A Proposed Music Therapy Program Framework for Persons Living with Dementia in Long-Term Care who are Experiencing Sundowning

Julia Blundon

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By: Julia Blundon

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complies with the regulations of the University and meets the accepted standards with respect to originality and quality.

Signed by the final Examining Committee:

_____ Chair
Laurel Young

_____ Examiner
Cynthia Bruce

_____ Examiner
Annabelle Brault

_____ Supervisor
Laurel Young

Approved by _____
Cynthia Bruce, Chair, Department of Creative Arts Therapies

____2024____YEAR _____
Annie Gérin, Dean, Faculty of Fine Arts

ABSTRACT

A Proposed Music Therapy Program Framework for Persons Living with Dementia in Long-Term Care who are Experiencing Sundowning

Julia Blundon

Sundowning is a relatively common phenomenon experienced by persons living with dementia that involves a worsening of symptoms (e.g., increased confusion, agitation, anxiety, aggression, etc.) that occurs regularly in the mid-late afternoon or early evening. While music therapy holds great potential to address challenges related to sundowning, a literature review revealed no consistent music therapy applications or existing program frameworks specific to this phenomenon. Therefore, the purpose of the present study was to develop a group music therapy program framework for persons living with dementia in long-term care facilities who are experiencing sundowning. The first 1.5 steps of intervention research design, as conceptualized by Fraser and Galinsky (2009; 2010), were used to define the problem, analyze the literature, and propose a theory of change. All of the information gathered and organized up to this point was then used to determine the structure and processes of the proposed group music therapy program. While this program is yet to be evaluated and further refined within a research or practice context, this study may still serve as a practical guide and advocacy tool for music therapists who would like to establish a similar type of program. Limitations of the study along with other implications for practice and future research are presented.

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Chapter 1. Introduction

Significance of the Inquiry

Dementia is not a disease; it is an umbrella term for a group of symptoms associated with various progressive neurological conditions. The most common of these is Alzheimer's disease (AD) which accounts for 60%-80% of cases (Alzheimer Society of Canada, n.d.). Other forms of dementia include vascular dementia, dementia with Lewy bodies (DLB), frontotemporal dementia (FTD), Huntington's disease, Creutzfeldt-Jakob disease, normal pressure hydrocephalus (NPH), Parkinson's disease dementia, Korsakoff syndrome, and mixed dementia (i.e., more than one cause, such as the simultaneous occurrence of Alzheimer's disease and vascular dementia; Alzheimer's Association, n.d.). Symptoms of dementia may vary according to the specific disease and the individual, but it typically includes memory loss, mood and behavioural changes, and progressive decline in other cognitive abilities such as thinking, attention, problem solving, and language (Alzheimer Society of Canada, n.d.).

Currently, there is no cure for most dementias; and existing pharmacological interventions have limited or negative effects (Alzheimer Society of Canada, n.d.; Gitlin et al., 2012). Some researchers have identified a need for more non-pharmacological interventions to help address the behavioral and psychological symptoms of dementia (BPSD; Raglio et al., 2020; Verdelho & Goncalves-Pereira, 2016; Vink & Hanser, 2018) whereas other researchers and dementia advocates have identified a need for more initiatives that will support persons living with dementia (PLWD) and their caregiver(s) to realize their full potential for quality of life throughout the progression of the disease (Alzheimer's Association, n.d.; Beer, 2014; Young, in press; Zwerling et al., 2016). The differences between these two perspectives will be further explored in Chapter Two. However, both broadly support the idea that there is a need for more initiatives that will help better the lives of PLWD in some way.

Although PLWD may exhibit a range of symptoms (as outlined above), a distinct phenomenon referred to as sundown syndrome, or sundowning[1] has been consistently observed in many PLWD—as many as 66% of those diagnosed with AD (Alzheimer Society of Canada, n.d.). Sundowning involves a *worsening* of symptoms (e.g., increased confusion, agitation,

[1] The terms *sundown syndrome* and *sundowning* are both used in scholarly literature to refer to the same phenomenon. However, to be consistent and to align with a philosophical stance that focuses on personhood rather than on pathology (explained further in Chapter 2), the term *sundowning* will be used throughout this thesis.

anxiety, aggression, etc.) that occurs regularly in the mid-late afternoon or early evening (Alzheimer Society of Canada, n.d.; Canevelli et al., 2016; Gnanasekaran, 2015; Kachiyants et al., 2011; Yevchak et al., 2012). Sundowning has adverse impacts on the quality of life of PLWD, and it can also increase stress, frustration, and emotional and physical fatigue of both personal and professional caregivers, in home, community, and long-term care contexts (Bliwise et al., 1993; Canevelli et al., 2016; Zwerling et al., 2016). This can impact the quality of care being provided, which in turn can inadvertently exacerbate the challenges related to sundowning, thus potentially perpetuating an unhelpful repetitive cycle for all concerned (Canevelli et al., 2016; Gnanasekaran, 2015; Kachiyants et al., 2011). Burnout in carers supporting PLWD occurs frequently, with more than 45% exhibiting a range of symptoms including anger, depression, and feelings of being unable to carry out caring-related activities (Canadian Institute for Health Information, n.d.).

Despite the prevalence and challenges of sundowning, literature indicates that its causes are not yet well understood (Canevelli et al., 2016; Cipriani et al., 2015; Gnanasekaran, 2015) and it is not being addressed (i.e., prevented or treated) in consistent ways (Canevelli et al., 2016; Kachiyants et al., 2011). Antipsychotics may be prescribed (Canevelli et al., 2016; Gnanasekaran, 2015; Kachiyants et al., 2011; Lineweaver et al., 2021), but these have not been found to be particularly effective and may even result in adverse effects including over-medication (Canevelli et al., 2016; Mueller et al., 2018). There is a growing consensus on the need for non-pharmacological solutions that will prevent or address the BPSD and/or improve quality of life for PLWD at large (Canevelli et al., 2016; Gitlin et al., 2012; Vink & Hanser, 2018). Given the prevalence of sundowning among PLWD (noted above), non-pharmacological solutions that target this issue specifically could be particularly helpful in establishing more consistent best practice approach frameworks in dementia care.

Literature indicates that music therapy may serve as a particularly promising non-pharmacological option to improve quality of life for PLWD (e.g., Baird et al., 2020; Clements-Cortés, 2020; Janus et al., 2020; McDermott et al., 2012; Young, 2013, in press). Although the role of a certified music therapist may vary in different dementia care contexts (e.g., community day programs versus long-term care, see Young, 2013), music therapy may be defined as the informed use of various facets of music experiences and the relationships that develop through them as the impetus for positive change within these contexts (Bruscia, 2014). Music may be

particularly important for PLWD because areas of the brain related to musical functioning usually remain relatively intact even into the later stages of the disease (Jacobsen et al., 2015; McDermott et al., 2014; Young, 2013). PLWD, regardless of previous musical training or knowledge, are often able to engage with music in meaningful ways when other forms of communication or expression have become difficult (Jacobsen et al., 2015; Krøier et al., 2021; Young, 2013, in press). Musical engagement can promote feelings of wellbeing, provide a vehicle for self-expression, and enhance a sense of connection with self and others (Krøier et al., 2021; McDermott et al., 2012; Raglio et al., 2020; Ridder & Wheeler, 2015). This, in turn, can potentially prevent or reduce challenging behaviours/symptoms associated with dementia (Ray & Mittelman, 2015; Ridder et al., 2013; Ridder & Wheeler, 2015) or enhance environments that do not accommodate the evolving needs of PLWD and their ways of being in the world (Beer, 2016; Young, 2013, in press). However, my review of the literature and informal discussions with music therapists who practice in this area revealed that music therapy is not being delivered in consistent ways for PLWD. This inconsistency is evident even in relation to sundowning—a phenomenon that has been repeatedly identified as being challenging in various dementia care contexts, as noted above.

Personal Relationship to the Topic

Music has been my passion since I was 4 years old and enrolled in piano lessons. Even at this young age, music satiated my creative needs and was a vehicle for self-expression. Over time as I explored a variety of other instruments, including voice and guitar, my passion for music evolved into a much more layered and profound appreciation for all that it can convey, such as joy, despair, and tranquility.

As an adolescent, I witnessed the slow and then rapid decline of my grandmother's cognitive and physical health due to Alzheimer's disease. During the last few days of her life, my grandmother appeared unresponsive; she no longer opened her eyes and was placed on a ventilator which made her appear stiff and rigid. Hoping to help my grandmother find some comfort and peace, my mother put on some recorded classical music. As the music played, my grandmother's face and body relaxed, and she seemed to enter a state of calm. This experience impacted me profoundly and this image has stayed with me, sparking my interest in wanting to work with PLWD and eventually motivating my decision to pursue music therapy as a career. This decision was also influenced by my mother and sister, both of whom have worked in

healthcare-adjacent professions, where they had opportunities to interact with music therapists. They suggested that this profession was well aligned with my passions—music and helping others.

In the fall semester of 2020, I began my pre-professional music therapy training in the Music Therapy Graduate Diploma program at Concordia University, in Montreal, Canada. Over 400 hours of my 1200-hour internship were completed in a community day program for PLWD. Due to the Covid-19 pandemic, all group and individual music therapy sessions occurred online, with PLWD logging on from their homes, usually supported by a family caregiver. Despite the physical distance, I was able to observe how the participants connected with themselves and with each other through music experiences tailored to meet their needs in context. For example, while working with a group of men living with early to mid-stage dementia, I facilitated a song-writing experience where they were invited to share destinations for a trip they might like to take. As they participated in this discussion, I incorporated their ideas into a simple song framework, which I then sang for them, accompanying myself on guitar. Individuals had a range of emotional responses (e.g., smiles, tears, sharing of memories) and also commented on each other's contributions and responses. These types of meaningful experiences further affirmed my desire to work with this segment of the older adult population.

