A Music Therapy Program Design for Neuro-Palliative Care

Kirsten L. Davis

A Thesis

in

The Department

of

Creative Arts Therapies

Presented in Partial Fulfillment of the Requirements

for the Degree of Master of Arts in Creative Arts Therapies
(Music Therapy, Research with Thesis Option)
Concordia University

Montreal, Quebec, Canada

September 2018

CONCORDIA UNIVERSITY
School of Graduate Studies

This is to certify that the thesis prepared

By: Kirsten L. Davis

Entitled: A Music Therapy Program Model for Neuro-Palliative Care

And submitted in partial fulfillment of the requirements for the degree of

Master of Arts in Creative Arts Therapies (Music Therapy, Research with Thesis Option)

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
Guylaine Vaillancourt

_____ Examiner
Laurel Young

_____ Supervisor
Charles-Antoine Thibeault

Approved by _____
Guylaine Vaillancourt, Chair of Creative Arts Therapies Department

_____
Rebecca Taylor Duclos, Dean of Faculty of Fine Arts

ABSTRACT

A Music Therapy Program Design for Neuro-Palliative Care

Kirsten L. Davis

The use of music therapy to support patients and families receiving traditional (oncology-based) palliative care has been well established in research and practice (Bradt & Dileo, 2010). In this study, intervention research methodology (Fraser, Richman, Galinsky & Day, 2009) was used to develop a music therapy intervention manual for the emergent sub-specialty of neuro-palliative care. Two participants (one neuro-palliative care nurse clinician, one music therapist) were interviewed regarding applications of music therapy for patients with end-stage brain tumours, strokes, and progressive neurologic disorders. These findings, combined with the researcher's own clinical experience, suggest the essential components of a music therapy program for neuro-palliative care, give detailed descriptions of music therapy interventions for neuro-palliative care, and outline patient and family needs and goals which music therapy may address in a neuro-palliative care setting.

Acknowledgements

This thesis is dedicated to:

My Mum & Dad:
For giving me a love of learning and a love of music to last a lifetime,

Daniel, Jeannie & Stella:
For sending Mummy to La Belle Province to choose her own adventure,
and joining in the fun during the coldest months!

Marika, R.E.:
For faithfully boosting my morale by feeding my mailbox,

Donna, R.E., Joanopoulis, Trinidad & Tweezlicious:
For endless encouragement,

Linda Mulhall:
For helping me "find the juice!" in Montreal,

Dr. Helena Daudt:
For an inspiring example of balancing passion and organization in research,

Charles-Antoine Thibeault, Josephine Lee & Sarah Milis
For walking the thesis road ahead, and teaching our class from your experience,

My MA Music Therapy 2017-18 classmates:
For sharing the journey,

Deborah Salmon:
For proving that angels have feet as well as wings,

Dr. Hall, Justine Gauthier & the amazing team at the Montreal Neurologic Hospital:
For welcoming music therapy with open arms and hearts,

AND to all the patients & families who have been my teachers,
as they have allowed me to accompany them with music to the end of their journeys:
Keep on rockin' in the free world, Chris!

Table of Contents

LIST OF TABLES AND FIGURES:

Chapter 1. Introduction

Since its development in Britain in the 1960's, palliative care has been offered, primarily to cancer patients, to relieve suffering and improve quality of life when a cure for disease is not possible (Veronese et al., 2015). Palliative care is a holistic approach which incorporates psychosocial and spiritual aspects of care in addition to providing physical symptom control and relief. Palliative care provides support to the patient and their family members throughout the disease trajectory and after death, including grief and bereavement support (World Health Organization [WHO], 2017).

In the last 20 years, medical professionals have recognized that application of the palliative care approach to treatment of patients with neurologic disorders, and their families, is also appropriate and beneficial (León, Giraldo, Restrepo, & Rengifo-Varona, 2013; Robinson & Barrett, 2014). This has led to the development of neuro-palliative care, a sub-specialty combining palliative care and neurology (Robinson & Barrett, 2014), which addresses the specific needs of "patients with chronic, degenerative, incurable and end-stage neurologic disorders" (Robinson & Barrett, 2014, p. 182) and their families.

Music therapy is significant in its potential to address the psychosocial, physiological and spiritual needs of patients with life-limiting neurologic disorders receiving neuro-palliative care throughout their illness trajectories (Daveson, 2008; Magee, 2013; McNab, 2010). Patients with these diagnoses experience many physical and psychosocial losses, including the loss of independence, identity, and verbal communication, all of which contribute to decreased quality of life for both patients and their caregivers (Elman et al., 2007). However, patients with neurologic disorders can benefit from and value active involvement in managing their quality of life, such as participating in music therapy sessions (Aldrige et al., 2005), and music therapy experiences can be adapted to accommodate the abilities of these patients at all stages of their illness trajectories, from diagnosis to end of life, even as other abilities deteriorate (Magee, 2013).

Relevance to Music Therapy

Research in the neurologic foundations of music perception and processing has led to the development of specific music therapy approaches, particularly Neurologic Music Therapy (NMT; Thaut, 2005). This approach was originally designed for use in rehabilitation settings, for patients with neurologic disease or trauma, including Parkinson's disease and cerebrovascular accident, and has since been expanded to include applications to other neurologic diagnoses

including multiple sclerosis, traumatic brain injury, neurologic cancers and coma states. (Academy of Neurologic Music Therapy [ANMT], 2015). However, NMT does not focus on supporting the psychosocial and spiritual needs of patients with life-limiting neurologic disorders. These needs are often equally important as patients' physiological needs at end of life (Oliver, 2014). This indicates a need for a more holistic music therapy approach, which, as suggested by palliative care philosophy, may also include and support the patients' family members (WHO, 2017).

Research in this area could prove particularly relevant to current clinical practice, as a recent survey by Graham-Wisener (2018) indicates that 68% of music therapists working in palliative/end-of-life care in the United Kingdom most frequently provide services for patients with neurologic conditions (as compared to cancer or other life-limiting illnesses). As music therapy has already established a role in more traditional palliative care settings and populations (Bradt & Dileo, 2010; Krout, 2001), and as Aldrige et al. (2005), McNab (2010) and Magee and Davidson (2004) have recommended further investigation of the impact of music therapy on physical and psychosocial functioning in patients with neurodegenerative disorders, particularly in end-stage disease, this project will investigate the role of music therapy specific to neuro-palliative care.

Personal Relationship with the Topic

Throughout my years of music therapy practice, I have had the privilege of working with patients with life-limiting neurologic disorders in long term care, transitional care, and palliative care settings. These patients have inspired me with their courage and creativity (Davis, 1998). These experiences led to my recent completion of introductory training in Neurologic Music Therapy at Colorado State University. I was impressed with the method itself, but disappointed with its limited applications to my current clinical setting, which focuses on palliative care. It appeared to me that the strongly evidence-based medicine model of NMT may de-emphasize the psychosocial and spiritual needs of patients which are often prevalent in palliative care. I am interested in developing music therapy approaches and techniques which can support the unique needs of patients with neurologic disorders at end of life within a more holistic framework, and in defining the scope of practice and establishing the role of music therapy within an interdisciplinary neuro-palliative care team.

Purpose Statement

The purpose of this project is to develop a specialized music therapy program to meet the psychosocial, physiological, and spiritual needs of patients receiving neuro-palliative care, and their families.

Research Questions

Primary research question. What are the components of a music therapy program for patients and families receiving neuro-palliative care?

Subsidiary research questions. Which music therapy interventions are most appropriate for patients receiving neuro-palliative care, and their families? Which patient/family needs and goals can music therapy address in the neuro-palliative care setting?

Assumptions

I assumed that music therapy would benefit patients and families receiving neuro-palliative care, and that these benefits would be similar to those seen in traditional (oncology-based) palliative care settings and patients. I assumed that the role of the music therapist and music therapy interventions used in the neuro-palliative care setting would be similar to the role of the music therapist and music therapy interventions used in traditional (oncology-based) palliative care settings.

Delimitations

The results of this study were delimited by the ability to complete only steps 1 and 2a of the intervention research method (Fraser, Richman, Galinsky, & Day, 2009) within the time and ethics constraints of the MA Creative Arts Therapy program thesis. I additionally chose to delimit the research to involve only neuro-palliative care team members or consultants thereto as participants. I also chose to develop only music therapy interventions which can address the needs of patients receiving care within an inpatient neuro-palliative care program; thus, interventions which have rehabilitative goals or are best suited to patients above a Palliative Performance Scale (PPS) score of 60% (the typical maximum PPS level of patients referred to the neuro-palliative care program at the local neurologic hospital) are not included. I have limited literature referenced to sources published within the past 20 years.

