers and as citizens (Spencer, 2023). Thus far, this chapter has explored how the songwriters enacted relational citizenship through their participation in the songwriting process and in the song/film. By sharing their testimonies, demonstrating their capacity for learning, growth, and teaching, and asserting their embodied social identities, the songwriters positioned themselves as relational citizens. I now turn to the ways the song/film challenged broader perceptions and discourses surrounding dementia.

The Transformative Potential of Liberatory-Relational Songwriting

The final aim of this research was to explore the possibilities of a collaborative, liberatory songwriting project in challenging the stigma associated with dementia. To prompt change,

creative outputs need to elicit emotion and resonate with those engaging with them (Lotherington & Obstfelder, 2024; Mitchell et al., 2011). As argued throughout this dissertation, the arts, with their ability to convey and elicit emotion, offer a powerful means of disrupting taken-for-granted discourses, making visible alternative narratives and opening possibilities for social transformation (Foster, 2016; Greene, 2000; Hocoy, 2005). Songs, especially those shared in public spaces, have been particularly useful in shaping and transforming public discourse. As discussed in Chapter 4, music performances in community settings can foster relational connections between performers and audience members while also disrupting stigma and creating alternative ways of understanding marginalized experiences (Baker, 2015; O'Grady, 2009; Mitchell, 2021).

In the dementia context, arts-based initiatives, including research-based drama and film, have shown promise in reshaping stigmatizing attitudes towards PLwD (Dupuis et al., 2025a; Kontos et al., 2024; Mitchell et al., 2011). For example, Mitchell et al. (2011) found, in their performance of a research-based play depicting the dementia experience called *I'm Still Here,* that audience members gained new insights and understandings related to dementia and were even inspired to "take action" (p. 388). Similarly, a screening of a research-based drama called *Cracked: a new light on dementia* proved successful in shifting harmful narratives of dementia toward a "a more life-affirming perspective" (Kontos et al., 2020, p. 98). These transformative outcomes convey what Dupuis and Kontos (2026; see also Dupuis et al., 2025a) described as wide-awakeness (i.e., the power of aesthetic experiences in making us think or see the world around us differently) (Schutz, 1967). The results from audience surveys collected at the release of *Wisdom and Respect* similarly suggested moments of wide-awakeness among audience members, prompting them to reconsider taken-for-granted assumptions surrounding dementia

and the lives of PLwD. This section will explore how audience members reflected on shifting perceptions of dementia, particularly through recognizing the songwriters' capacities for creativity, expression, connection, and growth.

Recognizing the Relational and Embodied Capacities of PLwD

Though academic and public discourse surrounding dementia often portrays PLwD as unable to foster meaningful connections (Mitchell et al., 2013), audience responses revealed an awareness of and openness to the relational and embodied capacities of the songwriters. Specifically, audience members commented on the depth of connection within the group and the level of engagement demonstrated.

> *It was amazing to see the level of engagement and connection the songwriters had with the material and each other.*
>
> *There is a sense of great joy for everyone to be together in creative spirit and musical joy. There is a message behind the collaboration which is both beautiful and powerful.*
>
> *Community is so important. Something as seemingly simple as writing a song together made the participants' so joyous and fulfilled. One mentioned that they felt like a unit and I found that beautiful.*

These responses indicate an attunement to the relational processes between the songwriters and, particularly their capacities to connect with one another, experience belonging, and engage meaningfully in collaborative creative expression.

Audience members also commented on the embodied capacities of the songwriters. For example, one participant shared, "The level of engagement of the participants was remarkable. Even Bill, who was nonverbal, used his body to express his joy and engagement," highlighting the importance of attending to embodied forms of expression. Similarly, another audience member reflected that the experience served as "a reminder to see people as having richer inner

lives and abilities than we might otherwise think when seeing an older person or hearing their diagnosis," pointing to the recognition of relational capacities that may not be immediately visible. What is particularly significant about these responses is the extent to which audience members implicitly engaged with the concept of embodied selfhood. While not explicitly stated, their reflections on how Bill expressed himself through his body, and their recognition of the rich inner lives of PLwD, point to a shift away from understandings of selfhood rooted in the preservation of cognition. Instead, these responses suggest recognition that selfhood is embodied, relational, and expressed through multiple forms of communication.

Shifting Deficit-Based Perspectives

Responses also suggest that the song and film contributed to shifting deficit-based assumptions surrounding the dementia experience. Several audience members reflected on the expectations they brought to the event, revealing the persistence of deficit-oriented understandings of dementia prior to engaging with the project. For example, one audience member described coming with low expectations and being surprised by the experience.

> *I came not expecting much, emotionally or from the song. Instead, it was tremendous. I am extremely glad my father participated and that I got to see it.*

Notably, even when low expectations were not explicitly named, surprise emerged in how the songwriters resisted tragedy-based narratives of dementia. Specifically, audience members stated feeling surprised by the joy and sense of meaning expressed by the songwriters:

> *The joy of the participants and the degree to which they found meaning in the process. I was delighted to experience their joy in what they created.*

> *The sheer amount of joy. Even the participants who were less able to sing along to their song looked so happy. They were smiling and cheering for one another, and I could just tell how lovely this process was for them.*

These reflections suggest that expressions of joy and fulfillment were unexpected. What is exciting about this finding is that, rather than experiencing dementia solely as a tragic experience, audience members witnessed joy, pride, and meaning making.

Perceptions of dementia were further disrupted by audience members' surprise at the songwriter's capacity to learn and grow. Specifically, when asked what stood out to them about the film, audience members shared a sense of resonance and surprise that the songwriters were able to retain new material, grow, and develop new skills.

> *Surprised to see that the people with dementia retained the song and could learn new lyrics and melody.*
>
> *People with dementia are capable of wisdom, growth and artistry.*

As stated earlier in this chapter, despite continuing to assert their desires for meaning-making experiences, PLwD are often portrayed as unable or uninterested in learning, growth, or creative development (Ingebrand, et al., 2022; Bartlett & O'Connor, 2010; Sabat & Warren, 2023). However, when audience members were given the opportunity to witness the songwriters learning and performing an original song, they appeared more open to recognizing the ongoing capacities of PLwD for growth, creativity, and participation. These responses suggest that the song/film disrupted assumptions that a dementia diagnosis precludes learning and development, positioning the songwriters as individuals capable of continuing to evolve, contribute, and engage meaningfully in new experiences.

The Value of Music Beyond the Biomedical Model

Another important finding from audience responses was the ways in which they recognized the value of music within this project and in broader understandings of dementia. Despite music being commonly framed in dementia care as a tool for managing symptoms or

supporting cognitive functioning (Beard, 2011; Young, in press), audience members did not appear to adopt this perspective. For example, one audience member reflected that "We are conditioned to only see the disability and not the strengths. This was an eye-opener to realize the level of engagement that can be achieved through music." In this example, rather than commenting on music as a tool for symptom management or memory recall, the audience member recognized music as a medium through which the songwriters' strengths and relational capacities became visible.

After viewing the song/film, another audience member was opened to the possibilities of dementia.

> *Dementia is something is inherently sad, however, acts of musical collaboration bring happiness, which transports us all to a new place where dementia is all of a sudden manageable and full of positive possibilities.*

Seeing dementia as full of "positive possibilities" reflects the transformative potential of using music with PLwD beyond the biomedical model. In fact, engaging in collaborative music processes that support the relational citizenship of PLwD may reshape broader understandings of dementia by making visible the capacities, identities, relationships, and contributions of those living with dementia. Rather than positioning music as valuable solely because it manages symptoms or temporarily alleviates decline, these audience responses suggest that collaborative music-making can shift how dementia itself is imagined and understood. Similarly, an audience member emphasized the use of music to support the strengths of PLwD, noting the power of songwriting to "celebrate the wisdom" of PLwD.

> *I've always known that music is for all ages - but I think the messaging in the song celebrates the wisdom of older adults, and especially those that live with dementia.*

Even when audience members reflected on music and the brain, they emphasized that collaborative music-making is an inherently human process we can all engage in, despite illness or cognitive decline.

> *I see dementia entirely differently. I now understand that the brain longs for creative input and output, regardless of its health stage. There is something so human about making music together, that it almost doesn't matter what the body is dealing with - it still wants music.*

This quote not only highlights the transformative potential of songwriting in challenging stigma but also reflects the essence of the musical child (Nordoff & Robbins, 1977). By understanding musical engagement as an innate human need, this audience member recognized that music and the desire to engage with it for its creative potential exist within all of us, throughout our lives.

Together, these reflections suggest that when music is used in relational and collaborative ways with PLwD, it can reconfigure how the value of music itself is understood. In a context that often prioritizes fixing, compensating for loss, or producing measurable outcomes (Beard, 2011; Elliot & Gardner, 2018), these responses suggest a shift toward understanding music as a relational practice that supports connection, expression, creativity, and relational capacities. Importantly, these possibilities do not arise solely from engaging in music. Rather, they emerge through the intentional use of music within liberatory, collaborative and relational processes that support the citizenship, participation, and strengths of PLwD. The ways in which relational processes supported these transformations will be discussed later in this chapter.

Recognition of Testimony

Through participating in the songwriting process, the songwriters asserted themselves as embodied knowers capable of sharing their testimonies. What is especially significant about *Wisdom and Respect* is that the songwriters were supported not only in expressing their

testimonies but in sharing them publicly with a broader audience. By communicating their experiences, values, and perspectives through song and film, the songwriters asserted themselves as embodied knowers, challenging dominant discourses that frame the testimonies of PLwD as unreliable or lacking credibility (Spencer, 2023). Importantly, the public sharing of these testimonies also afforded audience members opportunities to witness, receive, and respond to them in ways that validated the songwriters' wants, needs, and humanity. For example, audience members emphasized the importance of being valued, respected, and recognized as more than a diagnosis, identifying the songwriters as individuals with meaningful messages to share and wisdom to offer.

> *People affected by dementia and Alzheimer's want to be valued and respected and seen as more than their diagnosis.*
>
> *The songwriters had a message they wanted to share about themselves to try to correct the ways that others often misunderstand them and to invite other listeners to consider the wisdom they've accumulated.*
>
> *It was a clear statement that revealed the personhood, agency, values and insight of the songwriters. Resonated strongly and would make it impossible to deny the capabilities and sincerity of the people who wrote and sang the song.*
>
> *This group has wisdom and feelings to share and with patience, respect and extra time, their words are valuable to themselves and others.*

Rather than dismissing or overlooking these testimonies as "meaningless" (Spencer, 2023, p. 68), audience members appeared willing to listen to, receive, and learn from the songwriters' testimonies. For example, audience members recognized the intentionality of the songwriters' messaging, drawing directly on the lyrics in their own reflections. Messages such as "we have wisdom that we would like to share," "we want to be treated with love and care, we want you to listen to these words we share," and "treat people with love and respect" resurfaced throughout audience responses, suggesting that the songwriters' testimonies resonated with

listeners and were meaningfully taken up by them. In these resonances, audience members saw the songwriters' capacities, specifically the wisdom and insights they had accumulated over their lives.

Taking Action

Audience members reflected not only on what the song and film changed for them in terms of understanding, but also on how they might change their own actions to better support PLwD. Many expressed intentions to treat PLwD differently, including paying closer attention to their voices and engaging more deliberately in relational engagement.

> *It reminds me to truly listen to their stories.*
>
> *I will endeavour not to make assumptions.*
>
> *A reminder to be more receptive, more patient and more inclined to see their abilities even if not immediately apparent.*
>
> *It reminds me to wait a bit longer for people to respond.*
>
> *I will pay more attention to what they are feeling and especially what they are trying to convey.*

These reflections suggest that audience members were not only inspired to think differently about dementia but also moved to reconsider the ways they actively engage with PLwD in their own lives. Notably, the changes audience members described were not centred on "managing" or "treating" dementia differently, but on engaging more relationally with PLwD. By listening more attentively, exercising patience, paying closer attention to feelings and expressions, and suspending assumptions, the song/film appeared to support audience members in considering how they might become more relationally attuned to the communicative and relational expressions of PLwD and be better relational citizens themselves.

The findings from the pilot study outlined in this section demonstrate the transformative potential of *Wisdom and Respect* in disrupting dominant narratives surrounding dementia and opening alternative ways of understanding the lives and capacities of PLwD. Through witnessing the product of the songwriters' liberatory-relational songwriting process, audience members were awakened to seeing dementia and people living with it differently (Dupuis et al., 2025a; Dupuis & Kontos, 2026; Schutz, 1967). Specifically, audience members recognized the songwriters' relational and embodied expressive capacities, demonstrated shifts in deficit-based understandings of dementia, reconsidered music as a creative and expressive resource rather than a "magic pill" used to treat symptoms of dementia (Young, in press, p. 6), understood the songwriters' testimonies as meaningful and credible, and articulated intentions to engage in more relational and attentive ways with PLwD in their own lives.

Relational Deepenings: From Inclusion to Belonging and Relational Solidarity

In supporting the relational citizenship of PLwD throughout this process, I have come to reflect on what is required to enact relational citizenship and the meanings of citizenship in and of itself. Dominant conceptualizations of citizenship often prioritize autonomy, independence, and cognitive capacity (Bartlett & O'Connor, 2010). When citizenship status depends on cognitive capacity, as PLwD experience cognitive decline, they are seen as not contributing members of our society (Latimer, 2012). This erasure of status contributes to what Gilleard and Higgs (2010) called a black hole of aging, where a dementia diagnosis insinuates a steady pace of physical and social decline, and represents what Lotherington and Obstfelder (2024) called a "point of no return" (p. 2685).

The literature on citizenship in dementia studies has begun to bring dementia out of this "black hole" by supporting PLwD in asserting their full capacities (Kontos & Grigorovich, 2018) and being included in decision-making about their lives (Bartlett & O'Connor, 2010; Brannelly, 2016; Dupuis et al., 2012a). As discussed earlier in this chapter, feminist understandings of citizenship have also advanced citizenship literature more broadly by conceptualizing citizenship not as a fixed status, but as something enacted through social, relational, and political processes (Lister, 2003; Nussbaum, 2011; Young, 2000). While these framings have been important in shifting citizenship away from status-based understandings, they still largely rely on normative assumptions regarding cognition and rationality and do not fully account for individuals who do not meet dominant conceptions of cognitive competence (Ursin & Lotherington, 2018). To address this limitation, Lotherington and Obstfelder (2024) introduced a posthumanist approach to citizenship in the dementia context. Within this framework, citizenship is understood not as a status possessed by an individual, but as something enacted through entanglements between human and non-human actors. In other words, citizenship emerges through relational processes between bodies, environments, objects, sounds, relationships, laws, etc. Additionally, the process of citizenship can be supported or hindered by the ways these entanglements interact with one another. Although I am not ready to move completely to non-representational understandings of citizenship, thinking about citizenship as emergent in relational processes brought new possibilities for citizenship that excited me, and resonated with some of what happened in the liberatory-relational songwriting process. I turn to this discussion next.

Posthumanist Conceptualizations of Citizenship

Wisdom and Respect and the collaborative songwriting process itself can be understood as the enactment of relational citizenship. Citizenship became possible, not as a result of what

the songwriters could or could not do, but because of all the relations that came together throughout the songwriting process, including: the songwriters themselves and what they each and together brought to the process; dementia and the ways it showed up (or not) at different points in our process; me as the facilitator and what I brought to the process; the other people (i.e., staff, family members) involved and what they brought to the process; the relational literacies we engaged with; all the aspects of the creative, musical space such as the instruments, sound, rhythm, and tempo; the space itself, and so forth. Together, these entanglements created the conditions and processes through which PLwD became friends, songwriters and artists, and social activists. Importantly, citizenship from this perspective is not something achieved at the end of the process, but something enacted within the process itself (Lotherington & Obstfelder, 2024).

Drawing from feminist literature on citizenship, Lotherington and Obstfelder (2024) further argued that enacting citizenship requires belonging, recognition, and agency. Belonging refers to "who belongs to, and are included, in a certain community" (Lotherington & Obstfelder, 2024, p. 2698). In the liberatory relational songwriting space, PLwD were not only included but also came to experience a sense of belonging to one another and to the wider world they felt responsible for contributing to. Belonging can also be understood through a social citizenship framework, and specifically through the movement from inclusion to participation described by Bartlett and O'Connor (2010). The term inclusion has been critiqued in the citizenship and dementia literature for focusing too narrowly on presence rather than active engagement (Bartlett, 2016; Bartlett & O'Connor, 2010). For example, PLwD are often included in activities in the spaces and places where they live, such as games, activities, and therapy in the home. However, while PLwD may be included in these activities, they are not always positioned as

active contributors. A resident living in LTC, for instance, may be present at a sing-along without being meaningfully engaged as a participant, decision-maker, or contributor. Additionally, someone can be included in an activity and still not feel a sense of belonging. Bartlett and O'Connor (2010) argued that PLwD are often not recognized as contributors to their communities, such as members of theatre groups, participants on boards and committees, learners in continuing education, or voters in elections (p. 44). Moving from inclusion to participation, and toward belonging, requires more than the physical inclusion of PLwD; it requires supporting PLwD to participate, act, and enact citizenship within their communities. Specifically, the songwriting process supported the songwriters as active participants through relational decision-making, relational attuning, creative expression, relationship-building, and meaningful opportunities to shape both the process and the final song.

It is also important to disrupt the association between presence and passivity. While Bartlett and O'Connor's (2010) critique is useful in advocating for the participation of PLwD in our communities, their framing of inclusion does not fully account for PLwD in later phases of the dementia journey who may participate in civic and social life through presence and embodied expression. Throughout the songwriting sessions, I often witnessed the songwriters participating meaningfully through gestures, facial expressions, vocalizations, stillness, attention, and shared presence. In this way, presence should not always be understood as passive. Rather, when supported relationally, presence itself can become a meaningful form of participation and belonging, supporting precisely what Kontos et al. (2017) described through the concept of embodied selfhood and its importance in recognizing and supporting the full relational citizenship of PLwD.