It was during my time in this day program setting that I learned about sundowning. The day program staff asked me if I would facilitate an online music therapy program for individuals experiencing this phenomenon, with additional technical and practical support for their participation being provided by family and professional caregivers when possible. Over a six-week period, I facilitated a weekly 30-minute program starting at 3pm. Over this short period of time, I learned a great deal through my own observations and through feedback received from participants, caregivers, staff, and music therapy supervisors. When my placement finished, I realized that I had more to learn and also wondered how this online program might be further refined and/or realized within an in-person music therapy context.

In the fall semester of 2021, I entered the Magisteriate in Arts, music therapy program at Concordia University and chose to pursue the research thesis option. When I started to formulate my research thesis proposal, I began to reflect upon my previous practicum experience and reviewed related literature. Although the potential for music therapy to support PLWD who are experiencing sundowning seemed evident, I found limited published information on applications

of music therapy for persons experiencing sundowning. Therefore, I decided that this would be the focus of my thesis.

Statement of Purpose

As noted above, the BPSD can negatively impact quality of life for PLWD and also pose various challenges for personal and professional caregivers. Because current pharmacological treatments have little or adverse effects, there is a need for more non-pharmacological approaches. Sundowning is a relatively common phenomenon experienced by PLWD but despite the potential that music holds to address related challenges, there are no consistent music therapy applications or program frameworks specific to this phenomenon. In addition to what I found in the literature regarding applications of music therapy for PLWD at large, my personal experience in facilitating an online music therapy program to address challenges related to sundowning suggested that a program framework realized according to best or promising practice guidelines[2] (i.e., those informed by current research, knowledge, and practical considerations) could be helpful for all relevant stakeholders (i.e., PLWD, their personal and professional caregivers, and music therapists). Therefore, the purpose of the present study was to develop a group music therapy program framework for PLWD in long-term care facilities who are experiencing sundowning. I chose to focus on long-term care as most of the relevant literature is situated in this context and many music therapists also work in this area. It is likely that aspects of this program framework can be adapted for use in other contexts (e.g., community day programs). Implications for future research and practice in other contexts (including online practice) are highlighted in Chapter Five.

Research Questions

The primary research question was: How can a music therapy program framework be designed to support PLWD who experience sundowning in long-term care contexts? Subsidiary questions were: (a) What are the needs of PLWD who are experiencing sundowning in long-term care contexts?; (b) What music therapy experiences may be used to address these needs?; and (c) How can these experiences be organized into a feasible program structure for long-term care contexts?

[2] A best practice approach refers to a program, intervention, or initiative, that demonstrates (through quality evidence) high impact, adaptability, and transferability. A promising practice is an intervention, program, service, or strategy that shows potential (based on theory) for developing into a best practice. (Public Health Agency of Canada, 2016).

Key Terms

There are key terms contained in the research questions not previously defined. *Music therapy* is "…a discipline in which Certified Music Therapists (MTA) 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." (Canadian Association of Music Therapists, 2020). Within the context of this research, a *music therapy program framework* is being defined as a set of guidelines informed by relevant research and practical knowledge wherein music therapy experiences can be realized in context to support persons experiencing sundowning. *Long-term care* refers to living accommodations for individuals who require a full continuum of care services, 24 hours a day, seven days a week. These include professional health care and social support services, personal care, and other practical services such as meals and housekeeping (Alzheimer Society of Canada, n.d.). *Music therapy experiences* are those where the agent of therapy is not just the music (i.e., an object which is external to the PLWD), but also the individual's experience of the music (i.e., the interaction between person, process, product, and context, and interactions among persons). Here, the music therapist's role involves shaping the client's experience of that music (Bruscia, 2014). The four main methods of music experience will be described in Chapter 2, and how they are applied or realized within the proposed program framework will be explained in Chapter 4. Other key concepts will be defined in context as they occur throughout this paper.

Chapters Summary

This thesis contains five chapters. Chapter 1 outlined the significance of the inquiry and described my personal relationship to the topic. The purpose of the study and research questions were also presented. Chapter 2 reviews relevant literature and is organized under two overarching categories: an overview of Sundown Syndrome (Sundowning) and an overview of music therapy in dementia care. This information was used to conduct a directed content analysis. Chapter 3 outlines how the first one and a half steps of Fraser and Galinsky's (2010) intervention research methodology were designed within the context of this research. Chapter 4 presents the results of a directed content analysis based on information extracted from the literature along with a proposed flexible program framework based on these results. Finally, Chapter 5 provides some final

reflections and discusses potential implications of this inquiry for future research, advocacy, and practice. Limitations of the study are also presented.

Chapter 2. Related Literature

The purpose of this chapter was to review literature relevant to the research questions and organize it in such a way that would help to facilitate a directed content analysis (described in Chapter 3). Part one provides an overview of sundowning. This includes a definition, description of symptoms, prevalence, possible causes, and existing treatments and supports. Part two provides an overview of music therapy in dementia care, with a focus on its applications in long-term care contexts.

An Overview of Sundowning

Definition, Symptoms, and Prevalence

As noted in Chapter 1, sundowning involves a worsening or heightening of BPSD that occurs regularly in the mid-late afternoon or early evening. There is some debate as to the duration of symptoms, with some researchers believing that they begin with the onset of darkness and last only a few hours while others speculate that they continue throughout the night. (Alzheimer Society of Canada, n.d.; Canevelli et al., 2016; Gnanasekaran, 2015; Kachiyants et al., 2011; Yevchak et al., 2012). The occurrence of sundowning is believed to be associated with an increased rate of cognitive decline (Canevelli et al., 2016; Cipriani et al., 2015; Yevchak et al., 2012). It is also important to note that some dementia scholars and researchers have proposed that BPSD (in general, not specific to sundowning per se) may not always be directly caused by individuals' neurological condition but rather by a failure to adequately accommodate their evolving needs; and, in this case, *symptoms* may also be understood as attempts to communicate these needs (Power, 2019; Ridder & Wheeler, 2015; Young, in press).

Although increased agitation is perhaps the most commonly noted symptom, others may include confusion, anxiety, depression, apathy, delusions, auditory and visual hallucinations, disorientation, wandering, seemingly random vocalizations, and poor sleep (Canevelli et al., 2016; Cipriani et al., 2015; Verdelho & Goncalves Pereira, 2016; Yevchak et al., 2012). Although prevalence rates in relation to age, race, and sex have not yet been conclusively determined, research suggests that up to 66% of all PLWD (in community and long-term care settings) experience sundowning (Alzheimer's Association, n.d.; Canevelli et al., 2016).

Possible Causes

Although exact mechanisms associated with the development of many dementias remain unclear, the literature indicates three overarching factors to consider as possible causes of

sundowning: physiological, environmental, and psychosocial. (Canevelli et al., 2016; Kachiyants et al., 2011; Menegardo et al., 2019; Yevchak et al., 2012).

Physiological Factors. To date, the potential link between sundowning and disruption of circadian rhythms appears to be the most widely researched hypothesis (Boronat et al., 2019; Canevelli et al., 2016; Cipriani, 2015; Kachiyants et al., 2011; Menegardo et al., 2019; Silva et al., 2017; Todd, 2020; Yevchak et al., 2012). Circadian rhythms are the body's natural cycle of sleep and wakefulness. However, when there is an alteration or damage to the suprachiasmatic nucleus (SCN), otherwise known as the circadian pacemaker of the body, this can interfere with normal circadian functioning (Canevelli et al., 2016). A decrease in volume of the SCN has been observed in many older adults as part of normal aging (especially those 80 years of age or older), and in persons living with AD and other dementias regardless of age (Boronat et al., 2019; Canevelli et al., 2016; Todd, 2020). Additionally, melatonin, an important hormone secreted by the SCN in response to darkness, also decreases as people age and even more so in PLWD (Canevelli et al., 2016; Menegardo et al., 2019; Xie et al., 2017). Cumulatively, this evidence appears to support the hypothesis proposed above; but, more research is needed because there may be other physiological factors to consider (Canevelli et al., 2016; Todd, 2020).

The cholinergic system is responsible for regulating various aspects of brain function (e.g., sensory processing, attention, sleep, and arousal (Canevelli et al., 2016; Cipriani et al., 2015; Menegardo et al., 2019). Degeneration of this system has been documented in people living with AD, and it is hypothesized that impaired cholinergic transmission may contribute to the disruption of circadian rhythms and behavioural regulation (Canevelli et al., 2016). Dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis, which is responsible for the secretion of cortisol, the body's main stress hormone, may also be related to heightened BPSD in the late afternoon since people living with AD who experience sundowning have been found to have higher levels of cortisol than those who are not experiencing this phenomenon (Canevelli et al., 2016; Venturelli et al., 2013). Although these contributing physiological factors to the etiology of sundowning are not definitive, they do suggest that sundowning is a complex multifactorial phenomenon (Canevelli et al., 2016; Kachiyants et al., 2011; Menegardo et al., 2019; Silva et al., 2017; Todd, 2020; Yevchak et al., 2012).