Definitions of Key Terms

Palliative care is "an approach that improves the quality of life of patients facing…life-threatening illness and their families, through the prevention and relief of suffering by…treatment of pain and other problems, physical, psychosocial and spiritual." (WHO, 2017).

Neuro-palliative care is a subspecialty of palliative care which meets the specific needs of patients with life-limiting neurologic disorders such as amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), Parkinson's disease (PD), stroke, and malignant brain tumors (Oliver, 2014).

Neurologic disorders are "diseases of the central and peripheral nervous system…the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junction, and muscles. These disorders include epilepsy, Alzheimer disease and other dementias, cerebrovascular diseases including stroke, migraine and other headache disorders, multiple sclerosis, Parkinson's disease, neuro-infections, brain tumours, traumatic disorders of the nervous system due to head trauma, and neurologic disorders as a result of malnutrition." (WHO, 2017).

Chapters Summary

This introductory chapter is followed by a literature review in Chapter 2, which describes characteristics of patients receiving neuro-palliative care, specifically those with progressive neurologic disorders, brain tumours, and stroke. Music therapy in traditional oncology-based palliative care is briefly outlined, followed by a description of music therapy approaches for working with patients with neurologic disorders, and the implications of these approaches for music therapy in the new subspecialty of neuro-palliative care. Chapter Three explains the design, procedures and ethical issues involved in this study's use of Fraser et al's (2009) intervention research methodology. Chapter Four then contains results: a summary of interview findings, applications of data to intervention research steps one and two, and the resulting Neuro-palliative Care Music Therapy Intervention Manual. Finally, Chapter Five discusses the limitations, challenges, implications of this study, and recommendations for future research.

Chapter 2. Literature Review

Characteristics of Patients Receiving Neuro-Palliative Care

Patients receiving neuro-palliative care are a diverse population, consisting of patients diagnosed with a broad range of neurologic disorders. Their diagnoses fall into three main categories: progressive neurologic disease, malignant brain tumour, and stroke.

In Canada, the most commonly occurring progressive neurologic diseases (PND) include multiple sclerosis (MS; 290/100,000), Parkinson's disease (PD;170/100,000), amyotrophic lateral sclerosis (ALS; 10/100,000), and Huntington's disease (HD; 10/100,000; Public Health Agency of Canada, 2014). All of these conditions are life-limiting, but patients with these conditions generally have longer disease trajectories and prognoses than palliative care patients with cancer (Veronese et al., 2015), and are often younger than other patients receiving palliative care (Oliver, 2014). The progression of these diseases is unpredictable and can vary widely from patient to patient (Oliver, 2014), consisting of multiple attacks and remissions or slow continuous deterioration (Boersma, Miyasaki, Kutner, & Kluger, 2014). Patients with PND are more likely to experience these diseases as an intrinsic part of themselves than cancer patients, who more often tend to view their disease as an external invasion. Therefore, patients with PND are at greater risk of seeing themselves as "useless" or "a burden" to others (Boersma et al., 2014).

Patients with malignant brain tumors also frequently require specialized palliative care. Primary brain tumours (originating in the brain) occur in 8/100,000 people in Canada, and approximately 32/100,000 when metastatic tumours (cancer originating in other areas of the body which has spread to the brain) are included. Average prognosis for patients with brain tumours, even with aggressive treatment, is usually less than one year (Brain Tumour Foundation of Canada, 2017). Patients with brain tumours often experience seizure disorders, as well as impaired cognition and communication during these contracted disease processes (Boersma et al., 2014).

Patients with severe neurologic damage due to stroke (cerebrovascular accident), also often require palliative care, as stroke mortality is 10%, and stroke is the third leading cause of death in Canada. The overall population prevalence of stroke in Canada is 1.15% (Krueger et al., 2015). Patients with stroke often experience swallowing disorders, hemiplegia (weakness or paralysis on one side of the body), visual deficits, and expressive and/or receptive aphasia (inability to produce or process language; Krueger et al., 2015).

Although the neurologic etiologies of these three types of diagnoses are diverse, the most frequently occurring physical symptoms across these diagnoses include motor impairment and related symptoms (rigidity, tremors, paralysis, falls, fatigue), swallowing disorders, pain, respiratory compromise, speech/communication impairment, bowel and bladder dysfunction, sleep disturbances, and skin breakdown (Elman et al., 2007; Veronese et al., 2015). Psychological symptoms patients with neurologic disorders experience include anxiety, depression, mood instability, and feelings of confusion, abandonment, concern, and guilt (Veronese et al., 2015). Patients with life-limiting neurologic disorders and their caregivers also describe many social issues resulting from their illnesses: family stress and breakdown; social isolation; needs for paid caregiver and/or volunteer support; decreased income; and difficulty obtaining benefits (Veronese et al., 2015). The spiritual impact of the disease process can also be significant, and patients describe needs for spiritual support, hope, and meaning as well as needs to express a sense of injustice, rage, hopelessness, and doubt (Veronese et al., 2015). As a result of their disease processes, patients with these diagnoses experience multiple physical and psychosocial losses, including loss of independence, identity, dignity, mobility, employment, social roles, and communication (Elman et al., 2007; Veronese et al., 2015). Dallara and Tolchin (2014) add that patients and families receiving care for neurologic diagnoses "require more frequent grief support for repeated losses than patients with more predictable disease courses" (p. 640). The multitude of symptoms, needs, and losses are likely to contribute to decreased quality of life for patients with life-limiting neurologic disease and their caregivers (Elman et al., 2007; Veronese et al., 2015).

The terminal nature of these neurologic diagnoses, the enormous burden of the symptoms, and the impact on both patients and their caregivers through to end of life (and beyond, in the case of caregivers) speaks to the appropriateness of offering palliative care services to those affected (Veronese et al., 2015). Steele (2005) observes that patients with terminal neurologic disorders experience enormous uncertainty regarding the future, grief resulting from ongoing losses, and anxiety regarding mortality. Additionally, as these patients' mobility, communication, and cognition tends to deteriorate well in advance of death, it is imperative that advance decision-making regarding end-of-life care take place early in the disease processes (Dallara & Tolchin, 2014). All of these are issues, which are commonly addressed from a palliative psychosocial care perspective, may not be well managed by neurologists as palliative care is not yet a standard aspect of neurology training (Oliver, 2014).

Music Therapy in Traditional (Oncology-Based) Palliative Care

Music therapy has demonstrated its unique contribution to an interdisciplinary palliative care approach, addressing the complex needs of palliative care patients and their families through the creative, expressive medium of music (Gallagher, 2006; Hilliard, 2005). Goals in these areas of need commonly addressed by music therapy interventions in palliative care include: physical (pain, dyspnea [shortness of breath]), emotional (anxiety, depression, frustration), social (isolation, loneliness) and spiritual (loss of hope, need for transcendence and legacy; Gallagher, 2006; Hilliard, 2005). Music therapy interventions commonly used in palliative care include song choice and singing, vocal and instrumental improvisation, music-facilitated life review, music-facilitated relaxation and imagery, song writing, and receptive music listening (Gallagher, 2006; Hilliard, 2005; Killoran, 2012).

Music Therapy with Neurologic Disorders

The literature specific to the application of music therapy in the neuro-palliative population is very limited (Magee, 2013; McNab, 2010). However, there is a greater body of extant research in music therapy and neurologic rehabilitation for patients in earlier stages of neurologic disease or disability, which may provide initial direction and information to music therapists wishing to develop and provide service appropriate to the neuro-palliative population.

Daveson's (2008) meta-model of music therapy in neuro-disability. Daveson's (2008) Meta-Model of Music Therapy in Neuro-Disability (MIND) provides a framework within which neuro-palliative music therapy may theoretically be included. The MIND is a comprehensive, broadly-based approach to patient-centred music therapy practice for patients of all ages receiving neurologic care in inpatient hospital, long-term, or home settings. The MIND recommends the flexible selection and application of a music therapy approach which best suits the individual patient's goals of care to (a) restore function, (b) compensate for losses and/or (c) meet psycho-social-emotional needs. The MIND assists the music therapist to develop goals using the acronym S.M.A.R.T. (Specific, Measurable, Attainable, Relevant, and Timely) to evaluate treatment outcomes. This meta-model also includes practical decision flowcharts and diagrams to assist the therapist in its application.