In addition to belonging, Lotherington and Obstfelder (2024) argued recognition is also essential in enacting citizenship. The representation of PLwD in society as passive, dependent, burdensome, and lacking capacity (Bartlett & O'Connor, 2010) ultimately undermines the recognition of PLwD as individuals capable of being active contributors to society. Both internal and external recognition were apparent in this process. Throughout the songwriting process, and specifically through relational attuning, the songwriters recognized and validated one another's experiences, identities, social positions, contributions, and diverse ways of participating within the group. Additionally, the act of songwriting itself represented a form of internal recognition. Through participating in the creative process, the songwriters recognized new and emerging aspects of themselves as creative, expressive, capable, and agentic; the process opened new possibilities for seeing and understanding themselves, and they came to recognize the difference they could make in the world. The public release of the song/film also served as a space for external recognition, positioning the songwriters as artists, storytellers, and contributors within the broader community. Through sharing their testimonies, creativity, humour, emotions, and perspectives publicly, the songwriters were recognized not through deficit-based assumptions about dementia, but through their capacities to create, communicate, connect, contribute, and for the wisdom they still hold. Therefore, it is only through recognizing PLwD as capable of participating in and contributing to social, cultural, and civic life that they can be fully supported in belonging to their communities and provided with opportunities to enact citizenship within them.

Lastly, Lotherington and Obstfelder (2024) stated that the enactment of citizenship requires agency. What I take agency to mean in a posthumanist context is not only the capacity of people to influence and transform social systems and structures, but also the ways non-human

entities can reflect and be forms of agency that inspire, shape, and promote change in the world. Lotherington and Obstfelder (2024) defined agency on three levels: individual, local, and societal. Individual agency, as it relates to the enactment of citizenship, can be understood through the ways PLwD affect, shape, and make a difference in their world. For example, participating in the songwriting process is one way the songwriters asserted their agency, through how they supported each other, through the collective decisions they made, through their resistance to dominant ways older adults are understood and treated, and so forth. The song/film itself is also the enactment of agency, a declaration of what the songwriters expect of others in the world to make a better world for all of us. Agency also relates to the ways the final song/film resonated, touched, and impacted others. At the local level, agency refers to how songwriters and what they created impacted audience members (i.e., family, friends, staff, volunteers, etc.) who engaged with it at the release party, and how it continues to impact members of the larger community as it is shared more broadly. For example, I presented *Wisdom and Respect* in a keynote presentation at a conference attended by care partners, healthcare leaders, and older adults in the community. Audience members described how the song/film inspired them to write songs with PLwD in their own workplaces and to ask more meaningful questions in their interactions with PLwD. As the song/film continues to be shown publicly, it can open up spaces for wider reflection, dialogue, and debate about dominant discourses of dementia and their implications (Dupuis et al., 2021a, 2025; Jonas-Simpson et al., 2020; Kontos et al., 2020).

At the societal level, the song/film becomes an agential entity within public discourse, with the possibilities to contribute to the culture change movement and transform the ways we think about and act in the dementia context (Lotherington & Obstfelder, 2024) In this way, *Wisdom and Respect* is a form of collective testimony, living on beyond the songwriting process

itself through continued circulation and audience engagement. It is my hope that by continuing to share this testimonial legacy of the songwriters, the project will challenge stigma associated with dementia and support broader, more relational, inclusive, and justice-oriented understandings of dementia (Gray et al., 2020).

In addition to belonging, recognition, and agency, enacting citizenship also requires solidarity. Jennings (2018) defined solidarity as "standing up beside another, thereby signaling publicly one's recognition of that person's (or group's) moral standing" (p. 557). Additionally, Jennings (2018) identified three positions one can take in asserting solidarity: standing up for, standing up with, and standing up as. Standing up for involves "assisting, defending, and pleading the cause of the other" (Jennings, 2018, p. 558). In this research, standing up for included the ways I came up with a research topic aimed at challenging stigma associated with dementia, the home recognizing this project as important and setting up the conditions for the project to take place, the ways the songwriters and I relationally attuned to one another (validating and supporting each other's experiences), and the coming together to write this song in the first place.

Standing up for to standing up with "requires deeper engagement with the experience and lifeworld of the other," and those who do this "may find their own initial prejudgments concerning others transformed by the encounter" (Jennings, 2018, p. 558). In this project, standing up with occurred in several respects. First, by participating in the songwriting process, my prejudgments of PLwD were challenged, as I was unsure whether the songwriters would be able to write and learn a new song. Though I thought of myself as someone who stood up for PLwD, standing up with PLwD required me to recognize and believe in their creative capacities. Staff and family members also moved from standing up for to standing up with. For example,

Bill's spouse, Marilyn, stated that while she was initially hesitant for Bill to join the songwriting project because she worried he would "hold the group back," she was ultimately surprised by how the process supported his participation and relational capacities. Audience members were also transformed by engaging with the song/film. For example, reflections from the pilot study indicated that audience members were surprised by the joy, wisdom, capacity for learning, and relational expression shown by the songwriters. Audience members began to imagine how they might relate to PLwD differently, which I also understand as one way of "standing up with."

Lastly, standing up as "involves finding a kind of covering connection that does not negate diversity among individuals at all, but rather establishes the grounds of its respect, protection, and perpetuation" (Jennings, 2018, p. 558). Moving from standing up with to standing up as requires not only recognizing and supporting the citizenship of PLwD, but also rethinking citizenship itself as fundamentally emergent, relational, embodied, and collectively enacted, through relational processes, and as a way of becoming. More broadly, I believe we need to better conceptualize citizenship in the ways I am suggesting, not only for PLwD, but for all of us. We are all relational citizens. We all exist through relationships, interdependence, embodiment, and relational processes, making citizenship something collectively enacted rather than individually possessed. However, it is through our engagement with all kinds of relationships, including those with humans, environments, objects, other living beings, creative practices, systems, and laws, that people can be better supported in enacting citizenship within their everyday lives.

Some examples of this are already emerging. Phinney et al. (2016) described the experiences of people living with young-onset dementia who participated in Paul's Club. Unlike typical day programs, Paul's Club resists strict scheduling of activities. Instead, members of the

club start their day engaging with one another over coffee and treats, reading the news, and participating in a group leisure activity (i.e. yoga, dance, etc.). They then eat lunch at a local restaurant and go for a walk around the neighbourhood (Phinney et al., 2016). What is particularly meaningful about these neighbourhood walks is the way PLwD are supported in interacting with everyday neighbourhood sights, sounds, people, and animals. For example, Phinney et al. (2016) described one relational encounter as the following:

> R. lit up when we walked by the dog park today - there was a lot of action on this beautiful fall day. ‘‘Look at them all’’ she said, highly animated. She spent the next 15 minutes or so handing out dog cookies, patting the odd dog, clearly loving it. Later, on the way back, walking along a city street she said ‘‘They. . . you know. . .’’ She paused. ‘‘. . . respond to me.’’ I guessed that she was talking about dogs, so I replied ‘‘Because they’re smart, they know. . .’’. She responded without hesitation. ‘‘They are, more than people.’’ (p. 388)

In Paul’s Club, PLwD interacted with people, animals, neighbourhood spaces, food, movement, and conversation. They enacted their citizenship through their care of each other and others in their community, including the animals they engaged with. What I find particularly meaningful about this example is the everyday nature of this enactment. Rather than citizenship being understood through large-scale political acts or formal participation, this example demonstrates how citizenship can be enacted through ordinary moments of connection and engagement with the world around us. It is my hope that, inspired by the liberatory-relational songwriting process used in this project, additional examples of how PLwD enact citizenship and the relational processes that support that enactment emerge and are better supported.

In this way, relational deepenings refers to the ways relationships were strengthened, expanded, and transformed throughout this process through experiences of belonging, recognition, agency, and solidarity. In this section, I have argued that the enactment of relational citizenship was made possible not solely through individual capacity, but through relational processes involving people, environments, creative practices, objects, systems, and communities. Through the songwriting process and the public sharing of the *Wisdom and Respect*, the songwriters deepened relationships with themselves, one another, family members, staff, audience members, and the wider world around them. Notably, these deepenings extended beyond the songwriting process and public sharing to include broader possibilities for participation, contribution, advocacy, connection, and social change. Therefore, relational deepenings refer not only to the strengthening of relationships but also to the creation of relational conditions through which citizenship can be enacted and more justice-oriented understandings of dementia can emerge.

Theoretical, Methodological and Practical Implications

This dissertation set out to explore how a collaborative, relational songwriting project might support the ongoing relational capacities of PLwD, amplify their voices, and create opportunities for the enactment of relational citizenship. By documenting the songwriting process and examining both the collaborative work and its public sharing, this research demonstrates how relational, embodied, and creative practices can challenge stigma associated with dementia and offer alternative ways of understanding the capacities of PLwD and supporting their relational citizenship. This section describes the theoretical, methodological, and practical implications of this research, considering how its relational and collaborative ethos might inform more just, participatory, liberatory, and relational arts-based approaches that not

only recognize but actively support the recognition, belonging, continued agency, and solidarity necessary for the enactment of relational citizenship.

Theoretical Implications

This research expands the literature on relational caring philosophy and relational citizenship by articulating additional ways these frameworks can be enacted in practice. While relational citizenship and relational caring have been influential in challenging deficit-based understandings of dementia (Dupuis et al., 2025a; Kontos et al., 2020), less attention has been given to the specific relational literacies that support their application in everyday care and creative contexts. The Liberatory-Relational Songwriting Framework described in Chapter 5 extends these theoretical frameworks by offering a practice-oriented framework grounded in relational processes. Central to this contribution is the articulation of relational processes, including relational knowledging, relational attuning, and relational decision-making, which supported the songwriters' participation and the enactment of their relational citizenship throughout the project. These processes were evident not only in the songwriting sessions themselves but also recognized by audience members through their engagement with the song and film.

Additionally, this research advances the citizenship literature by theorizing relational citizenship in broader relational ways that I continue to reflect on (Lotherington & Obstfelder, 2024). Situating relational citizenship as a process enacted through human and non-human entanglements inspires new possibilities for understanding citizenship not as a fixed status, but as an emergent, relational, embodied, and continually enacted process of participation, recognition, belonging, agency, and solidarity (Jennings, 2018; Lotherington & Obstfelder, 2024). Future

research exploring the intersections between posthumanist and relational citizenship, particularly within creative and embodied contexts, is worthy of further consideration.

This research also extends the literature on music therapy in the dementia context by offering a detailed account of how music-centred, relational, and community music therapy theories can inform collaborative songwriting with PLwD. While these approaches are not new within music therapy, they remain underrepresented in dementia-focused research, particularly in relation to songwriting as a liberatory, participatory and collaborative practice (Kelly et al., 2025). In this way, the contribution of this work lies not in proposing a new model of music therapy but in making these relational and music-centred approaches more visible within the music therapy and dementia literature. By positioning collaborative songwriting as a liberatory, relational, creative, and participatory practice, this research disrupts dominant framings of music in the dementia context by reorienting music towards its capacity to support embodied expression, agency, growth, relationality and solidarity. It also demonstrates the societal and political possibilities of music with PLwD to address social injustices and promote social transformation.

What is particularly exciting about the findings from the pilot of the song/film is that despite the ways music is predominately depicted in the literature as a means of improving memory or reducing behavioural symptoms associated with dementia (Clements-Cortes, 2020), audience members understood music in this project as a vehicle for relational engagement, creative and self-expression, and a medium to highlight the messages of the songwriters, providing a strong counter-narrative to the messages of loss and tragedy often associated with dementia. When music is presented in ways that foreground the strengths, creativity, and relational capacities and citizenship of PLwD, rather than as a medical intervention, audiences

are given space to reflect on and change assumptions and to imagine new ways of being and relating with PLwD. Lastly, while the literature often describes the benefits of familiar music in inducing memory recall (Elliot and Gardener, 2018; Lam et al., 2020), the liberatory-relational songwriting process demonstrates the capacities for PLwD to not only engage with new music but also be active creators of it. In fact, the creation of the song became an important enactment of citizenship for PLwD.

Methodological Implications

This research has important methodological implications, particularly in identifying the conditions necessary to support the meaningful participation of PLwD, including those in later phases of the dementia journey, in liberatory research processes. Drawing on principles of authentic partnerships (Dupuis et al., 2012a), liberatory arts (Watkins & Shulman, 2008), and CABI (Finely, 2008), this project sought to engage PLwD as active contributors throughout the research process. However, in trying to ensure this research was as collaborative as possible, it became clear that such participation does not occur automatically. Rather, it requires intentional relational, structural, and institutional supports to succeed. While participatory approaches to research with PLwD have been increasingly recognized in the literature (Dupuis et al., 2021a, 2025; Kontos et al., 2020), there remains limited attention to what is required to support engagement for those in later stages of the dementia journey (Dupuis et al., 2012a; Fortune et al., 2015; McKeown et al., 2016). This section will explore the conditions that enable this type of work and the constraints that often prevent it from occurring.

First, participatory research with PLwD requires organizational support. At the home where this research took place, staff and leadership actively facilitated participation. Staff supported recruitment, prepared the space each week, accompanied songwriters to sessions, and

contributed to facilitation by interpreting and responding to participants' expressions. Attending to the relational environment was also critical; for example, managing background noise and ensuring an accessible and supportive space were necessary to enable participation. This level of involvement was made possible by an organizational culture that valued relational engagement and recognized the project's importance to both residents and staff. Together, these elements highlight that participatory research with PLwD is not solely dependent on the researcher, but on a broader network of relational and institutional support.

In addition to these supports, this research illuminated constraints related to individual and structural forms of stigma. Because this project required consent from substitute decision-makers, participation was also shaped by family members' perceptions and stigma. For example, in the film, Marilyn (Bill's spouse) shared that she initially felt that the songwriting process would not be a good fit. However, after observing a session and witnessing the varied ways participants engaged, she reconsidered and chose to support her loved one's involvement. This moment highlights how assumptions about capacity can act as a barrier to participation, and how these assumptions can shift through relational exposure and experience.

Assumptions about the capacities of PLwD also operate at a structural level, and this was a significant constraint when identifying a home willing to support this research. For example, one LTC home that initially expressed interest in the project became hesitant when it learned that the research would involve obtaining residents' consent. Despite having a large resident population, the home stated that it would not be possible to identify participants who could consent and participate in the project. While this response might be interpreted as a lack of confidence in residents' capacities, I argue that it also reflects the complex pressures surrounding consent, risk management, staffing, and time within LTC settings. As Brijnath (2024) argued,

relational solidarity risks becoming tokenistic when they are not supported by broader institutional conditions. Structural constraints within LTC, including staffing limitations, workload demands, and organizational priorities, create significant barriers to PLwD participating in this type of research.

These structural and systemic constraints are important to consider because relational caring and relational citizenship also attend to the social, cultural and political contexts that shape experiences in the world. These structural and systemic constraints not only affect PLwD in LTC settings but also affect the staff who work there (Haslam-Larmer et al., 2023). Throughout my time working in LTC and my engagement with staff on this project, I have seen the hardships they face in these settings. Banerjee et al. (2012) described the treatment of staff working in dementia care settings as a form of structural violence. According to Galtung (1990), structural violence encompasses violence perpetrated by institutions, practices, and policies which exploit and marginalize workers, therefore causing immeasurable harm. For example, in a study on the experiences of Canadian long-term care workers, participants stated experiencing an extremely high workload and described their days as "stressful," "brutal," "out of control," "exhausting," and "demoralizing" (Banerjee et al., 2012, p. 396). As we know, these experiences have persisted to the present day, with staff expressing significant hardship related to working conditions in LTC (Haslam-Larmer et al., 2023; Ontario's Long-Term Care COVID-19 Commission, 2021). From this perspective, research that aims to support relational citizenship and solidarity must also attend to the relational care of staff and the conditions under which they work. As Brijnath (2024) argued, "the success of relational practices of solidarity and care is very much contingent on a suitably resourced, skilled, and appropriately rewarded care staff, not just idealized notions of personhood and care" (p. 2). Therefore, supporting the relational

citizenship and solidarity of PLwD requires recognizing and supporting the role of care staff, as well as creating the organizational cultures needed to foster relational caring and the relational processes advocated for in this work.

In this project, there was certainly additional strain on staff throughout the consent process and during project facilitation. In future research, I need to work closely with family members and staff to determine how I can better support them in all aspects of the project and the work required of them to support research. Looking back, I would have insisted on portering the residents to the songwriting room rather than relying on staff to do so. This might have reduced the burden on staff by not adding another task to their already demanding days. However, staff also reported to me each week how much they enjoyed attending sessions and that it was a meaningful and refreshing shift from their daily routines. Relational caring involves providing spaces for PLwD, families, and staff to come together to nurture relational deepenings (Jonas-Simpson et al., 2022). Having opportunities to actively participate in liberatory-relational songwriting processes is one way of doing this.

In my own work, I have sought to take up these insights through my role at Miya Creative Care (a creative arts-therapy agency), contributing to the development of the Creative Care Club, an online platform designed to support recreation staff in LTC settings in implementing relational arts-based programming. Drawing directly from many of the relational literacies discussed in this dissertation, the Creative Care Club provides accessible, step-by-step plans that reduce the burden of program development while integrating relational strategies such as collaborative decision-making, inclusive adaptations, and opportunities for learning and growth. In this way, the insights from this research also highlight how relational approaches can

be translated into practical tools that support both the relational capacities of PLwD and staff in care settings.