Environmental Factors. Researchers also postulate that several environmental factors may exacerbate the BPSD and subsequently lead to the onset of sundown syndrome and

negatively impact overall quality of life (Hansen et al. 2017). Many long-term care facilities have ambient light levels that are too low to support natural light-dependent sleep-wake cycles which in turn may contribute to the development or worsening of circadian disorders (Canevelli et al., 2016; Cipriani et al., 2015; Gnanasekaran, 2015; Todd, 2020; Yevchak et al., 2012). These facilities often have noisy, overstimulating environments that feel unfamiliar to PLWD, and trying to navigate or make sense of these environments may lead to mental and physical exhaustion (Chaudhury et al., 2018). Excessive noise coming from residents, staff, and/or technology (e.g., TVs, loud medical devices, radios, fans, etc.) occurs frequently in long-term care facilities (Chaudhury et al., 2018). This can agitate residents and precipitate negative social interactions (Campo & Chaudhury, 2012; Chaudhury et al., 2018). Spaces designated for leisure or social activities are often located near busy corridors, elevators, and nursing stations which can produce noise and unwelcome distractions (Campo & Chaudhury, 2012). Some PLWD continuously walk or pace, perhaps attempting to navigate their environment or express what they are experiencing (Alzheimer's Association, n.d.; Alzheimer Society of Canada, n.d.). This can result in heightened fatigue, stress, and agitation as the day progresses (Alzheimer's Association, n.d.; Canevelli et al., 2016; Khachiyants et al. 2011, Yevchak et al., 2012).

Psychosocial Factors. Psychosocial factors include psychological and social influences that affect individuals' mental health and behaviour (Merriam-Webster, 2018). Various interpersonal interactions that occur with others in specific roles and/or contexts appears to be an overarching salient psychosocial factor that impacts persons who are experiencing sundowning.

Quality of life for PLWD can be significantly impacted by the relationships that they have with personal and family caregivers. In Canada, it is estimated that 61% of PLWD live at home (Canadian Institute for Health Information, n.d.). Family members often assume primary caregiver roles (Smebye & Kirkevold, 2013) but often do not receive adequate training and support (Yaghmour, 2021). Furthermore, primary caregivers are often faced with a range of challenges, including financial hardship and the changing nature of their relationship with their loved one which can evoke complex feelings such as guilt, grief and loss, and anger (Alzheimer Society of Canada, n.d.). It is important for caregivers to find ways to navigate these challenges because lasting constructive relationships between personal/family caregivers and PLWD can help to sustain the latter's connection to their sense of self and personhood, foster feelings of

independence and agency, and contribute significantly to the overall success of their care (Hansen et al., 2017; Smebye & Kirkevold, 2013).

Relationships between PLWD and their professional caregivers are also affected by a number of factors, which in turn can impact how behaviours or feelings may be expressed by PLWD. Long-term care facilities are often understaffed, resulting in low staff-to-resident ratio. This minimizes the availability of supportive or preventative care and leads to a lack of structured and stimulating daily schedules and social activities tailored to meet residents' needs (Canevelli et al., 2016; Exum et al., 1993; Hansen et al., 2017; Khachiyants et al. 2011).

Literature also indicates that many long-term care facilities lack adequate numbers of professional psychosocial support staff (Cohen-Mansfield et al., 2015, 2017; Shiells et al., 2019). Professional caregivers (e.g., nurses, personal support workers, etc.) are typically challenged by heavy workload and time limitations, which can negatively impact their emotional and physical health. Furthermore, this lack of time can affect quality of care since many staff adopt a task-oriented approach that does not always prioritize meaningful relational interactions (Gallagher-Thompson et al., 1992; Khachiyants et al., 2011). Nursing staff often lack specific knowledge and training in dementia care and, as such, many do not communicate effectively with PLWD or adequately address complex needs such as pain management, feelings of grief and loss, and psychosocial needs (Cadieux et al., 2013; Cohen-Mansfield et al., 2015; Machiels et al., 2017; Shiells et al., 2019). As a result of unmet psychosocial needs, PLWD may experience boredom, sensory deprivation, anxiety, fear, depression, and loneliness which may be expressed as BPSD, within and outside of the context of sundowning (Cohen-Mansfield, 2001; Cohen-Mansfield et al., 2015).

Existing Treatments and Supports

Traditionally, pharmacological interventions have been the most common way to address symptoms associated with sundowning (Canevelli et al., 2016; Todd, 2020). These include antipsychotic medications, which are widely believed to be the most prescribed medication for treating PLWD and are often considered the first line response in addressing this issue (Canevelli et al., 2016; Kachiyants et al., 2011). Additionally, melatonin supplementation to address sleep-related issues associated with sundowning has been widely advocated in research on circadian disorders (presented above) and frequently used in long-term care facilities (Canevelli et al., 2016; Gnanasekaran, 2015; Yevchak et al., 2012). Other medical interventions, such as

cholinesterase inhibitors, antidepressants, benzodiazepines, and hypnotics have also been used to address sundowning upon onset of symptoms (Canevelli et al., 2016; Yevchak et al., 2012).

Although pharmacological interventions may appear to provide an immediate solution, they typically only pacify symptoms and are not an actual treatment for sundowning per se (Kachiyants et al., 2011; Park et al., 2017; Rados et al., 2021; Yevchak et al., 2012). Furthermore, these medications often have adverse side effects, and this risk increases when multiple medications are prescribed (i.e., polypharmacy; Canevelli et al., 2016; Gnanasekaran, 2015; Rados et al., 2021). This may include cardiac problems, increased falls, and increased cognitive impairment (Hernández et al., 2019; Rados et al., 2021). Subsequently, these adverse side effects may be misdiagnosed and treated as new ailments which may result in a drug-disease interaction (DDSI), meaning that the pharmacological treatment for one disease may result in the worsening of another (Gnanasekaran, 2015; van Tongeren et al., 2020).

Given these significant challenges, more non-pharmacological options are being explored. Light therapy, or bright light therapy (BLT), is used to treat seasonal affective and circadian rhythm disorders and is being considered as a potential treatment for PLWD who are experiencing sundowning. This involves sitting in front of a specially designed light source for a few hours each day (brighter than most ambient lighting in long-term care facilities), in order to help stabilize disrupted circadian rhythms. Although current research is limited, preliminary evidence has indicated that BLT may have potential to stabilize sleep cycles in PLWD, reduce feelings of restlessness, improve overall cognitive functioning, and reduce agitation (Khachiyants et al., 2011).

Various Alzheimer's associations provide practical information on how personal and professional caregivers can best support PLWD who are experiencing sundowning. Suggestions include environmental adaptations, such as ensuring proper lighting in personal rooms and common areas, playing soothing music that is aligned with individuals' personal preferences, and reducing noise, clutter, and excessive numbers of people in individuals' rooms. Dietary considerations include avoiding caffeine and foods high in sugar, especially in the evening. Establishing a routine of preferred activities as well as a stable sleep schedule is also important. Finally, they also suggest that caregivers can learn how to constructively redirect individuals who are experiencing negative symptoms toward more positive options, such as engaging in preferred

daily routine activities, as noted above. (Alzheimer Society of Canada, n.d.; Mayo Foundation for Medical Education and Research, 2024; National Institute on Aging, 2024).

Finally, it is important to note that music and/or music therapy is consistently noted in scholarly and other relevant literature (e.g., Alzheimer's Disease International, 2022; Public Health Agency of Canada, 2021) as a non-pharmacological option that can either help to address the BPSD and/or to improve quality of life for PLWD. However, because there are no established government healthcare standards regarding access to music therapy services for PLWD in Canada (and elsewhere), we can conclude that many of these individuals (including those experiencing sundowning) do not have consistent access to professional and personalized music therapy services that could help (Young, in press). The following section provides a brief overview of music therapy in dementia care and explains why music therapy holds unique potential for PLWD, and specifically for those experiencing sundowning.

Brief Overview of Music Therapy in Dementia Care

Why Music?

Research shows that the music functions of the brain, such as musical perception, emotion, and memory can remain relatively intact even into the late stages of most dementias. (Belgrave et al., 2011; Cuddy et al., 2012; Gagnon et al., 2012). This means that many PLWD can perceive and respond to music in meaningful ways, even when they have difficulty processing language and other forms of sensory input (Baird & Thompson, 2020; Ridder et al., 2013; Ridder & Wheeler, 2015; Young, 2013, in press). These preserved musical abilities may serve as a means through which PLWD can feel connected to others, their environments, and to their own sense of self thus contributing to their potential for realizing wellbeing and quality of life (Baird & Thompson, 2020; Belgrave et al., 2011; Cuddy et al., 2012; Ridder et al., 2013; Young, 2013, in press). Although public awareness regarding the potential value of music for PLWD has increased over the last decade, the rationale underlying this value is not always well understood (Young, in press). While neuroscientists continue to work toward increased understanding of the mechanisms underlying how music works in the brain (in general and for PLWD; Global Council on Brain Health, 2020), music therapist researchers and clinicians continue to develop and expand upon various applications of music in dementia care contexts (Baird et al., 2020; Tomaino, 2016; Young, in press).

Finally, scholars have proposed that there are seven capacities of music that contribute to its therapeutic value—music is engaging, emotional, physical, synchronous, personal, social, and persuasive (Brancatisano & Thompson, 2020). The relevance of these capacities to the present study will be further elucidated in Chapter 4.