Daveson's (2008) meta-model comprises three approaches to music therapy intervention for patients with brain injury or neuro-degenerative disease, derived from an extensive review of

music therapy literature. Daveson explains that the use of multiple models with this population is necessitated by the fact that:

> ...patients with brain injury and neuro-degenerative disease can present with various types of needs at one point in time…(they) may experience, as a result of their injury or disease process, changes in…cognitive, behavioural, psychological, emotional, communication and physical realms. Also, the severity and intensity of these changes may vary. (p.76)

The three approaches within the MIND are termed "restorative, compensatory, and psycho-social-emotional" (Daveson, 2008, p. 72).

Restorative. The MIND's restorative approach is based on the theory of neuro-plasticity, which suggests that "the brain can re-organize itself after neurological trauma to re-enable function" (Daveson, 2008, p.76). The restorative approach is most appropriate for use with patients who have realistic potential to make functional rehabilitative gains, are motivated to work towards these goals, and are able to participate in frequent sessions requiring focussed, active participation.

Neurologic Music Therapy (NMT; Thaut, 2005) is a method which may be applied to achieve restorative goals within Daveson's MIND meta-model. As mentioned, this method was designed for application in rehabilitation contexts for patients with neurologic damage caused by disease or trauma including Parkinson's disease, traumatic brain injury and cerebrovascular accident (Academy of Neurologic Music Therapy, 2015). NMT consists of standardized techniques applicable to the areas of sensorimotor function, speech/language function and cognitive function (Thaut, 2005). Examples of restorative goals addressed by the NMT approach include gait rehabilitation using the Rhythmic Auditory Stimulation technique and speech rehabilitation using the Musical Speech Stimulation technique (Thaut, 2005). Achievement of restorative music therapy goals, particularly within the NMT approach, requires that the patient be motivated to participate actively, and able to attend frequent sessions, as results are achieved through practice and repetition of tasks (Daveson, 2008).

Compensatory. Daveson (2008) describes the MIND's compensatory approach as applicable to maintaining a patient's social roles and identity. The compensatory approach is most often applied with patients who do not have rehabilitation potential, and/or have been admitted to hospital for symptom management due to neurodegenerative disease, which could certainly include those receiving neuro-palliative care. For example, Steele (2005) describes the compensatory use of both song-based and improvisatory music therapy approaches which aim to

maintain a patient's sense of identity as disease advances, and states that maintaining identity improves the ability to cope: "When individuals become increasingly debilitated by the progressive nature of the disease, music therapy sessions have the potential to emphasize the healthy characteristics of the person, despite their disabilities" (Steele, 2005, p. 73). Aldridge et al. (2005) also describe the compensatory use of music therapy to provide an alternate means of communication, and to address the changes in identity experienced by persons with MS as disease progresses. Likewise, Davis and Magee (2001) examine the use of music to compensate for speech in the case study of a woman with Huntington's disease. The patient, with the support of the music therapist, was able to use instrumental improvisation to establish an expressive, non-verbal relationship which helped to counteract the isolation caused by her disease (Davis and Magee, 2001).

Baker and Roth (2004) describe the differences between the applications of music therapy to provide a restorative intervention versus as a compensatory strategy. This distinction can be fine, and is often determined by the patient's stage of disease progression or trauma recovery.

Psycho-social-emotional. Lastly, the MIND's psycho-social-emotional approach in neuro-disability is most appropriate for patients who, at any stage of disease, are withdrawing from or cannot engage in other types of therapy due to psycho-social-emotional issues, or have other identified psycho-social-emotional needs (Daveson, 2008). This approach would also be applicable to patients receiving neuro-palliative care.

Schmidt and Aldridge (2004) describe a Creative Music Therapy group intervention which could be used within this approach to address psycho-social-emotional needs in patients with MS. Schmidt and Aldridge (2004) report significant changes in self-acceptance, depression, and anxiety measures, and group participants described benefits including increased self-confidence, well-being, and emotional expression. Magee and Davidson (2002) also describe the influence of music on mood in patients with MS. They found that brief individual sessions using song choice or improvisational interventions both resulted in significant changes in anxiety, hostility, and tiredness for hospitalized MS patients, but did not impact depression (Magee and Davidson, 2002).

Implications for Music Therapy in Neuro-Palliative Care

In my literature search to date, McNab (2010) and Magee (2013) have provided the only available perspectives on applications of music therapy in neuro-palliative care. Both authors also review the most frequently occurring diagnoses of Progressive Neurologic Disease (PND),

and describe the common symptoms and losses experienced by patients. McNab indicates that the approach to long-term treatment of PND should be holistic, including symptom control, communication interventions, adapted equipment, counselling and psychological support, and welfare advice.

McNab (2010) goes on to describe the ways in which music therapy can address the psychological symptoms of PND, such as providing a sense of control through improvisation, offering opportunities for reminiscence through song choice, increasing emotional expression, allowing redefinition of identity, and providing a means of symbolic communication and interaction. Parallels are drawn between the music therapy goals and interventions used in traditional palliative care populations with those used by McNab in her neuro-palliative work. She states that the primary goal of increased quality of life for patients and families remains at the core of palliative care music therapy with both populations. However, McNab defines the roles of music therapy in "neuro-palliative rehabilitation" as threefold, and similar to the approaches outlined by Daveson (2008): a) Music therapy as rehabilitative care to influence change in aspects of the patient's condition, b) Music therapy as rehabilitative care to maintain aspects of the patient's condition, and c) Music therapy as palliative care to comfort, affirm, and provide symptom control for the patient when no further change or maintenance of condition is possible.

Additionally, McNab (2010) emphasizes that the music therapist must be keenly aware of the diverse levels of functioning in neuro-palliative patients, and stresses that a person-centred, interdisciplinary team approach is extremely important in defining treatment goals. McNab recommends use of music therapy interventions similar to those used with patients in more traditional (oncology-based) palliative care, including song choice, song-writing, music relaxation, and music-facilitated life review, but also recommends music-based cognitive tasks and instrumental improvisation tailored to the neuro-palliative patient's level of functioning. McNab recommends the adaptation of NMT interventions (Thaut, 2005), particularly those relating to attention training and memory, when working with patients in end stage neurologic disease. These interventions may be particularly appropriate for patients whose physical functioning is very poor but whose cognition remains intact, such as those with ALS (McNab, 2010).

Specific to the physical symptoms and needs of patients with end-stage PND, Magee (2013) also recommends the application of NMT interventions in neuro-palliative rehabilitation,

specifically Rhythmic Auditory Stimulation (RAS) for gait improvement and Patterned Sensory Enhancement (PSE) for rehearsal of specific movement components of activities of daily living. Additionally, she suggests that NMT's Therapeutic Singing (TS) activities are useful in neuro-palliative settings, if broader-than-usual treatment goals are applied, such as "producing sung language within a well-learned familiar song" (p. 121). Magee (2013) describes the difference "between rehabilitation and palliative approaches. That is, enjoyment and pleasure should not be compromised for the sake of functional benefits" (p. 127).

Magee (2013) notes that even fewer authors address the ability of music therapy to support the spiritual needs of patients receiving neuro-palliative care. Magee cautions that spiritual exploration is very sensitive, and is not always appropriate or needed, but that music therapists should be open to the possibility and prepared to support patients in this way as music in itself is often spiritually comforting. Magee states that, in her experience, patients with neuro-palliative conditions are often focussed "on living. Thus, time spent in therapy is often spent looking back and coping with the present" (p. 51), rather than preparing for death.

Magee (2013) also specifically mentions the impact of PND on family members, remarking that the "profound changes to most aspects of daily living" (p.4) caused by neuro-palliative conditions effect "highly significant social and emotional consequences" (p.5) for patients' loved ones as well as patients themselves. Magee states that including family members in music therapy sessions provides a valuable, "action-oriented" (p. 160) way to improve coping skills.