Practical Implications

This research also has specific implications for music therapy practice and leisure practices with PLwD more broadly. In addition to the Liberatory-Relational Dementia Songwriting Framework, which provides a practice-informed guide for music therapists and leisure professionals to support the enactment of relational citizenship among PLwD, this research calls for alternative, more liberatory approaches to music therapy and leisure with PLwD. Engaging with this project prompted a deeper recognition of the limitations of many leisure-based programs for PLwD, particularly those that prioritize passive entertainment over opportunities for growth, learning, and meaning-making (Dupuis et al., 2024; Timonen & O'Dwyer, 2009; Theurer et al., 2015). It was through listening to the songwriters speak about the importance of learning, contributing, and sharing knowledge that I realized how rarely these desires are centred within leisure programming in care settings. According to Theurer et al. (2015), recreation programming in residential care settings often resembles what McCann (2013) termed cruise ship living. In this type of living environment, recreation programs are aimed at providing entertainment or distraction, requiring minimal effort from participants, and providing little opportunity for residents to grow or contribute to their communities (Alzheimer's Disease International, 2013; Choi et al., 2008; Knight & Mellor, 2007). Recreation and leisure programs in LTC and retirement homes have been further critiqued by scholars who suggest that programs are often tightly scheduled (Wiersma & Dupuis, 2010) and function as another form of institutionalization within the home (Theurer et al., 2015).

Importantly, PLwD themselves have articulated alternative visions of what meaningful leisure and community participation can look like. For example, in a guide created by PLwD titled *By Us for Us: Living and Celebrating Life Through Leisure* (https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Living-and-Celebrating-Life-Through-Leisure_AODA.pdf) (see also Dupuis et al., 2024), the authors described meaningful leisure as experiences that allow them to "express ourselves and be ourselves, help us find balance in our lives, provide an opportunity to have fun, laugh and enjoy life, contribute to our community in meaningful ways, provide a sense of freedom from the stresses in life, connect us with our friends and family, [and] offer opportunities to feel challenged, grow and develop" (p. 3). To address the lack of programming that connects PLwD to these aspects of self and community, Theurer et al. (2015) called for a social revolution in residential care which prioritizes programming that resists the "cruise ship" leisure model. I argue that *Wisdom and Respect* is one example of what this social revolution might look like. By engaging with PLwD in a project that supported the processes necessary for the enactment of relational citizenship, this research provided a framework for leading meaningful, liberatory, relational arts engagements that support PLwD in growth, knowledge-gathering, sharing, and making meaningful contributions to their communities.

However, as stated earlier, to support these types of engagements and processes, care professionals must recognize and believe in the relational and embodied capacities of PLwD, as well as their capacity to contribute to social justice initiatives. For example, after a conference presentation on the findings from this project, I was surprised by the number of recreation professionals who came up to me after and said, "I never thought of asking residents these types of questions." I realized in that moment that it is impossible for PLwD to participate in

meaningful, growth-oriented opportunities if we do not even believe we can ask them meaningful questions. This project demonstrates that PLwD are not only capable of participating in relational processes that support the enactment of relational citizenship, but that care professionals are also capable of facilitating these experiences when they approach their work from a relational lens and remain open to the possibilities of what residents can contribute. As one staff member reflected in the film:

> *When you challenge that stigma and present the residents with something that you're not completely sure that they can participate fully in, and then you see the results, like we've seen amazing results with this project, it shows you that sometimes trying new things and pushing the envelope with different programming can be really beneficial for the residents.*

In summary, while this research does not offer a singular solution to the structural challenges that shape dementia care, it makes possible what supporting relational citizenship requires in practice, and specifically, the ways music can be used relationally, collaboratively, and creatively to support the ongoing relational capacities of PLwD. By demonstrating how PLwD can be engaged as relational, creative, and contributing members of their communities, this work offers one example of what more just, participatory, and relational approaches to caring and engagement might look like. Importantly, this dissertation also demonstrates the transformative potential of collaborative arts-based practices not only for supporting the relational capacities and relational citizenship of PLwD but also for challenging stigma and reshaping broader social understandings of dementia.

Limitations and Directions for Future Research

There were several limitations to this research. First, all songwriters were recruited from a single retirement home in Toronto, Ontario and all identified as Jewish. While I argue that the social, ethnic, and religious backgrounds of the songwriters' provided opportunities for deeper

relational connections, it also meant that other cultural and ethnic groups did not have their voices heard. Jonas-Simpson et al. (2022) demonstrated that engaging with participants from diverse roles and backgrounds can open opportunities for discovery and strengthen relationships. In future research or projects using collaborative songwriting with PLwD, it is important to work with songwriters from other diverse backgrounds to ensure their perspectives and the music they create are fully represented. Further, though this project primarily centred on the experiences of PLwD, family members and staff also expressed a desire to participate in the songwriting process. Future research could build on this by intentionally including PLwD alongside family members and staff in collaborative songwriting processes to explore how relational citizenship is supported and enacted across these interconnected relationships.

Additionally, expanding this research to include other collaborative partners aligns with emerging interests in intergenerational collaborative initiatives to challenge stigma (Gerritzen et al., 2020; Lokon et al., 2017). While intergenerational arts programs such as choirs and visual-arts collaborations have demonstrated social and emotional benefits (Basting, 2018; Gerritzen et al., 2020), few if any have been informed by relational, arts-based frameworks (Dupuis et al., 2016a; Kontos et al., 2020) that intentionally address stigma and center PLwD as equal creative partners. Future research could fill these gaps by evaluating how collaborative intergenerational songwriting, grounded in a relational songwriting framework based on co-creation and shared storytelling, can support the relational capacities of PLwD, deepen connections between PLwD and youth, and support the enactment of citizenship for both PLwD and youth.

Further, while the songwriters were at different stages of the dementia journey and expressed themselves in diverse ways, all were able to communicate verbally in one form or another. This diversity enabled attention to multiple modes of expression, including embodied

and non-verbal forms of communication and assertion of citizenship. At the same time, future research could extend this work by including more PLwD who do not communicate verbally, to further explore and support relational citizenship across a wider range of communicative abilities. Such work would also invite consideration of how the relational songwriting process might shift to more fully accommodate and respond to differing forms of expression.

The release party for the song/film, which supported a pilot exploration of its potential for personal and social change, was held at the home where the research took place and involved a small sample of 19 participants who completed the questionnaire. While the audience responses offer important insights into how the song/film may challenge dominant discourses associated with dementia, all participants were connected to the home in some way, whether as family members, staff, or members of the broader community associated with the site. As such, responses may reflect pre-existing relationships, familiarity, or investment in the well-being of the songwriters. Future research should build on these findings by engaging a larger and more diverse audience, including individuals with no prior connection to the care home or to dementia, to better understand how liberatory-relational, arts-based projects may influence broader public perceptions of dementia and support the broader structural changes so needed in LTC settings.

Lastly, this research begins to highlight individual, organizational, and broader structural factors that can both constrain and support opportunities for relational solidarity among PLwD living in residential care. Time limitations, institutional routines, and consent processes shaped who could participate and how the songwriting process unfolded, at times constraining the full enactment of relational citizenship. At the same time, supportive staff, flexible facilitation, and an openness to creative engagement enabled meaningful participation and connection. Future research is needed to more directly examine these multilevel factors to better understand how

liberatory-relational songwriting and arts-based programming more broadly can be sustained, expanded, and more equitably accessed within care settings.

And in the End…

Throughout writing this dissertation, I have sometimes questioned whether this work matters or can have a meaningful impact. Can one song really make a difference? In these moments, I return to the experiences of the people I worked with in LTC, and the stories shared with me about the discrimination they have faced because of a dementia diagnosis. I think of my grandparents who had dementia and their encounters with the healthcare system: my Zaidy Jerry, who cried out for help in LTC and was ignored; my Grandma, who chose to die in hospital rather than enter LTC; my Grandpa, who described his LTC home as a "nice prison"; and my Zaidy Willie, who died alone in a hospital room thinking he was back in a concentration camp. These experiences reflect broader conditions that continue to constrain the dignity, agency, and relational citizenship of PLwD in our communities.

The testimonies of the songwriters, their expressions of hope, care for one another, warmth, humour, and wisdom, also affirm the significance of this work. I am changed by their openness and generosity, and grateful to have been invited into their lives. I am also moved by the ways the songwriters prompted others to listen more deeply, reconsider their assumptions surrounding dementia, and engage more relationally with PLwD in their own lives. As one audience member wrote:

> *This was a powerful document of the idea that it sought to convey. It is one grain of sand - an example than can be replicated endlessly if we as a society are prepared to meet older adults and persons living with dementia as they are and give resources and opportunities for this type of activity and expression. What follows is that respect for older adults is sorely lacking much of the time - if watching this video or hearing this song makes anyone pause to rethink that and shift their perspective, it is worth its weight in gold and [lead] to shaping attitudes in a positive and needed direction.*

To me, this reflection encapsulates what this project represents: what is possible when PLwD are supported in sharing and asserting their relational capacities and when resources are made available for creative, relational expression. Liberatory-relational songwriting processes create spaces for enacting relational citizenship, and the outputs of these processes enact agency, have the potential to affect and resonate with others, and prompt change (Lotherington & Obstfelder, 2024). Even a single shift in perspective can ripple outward, shaping attitudes, relationships, and policies and practices. It is my hope that this work contributes to these shifts and invites us to consider a future in which PLwD are recognized, supported, and valued as full relational citizens.

References

Aasgaard, T. (2002). *Song creations by children with cancer: Process and meaning*. [Doctoral Dissertation, Aalborg University] Aalborg.

Abad, V. (2003). A time of turmoil: music therapy interventions for adolescents in a paediatric oncology ward. *Australian Journal of Music Therapy*, *14*, 20–37.

Adrienne, J. K. (2006). A feminist sociology of professional issues in music therapy. In S. Hadley (Ed.), *Feminist perspectives in music therapy* (pp. 41–62). Barcelona Publishers.

Ahessy, B. (2017). Song writing with clients who have dementia: A case study. *The Arts in Psychotherapy*, *55*, 23–31. https://doi.org/10.1016/j.aip.2017.03.002

Aigen, K. (2002). *Playing in the band: A qualitative study of popular music styles as clinical improvisation.* Nordoff-Robbins Centre for Music Therapy, Steinhardt School of Education New York University.

Aigen, K. (2005). *Music-centered music therapy*. Barcelona.

Aigen, K. (2014a) *The study of music therapy: Current issues and concepts.* Routledge.

Aigen, K. (2014b). Music-centered dimensions of Nordoff-Robbins music therapy. *Music Therapy Perspectives*, *32*(1), 18-29.

Aigen, K. (2015). A critique of evidence-based practice in music therapy. *Music Therapy Perspectives, 33*(1), 12 – 24. https://doi-org.proxy.lib.uwaterloo.ca/10.1093/mtp/miv013

Albergato-Muterspaw, F., & Fenwick, T. (2007). Passion and politics through song: Recalling music to the arts-based debates in adult education. In D. Clover, & J. Stalker, (Eds.), *The Arts and Social Justice: Re-crafting Adult Education and Community Cultural Leadership* (pp. 147–164). NIACE.

Alzheimer Society of Canada. (n.d.). *What is dementia?* https://alzheimer.ca/en/about-dementia/what-dementia

Amir, D. (2006). Awakening the "wild women": Feminist music therapy with Israeli women who suffered trauma in their lives. In. S. Hadley (Ed.), *Feminist perspectives in music therapy* (pp. 267 – 290). Barcelona.

Ansdell, G. (1995). *Music for life: Aspects of creative music therapy with adult children*. Jessica Kingsley.

Ansdell, G. (2002). Community Music Therapy & The Winds of Change. *Voices : A World Forum for Music Therapy*, *2*(2). https://doi.org/10.15845/voices.v2i2.83

Ansdell, G. (2003). The Stories We Tell: Some Meta-theoretical Reflections on Music Therapy. *Nordic Journal of Music Therapy*, *12*(2), 192–159. https://doi.org/10.1080/08098130309478085

Ansdell, G. (2014). *How music helps in music therapy and everyday life*. Ashgate.

Ansdell, G., & Stige, B. (2015) Community Music Therapy. In J. Edwards (Ed.), *The Oxford Handbook of Music Therapy* (pp. 595 – 622). Oxford University Press.

Antipas, H., & Woon, M. L. (2022). Always Taking a Chance: A Reflection on a Song of Advocacy by People Living Well with Young Onset Dementia, Their Family, and Supporters. *Australian Journal of Music Therapy*, *33*(2), 47–56.

Aufderheide, P. (2008). "You see the world of the other and you look at your own": The evolution of the video in the villages project. *Journal of Film and Video, 60*(2), 26 – 34.

Auslander, B. H. (1981). "If You Wanna End War and Stuff, You Gotta Sing Loud." *Journal of American Culture, 4,* 108. https://doi.org/10/1111/j.1542-734X.1981.0402_108.x.

Baker, F. A. (2015). *Therapeutic Songwriting: Developments in theory, methods and practice*. Palgrave Macmillan.

Baker, F., Kennelly, J., & Tamplin, J. (2005). Themes within Songs Written by People with Traumatic Brain Injury: Gender Differences. *The Journal of Music Therapy*, *42*(2), 111–122. https://doi.org/10.1093/jmt/42.2.111

Baker, F. A., & Stretton-Smith, P. A. (2018). Group Therapeutic Songwriting and Dementia: Exploring the Perspectives of Participants Through Interpretative Phenomenological Analysis. *Music Therapy Perspectives*, *36*(1), 50–66. https://doi.org/10.1093/mtp/mix016

Baker, F. A., & Wigram, T. (Eds.). (2005). *Songwriting: Methods, techniques and clinical applications for music therapy clinicians, educators and students*. Jessica Kingsley.

Banerjee, A., Daly, T., Armstrong, P., Szebehely, M., Armstrong, H., & Lafrance, S. (2012). Structural violence in long-term, residential care for older people: Comparing Canada and Scandinavia. *Social Science & Medicine, 74*(3), 390–398. https://doi.org/10.1016/j.socscimed.2011.10.037

Barker, C. (2004). *The Sage dictionary of cultural studies*. Sage Publications.

Banerjee, A., Daly, T., Armstrong, P., Szebehely, M., Armstrong, H., & Lafrance, S. (2012). Structural violence in long-term residential care for older people: Comparing Canada and Scandinavia. *Social Science & Medicine, 74*(3), 390–398. https://doi.org/10.1016/j.socscimed.2011.10.037

Barndt, D. (2008). Touching minds and hearts: community arts as collaborative research. In J. G. Knowles, A. L. Cole (Eds.) *Touching minds and hearts: Community arts as collaborative research* (pp. 352-363). SAGE Publications. https://doi.org/10.4135/9781452226545.n29

Bartlett, R. (2016). Scanning the conceptual horizons of citizenship. *Dementia (London, England)*, *15*(3), 453–461. https://doi.org/10.1177/1471301216644114

Bartlett, R., & Lid, I. M. (2025). Supported everyday citizenship: widening the discourse to include persons living with intellectual disability or dementia. *Nordic Social Work Research*, *15*(4), 533–545. https://doi.org/10.1080/2156857X.2025.2450343

Bartlett, H., & Martin, W. (2002). Ethical issues in dementia care research. In H. Wilkinson (Ed.), *The perspectives of people with dementia: Research methods and motivations* (pp 47–62). Jessica Kingsley.

Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, *21*(2), 107–118. https://doi.org/10.1016/j.jaging.2006.09.002

Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship.* The Policy Press.

Basting, A. (2018). Building creative communities of care: Arts, dementia, and hope in the United States. *Dementia, 17*(6), 744 – 754. https:doi.org/10.1177/1471301217740959

Beard, R. L. (2011). Art therapies and dementia: A systematic review. *Dementia, 11*(5), 633 – 656. https://doi.org/10.1177/1471301211421090

Bellass, S., Balmer, A., May, V., Keady, J., Buse, C., Capstick, A., Burke, L., Bartlett, R., & Hodgson, J. (2019). Broadening the debate on creativity and dementia: A critical approach. *Dementia*, *18*(7–8), 2799–2820. https://doi.org/10.1177/1471301218760906

Bittman, B. B. M., Snyder, C. M., Bruhn, K. T., Liebfreid, F. B., Stevens, C. K. M., Westengard, J. B., & Umbach, P. O. M. (2004). Recreational Music-making: An Integrative Group Intervention for Reducing Burnout and Improving Mood States in First Year Associate Degree Nursing Students: Insights and Economic Impact. *International Journal of Nursing Education Scholarship*, *1*(1). https://doi.org/10.2202/1548-923X.1044

Boscart, V. M., McNeill, S., & Grinspun, D. (2019). Dementia Care in Canada: Nursing Recommendations. *Canadian Journal on Aging*, *38*(3), 407–418. https://doi.org/10.1017/S071498081800065X

Bourdieu, P. (1977). *Outline of a theory of practice (*R. Nice, trans.). Cambridge University Press.

Bourdieu, P. (1990*). The logic of practice* (R. Nice, trans.). Polity Press.

Bowman. W. D. (2000). A Somatic, "Here and Now" Semantic: Music, Body, and Self. *Bulletin of the Council for Research in Music Education*, *144*, 45–60.

Bowman, W. D. (2004). Cognition and the body: Perspectives from music education. In L.

Boyd, M.P., & Sherry, M. B. (2024). Dialogic space: An introduction. *Theory into Practice, 63*(2), 11-120.

Boyle, G. (2014). Recognising the agency of people with dementia. *Disability & society*, *29*(7), 1130-1144. https://doi.org/10.1080/09687599.2014.910108

Bowman, W. D., & Powell, K. (2007). The body in a state of music. In L. Bresler (Ed.), *International handbook of research in arts education* (pp. 1087 - 1106). Springer.

Brannelly, T. (2016). Citizenship and people living with dementia: A case for the ethics of care. *Dementia*, *15*(3), 304-314. https://doi.org/10.1177/1471301216639463

Braun, V., & Clarke. V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352. https://doi.org/10.1080/14780887.2020.1769238

Bresler (Ed.), *Knowing bodies, moving minds: Toward embodied teaching and learning* (pp. 29–50). Kluwer Academic Press.