Brief History of Music Therapy in Dementia Care

It has long been understood across various cultures that singing, playing instruments, dancing, and/or listening to music can positively impact health and well-being. Music therapy, however, did not become an organized profession in North America until 1950 with the founding of the National Association of Music Therapy in the United States. This was due in great part to the work of musicians who had been playing for hospitalized World War I and II veterans as a means of helping them manage their physical and emotional trauma (American Music Therapy Association, n.d.). Since that time, music therapists have been working with older adults, including PLWD, in a range of treatment and living contexts, also creating practical resources and conducting research on music therapy in dementia care. Some foundational authors and scholars in this area include David Aldridge (2000), Ruth Bright (2017), Alicia Clair (2017), Melissa Mercadal-Brotons (2018), Helen Odell-Miller (2017), and Concetta Tomaino (2017). Areas of focus included: developing approaches to music therapy assessment and evaluation, theory building, defining the music therapist's role in dementia care within multidisciplinary teams, developing specific approaches/music experiences to meet the needs of PLWD, music and the brain, music therapy advocacy, and research that examined clinical outcomes. Current music therapy research and practice has continued to evolve from the foundation laid by this early work and several of these noted music therapist scholars currently continue to add to our body of knowledge in music therapy and dementia care.

Current Music Therapy Practices for PLWD in Long-Term Care

Introduction. Given the large amount of literature that has emerged in this area over the last 20 years (i.e., hundreds of publications) it is impossible to name all individuals who have continued to build on the work of the pioneer music therapist scholars noted above. However, publications by Abbott (2013), Belgrave et al. (2011), Clements-Cortés (2020), Ridder and McDermott (e.g., McDermott et al. 2014; 2021), and Young, 2013, in press) served as key resources for the current thesis and, these music therapist scholars are considered as notable contributors to the area of music therapy and dementia care.

Referral and Assessment.[3] In long-term care, referrals to music therapy for PLWD may be made informally (e.g., a verbal request from a loved one or healthcare staff) or formally (e.g., through an established online or paper referral system). Music therapists follow up on these referrals by conducting an initial music therapy assessment that utilizes a music-based protocol to determine how various music experiences may be personalized and applied to help to improve individuals' quality of life in various domains (e.g., psychosocial, emotional, behavioral, cognitive, sensory, etc.). This assessment may occur within a single session or over the course of two or more sessions. The music therapist may also note observations in a group music therapy (or other) setting. Relevant background information is also gathered (including information about musical preferences and experiences) by reviewing an individual's healthcare chart and, when possible, by speaking to persons who know the client (e.g., loved ones, other health care professionals, etc.) or the client themself (Young, 2013; 2024).

Many music therapists who work in dementia care often create their own initial assessment protocols/approaches based on their own training, practical experiences, knowledge, and philosophical orientation (Young, 2013). In my music therapy training, I used a descriptive assessment format, where responses to a pre-planned or emergent music-based assessment protocol were noted within the following domains: communication, cognitive, motor, musical, emotional, and social (Concordia University, 2020). However, the literature also contains published music therapy assessment tools that may be used specifically for PLWD in long-term care.

Munk-Madsen (2001) created a music therapy assessment model designed for PLWD that was published in the *Nordic Journal of Music Therapy*. It emerged out of a research project conducted in a residential home for older adults in Denmark. Similar to the descriptive assessment used during my music therapy training, responses to a music-based assessment protocol (that may occur over 3-4 sessions) are noted via questions contained within six distinct sections: (a) musical activities (i.e., musical responses and/or responses to music), (b) type and quality of motor activities, (c) mood and emotional responses, (d) cognition, (e) attention and contact (i.e., energy level and responses to various stimuli) and (f) verbal comments or other overall reactions to the music therapy [assessment] session. It is important to note that this model

[3] Although outcomes from various diagnostic and cognitive assessment procedures may contain relevant information for music therapists, this section focuses only on initial assessment procedures used by music therapists to help to determine how music therapy may contribute to the individual care plans of PLWD.

is based on the work of one music therapist, and the level of detailed documentation required necessitates video recording of sessions or utilization of an outside observer, which may make it more realistic for use in research, rather than in clinical practice. This also appears to be the case for the *Music Therapy Assessment for People with Dementia* (MTAPD; Mitsudome, 2013) and the *Music in Dementia Assessment Scales* (MiDAS; McDermott et al., 2014), both of which are further developed than Munk-Madsen's assessment model (i.e., reliability and validity of these tools have been examined). However, it also appears that these tools are not a typical type of initial assessment that would quickly help to establish a care plan but rather more like evaluation tools that may be used over more extended periods of time for ongoing assessment and/or evaluation of musical and non-musical *responses* and *behaviours* and/or *processes* and *outcomes*.

Norman (2012) created a music therapy assessment tool to provide music therapists with an efficient, holistic, strengths-based approach that would help determine if/and/or how music therapy might be an appropriate option for individuals in long-term care, including PLWD. As this tool is meant to complement previous assessments completed by other professionals, the music therapist first reviews this documentation, if it is available, and also gathers other background information in the same ways as previously noted. This assessment focuses on making observations of the residents' behaviour and physical demeanor in response to music experiences that include singing, movement, and exploring musical instruments. Observations are reported by selecting checkmarks of potential observed behaviours within five distinct sections: (a) musical training and musical preferences, (b) communication and social interactions, (c) cognitive and motor skills, (d) affective response to interventions (e.g., making eye contact and holding gaze, participating in activity), and (e) overall assessment and music therapy recommendations. Given the efficiency of this format, music therapists working in long-term care may find this tool (or a version that is modified to suit a specific context) to be particularly useful.

Goals. In addition to determining how music therapy may be incorporated into an individual's care plan, initial assessment procedures also help to establish personalized goals that may be addressed through music therapy. Typical goals may include (but are not limited to): improving quality of life, decreasing social isolation, reducing anxiety, reducing or preventing aggressive behaviour, stimulating reminiscence, maximizing existing personal and functional capacities, promoting communication and/or constructive interactions with others (including

loved one and care providers), and improving or maintaining cognitive skills, social skills, and/or motor skills, and improving mood (Clements-Cortés, 2020; Ridder & Wheeler, 2015; Young, 2013). Goals may be individualized, general, measurable (quantitative), and descriptive (qualitative; Borczon, 2017; Concordia Music Therapy Handbook, 2020; Young, 2013). They may also be emergent in that they are revealed as a music therapy process evolves over time (Bruscia, 2014; Madsø, 2022; Young, 2013). Goals may be realized within a symptom focused approach (e.g., focus on treating behavioral or psychological symptoms) and/or within a strengths-based/resource-oriented approach (e.g., focus on supporting engagement in personalized music experiences to enhance quality of life). While it goes beyond the scope of this thesis to present underlying premises of these two approaches or perspectives in detail, a brief summary overview follows.

Two Perspectives. Given the prevalence of bio-medical and evidence-based medicine (EBM) approaches in many healthcare contexts, it is not surprising that much of the current research to date focuses on using music or music therapy to *treat* the BPSD. Although this approach to research may yield some interesting and relevant scientific knowledge, an exclusive focus on this one type of evidence does not capture the full essence and creative complexities of *real-world* music therapy processes (Aigen, 2015; Bradt, 2012). Furthermore, other music therapy clinicians and scholars have been advocating for the adoption of more person-centered and resource-oriented applications of music therapy in dementia care. In this orientation, music is regarded as a potential resource for health and wellbeing and is utilized in ways that nurture the strengths and potentials of each individual in context (McDermott et al., 2012; Rolvjord, 2016; Ross, 2017; Young, in press). Young (in press) argues the following:

> Applying music like a pill to *treat* BPSD inherently situates it within a biomedical model that is antithetical to a holistic, person-centered approach wherein PLWD are not pathologized but rather afforded opportunities to express themselves, interact with others, feel a sense of agency, and explore their evolving potentials and love of music for its own sake. (para. 16)

The ways in which these two perspectives are considered within the proposed music therapy program framework that emerged out of this study are briefly addressed in Chapter 4.

Music Therapy and Sundowning

Although much has been written on the ways in which music and music therapy may be applied to address the BPSD, and some has been written on resource-oriented music therapy approaches for PLWD, very little has been published on music and/or music therapy and applications that are specific to sundowning. I found four relevant articles that I will briefly summarize here.

Whitcomb (1994) was the first music therapist to publish a paper on this topic. Here, she provided a rationale as to why music therapy is important for PLWD and outlined strategies (based on her personal and professional experiences) for facilitating music therapy groups for PLWD who are experiencing sundowning. These strategies include: (a) environmental modifications (e.g., seating arrangement that supports participant interaction, reduce visual/auditory distractions and clutter, and control lighting), (b) approaches to music facilitation (e.g., utilization of live music for adaptability and flexibility, playing familiar music to mitigate anxiety, repetition of lines/choruses and simplifying lyrics to encourage participation and confidence), and (c) resident centered therapeutic programming (e.g., consideration of residents' ages, musical preferences, ethnic backgrounds, religious orientation, unique needs, and how these affect participation).

A study by Pecotz and Lesta (2006) that examined the effects of music therapy sing-along groups (using recorded and live familiar music) during sundowning, found that this experience fostered social interactions, improved overall well-being, enhanced mood, and resulted in increased non-verbal social behaviors. Finally, two studies conducted by Lineweaver et al. (2021; 2022) examined the use of personalized playlists (utilized with trained researchers present) as a means of addressing symptoms and behaviours associated with sundowning. Results indicated that immediately following music listening sessions, many participants showed significant improvement in BPSD-related behaviours, such as agitation and depression, and increased positive engagement with others. However, they also found that some sundowning symptoms were more amenable (i.e., symptoms improved) to this music listening application than others. Symptoms that were more amenable included disengagement, confusion, and unresponsiveness (Lineweaver et al., 2021). Symptoms that were less amenable included repetitiveness and restlessness. While aggression was also cited as being less amenable (i.e., little to no change) the authors indicated that this may have been due to the fact that participants exhibited low baseline aggression levels (Lineweaver et al., 2021). While these two research articles examine music

listening experiences that fall outside of a music therapy context, they are still important to consider because they offer relevant information that may be re-conceptualized and applied within music therapy contexts that aim to address sundowning.