Some concepts from the broader neuro-rehabilitation literature also appear to be applicable to neuro-palliative care. For example, several authors identify the importance of patient-centred care in neuro-rehabilitation, which includes opportunities for patients to articulate self-determined goals. This recommendation is consistent with a palliative and/or neuro-palliative approach. Aldridge, Schmid, Kaeder, Schmidt, and Ostermann (2005) indicate that patients' desire for active participation in coping with the effects of their disease is the primary reason that patients with MS seek complementary therapies. Music therapy may address the identified need of patients with MS to participate actively in managing the effects of their disease processes on the quality of their lives (Aldridge et al., 2005). Steele (2005) also identifies the role of music therapy in giving patients with MS a greater sense of control over their lives. Steele (2005) observes that music therapy also strengthened patients' sense of self, and that this, combined with a heightened sense of self-control, resulted in improved coping skills for patients with MS.

As other life-limiting neurologic disorders have some similar characteristics to MS, it is logical that some of these factors may impact patients with other neurologic diagnoses as well, particularly at end of life, when many other losses of control have previously been experienced.

It also appears possible to infer from the literature that music therapy interventions which are effective in the earlier stages of progressive neurologic disease may also be adapted for use in neuro-palliative care. For example, Schmidt and Aldridge (2004) note that, in advanced stages of MS, song-writing can offer beneficial opportunities for life review and allow patients to express physical, psychosocial, and emotional needs. Although the participants in their research were not receiving palliative care at the time of the study, Schmidt and Aldridge (2004) comment, "As there are no curative therapeutic interventions [for MS], we are reliant upon palliative interventions. Only a limited number of studies have explored arts and music therapy" (p.227). Schmidt and Aldridge (2004) identify a significant gap in the research, as also noted by Aldridge (2005), McNab (2010), and Magee and Davidson (2004). These authors suggest further investigation into the ways in which music therapy impacts physical and psychosocial functioning in patients with PND, particularly in end-stage disease.

Chapter Summary

Upon reviewing the literature related to the needs of patients in traditional palliative care and those with life-limiting neurologic disorders, more similarities than differences are apparent (Oliver, 2014). It appears that music therapy approaches, goals and interventions can co-exist on a flexible continuum of practice between neuro-rehabilitation and neuro-palliative care (Daveson, 2008; Magee, 2013; McNab, 2010). However, more research is needed to define the specific music therapy approaches, goals, and interventions most appropriate, helpful and effective for meeting the needs of patients with life-limiting neurologic disorders and their families receiving end-of-life care.

Chapter 3. Methodology

My research was conducted from an interpretivist stance, which aims to "…describe and understand a phenomenon in its wholeness and within a real world context. The goal is…to allow contextually relevant variables to emerge" (Baker & Young, 2016, p. 29). Interpretivism supports collaboration between researcher and participants, and can "provide descriptive evidence that will help [music therapists] to identify, adapt, implement and integrate relevant interventions within the realities of varying practice contexts" (Baker & Young, 2016, p. 30).

Design

This project employed steps 1 and 2a of Fraser et al.'s (2009) intervention research methodology, which offers the strong advantage of yielding a clinical program targeted to a specific population. Step 1 includes (a) specifying the problem, (b) developing a structural model including risk and protective factors, (c) developing a program theory of malleable mediators, (d) identifying the intervention level, setting, and agent(s), and (e) developing a theory of change and/or logic model. Step 2 encompasses the creation and revision of program materials, including (a) developing a first draft of treatment manual and other related materials, (b) submitting these for expert review, (c) specifying essential program content, (d) piloting the program manual and materials, and (e) expanding content to address training and implementation. The final three steps of the process include refining, testing (in both pilot and full-scale practice settings), and disseminating results of the research (Fraser et al., 2009).

Intervention research methodology was developed within the field of social work, and has since been successfully implemented in psychology, health promotion, and oncology. It is ideal for addressing my research topic and questions in that it can develop interventions at "individual, family, group, [and] organizational levels" (Fraser et al., 2009, p. 9), all of which may be needed for and beneficial to the application of music therapy in neuro-palliative care. Intervention research outcomes can "determine the extent to which an intervention is defined by explicit principles, goals, and activities" (Fraser & Galinsky, 2010, p.459), for both dialogical and prescriptive interventions, which may accommodate a broad range of music therapy approaches. The intervention research process places an emphasis on "specifying social and health problems in such a way that research can inform practice activities" (Fraser & Galinsky, 2010, p. 460), which meets my goal of research transferability to clinical settings. Additionally, the process ensures that "intervention materials will be developed with sensitivity to the setting and organizational culture" (Fraser & Galinsky, 2010, p. 463), which, in my experience, can

have an enormous influence on the integration and success of music therapy services in institutional settings. Fraser et al. (2009) state that interventions may have effects on more than one level simultaneously. In the case of this research, the music therapy program developed is primarily intended to impact patients and families receiving neuro-palliative care, however, it is hoped that its development has also had spillover effects at the organizational level, by changing team members' understanding of music therapy and its outcomes.

Procedures

Prior to beginning participant recruitment and data collection procedures, ethical approval for this study was received from the Concordia University Human Research Ethics Committee (See Appendix A for a copy of the consent form granted).

Participants. Potential participants were selected and invited to participate by e-mail (See Appendix B for Invitation E-mail). If invitees agreed to participate, I arranged interviews at their convenience. Both participants chose to be interviewed in person. Participants received the Participant Consent Form (See Appendix C) by e-mail in advance of their interview, and were then asked to sign a paper copy on the day of the interview. Given a range of confidentiality options, both research participants chose to be fully identified, by name and role. This choice was partially due to the specificity of the research, which would cause their identities to be easily determined, even if not intentionally included, and partially as recognition of their participation is also beneficial. Participants included: one member of the neuro-palliative care team at the local neurologic hospital (nurse clinician Justine Gauthier), and one consultant to the neuro-palliative care team (music therapist Deborah Salmon). The opinions expressed by the participants and included in this research are representative only of themselves, not of the facilities for which they work.

Justine Gauthier (JG), BScN, MScN, is the Nurse Clinician for the Neuro-palliative Care program at the local neurologic hospital. She has held this position for 1.5 years, and was previously a nurse in both the oncology (4 years) and neurosurgery (4 years) programs in this facility.

Deborah Salmon (DS), MA, MTA, has worked as Music Therapist with a local palliative care service since 1984. She holds a Bachelor of Music degree in flute performance, a Master of Arts degree in music therapy, and two post-graduate diplomas; in individual psychotherapy, and in couple and family therapy.

These professionals provided expertise and guidance during the development of the first neuro-palliative music therapy practicum in this hospital, from January – April 2018. Inclusion of neuro-palliative care team members and consultants as clinician participants is supported by the interpretivist stance (Baker & Young, 2016), as the goal of the interpretivist research process is to create "a collaboration between the researcher and the participants" (p.31) which allows clinician-participants an opportunity to reflect on their clinical practice experiences, and re-apply these reflections to their work as well as to share them with others.

Materials. Materials used included a MacBook Pro laptop computer, for accessing online resources and document composition; digital and print library resources for literature review; a digital audio recording device (Zoom M2) and SD card for audio recording of interviews, and an external hard drive for saving backup copies of all data.

Data collection.

Literature review. A comprehensive review of current, pertinent research literature was undertaken, including the fields of music therapy, palliative care, neuro-palliative care, life-limiting neurologic conditions, and related terms. The literature review served to identify existing areas of knowledge as well as gaps in current research, which assisted with formulation of interview questions.

Interviews. As there is minimal literature specific to music therapy in neuro-palliative care, and as I had a unique opportunity to work closely with a neuro-palliative care nurse clinician (JG) and music therapist consultant with experience in this population (DS;) during my graduate practicum, I felt it would be advantageous to gather data from these team members. (DS, the inceptor of the neuro-palliative care practicum, was not a staff member at the practicum site, but gained clearance for the practicum from the neuropalliative program director and remained involved as an off-site consultant throughout.) Following the practicum term and the completion of supervisory relationships, I interviewed JG and DS, regarding the application of music therapy in the neuro-palliative care program. Inclusion of data gathered from neuro-palliative care team practitioners is consistent with Fraser and Galinsky's (2010) recommendations to "collaborate with the intended intervention agents during the design process, because they may have knowledge that is nuanced by a deeper understanding of the organizational and other contingencies affecting practice" (Fraser & Galinsky, 2010, p.461).