Brijnath, B., Rao, R., Baruah, U., Antoniades, J., Loganathan, S., Varghese, M., Cooper, C., Kent, M., & Dow, B. (2024). Relational solidarity and conflicting ethics in dementia care in urban India. *The Journals of Gerontology: Series B, Psychological Sciences and Social Sciences, 79*(7). https://doi.org/10.1093/geronb/gbae079

Brookfield, S. D. (2014). Foundations of Critical Theory. *Advances in Developing Human Resources, 16*(4), 417 – 428. https://doi.org/10.1177/1523422314543819

Brotons, M., & Marti, P. (2003). Music Therapy with Alzheimer's Patients and Their Family Caregivers: A Pilot Project. *The Journal of Music Therapy*, *40*(2), 138–150. https://doi.org/10.1093/jmt/40.2.138

Brown, B. A. (1996). *Expanding circles: Women, art, and community*. Midmarch Arts Press.

Bruscia, K. E. (1987). *Improvisational models of music therapy*. Charles C. Thomas.

Bunt, L., & Stige, B. (2014). *Music therapy: an art beyond words* (2nd ed.). Routledge, Taylor & Francis Group.

Burgoon, J. K., L. K. Guerrero, and K. Floyd. 2010. *Nonverbal Communication*. Boston, Allyn and Bacon.

Burns, V., Kwan, C., & Walsh, C. A. (2020). Co-producing Knowledge Through Documentary Film: A Community-Based Participatory Study With Older Adults With Homeless Histories. *Journal of Social Work Education*, *56*, S119–S130. https://doi.org/10.1080/10437797.2020.1723763

Burr, V. (1995). *An Introduction to Social Constructionism*. Routledge.

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., Bywaters, D., & Walker, K. (2020). Purposive sampling: complex or simple? Research case examples. *Journal of Research in Nursing*, *25*(8), 652–661. https://doi.org/10.1177/1744987120927206

Canadian Association of Music Therapists (n.d.). *About Music Therapy*. https://www.musictherapy.ca/about-camt-music-therapy/about-music-therapy/

Cantley, C., & Bowes, A. (2004). Dementia and social inclusion: The way Forward. In A. Innes., C. Archibald & C. Murphy (Eds.), *Dementia and social inclusions: Marginalized groups and marginalized areas of dementia research, care and practice*. Jessica Kingsley.

Carpente, J. A., & Aigen, K. (2019). A music-centered perspective on music therapy assessment. In D. J. David., M. Silverman & G. McPherson (Eds.), *The Oxford handbook of philosophical and qualitative assessment in music education* (pp. 243-256) Oxford University Press.

Cheong, C. Y., Tan, J. A. Q., Foong, Y.-L., Koh, H. M., Chen, D. Z. Y., Tan, J. J. C., Ng, C. J., & Yap, P. (2016). Creative Music Therapy in an Acute Care Setting for Older Patients with Delirium and Dementia. *Dementia and Geriatric Cognitive Disorders Extra*, *6*(2), 268–275. https://doi.org/10.1159/000445883

Choi, N. G., Ransom, S., & Wyllie, R. J. (2008). Depression in older nursing home residents: The influence of nursing home environmental stressors, coping, and acceptance of group and individual therapy. *Aging & Mental Health*, *12*(5), 536–547. https://doi.org/10.1080/13607860802343001

Clark, I. N., Baker, F. A., Tamplin, J., Lee, Y.-E. C., Cotton, A., & Stretton-Smith, P. A. (2021). "Doing Things Together is What it's About": An Interpretative Phenomenological Analysis of the Experience of Group Therapeutic Songwriting from the Perspectives of People with Dementia

and Their Family Caregivers. *Frontiers in Psychology*, *12*, 598979–598979. https://doi.org/10.3389/fpsyg.2021.598979

Clark, I. N., Stretton-Smith, P. A., Baker, F. A., Lee, Y.-E. C., & Tamplin, J. (2020). "It's Feasible to Write a Song": A Feasibility Study Examining Group Therapeutic Songwriting for People Living with Dementia and Their Family Caregivers. *Frontiers in Psychology*, *11*, 1951–1951. https://doi.org/10.3389/fpsyg.2020.01951

Clements-Cortés, A. (2009). *Episodes of relationship completion through song: case studies of music therapy research in palliative care*. VDM Verlag.

Clements-Cortes, A. (2020). Understanding the continuum of musical experiences for people with dementia. In. A. Baird., S. Garrido & J. Tamplin (Eds.), *Music and dementia: From cognition to therapy* (pp. 3 – 23). Oxford University Press.

Conrad, P., & Barker, K. K. (2010). The Social Construction of Illness: Key Insights and Policy Implications. *Journal of Health and Social Behavior*, *51*(1), S67–S79. https://doi.org/10.1177/0022146510383495

Craftman, Å. G., Swall, A., Båkman, K., Grundberg, Å., & Hagelin, C. L. (2020). Caring for older people with dementia reliving past trauma. *Nursing Ethics*, *27*(2), 621–633. https://doi.org/10.1177/0969733019864152

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, *43*(6), 1241–1299. https://doi.org/10.2307/1229039

Crotty, M. (1998). *The Foundations of Social Research: Meaning and Perspective in the Research Process*. Sage Publications.

Curtis, S. L. (2006). Feminist music therapy: Transforming theory, transforming lives. In S. Hadley (Ed.), *Feminist perspectives in music therapy* (pp. 227 - 244). Barcelona.

Curtis, S. (2012). Music therapy and social justice: A personal journey. *The Arts in Psychotherapy, 39*(3), 209–213.

Dall'Alba, G. (2024). Toward responsive attunement as health professionals. *Studies in Continuing Education*, *46*(3), 299–316. https://doi.org/10.1080/0158037X.2023.2193388

David, P. (1995). *The Terrace Holocaust Survivors' Group: Collective poems.* Baycrest Centre for Geriatric Care.

David, P. (2002). Aging Survivors of the Holocaust in Long Term Care: Unique Needs, Unique Responses. *Journal of Social Work in Long Term Care, 1*(3), 1 – 14.

David, P. (2003, November). *Creative Expressions of Trauma, Part 1* [Conference presentation]. World Conference on Jewish Communal Services International Conference. Jerusalem, Israel.

Davis, L. (1997). *The Disability Studies Reader*. London: Routledge Kegan Paul.

Davis, L. (2000). Dr. Johnson, Amelia, and the Discourse of Disability in the Eighteenth Century. In H. Deutsch & F. Nussbaum (Eds.), *Defects: Engendering the Modern Body* (pp. 54 – 74). University of Michigan Press.

Day, T., Baker, F., & Darlington, Y. (2009). Beyond the Therapy Room: Women's Experiences of 'Going Public' with Song Creations. *British Journal of Music Therapy, 23*(1), 19–26. https://doi.org/10.1177/135945750902300103

Daykin, N., Parry, B., Ball, K., Walters, D., Henry, A., Platten, B., & Hayden, R. (2018). The role of participatory music making in supporting people with dementia in hospital environments. *Dementia*, *17*(6), 686–701. https://doi.org/10.1177/1471301217739722

Deep, K., Hunter, A., Murphy, K., & Volandes, A. (2010). "It helps to see with my heart": How video informs patients' rationale for decisions about future care in advanced dementia. *Patient Education & Counselling, 81(*2), 229 – 234.

de L'Etoile, S., & Jones, C. (2025). Associative mood and memory training. In M. H. Thaut & V. Hoemberg (Eds.), *Handbook of neurologic music therapy* (2nd ed.). Oxford University Press.

Dennis, P., & Rickson, D. J. (2014). The Leader of the Band: A Case Story of Community Music Therapy on a Hospital Ward for People Who Have Dementia. *Voices: A World Forum for Music Therapy*, *14*(1). https://doi.org/10.15845/voices.v14i1.728

Dewey, J., & Bentley, A. F. (1949). *Knowing and the known*. Beacon.

Dewing, J. (2002). From ritual to relationship: A person-centred approach to consent in qualitative research with older people who have a dementia. Dementia. *The International Journal of Social Research and Practice, 1*(2), 156–171.

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia, 6*(1), 11-25.

Dileo, C., & Bradt, J. (2005). *Medical music therapy: A meta-analysis of the literature and an agenda for future research.* Jeffrey Books.

Dowlen, R., Keady, J., Milligan, C., Swarbrick, C., Ponsillo, N., Geddes, L., & Riley, B. (2018). The personal benefits of musicking for people living with dementia: a thematic synthesis of the qualitative literature. *Arts & Health*, *10*(3), 197–212. https://doi.org/10.1080/17533015.2017.1370718

Dowlen, R., Keady, J., Milligan, C., Swarbrick, C., Ponsillo, N., Geddes, L., & Riley, B. (2022). In the moment with music: an exploration of the embodied and sensory experiences of people living with dementia during improvised music-making. *Ageing and Society, 42*(11), 2642–2664. https://doi.org/10.1017/S0144686X21000210

Downs, M. (1997). The Emergence of the Person in Dementia Research. *Ageing & Society*, *17*(5), 597–607. https://doi.org/10.1017/S0144686X9700665X

Dupuis, S. L., & Gillies, J. (2014). Learning as a Vehicle for Individual and Social Transformation: Rethinking Leisure Education. *Therapeutic Recreation Journal*, *48*(2), 113.

Dupuis, S. L., Gillies, J., Carson, J., Whyte, C., (2009) Moving beyond patient and client approaches: Mobilizing 'authentic partnerships' in dementia care, support and services, *Dementia, 11*(4), 427–452.

Dupuis, S., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., & Sadler, L. (2012a). Moving beyond patient and client approaches: Mobilizing 'authentic partnerships' in dementia care, support and services. *Dementia: The International Journal of Social Research and Practice*, 11(4), 427 - 452. https://doi.org/10.1177/1471301211421063

Dupuis, S.L., Jonas-Simpson, C., Kontos, P., & Mitchell, G. (2021b, May). *Music Is Life*: Disrupting stigma associated with dementia through research-based documentary. In S. Kono, S. Barrick, J. Leighton, N. Yan, & F. Yuen with assistance from J. Baribault (Eds.), *The 2021 Canadian Congress on Leisure Research (CCLR) Book of Proceedings* (pp. 65-68). Edmonton, Alberta: Canadian Association for Leisure Studies.

Dupuis, S.L., & Kontos, P. (2026). Leisure/arts activism: Doing activist arts-based research in the context of dementia. In B. Lashua, K. Spracklen, and F. Yuen (Eds.), *Research Handbook on the Sociology of Leisure.* Edward Elgar Press.

Dupuis, S. L., Kontos, P., Gray, J., & Jonas-Simpson, C. (2021a). A conversation about theatre, dementia and transformation. In E. Stickland (Ed.), *No Harm Done: Three plays about medical conditions*. UpRoute Books.

Dupuis, S.L., Kontos, P., Jonas-Simpson, C., & Gray, J. (2025a). Translating relational theories into dementia care using research-informed drama. *Educational Gerontology, 51*(6), 582-597. https://doi.org/10.1080/03601277.2024.2396649

Dupuis, S. L., Kontos, P., Mitchell, G., Jonas-Simpson, C., & Gray, J. (2016a). Re-claiming citizenship through the arts. *Dementia, 15*(3), 358 – 380. https://doi.org/10.1177/1471301216637206

Dupuis, S.L., Kurta, T., Champagne, E., Steh, S., & Engell, K. (2022, November). The Bitove Method: The experiences of transitioning relational caring principles to an on-line platform: Final Report. Prepared for The Bitove Method. Waterloo, ON: Partnerships in Dementia Care Alliance.

Dupuis, S., Kurta, T., Champagne, E., Steh, S., & Engell, K. (2025b). Transitioning relational arts for persons living with dementia to a virtual space. *Arts & Health*, 1–15. https://doi.org/10.1080/17533015.2025.2469676

Dupuis, S.L., Kurta, T., Kontos, P., Law, S., Gertin, R., Marland, H., Cox, W., Leblanc, B., Montgomery, T., Carson, J., & Acklin, C. (2023, May). Re-imagining dementia through collaborative music-making. In T. Ritondo (Ed.), *Towards a more inclusive future: Program Guide and Book of Abstracts* for the 17th Canadian Congress on Leisure Research (pp. 92-94). Ottawa, Ontario: Canadian Association for Leisure Studies

Dupuis, S. L., McKeown, J., & Fortune, D. (2016b). Possibilities in the study of ageing and leisure in late life. In D. A. Kleiber & F. A. McGuire (Eds.), *Leisure and human development* (pp. 319–346). Sagamore.

Dupuis, S.L., Whyte, C., Carson, J., & Hounam, B. (2024). Framing the meanings of leisure. In K. Gray, C. Russell, & J. Twigg (Eds.), *Leisure and Everyday Life with Dementia* (pp11-26). Open University Press 'Reconsidering Dementia' Series.

Dupuis, S. L., *Wiersma, E., & Loiselle, L. (2012b). Pathologizing behaviour: Meanings of behaviours in dementia care. *Journal of Aging Studies*, *26*(2), 162-173.

Edwards, J. (2008). The Use of Music in Healthcare Contexts: A Select Review of Writings from the 1890s to the 1940s. *Voices: A World Forum for Music Therapy, 8*(2).

El Haj, M., Moustafa, A. A., Antoine, P., & Chapelet, G. (2024). Relationship Between Future Thinking and Prospective Memory in Alzheimer's Disease. *JAD Reports*, *8*(1), 33–42. https://doi.org/10.3233/ADR-230144

Elliot, D. J. (1995). *Music matters: A new philosophy of music education*. Oxford University Press.

Elliott, M., & Gardner, P. (2018). The role of music in the lives of older adults with dementia ageing in place: A scoping review. *Dementia*, *17*(2), 199–213. https://doi.org/10.1177/1471301216639424

Elliott, M., Gardner, P., Narushima, M., & McCleary, L. (2020). Music Lessons: Exploring the Role and Meaning of Music for Older Adults with Dementia. *Canadian Journal on Aging*, *39*(4), 586–599. https://doi.org/10.1017/S071498081900076X

Farber, T., Eagle, G. & Smith, C. (2023). *Catastrophic Grief, Trauma, and Resilience in Child Concentration Camp Survivors: A Retrospective View of Their Holocaust Experiences*. Academic Studies Press. https://doi.org/10.1515/9781644696354

Finley, S. (2008). *Arts Based Research.* In J.G. Knowles and A.L. Cole (Eds.), *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues* (pp. 71-81). Sage.

Finley, S. (2011). Critical arts-based inquiry: The pedagogy and performance of a radical ethical aesthetic. In N. Denzin & Y. Lincoln (Eds.), *The Sage handbook of qualitative research* (4th ed., pp. 435–450). Sage.

Fish, S. (1990). How to recognize a poem when you see one. In D. Bartholomae & A. Petrosky (Eds.), *Ways of Reading: An Anthology for Writers* (2nd ed., pp. 178 – 191). Bedford Books.

Forinash, M. (2006). Feminist music therapy supervision. In S. Hadley (ed.), *Feminist Perspectives in Music Therapy* (pp. 415 – 427). Barcelona Publishers.

Fortune, D., McKeown, J., Dupuis, S., & de Witt, L. (2015). “It was like reading a detective novel”: Using PAR to work together for culture change. *Journal of Aging Studies*, *34*, 38–47. https://doi.org/10.1016/j.jaging.2015.04.002

Foster, V. (2016). *Collaborative Arts-based Research for Social Justice*. Routledge.

Foucault, M. (1965). *Madness and civilization: A history of insanity in the age of reason*. Pantheon Books.

Foucault, M. (1978). *The history of sexuality: Vol. 1. An introduction* (R. Hurley, Trans). New York: Vintage Books.

Foucault, M. (1991). *Discipline and Punish: the birth of a prison.* London, Penguin.

Fraser, K. D., O’Rourke, H. M., Wiens, H., Lai, J., Howell, C., & Brett-MacLean, P. (2015). A scoping review of research on the arts, aging, and quality of life. *The Gerontologist, 55*(4), 719–729. https://doi.org/10.1093/geront/gnv027

Friend, J., & Caruthers, L. (2016). Documentary film: The next step in qualitative research to illuminate issues of social justice in urban education. *International Journal of Learning, Teaching & Educational Research, 15*(6), 33 – 47.

Freire, P. (1972). *Pedagogy of the oppressed*. Penguin.

Galtung, J. (1990). Cultural Violence. *Journal of Peace Research*, *27*(3), 291–305. https://doi.org/10.1177/0022343390027003005

Gergen, K. J. (2009). *Relational being: Beyond self and community*. Oxford University Press.

Gergen, K. J. (2015). Toward a Relational Humanism. *Journal of Humanistic Counseling, 54*(2), 149 - 165. https://doi.org/10.1002/johc.12009

Gerritzen, E. V., Hull, M. J., Verbeek, H., Smith, A. E., & de Boer, B. (2020). Successful Elements of Intergenerational Dementia Programs: A Scoping Review: Research. *Journal of*

Intergenerational Relationships, *18*(2), 214–245. https://doi.org/10.1080/15350770.2019.1670770

Gilleard, C., & Higgs, P. (2010). Aging without agency: Theorizing the fourth age. *Aging & Mental Health*, *14*(2), 121–128. https://doi.org/10.1080/13607860903228762

Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Harvard University Press.

Gouk, Penelope. (2000). *Musical healing in cultural contexts*. Ashgate.

Government of Ontario. (2021). *Ontario's Long-Term Care COVID-19 Commission Final Report*. Retrieved from https://www.ontario.ca/page/long-term-care-covid-19-commission-progress-interim-recommendations

Gray, D. E. (2013). *Doing research in the real world* (3rd ed.). Sage.

Gray, J., Dupuis, S.L., Kontos, P., Jonas-Simpson, C., & Mitchell, G. (2020) Knowledge as embodied, imaginative, foolish enactment: Exploring dementia experiences through theatre. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *21*(3), 2. http://dx.doi.org/10.17169/fqs-21.3.3444

Greene, M. (1995). *Releasing the imagination: Essays on education, the arts, and social change.* Jossey-Bass.