The following section will provide summary overviews on types of music experiences (also referred to as music interventions) noted in the literature that have been used to support and/or meet diverse needs of PLWD in long-term care. Given the purpose and research questions of the present inquiry, only music experiences that have potential applicability for group music therapy programs within the targeted context have been included.

Types of Music Experiences. Although there are several publications indicating various types of music experiences that may be applied in music therapy for PLWD, this thesis will focus on succinctly integrating information contained in three publications that synthesize and/or provide summary overviews on this literature: Young (2013), Ridder and Wheeler (2015), and Clements-Cortés (2020), along with two publications that focus on music therapy and sundowning specifically (Petocz & Lesta, 2006; Whitcomb, 1994). This material will be organized within four overarching methods of music experiences as described by Bruscia (2014): receptive, re-creative, improvisational, and compositional.

Receptive music experiences. Receptive music experiences are those where "the client listens to [pre-recorded or live] music and responds either silently, verbally, or in another modality" (Bruscia, 2014, p. 304). See Table 1.

Table 1

Selected Examples of Receptive Music Therapy Experiences

Receptive experiences	Summary Descriptions and Sources
Listening to pre-composed live or recorded music	Clients listen to music that is organized and/or tailored by music therapist to produce and/or maintain specific responses (e.g., relaxation). The music therapist adjusts live music based on clients' responses. In environmental music, goals focus on creating a supportive and therapeutic sound environment in context (e.g., in a dining area). Use of nature sounds (could be confusing) or music that is overstimulating may be contraindicated. (Clements-Cortés 2020, pp. 8,16; Petocz & Lesta, 2006, p. 9; Ridder & Wheeler, 2015), p. 1060; Young 2013, p. 729).
Therapist improvising music for clients	The music therapist starts with music that matches the clients' demeanour or energy level. Music elements (e.g., volume, tempo, etc.) are modified gradually to help clients achieve more optimal state of being (i.e., the iso principle). Typically use voice and/or harmonic instruments (i.e., piano: Clements-Cortés, 2020, p. 16; Young, 2013, p. 737.)
Therapeutic singing	The music therapist sings preferred songs to individuals in a group context and encourages musical or other relational interactions among clients. In Neurologic Music Therapy (NMT), goals may also focus on maintaining verbal abilities and respiratory capacity (Clements-Cortés, 2020, p. 15; Ridder & Wheeler, 2015, p. 1066; Young, 2013, p. 729.)
Vibrotactile stimulation and music-assisted sensory stimulation theme groups	The use of tactile stimulation and vibrations produced by musical instruments used to elicit sensory responses and/or constructive interactive engagements. This may be used alone or to support a theme (e.g., singing *My Bonnie Lies Over the Ocean* accompanied by an ocean drum: Clements-Cortés, 2020, p.16; Ridder & Wheeler, 2015, p. 1060; Young, 2013, pp. 729, 738-740.)
Dancing/moving to live or recorded music	Participants move (independently or interactively) in organized or improvised ways in response to music. The music therapist provides musical, verbal, visual, gestural, and/or sensory cues (Young, 2013, pp. 728-729; Ridder & Wheeler, 2015, p.375).

Re-creative music experiences. Re-creative music experiences are those where "the client learns, sings, plays or performs pre-composed music" and involves "rendering, reproducing, realizing, or interpreting any part or all of an existing musical work" (Bruscia, 2014, p. 298). See Table 2.

Table 2

Selected Examples of Re-creative Music Therapy Experiences

Re-creative experiences	Summary Descriptions and Sources
Group sing along	The music therapist sings familiar pre-composed songs with live accompaniment and may encourage clients to participate by singing along. Adaptations to consider include: Create a calm environment (e.g., dim lights, draw curtains, strategic seating), prioritize anxiety reduction, relaxation, and reassurance; exclude individuals whose anxiety/agitation may be exacerbated by this type of activity, use a soothing/low-medium energy song for closure, and/or to help orient/transition clients to the next activity (Clements-Cortés, 2020, p. 16; Petocz and Lesta, 2006, p. 9; Whitcomb, 1994, pp. 70, 73-74; Young, 2013, p. 730.)
Adapted Lyric Analysis	Music therapists utilize familiar song lyrics to convey positive messages to a group of clients and/or validate their feelings, without extensive (or any) verbal processing. This is indicated for clients who respond constructively to messages in songs or emotions contained in lyrics (Young, 2013, p. 749).
Playing Familiar (Known) Instruments	Music therapists provide resources and support for clients who are/were musicians (amateur or professional), facilitating the enjoyment and fulfillment of playing a familiar instrument. Clients may be given opportunities to perform with and/or for others (e.g., clients, music therapist) in a supportive environment. Instruments may be adapted to meet clients' needs (e.g., open-tuned guitar) and clients may explore other accessible instruments or alternative music experiences as needed (i.e., to enhance the client's experience and/or to transition to another instrument/music experience if the client's ability to play their own [adapted] instrument deteriorates; Clements-Cortés, 2020, p. 16; Ridder & Wheeler, 2015, p. 1060; Young, 2013, pp. 749-750).

Improvisational music experiences. Improvisational music experiences involve those where "the client makes up music while playing or singing, extemporaneously creating a melody, rhythm, song, or instrumental piece" (Bruscia, 2014, p. 295). See Table 3.

Table 3

Selected Examples of Improvisational Music Therapy Experiences

Improvisational experiences	Summary Descriptions and Sources
Playing percussion instruments	Group members play small percussion and/or rhythm instruments in response to a musical and/or rhythmic structure provided by the music therapist, which can be precomposed or improvised. Adaptations include using one kind of instrument (e.g., drums) or softer instruments, such as egg shakers, which may be better suited for clients who struggle maintaining a rhythmic pulse. Clients may play along to carefully chosen recorded music that aligns with their preferences and/or has strong rhythmic pulse. It is not essential for all group members to play an instrument during this experience (Young, 2013, pp. 741- 742).
Small group improvisation	An improvised musical structure is created by the music therapist based on sounds and/or music (vocally and/or with instruments) provided by group members. In a large group setting this type of experience may not be feasible (Young, 2013, pp. 740-741).

Compositional music experiences. Compositional music experiences are those where "the therapist helps the client to write songs, lyrics, or instrumental pieces or to create any kind of musical product, such as music videos or audiotapes" (Bruscia, 2014, pp. 301). See Table 4.

Table 4

Selected Examples of Compositional Music Therapy Experiences

Compositional experiences	Description and Sources
Group songwriting	The music therapist helps clients write a song by providing a structured framework for them to create lyrics within a group theme. This is best suited for small groups (4-6 members), however the therapist can also independently compose/improvise lyrics that align with the chosen theme. For example, creating a song that describes a component of each client's attire or features of the weather. Compositions may be accompanied by either a pre-established melody chosen or composed by the music therapist or an improvised tune. It may be confusing for some clients to use a familiar pre-composed song melody for this purpose – i.e., putting new words to a familiar song (Clements-Cortés, 2020, p. 16; Young, 2013, pp. 751-752.)

Evaluation

As previously noted, when working with PLWD in long-term care, evaluation of an individual's music therapy care plan may be ongoing because goals and music experiences may need to be adapted to meet a client's needs in the present and/or to support them as their needs and potentials evolve over time (Young, 2013; in press). While tools such as the Music in Dementia Assessment Scales (MiDAS) have been designed to examine music therapy processes and outcomes (McDermott et al., 2014), these detailed evaluations are typically used for research purposes, perhaps because they do not accommodate time and resource restraints that often exist in *real world* dementia care contexts. Facilities may also have established standards where they review multidisciplinary care plans according to a pre-determined schedule (e.g., every six months) and revise accordingly (Alzheimer Society of Canada, n.d.; McDermott et al., 2014), which may have implications for music therapy services. Fundamental considerations regarding music therapy program and care plan evaluation will be further addressed in Chapter 4 in relation to the proposed music therapy framework.

Summary Conclusion

Sundowning is a common yet complex phenomenon that involves a worsening of BPSD during late afternoon and evening hours. Although the exact cause is not known, it appears to be influenced by physiological, environmental, and psychosocial factors. Pharmacological treatments are commonly used to address the BPSD, but they often have limited positive impact

and can also result in unwanted side effects, posing challenges for all concerned. While music or music therapy is often cited as a viable non-pharmacological option to *treat* the BPSD (including those associated with sundowning), PLWD in long-term care often do not have consistent access to a full range of music therapy services. Furthermore, some dementia advocates and music therapy scholars advocate not only for a broader range of support services but also for a more person-centered approach where music is considered as a health and wellness resource rather than as a treatment. While music therapists have an established history of working in long-term care settings with PLWD using various music experiences to address relevant goals, very little has been written on how music therapy might be used to address sundowning for PLWD, and specifically in long-term care. Therefore, as noted in Chapter 1, the purpose of this study was to develop a group music therapy program framework for PLWD in long-term care who are experiencing sundowning. The following chapter will outline how an intervention research methodology was conceptualized within the context of the present study.