Interviews took place individually, in person, at the participants' convenience. Interviews were semi-structured, using an open-ended question framework and including several questions

specific to each participant's discipline and clinical experience (See Appendix D). Participants were provided with the questions in advance via e-mail, to allow them to prepare for the interview. During the interview, participants were provided with a paper copy of the questions, and were invited to choose the questions they were most interested in answering, and the order in which they would like to answer them. Participants were also invited to contribute their own additional comments, and to ask questions of me.

I transcribed the interview recordings with repeated listenings to confirm accuracy. Transcripts were then returned to participants for member checking, and to ask specific questions for clarification of data gathered. Participants' amendments, clarifications, and additional suggestions were subsequently incorporated into the data.

Data analysis. An emergent qualitative content analysis (Neuman, 2006) was used to identify themes occurring in transcribed interview data gathered. Research participants were also invited to review the themes extracted, to verify that the meanings of their interview data were adequately represented, and invited to adjust as needed. The qualitative content analysis used open, axial and selective coding to provide collated data needed to complete steps 1 and 2a of the intervention research process outlined by Fraser et al. (2009)**:** step 1, "Specify the problem and develop a program theory", and step 2a, "Create program materials: Develop first draft of treatment manual and other related materials".

In completing step 1 of the intervention research process, after collating findings from the literature and interview data, I added my own insights pertaining to the process of developing a neuro-palliative music therapy (practicum) program at the local neurologic hospital. When completing step 2a, following the preparation of the first draft of a treatment manual, using the literature review and interview data, it became apparent that there was a lack of some specific relevant clinical case examples in the literature which specifically described some of the music therapy techniques recommended for use in neuro-palliative care. Having previous music therapy experience in palliative care, including work with patients with primary and secondary neurologic diagnoses, I chose to add general, typical examples from my own previous (prior to Concordia MA practica) clinical work, only if and when examples from primary sources were unavailable. Patient identifiers in these case examples were purposely omitted, to protect the anonymity and confidentiality of patients and family members.

Ethical Issues

Potential ethical issues connected to this study and to the use of this particular method included identified dual relationships within myself (as clinician and researcher), between myself and the research participants (as a former practicum student and researcher), possible risk of coercion to participate, possible influence of my bias and assumptions on outcomes, and risk of participant discomfort during interviews.

Chapter 4. Results

This chapter begins with a summary of data collected during research interviews, which will then be used, in combination with literature reviewed and my own clinical experience in palliative and neuro-palliative care, to complete steps 1 and 2a of Fraser et al.'s (2009) intervention research method.

Summary of Interview Findings

Interview data clustered around the axes of the three research questions, and some additional points of interest were contributed spontaneously. However, as the participants' roles and professional backgrounds were different, and as the interview questions used reflected this (see Appendix D), the participants included and emphasized different aspects of the topic. All codes identified are included, regardless of whether they were mentioned by only one participant or both. The four main emergent themes were: needs of patients in neuro-palliative care, needs of family members in neuro-palliative care, music therapy interventions appropriate for use in neuro-palliative care, and components of a neuro-palliative care music therapy program, with subthemes emerging within some of these.

Needs of patients in neuro-palliative care. Patients' needs were separated into physical, psychosocial, and spiritual categories, and upon reviewing the transcribed data and codes, JG suggested adding a cognitive/neurological needs category as well. It was interesting to note that JG identified an approximately equal number of needs within each category, whereas DS identified almost twice the number of needs in the psychosocial category than in any other.

Physical needs. Physical needs of patients in neuro-palliative care were identified as: management or control of pain, dysphagia management, mobility support, physical relaxation (relief from restlessness/agitation), regulation of respirations (relief from dyspnea), and hemiplegia management strategies.

Cognitive and neurological needs. Cognitive and neurological needs of patients in neuro-palliative care were described as: seizure control, stimulation and engagement (for cognitively intact patients), stimulation and alertness (for patients in low awareness states), impulse control, stimulation or enhancement of language and communication, opportunities to make choices, stimulation of memory, control over one's environment (including music in the environment), and compensatory strategies to manage cognitive losses (e.g. memory). Comparing these two categories of patient needs, JG commented,

> "I have always found that [patients] struggled way more with cognitive loss than physical loss….and [family members] around them, as well. Because, of course, it's hard to have someone at home that's wheelchair-bound…but having someone who's got their two legs [working] but can't remember where they're living, that's…a lot more of a challenge." (JG, personal communication, May 22, 2018).

Psychosocial needs. Psychosocial needs of patients in neuro-palliative care were identified as: verbal and non-verbal self-expression, emotional support, anxiety reduction/relaxation, mood regulation, enjoyment, reminiscence, creativity, involvement in positive and productive activities, opportunities for reflection on the experience of disease and/or disability, connection with family, a sense of familiarity, respite from the hospital environment, recognition and development of coping strategies, respect for the patient's (musical) preferences, and for health care professionals to understand the patient's lived experience.

Spiritual needs. Spiritual needs of patients in neuro-palliative care were described as: a sense of hope and/or meaning, a sense of agency, support before, during, and after losses; creation and passing on of legacy; preservation of memories, support for and expression of religious beliefs and practices, and relief of suffering.

Over-arching needs of patients. Several over-arching patient needs, which did not fit specifically within one of the other themes, were also mentioned by the participants. These needs were (a) to achieve the best possible quality of life; (b) for health care professionals to recognize and support neuro-palliative care patients' less-commonly occurring disease trajectories; and (c) for health care professionals to understand that patient needs do not remain static, but change as disease progresses.

Needs of family members in neuro-palliative care. Family members' needs identified by interview participants clustered into two themes: psychosocial and spiritual.

Psychosocial needs. Psychosocial needs of patients' family members in neuro-palliative care were identified as: support for managing patients' cognitive and physical losses, emotional expression (particularly of anger and sadness), a sense of empowerment in regards to patient care, emotional support and comfort, companionship, coping strategies, communication and connection with the patient, shared experience and enjoyment with the patient, and a sense of trust that the patient is cared for when family is not present.

Spiritual needs. Spiritual needs of patients' family members in neuro-palliative care included: expression of spiritual or religious beliefs, expression of hope and meaning, spiritual support for existential questions, and expression of gratitude for patient's care.

Over-arching need of family members. As with patient needs, an over-arching need of family members was also identified, but did not fit specifically within one of the categories above. This need was for health care professionals to understand that family members' needs change as the patient's condition declines.

Music therapy interventions appropriate for use in neuro-palliative care. Given their different backgrounds, interview participants were not equally able or qualified to speak to this topic, but both contributed. JG was asked to describe music therapy interventions she had observed (during an orientation visit at another local palliative care unit, as well as during my practicum work in her facility), whereas DS was asked to describe interventions she herself had implemented. The music therapy interventions identified were:

- *Family song circle*:Family members singing at bedside of dying patient, with music therapist supporting and accompanying.
- *Accompanying*: Music therapist (MT) provides live music support for patients who are alone and are minimally responsive or unresponsive. MT may or may not use familiar music, based on knowledge of patient's preference from previous sessions, and/or careful observation.
- *Music for low awareness states*:
    - MT provides stimulation and supports patient's connection with family through use of familiar live music; or
    - MT provides meaningful recorded music, which MT is unable to play or sing live (e.g. specific to patient's culture, or preferred artist) to increase sense of security and familiarity, support connection between patient and family.
- *Entrainment*: MT provides musical matching of patient's respirations, vocalizations and/or mood, then slowly adjusts these in the desired direction, by changing the accompanying music, for management of pain/discomfort/tension, restlessness and/or dyspnea. MT stays with patient to monitor response.
- *Refocussing*: MT provides music interventions to help patient refocus attention away from pain or other symptoms onto more pleasurable stimuli.
- *Active music for relaxation*: MT provides "nourishing" live or recorded music of patient's choice for relaxation.