Greene, M. (2000). *Releasing the Imagination: Essays on Education, the Arts, and Social Change*. Jossey-Bass.

Grigorovich, A., Kontos, P. (2020). COVID-19, stigma and the scandalous neglect of people living with dementia. *The Conversation*. https://theconversation.com/covid-19-stigma-and-the-scandalous-neglect-of-people-living-with-dementia-140817

Grigorovich, A., Kontos, P., & Kontos, A. P. (2019). The "Violent Resident": A Critical Exploration of the Ethics of Resident-to-Resident Aggression. *Journal of Bioethical Inquiry*, *16*(2), 173–183. https://doi.org/10.1007/s11673-019-09898-1

Grodin, M. A. (2011). Caring for aging Holocaust survivors and subsequent generations. *American Imago*, *68*(3), 543–559. https://doi.org/10.1353/aim.2011.0034

Grout, G. (2004). Negotiated consent in research. *Nursing Older People, 16*(4), 18–20.

Gubrium, J. (1975). *Living and dying at Murray Manor.* St. Martin's Press.

Guerrero, N., Marcus, D., & Turry, A. (2015). Poised in the Creative Now: Principles of Nordoff-Robbins Music Therapy. In J. Edwards (ed.), *The Oxford Handbook of Music Therapy* (pp. 482 – 493). Oxford University Press

Gutting, G. (2005). *Foucault: A very short introduction.* Oxford University Press.

Habermas, J. (1984). *The theory of communicative action: Reason and the rationalization of society*. Beacon Press.

Hadley, S. (2013). Feminist music therapy. In K. Kirkwood (Ed.), *Dictionary of music therapy* (p. 47). Routledge.

Hamilton, W. (1860). *Lectures on metaphysics and logic* (Vols. 1–4). Gould and Lincoln.

Harris, P. B., & Caporella, C. A. (2019). Making a university community more dementia friendly through participation in an intergenerational choir. *Dementia, 18*(7–8), 2556–2575. https://doi.org/10.1177/1471301217752209

Haslam-Larmer, L., Grigorovich, A., Quirt, H., Engel, K., Stewart, S., Rodrigues, K., Kontos, P., Astell, A., McMurray, J., Levy, A., Bingham, K. S., Flint, A. J., Maxwell, C., & Iaboni, A. (2023). Prevalence, causes, and consequences of moral distress in healthcare providers caring for people

living with dementia in long-term care during a pandemic. *Dementia*, *22*(1), 5–27. https://doi.org/10.1177/14713012221124995

Hazan, H. (2002). The home over the hill: Towards a modern cosmology of institutionalization. *Journal of Aging Studies*, *16*, 323-344.

Heath, S. B. (1982). Protean shapes in literacy events: Ever-shifting oral and literate traditions. In D. Tannen (Ed.), *Spoken and written language: Exploring orality and literacy* (pp. 91–117). Ablex.

Heidegger, M. (1962). *Being and time.* Harper & Row.

Ho, K. H. M., Chiang, V. C. L., & Leung, D. (2017). Hermeneutic phenomenological analysis: the 'possibility' beyond 'actuality' in thematic analysis. *Journal of Advanced Nursing*, *73*(7), 1757–1766. https://doi.org/10.1111/jan.13255

Hocoy, D. (2005). Art therapy and social action: A transpersonal framework. Art Therapy, 22(1), 7–16. https://doi.org/10.1080/07421656.2005.10129466

Holiday, B. (1939). Strange Fruit. Commodore.

Hong, I. S., & Choi, M. J. (2011). Songwriting oriented activities improve the cognitive functions of the aged with dementia. *The Arts in Psychotherapy*, *38*(4), 221–228. https://doi.org/10.1016/j.aip.2011.07.002

Hooks, B. (1994). *Teaching to transgress: education as the practice of freedom.* Routledge.

Horkheimer, M. (1995). *Critical theory: Selected essays*. Continuum.

Horkheimer, M. & Adorno, T.W. (1972). *Dialectic of Enlightenment.* Continuum.

Ijaopo, E. O. (2017). Dementia-related agitation: a review of non-pharmacological interventions and analysis of risks and benefits of pharmacotherapy. *Translational Psychiatry*, *7*(10), e1250–e1250. https://doi.org/10.1038/tp.2017.199

Ingebrand, E., Samuelsson, C., & Hydén, L.-C. (2022). A person living with dementia learning to navigate an iPad: a case study. *Disability and Rehabilitation: Assistive Technology, 17*(5), 570–579. https://doi.org/10.1080/17483107.2020.1800117

Jennings, B. (2018). Solidarity and care as relational practices. *Bioethics*, *32*(9), 553–561. https://doi.org/10.1111/bioe.12510

Joffe, C., Brodaty, H., Luscombe, G., & Ehrlich, F. (2003). The Sydney Holocaust study: Posttraumatic stress disorder and other psychosocial morbidity in an aged community sample. *Journal of Traumatic Stress, 16*(1), 39–47. https://doi.org/10.1023/A:102205931114J

Johnson, C. W., & Parry, D. C. (2015). *Fostering social justice through qualitative inquiry: A methodological guide.* Left Coast Press.

Jonas-Simpson, C. (Producer), Dupuis, S., Kontos, P. Mitchell, G. (2019). *Music Is Life.* (Research-based documentary). Toronto, ON, Canada.

Jonas-Simpson, C., Dupuis, S.L., Kontos, P., Mitchell, G., & Donovan, L. (2020, October). *Music is Life: Experiences of relational caring through musical engagement.* Invited presentation at the virtual Alzheimer Society of Canada Research Program Knowledge Exchange Forum.

Jonas-Simpson, C., Mitchell, G., Dupuis, S., Donovan, L., & Kontos, P. (2022). Free to be: Experiences of arts-based relational caring in a community living and thriving with dementia. *Dementia, 21*(1), 61- 76. https://doi.org/10.1177/14713012211027016

Jordan, J. V., (2008). Recent Developments in Relational-Cultural Theory. *Women & Therapy*, *31*(2), 1-4.

Jordan, J. V., (2017). Relational-Cultural Theory: The Power of Connection to Transform Our Lives. *Journal of Humanistic Counseling*. *56,* 228-243. https://doi.org/10.1002/johc.12055

Jordan, J. V., Walker, M., & Hartling, L. M. (2004). *The complexity of connection: Writings from the Stone Center's Jean Baker Miller Training Institute*. The Guilford Press.

Keifer-Boyd, K. (2011) Arts-based Research as Social Justice Activism Insight, Inquiry, Imagination, Embodiment, Relationality. *International Review of Qualitative Research, 4*(1), 3 - 20.

Kellermann, N. P. F. (2001). The long-term psychological effects and treatment of holocaust trauma. *Journal of Loss & Trauma, 6*(3), 197–218. https://doi.org/10.1080/108114401753201660

Kelly, L., Corcoran, C., Paley, G., Paley, N., Quaid, K., Quaid, H., Rochford-Brennan, H., Geoghegan, C., Richardson, I., & Moss, H. (2025). "We will tell everyone!" Capturing the impact of public and patient involvement in music therapy and dementia research through songwriting. *Dementia, 24*(8), 1600–1614. https://doi.org/10.1177/14713012251333839

Kenny, C. B. (1982). *The mythic artery: The magic of music therapy.* Ridgeview.

Kenny, C. B. (1987). *The field of play: A theoretical study of music therapy process.* [Doctoral dissertation, The Fielding Institute].

Kester, G. H. (2004). *Conversation Pieces: Community and Communication in Modern Art*. University of California Press.

Kincheloe, J. L., & Mclaren, P. (2011). Rethinking Critical Theory and Qualitative Research. In S. R. Steinberg, K. Tobin, & Kecia Hayes (Eds.), *Key Works in Critical Pedagogy* (Vol. 32, pp. 285–326). Springer. https://doi.org/10.1007/978-94-6091-397-6_23

Kitwood, T. (1997) *Dementia Reconsidered: The Person Comes First*. Open University Press.

Knight, T., & Mellor, D. (2007). Social inclusion of older adults in care: Is it just a question of providing activities? *International Journal of Qualitative Studies on Health and Well-Being*, *2*(2), 76–85. https://doi.org/10.1080/17482620701320802

Kontos, P. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and Society*, *24*(6), 829–849. https://doi.org/10.1017/S0144686X04002375

Kontos, P. (2005). Embodied selfhood in Alzheimer's disease. *Dementia, 4*(4), 553-570. https://doi.org/10.1177/1471301205058311

Kontos, P. (2012). Rethinking sociability in long-term care: an embodied dimension of selfhood, Dementia: *The International Journal of Social Research and Practice, 11*(3), 329–46.

Kontos, P. (2014). Musical embodiment, selfhood, and dementia. In. C. Hydén, J. Brockmeier & H. Lindermann (Eds.), *Beyond loss: dementia, identity, personhood* (pp. 107 - 119). Oxford University Press.

Kontos, P. (2026). Dementia and embodiment. In J. Twigg & W. Martin (Eds.), *Routledge handbook of cultural gerontology* (2nd ed., pp. 244 - 251). Routledge.

Kontos, P., Grigorovich, A., & Miller, K. L. (2016). Citizenship, human rights, and dementia: Towards a new embodied relational ethic of sexuality. *Dementia: The International Journal of Social Research and Practice*, *15*(3), 315-329. https://doi.org/10.1177/1471301216636258

Kontos, P. & Grigorovich, A. (2018) Rethinking musicality in dementia as embodied and relational. *Journal of Aging Studies, 45*, 39-48. https://doi.org/10.1016/j.jaging.2018.01.006.

Kontos, P., Grigorovich, A., & Colobong, R. (2020). Creativity and Dementia: New Directions From Embodiment, Relationality, and Citizenship Discourse. *Innovation in Aging*, *4*(1), 34–34. https://doi.org/10.1093/geroni/igaa057.110

Kontos, P., Grigorovich, A., Dupuis, S. L., Colobong, R., Gray, J., Jonas-Simpson, C., & Serota, A. (2024). Projecting a Critique of Stigma Associated With Dementia on Screen: The Impact of a Canadian Film on the Importance of Relational Caring in the Community. *The Gerontologist*, *64*(2), 1. https://doi.org/10.1093/geront/gnad045

Kontos, P., Grigorovich, A., Dupuis, S., Jonas-Simpson, C., Mitchell, G., & Gray, J. (2018). Raising the curtain on stigma associated with dementia: Fostering a new cultural imaginary for a more include society. *Critical Public Health, 30*(1), 91 – 102. https://doi-org.proxy.lib.uwaterloo.ca/10.1080/09581596.2018.1508822

Kontos, P., Grigorovich, A., Dupuis, S., Jonas-Simpson, C., Mitchell, G., Gray, J. (2020). Raising the curtain on stigma associated with dementia: fostering a new cultural imaginary for a more inclusive society. *Critical Public Health, 30*(1), 91 – 102. https://doi-org.proxy.lib.uwaterloo.ca/10.1080/09581596.2018.1508822

Kontos, P., & Martin, W. (2013). Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia, 12*(3), 288–302. https://doi.org/10.1177/1471301213479787

Kontos, P., & Miller, K., & Kontos, A. P. (2017). Relational citizenship: supporting embodied selfhood and relationality in dementia care. *Sociology of Health & Illness*, *39*(2), 182–198. https://doi.org/10.1111/1467-9566.12453

Kontos, P., Radnofsky, M. L., Fehr, P., Belleville, M. R., Bottenberg, F., Fridley, M., Massad, S., Grigorovich, A., Carson, J., Rogenski, K., Carpenter, K. S., Dupuis, S., Battalen, J., McDonagh, D., Fassbender, K., & Whitehouse, P. (2021). Separate and unequal: A time to reimagine dementia. *Journal of Alzheimer's Disease, 80*(4), 1395 – 1399. https://doi.org/10.3233/JAD210057

Kraehe, A., & Brown, K. (2011). Awakening teachers' capacities for social justice within arts-based inquiries, equity and excellence. *Education*, *44*(4), 488-511.

Krajnc, A. (2000). The art of green learning: From protest songs to media and mind bombs. *International Politics, 37*(1), 19 – 40.

Krüger, V., & Stige, B. (2015). Between rights and realities - music as a structuring resource in child welfare everyday life: a qualitative study. *Nordic Journal of Music Therapy*, *24*(2), 99–122. https://doi.org/10.1080/08098131.2014.890242

Lam, H. L., Li, W. T. V., Laher, I., & Wong, R. Y. (2020). Effects of Music Therapy on Patients with Dementia—A Systematic Review. *Geriatrics*, *5*(4), 62. https://doi.org/10.3390/geriatrics5040062

Latimer, J. (2012). Home care and frail older people: Relational extension and the art of dwelling. In C. Ceci, K. Björnsdóttir, & M. E. Purkis (Eds.), *Perspectives on care at home for older people* (pp. 35–61). Routledge.

Leavy, P. (2013). *Fiction as research practice: Short stories, novellas, and novels*. Left Coast Press, Inc.

Lee, C. A. (2003). *The Architecture of Aesthetic Music Therapy.* Barcelona Publishers.

Lee, C. A. (2015). Aesthetic Music Therapy. In J. Edwards (Ed.), *The Oxford Handbook of Music Therapy* (pp. 513 – 537). Oxford University Press.

Lee, S., O'Neill, D., & Moss, H. (2022). Dementia-inclusive group-singing online during COVID-19: A qualitative exploration. *Nordic Journal of Music Therapy*, *31*(4), 308–326. https://doi.org/10.1080/08098131.2021.1963315

Lee C. A., & Houde, M. (2011). *Improvising in Styles. A Workbook for Music Therapists, Educators and Musicians.* Barcelona Publishers.

Levinas. E. (1985). *Ethics and infinity*. (R. A. Cohen, Trans.). University Press

Licona, A. C., & Chávez, K. R. (2015). Relational literacies and their coalitional possibilities. *Peitho*, 18(1), 96–107. https://wacclearinghouse.org/docs/peitho/files/2015/10/18.1LiconaChavez.pdf

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Sage.

Lister R (2003) *Citizenship. Feminist Perspectives.* Basingstoke, UK: Palgrave Macmillan.

Lokon, E., Li, Y., & Parajuli, J. (2017). Using art in an intergenerational program to improve students' attitudes toward people with dementia. *Gerontology & Geriatrics Education*, *38*(4), 407–424. https://doi.org/10.1080/02701960.2017.1281804

Lotherington, A. T., & Obstfelder, A. U. (2024). Enacting citizenship through writing: an analysis of a diary written by a man with Alzheimer's disease. *Ageing and Society*, *44*(12), 2684–2702. https://doi.org/10.1017/S0144686X23000223

Mabire, J.B., Bouaziz, N., de Malherbe, A., & Charras, K. (2023). Inclusive Choir for Persons Living with Dementia: A Qualitative Study. *Activities, Adaptation, & Aging*, *47*(4), 501–518. https://doi.org/10.1080/01924788.2022.2151801

MacDonald, S., & Viega, M. (2012). Hear our voices: A music therapy songwriting program and the message of the Little Saints through the medium of rap. In S. Hadley & G. Yancy (Eds.), *Therapeutic uses of rap and hip-hop* (pp. 153 – 171). Brunner-Routledge.

MacTavish, E. (2025). *Exploring Social Citizenship in the Context of Leisure in Residential Care Settings.* Unpublished Master's Thesis. University of Waterloo.

Mair, H. (2002). Civil leisure? Exploring the relationship between leisure, activism and social change. *Leisure, 27*(3–4), 213–237. https://doi.org/10.1080/14927713.2002.9651304

Margolick, D. (1999). Performance as a Force for Change: The Case of Billie Holiday and "Strange Fruit." *Law & Literature, 11(1)*, 99 – 109.

McCabe, L., Greasley-Adams, C., & Goodson, K. (2015). 'What I want to do is get half a dozen of them and go and see Simon Cowell': Reflecting on participation and outcomes for people with dementia taking part in a creative musical project. *Dementia, 14*, 734–750. https://doi.org/10.1177/1471301213508128

McColgan, G. (2005). A Place to Sit: Resistance Strategies Used to Create Privacy and Home by People with Dementia. *Journal of Contemporary Ethnography*, *34*(4), 410–433. https://doi.org/10.1177/0891241605275574

McDermott, O., Crellin, N., Ridder, H. M., & Orrell, M. (2013). Music therapy in dementia: a narrative synthesis systematic review. *International Journal of Geriatric Psychiatry*, *28*(8), 781–794. https://doi.org/10.1002/gps.3895

McDermott, O., Orrell, M., & Ridder, H. M. (2014). The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists. *Aging & Mental Health*, *18*(6), 706–716. https://doi.org/10.1080/13607863.2013.875124

McKeown, J. K., Fortune, D., & Dupuis, S. L. (2016). "It is like stepping into another world": Exploring the possibilities of using appreciative participatory action research to guide culture change work in community and long-term care. *Action Research (London, England)*, *14*(3), 318–334. https://doi.org/10.1177/1476750315618763

McMahon, K., Baker, F. A., Stretton-Smith, P., & Clark, I. N. (2021). Using group therapeutic songwriting to support the dyadic relationship between people living with dementia and their family caregivers: Perspectives from music therapists. *Australian Journal of Music Therapy*, *32*(2), 57-78.

Merill, T. (2006). Power and voice in the institutional setting: A journey toward activating a feminist music therapy approach. In S. Hadley (Ed.)*, Feminist perspectives in music therapy* (pp. 187 – 204). Barcelona

Merleau-Ponty, M. (1962). *Phenomenology of perception*. Routledge.

Miles, M., & Huberman, A. (1994). *An expanded sourcebook: Qualitative data analysis* (2nd ed.). Sage Publications.

Miller, J. B. (1988). Connections, disconnections, and violations. *Work in Progress, No. 33*. Stone Center Working Paper Series.

Miller, J. B. (2004). Prefect. In J. Jordan., L Hartling & M. Walker (Eds.), *The complexity of connection* (pp. i-iv). Guilford Press.