Chapter 3. Methodology

Research Design

This study was informed by intervention research design as conceptualized by Fraser and Galinsky (2010). This methodology involves a systematic process wherein research findings, theoretical knowledge, and practical knowledge are combined to create a new or modified program in order to bring about purposive change, such as altering a behaviour, reducing risk, or improving outcomes (Fraser et al., 2009; Fraser & Galinsky, 2010). This research design typically employs a five-step model. In Step One, a *problem* is defined. Relevant literature is examined and *risk*, *promotive*, and *protective* factors related to the problem are identified. From these identified factors, *malleable mediators* are determined along with appropriate interventions, settings, and levels of treatment. Once all of these factors are finalized, a theory of change is proposed which serves as the foundation for program development. Step Two uses the aforementioned information to design a draft of the structure and processes of the program. This draft is reviewed by experts and revised accordingly. The program is then piloted, and content is expanded to address training and implementation. Steps Three to Five involve creating efficacy tests, testing effectiveness in practice settings, and disseminating program findings and materials (Fraser et al., 2009; Fraser & Galinsky, 2010).

In order to focus this study and keep it within the scope of a master's thesis, only the first 1.5 steps of the intervention research design were employed (i.e., up to and including the point where a program framework is proposed). Other delimitations are noted in the data collection procedures outlined below.

Data Collection

Information relevant to the research questions was collected from scholarly literature including peer-reviewed articles, published books and book chapters, theses, dissertations, and implicated organization websites such as the Alzheimer Society of Canada (n.d.). Scholarly sources were delimited to those written in English and published between 2011 and 2023, with the exception of a few seminal articles. These sources were identified through keyword searches of online databases including Medline, EBSCO, Psych Info, APA Psych Net, Google Scholar, and Concordia's Sofia Discovery Tool. Search terms (entered in various combinations) included: *music therapy, sundown syndrome, sundowning, music, dementia, Alzheimer's disease, Alzheimer's, long-term care, nursing homes, and circadian disorders.* This resulted in 79 relevant

sources that included: 45 journal articles, 20 books/chapters, one doctoral thesis and 13 websites.[4] Thirty-nine of these sources address various aspects of music and/or music therapy in dementia care (with four focused specifically on sundowning), and 40 focus exclusively on sundowning.

Data Analysis

The initial step involved defining the problem (i.e., the overarching issue or need(s) that this program aimed to address) within the targeted setting (i.e., long-term care). I then conducted a directed content analysis of the literature (that had been organized and summarized in Chapter 2) wherein I extracted information and organized it into emergent themes contained within pre-determined categories that aligned with intervention research design. These categories included: *risk factors, promotive factors, protective factors, malleable mediators, identified problems* (i.e., needs)*, intervention level and outcomes, and intervention agents* (i.e., session leader and support personnel). Please note that contextualized definitions of these italicized terms will be included in Chapter 4 as part of the results. Once the organization of this material was finalized, I proposed a *theory of change* which summarizes the overarching rationale as to why the program framework that I am subsequently proposing will potentially address the identified problem (i.e., challenge and/or need). I then reviewed all of the information gathered and organized up to this point to help determine the structure and processes of the proposed group music therapy program for PLWD in long-term care who are experiencing sundowning. Throughout the entire duration of the data collection and analysis processes, I maintained a journal to record analytic memos, which also aided in drawing out connections between the data and my practical knowledge and experiences (to date) of working as a music therapist in dementia care contexts. This, in combination with ongoing consultations with my supervisor, helped me to understand how this information might be conceptualized in real-world practice.

[4] Given the overwhelming amount of material, only sources that seemed directly relevant to the research questions (including those written by known experts) were retained. The subjectiveness of this process is noted as a possible limitation in Chapter 5.

Chapter 4. Results

The Problem Theory

Identified Problems

After organizing and reviewing the information that was extracted from the literature, the main problem was revealed as follows: While sundowning may be associated with an expected progression of an individual's dementia, perceived symptoms and behaviours may be exacerbated or even caused by needs that are not being recognized or adequately addressed in many long-term care contexts. These needs fall within three overarching domains: physiological, environmental, and psychosocial (Canevelli et al., 2016; Kachiyants et al., 2011; Menegardo et al., 2019; Yevchak et al., 2012). Using directed-content analysis procedures, risk, promotive, and protective factors were identified within each of these three domains and are subsequently described below. It is important to note that aspects of these domains are inextricably linked and as such, the identified factors have varying degrees of relevance for all three domains.

Risk Factors

Risk factors encompass variables that affect the probability of a problem emerging or being sustained under certain conditions. These may include individual characteristics, life experiences, and contextual elements (Fraser et al., 1999; Fraser & Galinsky, 2010). Within the context of the present study, identified physiological risk factors include: (a) poor sleep/disturbed sleep patterns (possibly due to disruption of circadian rhythms), (b) poor nutrition, (c) poor hygiene, (d) lack of physical activity, (e) exhaustion (due to excessive *wandering* as well as sleep related issues), (e) unaddressed pain, and (e) adverse side effects of pharmacological interventions, including those caused by polypharmacy (see Chapter 2, p. 12). Environmental risk factors include: (a) ambient light levels that are too low to support natural light-dependent sleep-wake cycles, (b) excessive noise/other over stimulation that manifests within personal/common/social spaces, and (c) spaces that feel unfamiliar and/or restrictive. Psychosocial risk factors include: (a) breakdown in relationships with personal caregivers and loved ones, (b) inadequate/poor relationships with professional caregivers, (c) not enough professional psychosocial support staff, (d) boredom/sensory deprivation, (e) unaddressed feelings of grief and loss, and (f) overall social isolation. Alone or in combination, these various risk factors may contribute to feelings of fear, anxiety, loneliness, agitation, and depression; and, they may negatively impact overall quality of life.

Protective and Promotive Factors

Protective factors serve to mitigate the probability of adverse future outcomes by directly modifying risk factors, and they act as guidelines for designing more effective social programs. Similarly, promotive factors are variables or resources that promote positive outcomes. These factors mediate the effects of risks by moderating the interactions among risk factors, thereby buffering against their full impact (Fraser et al., 1999).

Within the context of the present study, factors that have been identified as protective against physiological manifestations of sundowning and/or promotive of positive physiological change include: adequate sleep, rest, physical activity, hygiene, nutrition, and appropriate usage and monitoring of medication. Environmental factors that have been identified as protective against perceived BPSD and/or promotive of positive change include: optimal lighting, optimal levels of sensory input and/or stimulation as determined by context, and living spaces that are designed to feel more like a home and/or part of a neighbourhood. Psychosocial factors that have been identified as protective against perceived BPSD and/or promotive of positive change include: opportunities to engage in constructive, supportive, and meaningful relationships (personal and professional), and opportunities to participate in personally meaningful social, leisure, creative, expressive, and/or other preferred activities.

The Program Theory

Malleable Mediators

Malleable mediators are variables that can be influenced or modified through intervention to bring about positive outcomes. These are determined through analysis of the identified risk, promotive, and protective factors (Fraser & Galinsky, 2010). Within the context of the present study, malleable mediators within the physiological domain include: reduced and/or more optimal use of medications, orientation to time of day (as a means of addressing symptoms due to disruption of circadian rhythms), and promoting increased relaxation and/or decreased levels of anxiety/agitation (as a means of improving sleep/rest, nutritional intake during meals, physical activity, etc.). It is also possible that addressing these aforementioned variables could help to maintain feelings of relaxation and/or prevent anxiety. Malleable mediators within the environmental domain include: lighting, noise and/or sounds that are over-stimulating or agitating, and design and location of personal/common/social spaces. Malleable mediators within the psychosocial domain include: enhancing relational interactions (i.e., between PLWD and:

other residents, professional and family/personal caregivers, and others), enhancing perceptions/understandings of dementia for professional and family/personal caregivers and others, and ensuring accessibility to a range of personally meaningful and supportive experiences and activities in social and other contexts.

Action Strategy

The proposed overarching action strategy to promote positive change involves creating a feasible group music therapy program framework designed to support PLWD who experience sundowning in long-term care contexts. It incorporates relevant music therapy experiences (as described in Chapter 2) and explicates how the malleable mediators identified above and more specific action strategies are realized within a flexible framework that can be adapted in context.

Theory of Change

As previously noted, perceived symptoms and behaviours associated with sundowning may be exacerbated or even caused by needs that are not being recognized or adequately addressed in many long-term care contexts. Many PLWD, even up to the late stages of their disease, can perceive and respond to music in meaningful ways, even when they have difficulty processing language and other forms of sensory input (Baird & Thompson, 2020; Ridder et al., 2013; Ridder & Wheeler, 2015; Young, 2013, in press). Scholars have proposed that there are seven capacities of music that contribute to its therapeutic value—music is engaging, emotional, physical, synchronous, personal, social, and persuasive (Brancatisano & Thompson, 2020). These capacities appear to contain inherent connections to the overarching domains of need identified above (physiological, environmental, and psychosocial). Therefore, the modification of relevant variables (i.e., malleable mediators) via a group music therapy program framework that aims to address the actual needs and enhance/strengthen personal resources of PLWD who are experiencing sundowning in long-term care contexts serves as the proposed logic model and theory of change for the present inquiry[5].