- *Active listening*: MT provides patient's choice of recorded music which is personally significant to them (specific recordings or performers are often important), and listens with patient. This is an experience of sharing beauty, listening and being together. The MT is open to both verbal and non-verbal sharing within the listening experience.
- *Music and imagery interventions*: Including visual imagery, improvisation and relaxation, e.g. "Going to the beach" experience with ocean drum and flute, in which patient (or family member) plays the ocean drum and creates imagery of a beach scene with multiple sensory details. MT improvises on flute as "a bird flying overhead" (DS, personal communication, May 31, 2018) to deepen the imagery.
- *Song choice (patient or family) and singing*: MT offers choice of song(s) to patient, from a songbook or list if needed. If patient is unable to choose, MT invites family members/friends (if present) to do so. MT sings and/or plays requested song(s), encouraging patient and family to sing or vocalize also. Song choice may assist with self-expression, and may lead to reminiscence and discussion.
- *Musical legacy creation & recording*: MT provides materials, verbal and musical support, and session structure for patient (and/or family members) to create or select and record original or pre-composed music to give as a gift/memento to a friend(s) or family member(s). This may include autobiographical material, written or recorded, images, and/or a written or verbal dedication.
- *Music for mood support & alteration*: MT asks questions to assess patient's mood, then may suggest using music to shift patient's mood toward patient's desired mood state. MT determines music activities most appropriate for patient's abilities, interests and energy level.MT may use iso principle, using improvised music to initially match and then gradually change patient's observed mood state, or MT may use patient's choice of pre-composed/familiar music to match patient's stated mood state, and ask patient to identify selection(s) which represents their desired state. MT may play both selections (live or recorded) and ask patient to reflect on their experience. (D.S., personal communication, May 31, 2018).
- *Singing with patients with aphasia*: Spontaneously, for example by singing along with the radio during care (not specifically aiming to stimulate speech) (J.S., personal communication, May 22, 2018).

- *Song-writing*: Patient adapts a known song (composes own lyrics to a pre-composed melody) or composes original lyrics and melody, with MT's support. Song topic may be a specific memory/event the patient wishes to encapsulate, a message to a loved one, working through of emotions, or any other topic of the patient's choice. Patient may sing and/or play instruments as able, and may wish to perform or audio/video record song with MT support.
- *Composition*: Patient composes original music or adapts pre-composed musical material. Patient selects composition topic or theme, with support from MT if needed; this may often be a specific memory, emotion or image the patient wishes to encapsulate, or a message to a loved one. Depending on patient's musical knowledge and experience, and current level of functioning, MT can assist patient to select melodic material and characteristics (tonality, meter, rhythm) and notate composition. MT can assist patient to select accompaniment (if needed) by offering choices (harmony, rhythm) and notate by hand or with computer software. MT may support patient with performing, audio/video recording or printing composition as per patient's wishes.
- *Instrumental or vocal improvisation*: MT provides opportunities for patients (particularly those who are aphasic) to express non-verbally with instruments or voice.

DS noted that music therapy interventions chosen are generally connected to the needs, interests, and abilities of each patient. She also noted that many of the passive interventions listed above are used with the assumption that a neurologic response to music endures even when a patient is no longer visibly responsive, and that undamaged regions or neural pathways in the brain may compensate for damaged ones.

Neuro-palliative care music therapy program components. Participants' different perspectives offered a variety of valuable comments in this category as well. JG, who was more familiar with the local neurologic hospital, made many suggestions about how music therapy could best be integrated into the neuro-palliative care interdisciplinary team, and the most effective ways to educate team members about music therapy, based on her own experience. DS gave more discipline-specific suggestions regarding music therapy program components. The items recommended for inclusion were assessment, evaluation, teaching (of Master's level music therapy students), research, staff education, and team consultation (including attending team rounds).

Assessment. Both participants highlighted the importance of assessment as a program component, particularly noting the ability of music therapy assessment to potentially access

domains not reached by other stimuli or assessment methods, such as the ability to sing when functional speech is not present.

Program implementation. Practical suggestions including setting a consistent on-site music therapy schedule (for predictability of access to services), offering a music therapy information pamphlet (for patients and families), and developing family education materials and music resources to empower family members to use music for patient and self-care, were also suggested.

Staff education. Recommendations specific to staff education included highlighting appropriate music therapy referral criteria, and encouraging staff to draw parallels between their own personal experiences with music and ways that music may be meaningful to patients. JG stated that she had appreciated the opportunity to observe a music therapist at work in another local palliative care unit as part of her orientation, and this experience clearly impacted both her understanding of the discipline and her openness to offering music therapy to her own patients. Thus, inviting staff members to observe music therapy sessions could prove to be an effective strategy for team education when introducing music therapy in neuro-palliative care.

Additional themes. The suggestion that music therapy could support rehabilitative goals in a neuro-palliative care context was introduced by JG:

> …in terms of treating physical *limitations,* I think that music therapy can help as much as any kind of other rehab, and…I don't think that rehabilitation is necessarily un-compatible with palliative care. I actually think that patients in palliative care *should* have some rehab, in order to achieve the best quality of life they can…[For example, if] a patient has a fatal diagnosis, the patient goes to surgery but the damage was already done by the tumour, and they're left with some pareisis, not full paralysis, but, you send them to rehab, and they regain a little bit, and yes, eventually the tumour will regrow, but, in the meantime, it is productive for them, and…they have a better quality of life… I think music therapy plays a role in the same *way*…because I have seen some cases where that's what helped…(JG, personal communication, May 22, 2018).

This spontaneous comment was surprising, given that one of the few references to neuro-palliative care in the music therapy literature also recommends this application (McNab, 2010). Despite the seeming contradiction in terms, rehabilitation may in fact be possible and appropriate in neuro-palliative care, depending on individual patients' needs and goals.

In contrast, during the interviews, DS described the importance of artistic "interpretation, intuition, and intention" in all types of palliative care music therapy, stating that although a music therapist's first instinct may be to "do something", that immediate intervention is not always best, as this may cause the therapist to neglect or minimize the patient's broader treatment goals. JG also stated that health care professionals' tendency for immediate intervention, the propensity to "do for" patients, may in fact be disempowering for them and their family members.

Intervention Research Step 1: Specify the Problem and Develop a Program Theory

Fraser et al. (2009) explain that "problem theory has to do with understanding the biopsychosocial processes that produce social and health problems. Typically, this involves considering both individual factors and environmental conditions." (p.47).

Problem theory. Patients with brain tumours, strokes, and progressive neurologic disease have life-limiting, incurable conditions. Therefore, they (and their families) need a specialized palliative care approach, but this is sometimes not recognized, available, or accessible (Oliver, 2014).

Risk factors, protective factors and promotive factors.

Risk. As a result of the non-existence of, or lack of access to, specialized neuro-palliative care services, patients with life-limiting neurologic disorders and their families risk experiencing poor quality of life and increased suffering.

Promotive factors. The inpatient, acute-care hospital settings in which patients with life-limiting neurologic disorders and their families often receive treatment may promote less-than-optimal quality of life and unnecessary suffering. These settings tend to be fast-paced and focussed on a high degree of medical intervention, rather than on comfort care. In these settings, staff members may have little understanding of, training in, or experience with a palliative care approach, which then further promotes the aggressive treatment of these patients as if they are *curable*. The specific needs of patients with life-limiting neurologic disorders, which differ from the needs of *typical* palliative care patients, are additionally promotive of poor quality of life: for example, these patients often have communication impairments which make it difficult for them to advocate for their own care.

Protective factors. Fraser et al. (2009), describe protective factors as "assets or strengths which reduce vulnerability in the presence of risk" (p. 48). JG and DS identified several factors during their interviews which may reduce patients' risk of reduced quality of life and increased

suffering: (a) comprehensive assessment, (b) spiritual support, (c) pain management and symptom control, (d) psychosocial support, (e) family involvement and empowerment, (f) enjoyment, fun, relaxation and humour, (g) sense of agency, (h) involvement in positive, productive, meaningful activities, (i) sense of optimism and hope, and (j) self-expression.

Malleable mediators. The above-mentioned protective factors can also be described in Fraser et al.'s (2009) terms as "malleable mediators", as these are able to be influenced by the proposed music therapy program, and if influenced positively, will increase patients' quality of life and decrease suffering. In contrast, the promotive factors identified above are ones on which music therapy would have little influence (setting, staff, patients' differing needs).

Program theory. Fraser et al. (2009) explain that a problem theory alone is not sufficient to plan an intervention because it does not provide adequate information. A program theory is also needed, to outline how the mediators will be changed by the intervention.

Logic model. According to Fraser et al. (2009), logic models are based on problem theory. These "show the connection between program objectives and inputs and distal outcomes." In the intervention research model, the core program elements of a music therapy program for neuro-palliative care consist of its objectives, inputs, and activities. Based on literature reviewed, interview data and my own clinical experience, these elements are as follows:

Program objectives.