Miller, K. L., & Kontos, P. (2016). The use of elder-clowning to foster relational citizenship in dementia care. In T. A. Andreassen, J. F. Gubrium & P. K. Solvang (Eds.), *Reimagining the human service relationship* (pp. 158–177). Columbia University Press.

Minkler, M., & Estes, C. L. (1999). *Critical gerontology: Perspectives from political and moral economy*. Baywood.

Mitchell, E. (2021). Performing Identities and Performing Relationships: Community Music Therapy and Adolescent Mental Health. *Music Therapy Perspectives*, *39*(2), 195–203. https://doi.org/10.1093/mtp/miab004

Mitchell, G. J., Dupuis, S. L., & Jonas-Simpson, C. (2011). Countering stigma with understanding: The role of theatre in social change and transformation. *Canadian Theatre Review*, 146, 22–27.

Mitchell, G., Dupuis, S. L., & Kontos, P. (2013). Dementia discourse: From imposed suffering to knowing otherwise. *Journal of Applied Hermeneutics.* Retrieved from http://jah.journalhosting.ucalgary.ca/jah/index.php/jah/article/view/41

Mitchell, G., Dupuis, S. L., Kontos, P., Jonas-Simpson, C., & Gray, J. (2020). Disrupting dehumanising and intersecting patterns of modernity with a relational ethic of caring. *International Practice Development Journal, 10*(1), 1 – 15. https://doi.org/10/19043/ipdj.101.002

Mitchell, G. J., Richards, J., Brown, S., Bitove, V., & Jonas-Simpson, C. (2021). Creating a relational arts-based academy for persons living with dementia. *Dementia, 20*(3), 1144 – 1153. https://doi.org/10.1177/147130121989

Moreno-Morales, C., Calero, R., Moreno-Morales, P., & Pintado, C. (2020). Music Therapy in the Treatment of Dementia: A Systematic Review and Meta-Analysis. *Frontiers in Medicine*, *7*, 160–160. https://doi.org/10.3389/fmed.2020.00160

Morgan, M.L., Franco, V., Felix, E., & Ramirez, N. M. (2023). "And the Ones that Survived had Hope": Resilience in Holocaust Survivors. Journal for Social Action in Counseling & *Psychology, 14*(2), 111 – 126. https://doi.org/0.33043/JSACP.14.2.111-126

Morhardt, D., & Spira, M. (2013). From Person-Centered Care to Relational Centered Care. *Generations, 37*(3), 37–44.

Nolan M.R., Brown J., Davies S., Nolan J. & Keady J. (2006). *The Senses Framework. Improving Care for Older People Through a Relationship Centred Approach. Getting Research into Practice Report no. 1,* University of Sheffield, Sheffield.

Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond "person-centred" care: a new vision for gerontological nursing. *Journal of Clinical Nursing*, *13*(1), 45–53. https://doi.org/10.1111/j.1365-2702.2004.00926.x

Nolan, M., Ryan, T., Enderby, P., & Reid, D. (2002). Towards a more inclusive vision of dementia care practice and research. *Dementia: The International Journal of Social Research and Practice, 1*(2), 193-211. https://doi.org/10. 1177/147130120200100206

Nordoff, P., & Robbins, C. (1977). *Creative music therapy: Individualized treatment for the handicapped child.* John Day.

Nussbaum, M. (2011). *Creating Capabilities.* Harvard University Press.

O'Connor, D., Sakamoto, M., Seetharaman, K., Chaudhury, H., & Phinney, A. (2022). Conceptualizing citizenship in dementia: A scoping review of the literature. *Dementia*, *21*(7), 2310–2350. https://doi.org/10.1177/14713012221111014

O'Grady, L. (2009). *Therapeutic potentials of creating and performing music with women in prison: A qualitative case study*. [Doctoral Dissertation, The University of Melbourne].

O'Grady, L. (2011). The therapeutic potentials of creating and performing music with women in prison: A qualitative case study. *Qualitative Inquiries in Music Therapy* (pp. 123 – 152). Barcelona Publishers.

O'Grady, L., & McFerran, K. (2006). Birthing feminist community music therapy: The progeny of Community Music Therapy practice and Feminist Music Therapy Theory. In S. Hadley (Ed.), *Feminist perspectives in music therapy* (pp. 63 – 80). Barcelona Publishers.

Ogston-Tuck, S., Baume, K., Clarke, C., & Heng, S. (2016). Understanding the patient experience through the power of film: A mixed method qualitative research study. *Nurse Education Today*, *46*, 69–74. https://doi.org/10.1016/j.nedt.2016.08.025

Oliver, M., & Barnes, C. (2012). *The new politics of disablement*. Palgrave MacMillan.

Olthius, J. H. (Ed.) (1997). *Knowing other-wise. Philosophy at the threshold of spirituality.* University Press.

Olthius, J. H. (2000). Otherwise than violence: Toward a hermeneutics of connection. In *The arts, community and cultural democracy* (pp. 137–164). Palgrave Macmillan.

Ontario's Long-Term Care COVID-19 Commission Final Report (2021).

Osei-Kofi, N. (2013). The emancipatory potential of arts-based research for social justice. *Equity & Excellence in Education*, *46*(1), 135-149.

Oxford English Dictionary. (2025). *Attune*. In *Oxford English Dictionary.* https://www.oed.com/dictionary/attune_n?tl=true

Oxford University Press. (n.d.). Testimony, n. In Oxford English dictionary. Retrieved April 14, 2026, from https://doi.org/10.1093/OED/7730014418

Palinkas, L. A., Horwitz, S. M., Green, C. A., (2015) Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(5), 533–544.

Palkki, J. (2022). "It just fills you up": The culture of monthly community singing events in one American city. *Research Studies in Music Education*, *44*(3), 475–490. https://doi.org/10.1177/1321103X221078534

Paterniti, D. A. (2003). Claiming Identity in a Nursing Home. In J. F. Gubrium & J. A. Holstein (Eds.), *Ways of Aging* (pp. 58–74). Blackwell Publishers Ltd.

Pavlicevic, M., & Ansdell, G. (2004). Introduction: "The ripple effect." In M. Pavlicevic & G. Ansdell (Eds.). *Community music therapy* (pp. 15 – 31). Jessica Kingsley.

Pavlicevic, M., Tsiris, G., Wood, S., Powell, H., Graham, J., Sanderson, R., Millman, R., & Gibson, J. (2015). The 'ripple effect': Towards researching improvisational music therapy in dementia care homes. *Dementia*, *14*(5), 659–679. https://doi.org/10.1177/1471301213514419

Phinney, A., Kelson, E., Baumbusch, J., O'Connor, D., & Purves, B. (2016). Walking in the neighbourhood: Performing social citizenship in dementia. *Dementia: The International Journal of Social Research and Practice, 15*(3), 381–394. https://doi.org/10.1177/1471301216638180

Pickles, V., & Jones, R. A. (2006). The person still comes first: The continuing musical self in dementia. *Journal of Consciousness Studies, 13*(3), 73–93.

Pyer, M., & Ward, A. (2024). Developing a dementia friendly approach to consent in dementia research. *Aging & Mental Health*, *28*(2), 294–301. https://doi.org/10.1080/13607863.2023.2264216

Reed, J., Weiner, R., & Cook, G. (2004). Partnership research with older people – moving towards making the rhetoric a reality. *Journal of Clinical Nursing, 13*(1), 3–10.

Reynolds, L., Innes, A., Poyner, C., & Hambidge, S. (2017). 'The stigma attached isn't true of real life': Challenging public perception of dementia through a participatory approach involving people with dementia (Innovative Practice). *Dementia, 16*(2), 219–225. https://doi.org/10.1177/1471301216635828

Rio, R. (2018). A Community-Based Music Therapy Support Group for People with Alzheimer's Disease and Their Caregivers: A Sustainable Partnership Model. *Frontiers in Medicine*, *5*, 293–293. https://doi.org/10.3389/fmed.2018.00293

Robinson, R. S. (2014). Purposive Sampling. In A. C. Michalos (Ed.), *Encyclopedia of Quality of Life and Well-Being Research* (pp. 5243–5245). Springer.

Rolvsjord, R. (2010). *Resource-oriented music therapy in mental health care.* Barcelona Publishers.

Rolvsjord, R. (2014). The Competent Client and the Complexity of Dis-ability. *Voices: A World Forum for Music Therapy*, *14*(3). https://doi.org/10.15845/voices.v14i3.787

Rolvsjord, R. (2015) Resource-Oriented Perspectives in Music Therapy. In J, Edwards (Ed.), *The Oxford Handbook of Music Therapy* (pp. 557 – 577). Oxford University Press.

Ryan, T., Nolan, M., Reid, D., & Enderby, P. (2008). Using the Senses Framework to achieve relationship-centred dementia care services: A case example. *Dementia, 7*(1), 71–93. https://doi.org/10.1177/1471301207085368

Sabat, S. R., & Warren, A. (2023). Exploring why "memory loss" is a misleading descriptor of people living with dementia and can lead to dysfunctional care. *Dementia, 22*(8), 1819–1832. https://doi.org/10.1177/14713012231200622

Schwandt, T. S. (2001). *Dictionary of qualitative research* (2nd ed). Sage.

Scotland, J. (2012). Exploring the philosophical underpinnings of research: Relating ontology and epistemology to the methodology and methods of the scientific, interpretive, and critical research paradigms. *English Language Teaching, 5*(9), 9 – 16. https://doi.org/10.5539/elt.v5n9p9

Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? *Research and Social Sciences and Disability, 2*, 9 – 28.

Shannon, P., & Hambacher, E. (2015). Authenticity in Constructivist Inquiry: Assessing an Elusive Construct. *Qualitative Report*, 19(52), 1 – 13. https://doi.org/10.46743/2160-3715/2014.1418

Shibazaki, K., & Marshall, N. A. (2017). Exploring the impact of music concerts in promoting well-being in dementia care. *Aging & Mental Health*, *21*(5), 468–476. https://doi.org/10.1080/13607863.2015.111458

Schutz, A. (1967). *Collected papers I: The problem of social reality* (2nd ed.). Martinus Nijhoff.

Silber, F., & Hes, J. (1995). The Use of Songwriting with Patients Diagnosed with Alzheimer's Disease. *Music Therapy Perspectives*, *13*(1), 31–34. https://doi.org/10.1093/mtp/13.1.31

Silverman, M. J. (2020). Therapeutic Songwriting for Perceived Stigma and Perceived Social Support in Adults with Substance Use Disorder: A Cluster-Randomized Effectiveness Study. *Substance Use & Misuse*, *55*(5), 763–771. https://doi.org/10.1080/10826084.2019.1701037

Sixsmith, A., & Gibson, G. (2007). Music and the wellbeing of people with dementia. *Ageing and Society*, *27*(1), 127–145. https://doi.org/10.1017/S0144686X06005228

Small, Christopher (1998). *Musicking. The Meanings of Performing and Listening.* Wesleyan University Press.

Smith, A. P., Kampen, R., Sheets, D. J., & MacDonald, S. W. S. (2026). Choir Singing for People With Dementia and Their Care Partners: Exploring the Role of Bonding Social Capital. *Dementia,* 14713012261464862. https://doi.org/10.1177/14713012261464862

Spencer, L. (2023). Epistemic Injustice in Late-Stage Dementia: A Case for Non-Verbal Testimonial Injustice. Social Epistemology, 37(1), 62–79. https://doi.org/10.1080/02691728.2022.2103474

Stige, B. (2002) *Culture-centered music therapy.* Barcelona

Stige, B. (2003). Elaborations toward a notion of community music therapy. [Doctoral Dissertation, University of Oslo].

Stige, B. (2012). *Elaborations toward a notion of community music therapy.* Barcelona

Stige, B. (2015). Community music therapy. In B. L. Wheeler (Ed.), *Handbook of Music Therapy* (pp 233 – 245). The Guilford Press.

Stige, B., & Aarø, L. E. (2012). *Invitation to community music therapy*. Routledge.

Stige, B., & Ansdell, G. (2016). Community Music Therapy. In J. Edwards (Ed.), *The Oxford Handbook of Music Therapy* (pp. 595 – 621). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780199639755.013.6

Stige, B., Ansdell, G., Elefant, C., & Pavlicevic, M. (2016). *Where music helps: Community music therapy in action and reflection.* Routledge

St. Pierre, E. (2000). Post-structural feminism in education: An overview. *International Journal of Qualitative Studies in Education, 13*(5), 477–515.

Teshuva, K., & Wells, Y. (2014). Experiences of ageing and aged care in Australia of older survivors of genocide. *Ageing and Society*, *34*(3), 518–537. https://doi.org/10.1017/S0144686X12001109

Thaut, M. H. (2005). *Rhythm, music and the brain*. Routledge.

Thaut, M. H., & Hoemberg, V. (Eds.). (2014) *The Oxford handbook of neurologic music therapy.* Oxford University Press.

Theurer, K., Mortenson, W. B., Stone, R., Suto, M., Timonen, V., & Rozanova, J. (2015). The need for a social revolution in residential care. *Journal of Aging Studies*, *35*, 201–210. https://doi.org/10.1016/j.jaging.2015.08.011

Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society*, *19*(6), 569–583. https://doi.org/10.1080/0968759042000252506

Thompson, J. (2015). Towards an aesthetics of care. *Research in Drama Education*, *20*(4), 430–441. https://doi.org/10.1080/13569783.2015.1068109

Timonen, V., & O'Dwyer, C. (2009). Living in Institutional Care: Residents' Experiences and Coping Strategies. *Social Work in Health Care*, *48*(6), 597–613. https://doi.org/10.1080/00981380902791267

Titchkosky, T., & Michalko, R. (2009). Introduction. In T. Titchkosky & R. Michalko (Eds.), *Rethinking normalcy: A disability studies reader* (pp. 1–14). Canadian Scholars Press.

Tornstam, L. (1989). Gero-transcendence: A reformulation of the disengagement theory. *Aging Clinical and Experimental Research*, *1*(1), 55–63. https://doi.org/10.1007/BF03323876

Unbehaun, D., Taugerbeck, S., Aal, K., Vaziri, D. D., Lehmann, J., Tolmie, P., Wieching, R., & Wulf, V. (2021). Notes of memories: Fostering social interaction, activity and reminiscence through an interactive music exergame developed for people with dementia and their caregivers. *Human–Computer Interaction*, *36*(5–6), 439–472. https://doi.org/10.1080/07370024.2020.1746910

Ursin, G., & Lotherington, A. T. (2018). Citizenship as distributed achievement: Shaping new conditions for an everyday life with dementia. *Scandinavian Journal of Disability Research: SJDR*, *20*(1).

Vaillancourt, G. (2012). Music therapy: A community approach to social justice. *The Arts in Psychotherapy*, *39*(3), 173–178. https://doi.org/10.1016/j.aip.2011.12.011

Van Lieshout, F., & Cardiff, S. (2011). Innovative ways of analysing data with practitioners as co-researchers: Dancing outside the ballroom. In J. Higgs, A. Titchen, D. Horsfall & D. Bridges (Eds.), *Creative spaces for qualitative researching: Living research* (pp. 223-234). Sense Publishers.

Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, *18*(1), 148–148. https://doi.org/10.1186/s12874-018-0594-7

Vidal, F. (2009). Brainhood, anthropological figure of modernity. *History of the Human Sciences*, *22*(1), 5–36. https://doi.org/10.1177/0952695108099133

Wadensten, B. (2005). Introducing older people to the theory of gerotranscendence. *Journal of Advanced Nursing*, *52*(4), 381–388. https://doi.org/10.1111/j.1365-2648.2005.03603.x

Wang, H. (2001). Aesthetic experience, the unexpected, and curriculum. *Journal of Curriculum and Supervision*, *17*(1), 90–94.

Watkins, M., & Shulman, H. (2008). *Toward psychologies of liberation*. Springer.

White, J. (2008). The arts of citizenship. In E. Isin & G. M. Nielsen (Eds.), *Acts of citizenship* (pp. 37–52). Zed Books.

Wigram, T. (2004). *Improvisation: methods and techniques for music therapy clinicians, educators, and students*. J. Kingsley Publishers.

Williams, F. (2001). In and beyond New Labour: towards a new political ethics of care. *Critical Social Policy*, *21*(4), 467–493. https://doi.org/10.1177/026101830102100405

Williams, R. (2017). Being with and being there: Our enactment of wide-awakeness. *International Journal of Education & the Arts, 18*(21), 1–27.

Wollan, G. (2023). Dementia, music, and field of care. *Norwegian Journal of Geography, 77*(5), 315 – 320. https://doi.org/10.1080/00291951.2023.2289522

Yang, H. D., Kim, D. H., Lee, S. B., & Young, L. D. (2016). History of Alzheimer's Disease. *Dementia and neurocognitive disorders*, *15*(4), 115–121. https://doi.org/10.12779/dnd.2016.15.4.115

Young, I. (1990). The Five Faces of Oppression. *In Justice and the Politics of Difference*, 39 – 63. Princeton University Press.

Young, I. M. (2000). *Inclusion and Democracy.* Oxford University Press.

Young, L. (in press). Deconstructing assumptions about how music helps persons living with dementia. In J. Lang (Ed.) *Music and Wellbeing in Education and Community Contexts*. Cambridge Scholar.

Zaks, Z. (2024). Changing the medical model of disability to the normalization model of disability: clarifying the past to create a new future direction. *Disability & Society*, *39*(12), 3233–3260. https://doi.org/10.1080/09687599.2023.2255926

Appendix A: Staff Recruitment Script for Residents – Verbal Script to be Used by Staff in Initial Contact with Potential Participants

I am meeting with you today to see if you might be interested and willing to participate in a research project led by Taylor Kurta, a PhD student at the University of Waterloo. Taylor uses songwriting to challenge people's perceptions of older adults and what it means to live with dementia.

Music, and specifically songwriting, has been used to change individual perceptions of different groups and in many different settings. However, very little research has explored the use of songwriting to challenge stigma related to dementia.