The Program Framework

Program Setting

The setting for this program is a long-term care facility. In order to provide physiological, environmental, and psychosocial supports to multiple residents who are experiencing

[5] It is important to note that language and procedures contained within the proposed program framework assume a person-centered, resource oriented-oriented stance that focuses on fostering strengths and potentials of PLWD rather than on treating BPSD which can inadvertently pathologize as previously explained.

sundowning in this setting, group music therapy was identified as the most appropriate level of intervention. It is important to note that there is a great deal of variation in how long-term care facilities are designed and run, each one containing unique environmental and systemic challenges that may be difficult to navigate. To create an optimal setting for a music therapy group for residents who are experiencing sundowning, it is recommended that the music therapist take the following factors into consideration, to the extent that they can, and adapt as needed.

Sessions can be held daily (as resources allow) for approximately 1-hour, preferably in the same room/location each time, and in the mid to late afternoon when signs of sundowning typically start to occur. The room should be an enclosed space (with the option of having an open or closed door), and free from any unnecessary auditory or visual distractions. A soundproof room would be ideal. On the other hand, if all of the group participants live on the same unit, it may be possible to create a designated open-concept type of space (e.g., at the end of a hallway), where residents can wander freely in and out of the group. Again, auditory or visual distractions need to be minimized as much as possible, and the music therapist needs to work in collaboration with unit staff to facilitate this outcome. If the designated space has windows, blinds or curtains are essential. Natural light exposure may be beneficial for some residents, especially in terms of orienting them to time of day. However, some residents may become distracted or confused by a window, so it is important to be able to adjust this component as needed. If the session location does not include windows, then, if possible, adjusting the indoor lighting may also help to establish an ambiance that aligns with the time of day. An open layout with minimal clutter will help to ensure that the space is accessible for residents in wheelchairs but not overly confining or hazardous for those who are ambulatory.

It is recommended that this program be structured as a combined open-closed group that consists of core members who attend regularly, and a few seats reserved for temporary or rotating members who join as needed (e.g., during occurrences of sundowning; Yalom & Leszcz, 2020). This structure supports a familiar and cohesive environment through the presence of core members while accommodating varying needs and circumstances, such as the open-concept space noted above. This structure also allows family members or caregivers to participate when appropriate, without risking overcapacity.

When arranging the session space, chairs should be set in a circle to promote eye contact and encourage interactive group dynamics. If feasible, a seating arrangement may be formulated

prior to the beginning of sessions, prioritizing positive group interactions. For example, place residents with known positive interactions next to each other, while avoiding pairing individuals who may have conflicts. For residents who are particularly sensitive to external stimuli, positioning them with their backs to potential distractions (e.g., hallway noise, a busy nurse station, or a window) may help enhance their focus and engagement during the session. Depending on the size of the room/designated space and the number of support staff present (addressed below), the number of residents who attend this group can vary but ideally should not exceed eight participants, especially in an enclosed space. This helps to ensure that individuals' needs can be accommodated as they emerge. Limiting the number of residents also avoids overstimulation as a result of too many people in the space, which may also detract from the therapeutic music and sound environment that the music therapist is trying to create.

Session Leader and Support Personnel

The session leader is a certified music therapist who has the necessary theoretical and practical training to enable them to realize and apply music experiences (i.e., musical action strategies) with flexibility and knowledgeable intent. Ideally, the music therapist has previous clinical experience working with PLWD and some acquired knowledge about sundowning. If not, this individual should engage in regular peer and/or professional supervision, especially in the planning, implementation, and early evaluation phases of the program.

If the group is being held in a room not located on the residents' unit, the music therapist will need to secure the services of one or more trained volunteers and/or professional assistants who can safely accompany residents back to their rooms if they indicate that they want to leave. In either an on-unit context or off unit context (i.e., a room located in a different area of the facility building), trained volunteers or professional assistants can support and model participation as indicated by the music therapist. Family members/friends (of participants) may also attend the group and while they may also support participation, if and how they do so should be determined on a case-by-case basis to ensure that everyone is getting the support that they need.[6]

[6] The proposed music therapy group framework focuses on supporting PLWD who are experiencing sundowning. A future study could propose a variation of this framework that integrates loved ones/friends as music therapy client participants. This is beyond the scope of the present study.

Resources[7]

In addition to securing a designated space, the music therapist will need to secure several chairs for ambulatory participants, support staff/volunteers and family members, and for themselves. The music therapist will also need access to a guitar, or other portable accompaniment for them to play, and a keyboard. A variety of percussion instruments is also required; some that are accessible for a variety of persons to explore tactically (e.g., egg shakers, maracas of varying sizes, hand drums), some that can be used for sensory stimulation (e.g., cabasa, rain stick, wood blocks), and some that may have cultural relevance for participants (e.g., bongo, djembe, frame drum). Additionally, a high-quality sound system with wireless internet connectivity is required, and a device to access the music (i.e., iPad or Android tablet). It is recommended that the music therapist (via the facility) also invest in a subscription to a music streaming platform service, such as Spotify or Apple Music. The music therapist should coordinate the availability of items provided by the facility (e.g., chairs and sound system) with their facility supervisor. A collection of musical repertoire, including playlists, music-books and/or lead sheets should be prepared ahead of time, ensuring it includes songs and pieces that are age appropriate, a range of genres, and music that reflects cultural diversity. Music therapists may consider utilizing an application to organize digital music, if applicable.

The music therapist must be compensated with a fair wage, and several factors need to be considered. This includes the total number of hours worked (on or off-site), which may involve time spent of session preparation and documentation. The music therapist's wage may also be set according to their years of previous professional experience.

Protocols

Referral. Referrals can be received formally or informally from family members/loved ones, or multidisciplinary team members. These referrals may be communicated verbally or submitted in written form (hard copy or online depending upon each facility's established process). Reasons for referral include addressing needs and/or strengthening potentials in various domains of functioning including: communication, cognitive, motor, musical, emotional, and social. Referrals may be made for music therapy at large or made specifically for the music therapy sundowning group (i.e., a PLWD is exhibiting BPS typically

[7] This thesis does not include a budget for resources needed as this may be highly variable. However, if this type of program is being presented as part of a proposal, music therapists will need to include a budget that is formulated taking specific contextual needs and considerations into account.

associated with sundowning). In either case, the music therapist will conduct an assessment (described below) to determine if an individual could potentially benefit by being part of this specific group. If the group is being held in an open-concept space (as described above), an individual could self-refer simply by choosing to join the group as it is occurring. In this case, the music therapist would assess them via their participation and then follow up with this individual to obtain further information that might help to support them in the future should they choose to join the group again (e.g., information pertaining to their cultural background and music preferences).

Assessment. Approaches to assessment will vary according to several contextual factors. If a music therapist is in a permanent part-time or full-time position at a long-term care facility and is integrated as part of the multidisciplinary team, they may have an established music therapy assessment process that can incorporate a music therapy sundowning group as a care plan option. The assessment tool created by Norman (2012; described in Chapter 2) could be adapted to align with the processes of a particular facility. In addition to gathering relevant background information (cultural, musical, and other), this assessment focuses on making observations of individual's behaviour and physical demeanor in response to music experiences (i.e., a protocol designed by the music therapist taking the background information into account) that include singing, movement, and exploring musical instruments. Observations are reported by selecting checkmarks of potential observed responses within five distinct sections: (a) musical training and musical preferences, (b) communication and social interactions, (c) cognitive and motor skills, (d) affective response to the music experiences, and (e) overall assessment and music therapy recommendations.

However, it may be the case that a music therapist facilitating a sundowning group will not be in a position to conduct a detailed assessment (e.g., they come to the facility once a week to run the group). In this case, much of the assessment process may need to take place in the group context (through observing an individual's participation) and through ensuring that the facility staff understand how to make appropriate referrals for this group.

Goal Examples

The goals formulated for this program guideline are typically qualitative, and focus on described observations related to individuals' expressed or perceived quality of life rather than on measuring quantifiable outcomes (Bruscia, 2014; Bunt, 1994). This is both a philosophical and

practical decision. Goals were created to align with the three overarching domains of need (i.e., physiological, environmental, and psychosocial) and their corresponding risk, promotive, and protective factors, and malleable mediators. Strategies—encompassing musical, practical, and therapeutic approaches—were provided to further support addressing the identified needs. See Table 5, Table 6, and Table 7 for an overview of some examples of potential goals and strategies in each domain.

Table 5

Physiological Goals and Strategies for a Music Therapy Program Framework

Need or Potential	Goal	Malleable Mediators	Musical and Other Strategies
Adequate sleep, rest, physical activity.	Release anxiety and/or tension.	Promote means of decreasing levels of anxiety/agitation. Orientation to time of day.	Encourage participation in a structured activity, such as playing instruments, dancing, and movement in response to an established musical framework; vocalized/sung prompts indicating time of day— and to ground client in the here-and-now while supporting ease of transition to and from activities (sing—"and now it's time for supper").
Appropriate usage and monitoring of medications that are typically used to address sundowning.	Minimize risk of experiencing adverse side effects from medications.	Reduced/more optimal use of medications. Promoting feelings of relaxation.	Adapting music elements (e.g., style, volume, and rhythm) in consistent and predictable ways that promote feelings of security and/or relaxation.

Table 6

Environmental Goals and Strategies for a Music Therapy Program Framework

Need or Potential	Goal	Malleable Mediator	Musical and Other Strategies
Optimal lighting.	Support natural sleep/wake cycles.	Light levels.	Open window drapes; adjust indoor light levels.
Levels of sensory input and/or stimulation as determined by context.	Experience a sensory friendly environment	Noise levels.	Simple instrumentation as needed (e.g., unaccompanied singing) closing doors to block out noise, visual distractions etc.
More home-like/welcoming designed living spaces.	Experience a supportive and comfortable environment.	Design and location of personal/common/ social spaces.	Private session spaces; open-concept seating arrangement; play recorded music (predictable, not too complex) to facilitate orientation and transition into the music space.