- To provide music therapy services for patients and families receiving inpatient neuro-palliative care.
- To fully integrate music therapy within the interdisciplinary team approach in an interdisciplinary, inpatient hospital setting through assessment, team consultation, documentation, program evaluation and staff education.
- To educate other team members regarding the goals, interventions, and outcomes of music therapy in neuro-palliative care.

Program inputs.

- Funding: for both staffing and capital equipment costs
- Equipment: musical instruments, wheeled cart (for transporting session materials to patient rooms), music books, iPad, iPods and/or CD players with headphones for loan to patients
- Facilities: office and equipment storage space

- Time: minimum 15 hours/week, divided into two-7.5 hour days or three 5-hour days (based on my experience that 1 day/week of practicum time on-site did not provide adequate continuity with patients and families)

Program components.

- Assessment: including chart review, team consultation, and initial patient visit
- Treatment: individual and family music therapy sessions, using interventions recommended by participants
- Documentation: added directly to patients' interdisciplinary progress records
- Evaluation
- Team consultation: regarding referrals, patient needs, and treatment outcomes, including attendance at interdisciplinary rounds
- Staff education: regarding appropriate music therapy referrals, referral process, opportunities for staff observation of sessions
- Family education: regarding use of music for patient and self-care outside of and in addition to music therapy sessions
- Bereavement support: regular family bereavement group and/or celebration of life event, co-facilitated by music therapist and other team members

Program outputs. The measurable products of music therapy program activities:

- Number of patients and families served
- Number of music therapy sessions provided
- Number of direct patient contact service hours provided
- Number of music therapy progress notes documented
- Number of referrals made to music therapy by team members

Intermediate outcomes (mediators). These outcomes correspond to positive changes in the malleable mediators identified by research participants. One or more of the following would be identified as music therapy treatment goals, depending on the patient and his/her needs:

- Enhanced spiritual support
- Optimized pain and symptom management
- Enhanced psychosocial support
- Enhanced family involvement and empowerment
- Heightened sense of enjoyment, fun, relaxation and humour
- Enhanced sense of agency

- Enhanced involvement in positive, productive, meaningful activities
- Enhanced sense of optimism and hope
- Enhanced self-expression

Distal outcomes. Distal outcomes of a music therapy program in neuro-palliative care may, as described by Fraser et al. (2009), "depend in part on interactions outside the control of the program" (p.56), such as availability of funding. However, distal outcomes would focus on amelioration of the previously identified risk factors, resulting in: (a) improved quality of life for patients receiving neuro-palliative care, and their families; and (b) decreased perception of suffering for patients receiving neuro-palliative care, and their families.

Theory of change. Fraser et al. (2009) state that the theory of change must specify "the intervention agents (who), the activities in which they will engage (what) and the setting in which interventions will occur (where)" (p. 58). In the context of the proposed program, the intervention agent will be a certified music therapist (MTA). The activities will be the music therapy program activities specified above, including the music therapy interventions specified by research participants, as refined in intervention research step 2. The setting will be an inpatient hospital or hospital unit specializing in neurologic or neuro-palliative care.

Intervention Research Step 2: Create and Revise Program Materials

Fraser et al. (2009) explain that the development of program materials actually takes place across all five steps of the intervention research process. This development is divided into four stages: formulation, revision, differentiation, and translation/adaptation of program materials.

Stage 1: Formulation of program manuals and materials. The creation of a program manual for music therapy in neuro-palliative care requires acknowledgement of the population's unique qualities. Unlike many other populations and settings in which music therapy is used, it is impossible to create a step-by-step session plan-based manual for neuro-palliative care because the duration of the intervention (the length and number of music therapy sessions which will take place during a given period of time) is always unknown, despite the best prognostication. It is also not possible to precisely plan session activities in advance, as these are generally selected according to patients' and families' preferences and needs in the moment. Likewise, music therapy in neuro-palliative care is dialectic, thus it is based on and varies according to patient responses within the session. Therefore, a manual organized by interventions or by goal areas, rather than sequentially in order of sessions, might be most practical for use in this population. Goal areas are so broad that an intervention may fit into more than one. Thus, I have chosen to

organize this music therapy program manual for neuro-palliative care by music therapy interventions. This connects to Fraser et al.'s (2009) recommendation that a treatment manual must outline the "mechanisms (or active ingredients) through which change is expected to operate" (p. 40), which are the music therapy interventions themselves.

However, it is acknowledged that this method may have its own inherent dangers. For example, it may be tempting to oversimplify the application of interventions to patients: a manual organized by interventions could be improperly used to match patients to interventions rather than vice-versa. Fraser et al. (2009) state that a program manual may include screening materials, or methods whereby "the selection of activities is guided by a needs assessment that is used in matching content to program participants" (p. 64). The patient and family's needs, interests, and abilities should always be the single greatest determinant of the music therapy interventions used in sessions. The music therapist's own assessment will provide supporting information as well, factoring in the patient's musical preferences and background. However, it may be helpful, particularly for newly qualified music therapists, or for those new to the neuro-palliative care population, to have additional resources to assist with choosing appropriate interventions. A tool which reflects both patients' physical and psychosocial needs in a brief format is recommended.

The Palliative Performance Scale (PPS) has been used in traditional hospice/palliative care settings worldwide for more than 20 years (Downing & Wainwright, 2006). It provides a brief "snapshot" of a patient's total functioning in a simple percentage score between 0% and 100% (in increments of 10%), based on five observable areas: ambulation, ability to do activities, self-care, food/fluid intake, and consciousness level. A PPS score is generally assigned by a patient's primary nurse and is re-assessed daily. Although many of the areas of functioning reflected in a patient's PPS score are very practical and nursing-oriented, a PPS score also provides useful information for psychosocial care providers (including music therapists) about how a patient is feeling, how much they can do for themselves, and how much they are able to interact. It may also give clues as to what the involvement and needs of family members may be at the current stage of the patient's illness. A music therapist would not normally be responsible for assessing the areas of functioning associated, or assigning PPS scores, but can benefit greatly from understanding how the score is interpreted. However, if a music therapist's workplace does not use the PPS, a music therapist may easily gather information necessary to approximate a patient's PPS score by attending interdisciplinary

rounds, reviewing the patient's chart, or consulting with the patient's nurse. A PPS score may assist a music therapist in selecting interventions appropriate for meeting each patient's individual needs, therefore the tool is included in the neuro-palliative care music therapy intervention manual (See p. 58; used by permission, see Appendices E and F) as an additional criterion for "matching content to program participants" (Fraser et al., 2009, p. 64). A neuro-palliative care music therapy treatment planning guide organized by PPS score, including suggestions regarding music therapy session design, common patient and family issues and needs, music therapy intervention type, and specific music therapy interventions (as described in the treatment manual) is also included (see p 60). As regulations for use of the PPS do not allow additions to or adaptations of the tool itself, the MT treatment planning guide immediately follows but is separated from the PPS tool as per its proprietor's instructions (See Appendices E and F). A similar tool is provided by Miller and O'Callaghan (2010) in their chart "Music Therapy in Adult Cancer Care: Across The Cancer Continuum", which pairs the phases of cancer diagnosis and treatment with music therapy interventions. Its authors explain, "This chart is not meant to be used as a 'cookbook' approach to music therapy, but rather as a guide or starting place for the music therapy clinician." (Miller & O'Callaghan, 2010, p. 252). Likewise, the neuro-palliative care music therapy treatment planning guide is not intended to be prescriptive or rigidly applied but to give general suggestions for therapists working in this newly identified subspecialty.

According to Fraser et al. (2009), "a key feature of a good treatment manual is…a detailed description of core practice activities and a prescribed course of action" (p. 65), but such a manual can include "flexibility of implementation" (p.65). In the case of this music therapy program manual for neuro-palliative care, the "degree to which practitioners are encouraged to adapt content" (p. 65) is very high. This manual is not intended to provide an exhaustive selection of interventions for this population, nor a complete range of options, it is simply a starting point. It is based on interventions which, according to the literature, and in DS's and my own experience, have worked well in palliative care (not just or specifically neuro-palliative care) and may require further adaptation.