Taylor is looking for people who enjoy music and are interested in participating in a group songwriting project which will be used to change the way people think about growing older and specifically dementia. You do not have to have any prior experience with music or songwriting to participate in this project, just a love for music and a desire to participate in the project.

As part of this project, Taylor will be leading five group songwriting sessions and one group research conversation here at (home name). Once the study is completed, there will be an opportunity for those who are interested to go to a professional recording studio to record the song and take part in a short documentary film that will be shared with the larger community. You are not required to participate if you do not want to, however, if you are interested, I will arrange for Taylor to meet with you so she can tell you more about the project and what it will entail.

If yes: connect resident with Taylor

If no: That is no problem at all. Thank you for your time!

Appendix B: Staff Recruitment Script for SDM – Email or Verbal Script to be Used by Staff

Hi **(Name of SDM)**

(Home name) is supporting our music therapist, Taylor Kurta, in her research study exploring the use of songwriting to challenge stigma associated with dementia. Music, and specifically songwriting has been used to as a tool for social justice in many different settings. However, very little research has explored the use of songwriting to challenge stigma related to dementia.

Taylor is looking for people who enjoy music and are interested in participating in a group songwriting project which will be used to change the way people think about growing older and specifically dementia. **(Name of resident)** has indicated their interest in participating in this study and we wanted to reach out to you about next steps in the process.

As part of this project, **(Name of resident)** would be invited to participate in five group songwriting sessions and one group research conversation here at (home name). Once the study is completed, there will be an opportunity for those who are interested to record the song and take part in a short documentary film that will be shared with the larger community. Participation in this project is completely voluntary and **(Name of resident's)** decision to participate or not will not impact the future or current services they are receiving. If you are interested in **(Name of resident)** being part of this project, I would be happy to introduce you to Taylor Kurta (the doctoral student who will be leading this study) so she can tell you more about the project and what it will entail.

Thank you and speak soon,

(Your Name)

Appendix C: Researcher Recruitment Script for SDM – Verbal Script to be Used by Researcher Prior to Gaining Initial Consent

R: Hi (SDM name), My name is Taylor, and I am a PhD student at the University of Waterloo completing a thesis titled, "Collaborative Songwriting with People Living with Dementia to Challenge Stigma". This research explores the use of songwriting to challenge the way people perceive older adults and specifically people living with dementia. I am meeting with you today because (family member name) indicated to (staff member name) that they are interested in participating in this project and I would like to share some more information with you. Is now a good time to chat?
SDM: No.

R: That is no problem at all. Is there a better time to meet?

SDM: Yes.

R: Okay (schedule time to meet).

OR

SDM: Yes.

R: Okay great. As part of this project, I will be leading five group songwriting sessions with about five to ten residents here at (home name) where we will be writing a song about what they want the world to know about them. Once the study is completed, there will be an opportunity for those who are interested to record the song and take part in a short documentary film that will be shared with the larger community. Participation in this project is completely voluntary and (Name of resident) decision to participate or not will not impact the future or current services they are receiving. Would you be interested in hearing more about the project? If so, I can walk you through the information letter.

SDM: No.

R: That is no problem. Thank you so much for taking the time to meet with me today.

OR

SDM: Yes.

R: Wonderful. Would now be an okay time to go over the information letter together?

SDM: Yes.

R: Excellent. Do you have any questions before we begin?

SDM: Yes.

R: Okay, what is your question?

SDM: Question(s)

R: Answer(s). Any other questions?

SDM: No

OR

SDM: No

R: (read through information letter with SDM) Do you have any questions?

SDM: Yes.

R: Okay, what is your question?

SDM: Question(s)

R: Answer(s). Any other questions?

SDM: No

OR

SDM: No

R: Okay, would you be interested in supporting your family member in participating in this study?

SDM: No

R: That is no problem. Thank you so much for taking the time to meet with me today.

OR

SDM: Yes.

R: Wonderful. Would now be an okay time to go over the consent form together or would you like me to leave this with you so you can discuss this with your family member?

SDM: No.

R: When would you like me to come back to meet with you to go over the consent form?

OR

SDM: Yes

R: (read through the consent form) and answer any questions. Thank you for your time today. I am looking forward to working with your family member on this collaborative songwriting project. Please feel free to reach out anytime if you have any questions.

Appendix D: SDM Information and Consent Form

Information and Consent Form to Participate in a Research Study for Substitute Decision-Makers in Long-Term Care and Retirement Homes

Study Title:	**Collaborative Songwriting with People Living with Dementia to Challenge Stigma**
Student Investigator:	**Taylor Kurta** **University of Waterloo** **(647-886-2258; tkurta@uwaterloo.ca)**
Student Advisor:	**Dr. Sherry Dupuis** **University of Waterloo** **(519-888-4567, ext 46188; sldupuis@uwaterloo.ca)**

Introduction:

You are being asked, as your family member's substitute decision maker, to consent to their participation in a research study. Please read the information about the study presented in this form. The form includes details on what your family member will be asked to do that you should know before you decide if you would like to consent for your family member to take part. You and your family member should take as much time as you need to make your decision. You should ask the study researcher 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 along with your family member who lives with dementia, feel free to talk about this study with anyone you wish including your friends, family, or a member of your family member's healthcare team.

What is the purpose of this project?

People living with dementia are highly stigmatised in society. For example, people living with dementia are often depicted in the media, policy documents, and the academic literature in terms of what they can't do rather than what they are still capable of doing. Stigma related to dementia has profound consequences for people living with dementia and their family members, shaping how people think about people living with dementia, their relationships with others, and the structures and experiences of care. A growing body of literature supports the use of the arts and specifically music as an effective way to challenge harmful societal narratives to create a better future for people living with dementia and their family members. However, the use of music to challenge stigma related to dementia is very rarely explored. This study aims to use collaborative songwriting to support people living with dementia in writing a song about what they want the world to know about them. By highlighting the strengths and capabilities of people living with dementia through collaborative songwriting, I hope that this study will work towards changing societal views on what it means to have dementia.

Who can participate in this project?

We are looking for approximately 5-8 residents with dementia living at (name of home) To participate your family member must:

- Have a diagnosis of dementia.
- Be able to communicate verbally and in English to some degree.
- Be willing to participate in the project and communicate their agreement to take part either verbally or in writing.

In order for your family member to participate, you will need to provide written or verbal consent as the substitute decision-maker. We will also be obtaining consent from all resident participants prior to beginning each songwriting session. Residents will be told that they are being asked to participate in a songwriting project that seeks to highlight what they want the world to know about them.

What will your family member's participation involve?

Your family member's participation in this study is voluntary. You and your family member may decide not to participate in this study, or to participate in the study now, and then change your minds later.

If you and your family member agree to participate, your family member will be asked to participate in the following:

- **A 15-minute one-to-one introduction conversation with the researcher –** Before we begin the songwriting process, I will meet with your family member to ask some questions about them including how they would describe themselves and their relationship/experiences with music.
- **Five one-hour group songwriting sessions (over the course of five-weeks)** that will take place here at the home. In these sessions, I will work with your family member and the other participants to create a song exploring what they want the world to know about them and how they feel people living with dementia should be treated. This may involve brainstorming lyrics for the song and discussing what the song should sound like. At the end of each session, there will be a group discussion on how your family member feels the project is going and what they would like to expand on in the next week. All of the songwriting sessions will be audio recorded so that I can have an accurate description of the sessions. I will also be writing notes about the process and conversations had in the sessions for analysis purposes.
- **A final one-hour group research conversation** – After the five songwriting sessions, I will meet with your family member and the other participants to discuss their experience of participating in this project. This discussion will be audio-recorded with your and your

family member's permission.

Once the study is completed, there will be an additional opportunity to record the song and take part in a short documentary film. The short documentary will then be shown at a release party at One Kenton Place. This opportunity is not part of the research and completely voluntary. If you are interested in your family member taking part in the recording and short documentary, you will receive information about this at a later time.
No songwriting or musical experience is required to participate in this project. Only a love for music and a desire to engage with others.

Withdrawal from the Study:

If you and your family member agree to participate in this project, you should know that your family member may leave the study at any time by you or them notifying me, Taylor Kurta, or a staff member at One Kenton Place. If your family member chooses to leave the project, any information they shared will be removed from the research unless you give me permission to use what they had already shared. Because this project includes collaborative songwriting, it cannot be guaranteed that your family member's ideas for the song will be able to be removed. Once the research findings are shared in reports, articles, and presentations, it will not be possible to remove your family member's information. Your family member can withdraw their consent and request for data to be removed up until study findings are submitted for publication, anticipated sometime in 2024 or early 2025. It is not possible to remove data once findings have been published.

What risks might be involved?

It is possible that your family member may feel anxiety/unease about participating in songwriting if they have not written a song before. Time will be taken in each songwriting session to discuss what your family member needs to feel comfortable participating in the process. Your family member will not be required to participate in any part of the process they are not comfortable with, and each part of the process will be guided by the researcher who is a professional songwriter and music therapist.

What are the benefits of participation?

This research offers an opportunity for your family member to meaningfully contribute to a project which aims to change the landscape of how society views people living with dementia. Further, participating in music is known to have many benefits for people living with dementia (e.g., social benefits, feelings of belonging, community engagement, creative self-expression) and my hope is that, in addition to participating in an important social justice initiative, participants may also experience many of these benefits.

How will information shared be protected?

At the beginning of each songwriting session, all participants will be asked to respect the confidentiality of all comments made by other group members by not repeating what was shared outside of the session. However, I cannot guarantee that every participant will honour this request. Your family member is free to share what they contributed to the sessions with others if they wish.

All information collected for this study and all study documents will be password protected and securely stored for at least seven years on a TEAMS site which is a protected site used by researchers at the University of Waterloo. With your permission, participant comments may be quoted when we discuss the results of the study in presentations and publications. As this is a participatory project, participants will be given the option to have their real name, or another name chosen by them (a pseudonym) used in the study results. The list of participants and their chosen pseudonyms, where applicable, as well as other documents with identifying information (e.g., consent forms, audio-recordings), will be stored separately from the rest of the data in password-protected files on the TEAMS site. Once the research findings are shared in the dissertation, reports, articles, and presentations, it will not be possible to remove your family member's information.

Only my supervisor and I will have access to study materials that contain identifying information. Audio recordings will be stored securely and deleted once they are transcribed.

Quotations from the audio-recordings of the songwriting sessions and final discussion session may be used in written reports of the findings (e.g., publications, teaching-learning resource materials), as well as at conferences or other speaking engagements. As mentioned earlier, you/your family member will be given the option to have their real name or a pseudonym chosen by them to be used in the study results.

Voluntary Participation:

Participation in this project is completely voluntary and your family member's decision to participate or not will not impact the future or current services they are receiving. You and/or your family member may decide for your family member not to be in this study, or to be in the study now, and then change their/your mind later. Your family member can also choose what they respond to and what they don't respond to during the songwriting and final discussion sessions. They can also choose what they participate in and what they don't participate in.

Along with initial consent, your family member will be asked at the beginning of each session if they wish to continue their participation in the study.

What if you have questions about the project?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46535). If you have questions for the Board, contact the Office of

Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

If you have any questions, concerns or would like to speak to the study team for any reason, you can email *Taylor Kurta* (tkurta@uwaterloo.ca). If you would rather a telephone conversation you can reach Taylor at (647)-886-2258. You may also contact the student advisor, *Sherry Dupuis* (sldupuis@uwaterloo.ca).

If you are willing to provide consent for your family member to participate in this study, please complete the attached consent form and email it to Taylor at tkurta@uwaterloo.ca once completed. If you would prefer to go over this information letter with Taylor and provide verbal consent, please contact Taylor and she will arrange a time to meet with you on Zoom or over the telephone at your convenience. Should you provide consent, you will be given a copy of the signed consent form (see next page).

Thank you for considering supporting your family member's involvement in this project on collaborative songwriting to challenge stigma.

Consent

This study has been explained to me and any questions I had have been answered. I know that my family member may leave the project at any time. I agree to the use of my family member's information as described in this form.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46535). If I have questions for the Board, I understand that I can contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

As my family member's substitute decision-maker, I consent to the following:

I agree to my family member participating in the song-writing sessions and the final discussion session for this project.

☐ **YES** ☐ **NO**

I agree to the audio-recording of all songwriting sessions and the final discussion session.

☐ **YES** ☐ **NO**

I understand that quotations from the songwriting sessions and final discussion session may be used in written reports of this project (e.g., publications, teaching-learning resource materials), as

well as at conferences or other speaking engagements and give permission for the use of my family member's quotations.

☐ **YES, use quotations with family member's full name**

☐ **YES, use quotations but only with my family member's first name**

☐ **YES, use quotations but only with my family member's chosen pseudonym**

☐ **NO, I do not consent to the use of my family member's quotations**

I am interested in learning more about my family member being involved in the process for recording the song and accompanying film and agree to be approached later with more information.

☐ **YES** ☐ **NO**

Signatures:

I understand the nature of this project and wish for my family member to participate. I am not waiving any of my legal rights by signing this form or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities. My signature below indicates my consent.

Participant's Name: _____

Substitute Decision-Maker's Name: _____

Substitute Decision-Maker's Signature: _____

Date: _____

My signature means that I have explained the study to the substitute decision-maker named above. I have answered all questions.

_____ _____ _____

Print Name of Person Obtaining Consent	Signature	Date

For verbal consent:

Participant's name: _____

Substitute decision-maker's name: _____

[ ] Verbal consent was obtained by:

Researcher's name: _____

Researcher's signature: _____

Date verbal consent obtained: _____

Appendix E: Resident Information and Consent Form

Information and Consent Form to Participate in a Research Study for Residents in Long-Term Care and Retirement Homes

Study Title:	**Collaborative Songwriting to Challenge Stigma Associated with Dementia**
Student Investigator:	**Taylor Kurta** **University of Waterloo** **(647-886-2258; tkurta@uwaterloo.ca)**
Student Advisor:	**Dr. Sherry Dupuis** **University of Waterloo** **(519-888-4567, ext. 46188; sldupuis@uwaterloo.ca)**

What is the purpose of this project?

Songs have long been used to as a way to address important social issues. This project will use songwriting to support people like yourself in sharing what you want the world to know about you and how you want to be treated in the world. I am hoping this project can help show people that older adults and people living with dementia have a lot to contribute and important messages to share with the world.

What will you be asked to do if you are in the project?

I am looking for residents like yourself who are willing engage in a group songwriting project. Involvement in this project will include:

- **A 15-minute one-to-one introduction conversation with the researcher –** Before we begin the songwriting process, I will meet with you to ask some questions about yourself including how you would describe yourself and your relationship/experiences with music.
- **Five one-hour group songwriting sessions (over the course of five-weeks)** that will take place here at the home. In these sessions, we will work together with other people who live here to create a song exploring what you want the world to know about you and how you feel people like yourself should be treated. This may involve brainstorming lyrics for the song and discussing what the song should sound like. At the end of each session, we will have a group discussion on how you feel the project is going and what you would like to expand on in the next week. With your permission, these discussions will be audio recorded so that I can have an accurate description of what was expressed. I will also be writing notes about the process and conversations had in the sessions for

analysis purposes.

- **A final one-hour group research conversation** – After the five songwriting sessions, we will meet as a group to discuss your experience of participating in this project. This discussion will be audio-recorded with your permission.

Once the study is completed, there will be an additional opportunity to record the song and take part in a short documentary film. The short documentary will then be shown at a release party at (name of home). This opportunity is not part of the research and completely voluntary. If you are interested in taking part in the recording and short documentary, you will receive information about this at a later time. No songwriting or musical experience is required to participate in this project. Only a love for music and a desire to engage with others.

Do you have to be in the project?

Participation in this project is completely voluntary and your decision to participate or not will not impact the future or current services you are receiving. If you decide to participate now but later you change your mind, then you can tell me, your family member, or a staff member that you do not want to be in the study anymore. If you choose to leave the project, any information you shared will be removed from the research unless you give me permission to use what you had already shared. Because of the group format of the song writing sessions, it may not be possible to remove all your ideas for the song.

What risks might be involved?

It is possible you may feel anxiety/unease about participating in songwriting if you have not written a song before. Time will be taken in each songwriting session to discuss what you need to feel comfortable participating in the process. You will not be required to participate in any part of the process you are not comfortable with, and each part of the process will be guided by the researcher who is a professional songwriter and music therapist.

What are the benefits of participating in the project?

This research offers an opportunity to contribute to a project which aims to change the way people view older adults and people living with dementia.

Will you have to answer all questions and do everything you are asked to do?

You can choose what you respond to what you don't respond to during our songwriting and final discussion sessions. You can also choose what you participate in and what you don't participate in. If you prefer not to engage in any of the sessions, let Taylor, your family member, or a staff member know.

How will information you share be protected?

At the beginning of each songwriting session, all participants will be asked to respect the confidentiality of all comments made by other group members by not repeating what was shared outside of the session. However, I cannot guarantee that every participant will honour this request. Of course, you are free to share what you contributed to the sessions with others if you wish.

All information collected for this study and all study documents will be password protected and securely stored for at least seven years on a TEAMS site which is a protected site used by researchers at the University of Waterloo. With your permission, your comments may be quoted when we discuss the results of the study in presentations and publications. As this is a participatory project, participants will be given the option to have their real name, or another name chosen by them (a pseudonym) used in the study results. The list of participants and their chosen pseudonyms, where applicable, as well as other documents with identifying information (e.g., consent forms, audio-recordings), will be stored separately from the rest of the data in password-protected files on the TEAMS site. Once the research findings are shared in the dissertation, reports, articles, and presentations, it will not be possible to remove your information.

Only my supervisor and I will have access to study materials that contain identifying information. Audio recordings will be stored securely and deleted once they are transcribed.

Has the study received ethics clearance?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46535). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

What if you have questions about the project?

You can ask questions at any time. You can ask now, or you can ask later. You can talk to me now or I can be reached by telephone at (647)-886-2258. You may also contact the student advisor, *Sherry Dupuis* (sldupuis@uwaterloo.ca).