Table 7

Psychosocial Goals and Strategies for a Music Therapy Program Framework

Need or Potential	Goal	Malleable Mediator	Musical and Other Strategies
Opportunities to engage in constructive, supportive, and meaningful personal/professional relationships.	Experience social engagement and constructive relational interactions.	Enhance interactions between PLWD, caregivers, and other residents; shift focus from deficit to potential.	Use positive reinforcement and validate participation (e.g., singing, humming, clapping) to encourage family members/loved ones/support staff to engage in activities (e.g., group singing) with residents; musical/verbal orienting to other residents.
Opportunities to participate in personally meaningful social, leisure, creative, expressive, and/or other preferred activities.	Explore creativity, self-expression, and experience feelings of confidence and meaningful social engagement.	Access to a variety of meaningful, supportive, and interactive experiences.	Offer variety of personalized music experiences (cultural and individual considerations); repeat familiar songs verses/choruses; vocalize familiar tunes (i.e., use "la-la" rather than words); incorporate participants' names into a song.

Flexible Session Plan Structure

The following flexible session plan (see Table 8) has been developed from information described above and from data collected in Chapter 2. It is intended to serve as a guideline for music therapists to adapt according to their specific long-term care context. Selected music therapy experiences have been included as examples, but music therapists may choose from the range of music experiences outlined in Chapter 2 and incorporate them into this framework as they see fit.

Table 8

Flexible Session Plan Structure for a Music Therapy Program to Address Sundowning in PLWD

Music Therapy Experiences	Description and Purpose
Orientation/transition to the Music Space	Residents are oriented to the music space as they hear recorded music upon entering the session room. Number of selections offered is dependent on time it takes for residents to enter and settle in to space. Medium-tempo instrumental music can be used to create a welcoming atmosphere. Avoid music with overstimulating rhythms. Multiple pre-planned playlists are recommended, which would be refined over time to align with participants' evolving preferences and daily needs.
Opening/warm up music	The music therapist sings a song with simple accompaniment that aligns' with residents' preferred music or is musically accessible in terms of genre/style. This indicates the start of session and primes participants to receive and engage in music.
Musical greeting	Original music is offered to participants; lyrics are designed to create a welcoming atmosphere, to aid in orienting participants to their environment/other group members, focus attention on the *here-and-now*. This is intended to enhance feelings of belonging/community.
Group sing-along	Residents are encouraged to sing along to familiar songs with live accompaniment. Music therapist may support and/or encourage residents (if they so desire) to dance/move along to music, either independently or with others (i.e., family/loved ones, staff, other residents). Safety considerations may need to be addressed.
Dancing/movement to music	
Playing small percussion instruments	Music therapist provides small percussion instruments that compliments residents' tactile needs, modeling engagement with gentle hand-over-hand if needed. Alternative participation methods include body percussion (e.g., clapping), singing, or listening. For small groups (4-6 participants), group improvisation may be explored. Individuals are encouraged to participate in meaningful ways (i.e., not just make noise). Be mindful of potential for overstimulation.
Small group improvisation	
Cooling down experience	Participants are re-oriented to group singing and familiar music (or genre) with a slow(er), steady beat that assists them in feeling grounded. Lyrics may be simple, if used.
Closing/transition music	Final closing song is presented; residents are encouraged to participate as they wish (sing, listen, sway, etc.) Music and lyrics convey a sense of closure; residents are cued to transition to the next activity (e.g., dinner time) through lyrics and/or other prompts.

Note. Activities that fall under *Group sing-along*, *Dancing/movement to music* can be alternated and/or repeated with *Playing small instruments* and *Small group improvisation* as the session unfolds depending on the residents' needs.

Other Select Considerations

In addition to the information outlined in the program framework above, selected details are included in this section for music therapists to consider when facilitating a sundowning group. This is by no means an exhaustive list and could be further developed and refined in subsequent research projects or clinical papers.

There may be some residents who are experiencing sundowning but who may feel uncomfortable in group settings or who become overwhelmed or agitated by the music, sounds, and/or people. In these cases, individualized music therapy sessions may be more helpful. Residents who are prone to wandering or pacing may not feel comfortable in a closed room. In these cases, a sundowning group that occurs in an open area (e.g., at the end of a hallway as previously described) may allow these individuals to participate in ways that enable them to move in and out of the group as they please, but still reap benefit from participating in the group. In addition to sensory environment adaptations previously outlined, the music therapist could also consider adapting percussion instruments to make them less *stimulating* (e.g., decrease volume and lower frequency) while at the same time maintaining the instrument's integrity. For example, removing some of the metal cymbals from a tambourine or wrapping felt around a shaker. However, cultural significance of particular instruments may need to be considered and, in some instances, adaptations may not be appropriate. Finally, while trained volunteers and/or support staff greatly enhance what can be done in a music therapy group to support residents who are experiencing sundowning (as previously discussed), it may be the case that consistent support personnel are not available (for various reasons). In this case, the music therapist may need to limit the number of participants according to what they feel they can adequately support without assistance.

Chapter Summary

In order to develop the program theory for a group music therapy framework to address sundowning, key elements such as risk factors, promotive and protective factors, malleable mediators, identified needs, and intervention levels and program settings were identified. This informed a proposed program framework, which included an action strategy, theory of change, resource development, and protocols. A flexible session plan structure was then created and selected considerations highlighted.

Chapter 5. Discussion

This final chapter offers some brief reflections upon the research process and results, including some of the challenges encountered in aligning an intervention research methodology and much of the implicated existing literature with a client-centered philosophy and a resource-oriented approach to music therapy practice for PLWD experiencing sundowning. Limitations of the study will also be presented along with implications for future research, practice, and advocacy.

Brief Reflections

A significant challenge in conducting this research was working to align an intervention research design (which is inherently problem focused) with a resource-oriented, person-centered philosophy. Furthermore, I only found four articles that addressed music therapy and sundowning, and much of the existing literature in dementia care conceptualizes music therapy as a *treatment* for BPSD, where music is regarded as a means of fixing a problem (i.e., perceived behaviours and symptoms) rather than as a resource to enhance quality of life. In practice, most music therapists working in dementia care indicate that they use a person-centered approach, emphasizing individual needs and quality of life over using music as a *treatment* per se (Young, in press). This disconnect between research and practice calls into question the relevance of much of the current literature in the field. If research is not aligned with how a practice is being realized, its applicability to real-world care may be limited. This also highlights a broader tendency in many long-term care settings, to medicate and *problematize* PLWD, rather than engage and support them in meaningful ways that will help them to fulfill their personal potentials for quality of life, even as their needs and circumstances change over time (Young, in press). Music therapy has much to offer in this regard and its full potential to support PLWD in long-term care, including those who are experiencing sundowning, has yet to be realized.

Limitations

Throughout the course of this research, I held certain assumptions that could be considered as limitations, as they may have unintentionally influenced the data collection and analysis processes. I assumed that a music therapy program framework that specifically addresses sundowning would be a welcome means of support for PLWD in all long-term care contexts. I also assumed that music therapists would have opportunities to integrate this type of program into long-term care settings as part of their residents' overall care. However, this may not always be

the case, and my suggestions could be limited by the constraints of individual music therapists' employment situations. Finally, given the large amount of literature pertaining to music/music therapy and dementia care, I found it difficult to distill all of this information into relevant fundamental components that may have further informed the development of the program theory and the proposed music therapy program framework.

Implications

Research

As this research was delimited to the first 1.5 steps of Fraser and Galinsky's (2010) intervention research methodology, the proposed program has not been tested. Future research that evaluates the proposed program in various long term care settings would help to validate and/or further refine various components. Qualitative or quantitative tools that assess quality of life could be part of this research. It would also be interesting to conduct surveys or interviews that explore the types of music experiences that music therapists actually use when working with PLWD as what was cited in the literature was somewhat limited, particularly with regard to compositional and improvisational experiences. Finally, future research could explore adapting the proposed framework or creating a new group music therapy program framework to provide support to others who are affected by dementia/issues related to sundowning (e.g., that personal and professional caregivers, spouses, other family members and friends, etc.).

Practice

The flexibility of the present framework allows opportunities for both novice and experienced music therapists to adapt it to various contexts, including online practice, practicum sites, part time and full-time work settings. As such, they will need to consider factors not fully addressed in this study, such as budgetary constraints, technology considerations, contextual issues, and resource availability. Practitioners may also consider adapting elements of this program to ensure that residents experiencing sundowning continue to receive music support during times when the music therapist may be absent (e.g., on weekends or during vacations). The music therapist could compile a selection of playlists and/or audio record music sessions that could be implemented by others. Rather than aiming to facilitate the same program, the idea would be to train individuals (volunteers and/or staff) on how to use music safely, respectfully, and appropriately within the scope of their own knowledge and skill set. Ongoing consultation with the music therapist would be essential.

Advocacy

This thesis provides a strong rationale as to why and how music therapy can be important means of addressing sundowning in long-term care. It also provides a clear but flexible group program framework. Therefore, it can be used as a resource to help music therapists to advocate for this type of service in long-term care facilities where they currently work or hope to work. It can help them to plan, implement, and maintain a program based on current knowledge and evidence without having to *reinvent the wheel*. Finally, and most importantly, this thesis advocates for widespread implementation of a service that could significantly improve quality of life for PLWD in long-term care who are experiencing sundowning.

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