You should take as much time as you need to make your decision. Before you make your decision, feel free to talk about this study with anyone you wish including your friends or a family member.
If you are willing to participate in this study, you will need to provide written consent by signing the consent form on the next page or provide verbal consent by letting me know that you wish to participate, and I will complete the consent form with you. Should you choose to participate, you will be given a copy of the signed consent form.

Thank you for considering participating in this project on collaborative songwriting to challenge stigma.

Consent

This study has been explained to me and any questions I had have been answered. I know that I may leave the project at any time. I agree to the use of my information as described in this form.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46535). If I have questions for the Board, I understand that I can contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

I consent to the following:

I agree to participating in the song-writing sessions and the final discussion session for this project.

☐ **YES** ☐ **NO**

I agree to the audio-recording of all songwriting sessions and the final discussion session.

☐ **YES** ☐ **NO**

I understand that quotations from the songwriting sessions and final discussion session may be used in written reports of this project (e.g., publications, teaching-learning resource materials), as well as at conferences or other speaking engagements and give permission for the use of my quotations.

☐ **YES, use quotations with my full name**

☐ **YES, use quotations but only with my first name**

☐ **YES, use quotations but only with my chosen pseudonym**

☐ **NO, I do not consent to the use of my quotations**

I am interested in learning more about being involved in the process for recording the song and accompanying film and agree to be approached later with more information.

☐ **YES** ☐ **NO**

Signatures:

I understand the nature of this project and wish to participate. My signature below indicates my consent.

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

For verbal consent:

Participant's name: _____

[ ] Verbal consent was obtained by:

Researcher's name: _____

Researcher's signature: _____

Date verbal consent obtained: _____

Appendix F: Verbal Assent Script

Researcher (R): Hello, thank you for making the time to be here today. As you know, my name is Taylor and I am a PhD student at the University of Waterloo completing a thesis titled, "Collaborative Songwriting with People Living with Dementia to Challenge Stigma". This research explores the use of songwriting to challenge the way people perceive older adults and specifically people living with dementia. You have previously agreed to participate in a series of songwriting sessions where we will be working together to create a song that highlights the ways you want to be seen and treated in the world. This is our [?] session together.

A few reminders before we begin today:

- Your participation in this project and in this session today is completely voluntary.
- During the songwriting process, you may decline to answer any questions that you prefer not to answer. If you feel you need to take a pause during our session, please feel free to ask for a break and we can continue when you are ready.
- In order for me to capture our collaborative songwriting process, I will be audio-recording this session. This recording is being used as a way to document our process and be able to provide recommendations so others can engage in similar projects. Direct quotes from these recordings may be used in the write up of this research if you gave permission to use your quotes in the consent form. Additionally, I will only refer to you by name if you have requested that in your consent form.
- This is a collaborative project and therefore other group members involved will know who else is involved and what was shared in these sessions. While I cannot promise complete confidentiality, it is important that we respect the confidentiality of all comments shared during these sessions.
- Your name will not appear in any publication or presentation resulting from this research, unless you have provided consent to do so.
- You may leave the study at any time by letting me know that you no longer want to participate. The information you have shared during our songwriting sessions will be removed from the research unless you give me permission to use what you had already contributed. Once I have submitted the research for publication and once the song is released, it will not be possible to remove the information you have shared.
- I want to remind you that this study has received ethics clearance through a University of Waterloo Research Ethics Board. Should you have any questions or concerns resulting from your involvement in this study, you are encouraged to contact this office using the contact information in the Information and Consent Form you should have a copy of.

R: Do you have any questions?

Participants (P): No

OR

P: Yes

R: Okay, what is your question?

P: Question(s)

R: Answer(s). Any other questions?

P: No

R: Please indicate yes or no that you agree to participate in this songwriting session.

P: Yes

OR

P: No

R: (If participant says ‘No’) Okay, no problem I will be in touch within the next couple of days to discuss whether or not you still wish to participate in this project. Thank you for your time today and I will talk to you soon.

R: [Once participant has agreed to this] Okay let’s begin.

Appendix G: Getting to Know the Songwriters Interview Questions

Date:

Songwriter name or pseudonym:

- How would you describe yourself?

- What do you feel is important for me to know about you?

- What is your relationship with music? What experiences, if any, do you have with music?

Appendix H: Weekly Session Plans

Week 1

Welcome and group introductions

- Introduce myself to the group (I will say something along the lines of "before we get into the purpose of this project, I wanted all of us to introduce ourselves to one another and sing a few songs to get us in a musical mood") à the issue is that I won't be able to record this part as it is before consent but I think that is okay.
- Ask everyone to introduce themselves to the group à (name and how music makes you feel)
- We will play/sing a few songs together based on group musical preferences. I will hand out instruments for this activity.

Introduction to the project and group consent

- I will introduce the objectives and aims of the project (writing a song about what we want the world to know about us) à this is how I have introduced the project during the consent process à I will also give a brief introduction to how I got to this work (i.e., speaking about my grandparents). The residents often ask about my grandparents, and I think they will appreciate this (I can also tie this back to relational caring principles of vulnerability and mutual sharing).
- Consent script

Critical reflection and beginning of the songwriting process

- Explain how songwriting can share messages with the world to change the way people are viewed (tie to 1960s songs). Share that the purpose of writing a song together is to share a message with the world and re-state that each week we will meet to write a song which shows the world what you want them to know about you and how you think people like yourself should be treated. I will also share that the first step in the songwriting process is to come up with a general direction for the song. To get this started I have come up with the following questions to ask the group (I will write answers on the whiteboard). For the first week, I want to ask questions similar to those on the interview sheet.

1) How would you describe yourself? (this question elicited a lot of responses about identity when I asked it during the interviews)
2) What do you value?
3) What is important to you?
4) What makes you happy? (next week, I will get into more critical questions)

- After we answer these questions, I will re-read our answers and ask the following question (this question is meant to begin brainstorming what the song might sound like and I will share this with the group):

    1) What kind of mood do you feel these answers convey?

Closing critical reflection

Each week, I will ask songwriters to engage in a group discussion on what they are taking from the songwriting process and what they would like to see changed or expanded upon in coming weeks. Example guiding questions for this week might include:

1) What excites you about this project?
2) What are you hoping comes from this project?
3) How does everyone feel about this first session?
4) What's one word you would use to describe how you feel from today's session?

Musical closing

Each week will close with a musical activity. This activity will vary weekly depending on the preferences of the group. Some examples might include group singing and improvisation. I will ask the group what they would like to sing.

Week 2

Welcome and overview of the session

- Welcome everyone
- Re-state project objectives à grandparents
- What we will be doing today

Consent

- Read consent form
- Start recording

Musical warm-up

- A song about how we feel today à what does the group want to do?

Critical reflection

This week we will be continuing to write the words for the song (to get a general direction of where we want to go)

Last week, we answered the following questions:

1. How would you describe yourself

2. What makes you happy
3. What is important to you

Today we are going to expand on these questions and then start to think about what we want our song to sound like.

1. How would you describe yourself à summarize (anything else)?
2. What makes you happy? (on the sunny side of the street)
   à What doesn't make you happy?
3. What is important to you?
   à (re-state story of grandparents) How do you want to be treated? (what a wonderful world, side by side?)

So….

- Based on today – what do you think the main idea of this song should be? (create an arch)
- What does it sound like?

Critical reflection on process

1. How are you feeling at the end of this session? How are you feeling about what we are creating together?
2. What excites you from what we created this week? What concerns do you have, if any?
3. How might the song we are creating change you?
4. How might the song change someone who hears it?
5. What did you feel was missing that we could address in future weeks?
6. What could have been done differently?

Summary of the session and plan for next week *à* Putting these words to music!

Musical closing

Week 3

Welcome and overview of the session

- Welcome everyone
- Re-state project objectives - writing a song about what we want the world to know about us
- What we will be doing today à today, we are going to start putting our song together (adding music and lyrics)

Consent

- Read consent form
- Start recording

Musical warm-up

- A song about how we feel today à what does the group want to do?
- Last week we sang a lot about the sun – I learned let your smile be your umbrella!
- When you're smiling?

Critical reflection/collaborative songwriting

Summarize from last week

- Last week we built on the questions we explored in the first week:
    1. How would you describe yourself
    2. What makes you happy
    3. What is important to you

- We also answered the following questions:
    1. How do you want to be treated in the world?
    2. What wisdom do we want to share with others?

What I heard from all of these answers is that we want to be treated with respect and we have wisdom and lessons to share with the world. With that in mind, I summarized what we talked about over the past two weeks here. à Go through process for verse, verse, verse, chorus (the main idea is always the chorus – we keep coming back to it)
à Today, we will create a melody for the song, and then I will put these lyrics to music this week.

- What does this song sound like to you? (overall feel of the song)

Start playing with some melodies à Once we find one we like, hand out tone bars and drums à What do we think the title for this song is?

Closing critical reflection

1. How are you feeling at the end of this session?
2. How are you feeling about what we are creating together?
3. What excites you from what we created this week? What concerns do you have, if any?
4. How might the song we are creating change you? How might the song change someone who hears it?
5. What did you feel was missing that we could address in future weeks?
6. What could have been done differently?

Summary of the session and plan for next week *à* Adding instrumentation!

Closing musical activity

Week 4

Welcome and overview of the session

- Welcome everyone
- Re-state project objectives - writing a song about what we want the world to know about us
- What we will be doing today - today, we are going to continue creating our song and decide on what instruments we would like to hear on it (introduce Alex)

Consent

- Read consent form
- Start recording

Musical warm-up

- A song about how we feel today à what does the group want to do?

Collaborative songwriting

Summarize from last week

- Last week we took the lyrics we wrote about the lessons we want to share with the world and created a chorus. à read the lyrics
- Last week some of you said that it doesn't need to be a rainy day to smile. Do you think we should change the lyric here? à if yes ask what they would like to change it to (some ideas: and try to smile everyday)
- I was also wondering if you wanted to change don't undermine to keep others in mind
- Show lyrics from the chorus and sing it with the group (start on la – sing it a few times through) à hand out instruments and tone bars

Create one verse (more if time)

- So now that we have finished our chorus it is time to write the verses
- Besides the lessons and wisdom that you shared over the last few weeks (which comprises the lyrics for the chorus), we also discussed who we are as people, how we want to be treated in the world, and what makes us happy. I thought these could become the topics for our verses (read out answers) - read out answers
- So let's start with the chords and melody – what mood do you feel this message shares – create chords (feedback), melody (feedback)
- Okay so let's write a verse about who we are and how we want to be treated (read the answers and write down verse) - feedback
- Sing it together

Instrumentation creation

- So now that we have the first verse and chorus, I thought we could brainstorm instruments we would like to hear on it
    - Re-introduce Alex

- Ask participants what instruments they think would sound good on the song (Alex will show us what this sounds like)
- Make changes/decide on instrumentation
- Sing a few times with new instrumentation

Summary and plan for next week

- Summarize what we did today and describe what will happen next week
- Sing a familiar song

Closing critical reflection

1. What excites you from what we created this week?
2. How might the song we are creating change you?
3. How might the song change someone who hears it?
4. What do you feel is still missing from the song?

Musical closing

Week 5

Welcome and overview of the session

- Welcome everyone
- Re-state project objectives (writing a song about what we want the world to know about us)
- What we will be doing today - Finishing the song!

Consent

- Read consent form
- Start recording

Musical warm-up

- A song about how we feel today

Collaborative songwriting

- Summarize from last week
  - Last week we had Alex help us add instruments to the song (we added drums, piano, and violin)! Alex has worked hard to put together an initial mix that I will play for you shortly.
  - We also wrote a verse for the song – today we will write the final verses!

- Before we write our final verses, I want to share what we have so far!
  - So last week we wrote a verse to the song which highlights who we are as people and how we want to be treated in the world (read lyrics)

- Before we write more verses, let's try singing what we already have – sing verse a few times and then sing chorus
- Hand out lyric sheet and sing again
- Sing with music

- How do we feel about the music? Add or change anything?

- Create verses → So now that we have one verse and a chorus – it is time to write the final verses
  - So over the last few weeks I asked you questions like who are you and how you want to be treated (which became a verse). I asked what lessons and wisdom you want to share with others (which became the chorus).
  - However, I feel like it might be good to have a verse that introduces the song – over the last few weeks, I took in what you all said to me about what you want this song to achieve in the world and how you feel that even though you are older, you have wisdom, in fact a lot of wisdom and knowledge and you would like to share this with the world. So what I did is I took these ideas and came up with a few lines. How does that feel? Do we want to add or change anything? Do we want to get rid of it totally?
  - I also asked you a question about what makes you happy. I thought this could become the topic for the next verse
  - So when I asked you what makes you happy, you said…. (read sheet) à we can't add everything but I thought about something like this (add in Robert's line about music soothing the soul)

Summary and plan for next week

- Summarize what we did today and describe what will happen next week

Closing critical reflection

1. What excites you from what we created this week?
2. How has this songwriting process been like for you?
3. How might this song change someone who hears it?

Musical closing

Week 6

Welcome and overview of the session

- Welcome everyone
- Re-state project objectives (writing a song about what we want the world to know about us)
- What we will be doing today – learning/singing the final song and reflecting on our experience.

Consent

- Read consent form
- Start recording

Musical warm-up

- A song about how we feel today

Collaborative songwriting

- Summarize from last week
    - Last week, we finished writing the song! Today, we are going to learn the song and reflect on the songwriting process

- Before we sing the song, I wanted to read out the lyrics we have created together.
    - So over the last six weeks, I have asked you all questions such as what is important to you, what makes you happy, how do you want to be treated in the world – in this process we talked about…. (go through questions and answers)
    - These are the lyrics we came up with (hand out lyric sheets)…
    - How do we feel about these lyrics?
    - What should the title of the song be?

- Sing the song (see how it goes) might need to sing it in parts or switch from music to guitar

Closing critical reflection

1. How do we want people to feel when they hear this song? What do we want people to do after they hear this song?
2. How do you hope people treat people like yourself after hearing the song?
3. What was it like participating in this process? What if anything has changed for you?
4. What would you want us to do differently if we did this process again?
5. What advice do you have for others who want to write a song like we did?
6. If there's one message you want the world to remember from this song what would it be?

Closing song and summary

- Thank everyone for their participation
- Next steps (recording the song and a release party)
- Closing song

Appendix I: Songwriting Reflection Worksheet

Week:
Songwriter's present:

Descriptive Notes	**Reflective Notes**
1. Physical Setting (Note the specific location and characteristics, such as furniture, equipment, noise, privacy, spatial arrangements, positioning of participants, etc. – sketch if appropriate)	Aspects of the physical setting that appears to influence relational principles and collaborative music making: Supports: Hinders: Does not affect: Notes:
2. Songwriters (Describe who is present, physical characteristics (are participants standing/sitting etc.), nonverbal behaviour indicating level of engagement, nature of relating, etc.)	Do participants appear comfortable with each other? How do you know? Do participants appear supportive of one another? How do you know? Examples of embodied selfhood

	Notes:
3. Events/Activities Outline briefly the sequence of events including how the session begins and ends How is this focus of the session determined and who determines it? How is the end of the interaction signaled?	How are the songwriter's included as 'active' participants? Are there things that the songwriter attempts to discuss but is unable to? (e.g., not enough time, discouraged, etc.) How were relational principles embedded into the session? How did relationality show up in the session? How could relational principles have been better supported in this session? How did relationality and participatory processes show up in the songwriting process and music-making activities? Notes:

Appendix J: Information Form and Questionnaire for Event

Welcome to the online questionnaire about your experience engaging with the song/video "Wisdom and Respect". This questionnaire is hosted by Qualtrics, which has multiple safeguards in place, although no Internet transmission is ever fully secure.

By completing and submitting the questionnaire, you are giving permission to me to use the data for academic, professional and educational presentations and publications. Your words and phrases may be used in reports of my research. You will remain anonymous, and your responses will be confidential as you are not asked to provide your name or any identifying information on the questionnaire. Once submitted, it is not possible to remove your data from the study because the data is anonymous.

Completion of the questionnaire should take no more than 10 minutes. Your participation is voluntary – you do not have to complete the questionnaire, and you do not have to answer every question.

There are no known or anticipated risks to participation in this study. I will not know who participated or did not. Your decision to participate or not will have no consequence on the care you or your family member receives or your employment here.

Only my supervisor and I will have access to the questionnaire results. The results from the questionnaires will be stored for at least seven years on a secure TEAMS site, which is a protected site used by researchers at the University of Waterloo. All documents will then be destroyed as per the policy required by the Office of Research Services at the University of Waterloo.

An executive summary of the findings will be made available to the facility upon completion of the study. You can either receive the findings by contacting One Kenton Place directly or by emailing me at tkurta@uwaterloo.ca.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB [#46535]). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

"Wisdom and Respect" Questionnaire

Thank you for attending the release party for our songwriting research project. Please take a few minutes to tell us about your experience engaging with the song and film.

1. **How would you best describe yourself?**

    □ Health care aide or personal support worker
    □ RN/RPN

□ Other health professional (Physical therapist, occupational therapist, social worker, recreation therapist/activation staff)
    - □ Other support staff (chaplain, dietary, housekeeping, maintenance, etc.)
    - □ Manager/Supervisor
    - □ Volunteer
    - □ Family Member
    - □ Friend
    - □ Person living with dementia
    - □ Other: _____

2. **What are your overall impressions and/or feelings about the song/video?**

3. **What key messages did you take from the song/video? What stands out for you?**

4. **What, if anything, surprised you about what you saw/heard in the song/video?**

5. **What, if anything, has changed for you after hearing/seeing the song/video?**

6. **How might the song/video change how you interact with older adults?**

7. **On a scale of one to 10, with 10 being the highest, how relevant do you think this song/video is in helping to challenge negative attitudes about older adults, later life, long-term care and/or dementia?**

8. **Other comments?**