Fraser et al. (2009) describe interventions which are "process oriented" (p. 18) and contrast these with "prescribed" (p. 18) interventions, both of which can be developed using the intervention research model. Music therapy in neuro-palliative care classifies as a "process oriented – that is, relatively un-prescribed" (p. 18) intervention, as it is specifically adapted by

the clinician to the patient's needs in the moment, which "requires the practitioner to make instantaneous decisions about the nature and sequencing of content" (p. 18). Fraser et al. describe this as type of intervention as "an adaptive process that arises from the confluence of a problem, a change agent's skill, the content of the intervention, the response of those involved, and the response of the environment." (p.18)

Fraser et al. (2009) also encourage careful consideration of the format of the treatment manual, always keeping in mind its audience: in this case, a music therapist working in inpatient neuro-palliative care. A standardized format is recommended; thus I have applied the same brief table format to all interventions for ease of access to content, and comparison among interventions. As Fraser et al. recommend considering not only which interventions should be included, but in what order to include them, I have chosen to sequence the recommended music therapy interventions by PPS level of patients to whom they are best suited, from lowest to highest. Fraser et al. (suggest that a treatment manual should always include an introduction, which outlines the goals of the intervention and its rationale, both of which have been summarized in previous chapters of this thesis. Fraser et al. explain that program objectives should give a "detailed description of the intervention process" and should include "how to convert general goals from program theory into actionable objectives" (p.76). Therefore, sample objectives for each intervention are given, but in clinical application, objectives would be formulated individually according to patients' needs and goals. As previously noted, music therapy intervention fits Fraser et al.'s description of an "unstructured, reflective interaction" (p. 76), so this treatment manual includes case excerpts (from interview participants' as well as my own clinical experience, and from relevant literature) to give a sense of how each intervention may work in practice.

Fraser et al. (2009) also suggest inclusion of "between-session supplemental content" (p.74) in a comprehensive treatment manual. In light of the interview findings regarding needs for family empowerment and staff education in this setting and population, handout material for family members and neuro-palliative care team members is also included in the "resources for facilitators" (p. 99) section of the treatment manual (See Appendix G and H). These handouts suggest ways in which family members and staff caregivers can provide music (live and recorded) for patients, and include space for the music therapist's contact information. Providing music for the patient, although a relatively simple action, may be one that family members under stress, and busy team members, do not readily think of. Providing and sharing music may also

address family members' identified needs to communicate and connect with the patient, share experiences and enjoyment with the patient, share expressions of hope, meaning and spirituality with the patient, and give family members a sense of trust that some patient needs are met with the family is not present. Providing some general guidelines for busy team members, including volunteers, may help to ensure that recorded music provided when the music therapist is not available or on-site is appropriate, supportive, and meaningful to the patient. I have developed these handouts based on interview findings, relevant literature, and my own clinical experience, they may require adaptation for use in different clinical settings.

Table 1
Neuro-Palliative Care Music Therapy Intervention Manual: Introduction

The parameters below apply to all music therapy interventions included.

System level of change:	Staff, family or individual patient
System level of implementation:	Family or individual patient
Duration of music therapy sessions:	Variable according to patient and family needs (10-60 minutes)
Frequency of music therapy sessions:	Variable according to patient needs & MT schedule (ideally more than once per week for continuity)
Number of music therapy sessions:	Variable according to patient and family needs and preferences, length of hospital stay.
Session structure & order of content:	Variable depending on patient's condition & needs
Setting:	Inpatient hospital, patient room (or lounge)
Method of delivery:	Hands-on activities, active or passive
Intervention agent:	Certified music therapist (MTA)
Mode of intervention:	In-person
Means for starting each session:	Introductions, check-in, bedside "mini-assessment": how is the patient today, would they like music? Selection of MT interventions based on patient's needs, preferences, & interests
Barriers to participation:	Mealtimes, drowsiness, symptoms, nursing care requirements, visitors, environmental distractions, etc.
Proximal outcomes:	Optimized pain and symptom management Increased psychosocial support Increased spiritual support Increased family involvement and empowerment Increased enjoyment, fun, relaxation and humour Increased sense of agency Increased involvement in positive, meaningful activities Increased sense of optimism and hope Increased self-expression
Distal outcomes:	Improved quality of life Decreased suffering

N.B. Case examples not otherwise referenced are general examples from my previous clinical work. Identifiers of specific patients or family members have been omitted. Pseudonyms used are in *italics.*

Table 2
Neuro-Palliative Care Music Therapy Intervention: Music for Patients in Low Awareness States

Participant selection guidelines:	PPS 20 – 10% Family participation encouraged
Session design:	Single
Treatment goals: (one or more of:)	● Optimized pain and symptom management ● Increased psychosocial support ● Increased spiritual support ● Increased self-expression ● Increased family involvement & empowerment
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will demonstrate increased alertness by opening eyes during music. ● Patient will demonstrate increased non-verbal self-expression by vocalizing during music. ● Patient will demonstrate increased connection with family through touch and/or eye contact.
Details of intervention activities:	● MT provides familiar live vocal and/or instrumental music at bedside, according to knowledge of patient's preferences gathered during previous sessions or from family requests; ● *or* MT provides familiar, meaningful recorded music (if not able to provide music requested as live) and monitors volume/stimulation level. ● MT stays with patient (even if recorded music is used), to carefully monitor patient response (D.S., personal communication, May 31, 2018).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	MT may offer recorded music if unable to provide live music requested (e.g. language unknown, genre unfamiliar; (D.S., personal communication, May 31, 2018).
Decision rules for choices among alternative interventions (if applicable):	Depending on patient's response, activity may be adjusted to provide more or less stimulation. For example, if patient rouses and begins to sing, MT may repeat song(s). If patient rouses but begins to frown or moan, tempo and volume may be decreased. (D.S., personal communication, May 31, 2018).
Directions for inclusion of essential vs. enrichment content:	Additional accompanying instruments may also be added by music therapist or family members, with attention to possibility of overstimulation for patient.
Implementation cues or tips:	Involvement of family members is recommended whenever possible. This may include inviting family members to sing to, touch or massage the patient, choose songs, tell stories which involve the patient.

Case excerpts or examples:	*Muge,* an elderly woman with lung cancer which had metastasized to her brain, was in a semi-comatose state. She was minimally responsive, her eyes open, and she was restless, reaching out for her son, who was at her bedside. The music therapist was able to provide a CD recording of music from *Muge*'s culture and faith tradition. When *Muge's* son began to play the CD, it was as if something *different* was happening, and she stilled. The music therapist sat with them during the music, and observed as *Muge's* movements calmed down; it seemed as if *Muge* was listening. This was music that would have been familiar and meaningful to her.

Table 3
Neuro-Palliative Care Music Therapy Intervention: Entrainment

Participant selection guidelines:	PPS 20-10%
Session design:	Single
Treatment goals (one or more of):	● Optimized pain and symptom management ● Increased psychosocial support ● Increased relaxation
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will demonstrate decreased pain perception by decreased moaning and decreased facial tension. ● Patient will demonstrate decreased dyspnea by returning to normal respiration rate. ● Patient will demonstrate decreased restlessness by fewer attempts to get out of bed per 10 minutes.
Details of intervention activities:	● With improvised vocal and/or instrumental music, MT matches patient's respirations, vocalizations and/or mood, then slowly alters these using the iso principle. ● MT stays with patient to carefully monitor response (D.S., personal communication, May 31, 2018).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Use accompanying instruments as per patient's culture if available. ● Use language and/or lyric content (stories, symbols) as per patient's culture. ● Use musical elements (scale/tonality, rhythm, style, harmony) as per patient's culture.
Decision rules for choices among alternative interventions (if applicable):	● If patient is 30% or higher, and able to engage verbally, use Music for Relaxation or Refocussing interventions (D.S., personal communication, May 31, 2018).
Implementation cues or tips:	Intervention may be discontinued if patient falls asleep.
Case excerpts or examples:	*"*When I arrived to see Janet on the second day of the assessment, she was experiencing considerable pain and was restless. She was clearly finding it challenging to get into a comfortable position, either lying down or partially sitting up... As the session began, I started to improvise on the piano and slowly reduce the speed of Janet's breathing to a more relaxed rate. As she began to relax, I continued to improvise, adding vocal lines…" (Clements-Cortes, 2016, p. 63)

Table 4

Neuro-Palliative Care Music Therapy Intervention: Accompanying

Participant selection guidelines:	PPS 20-10%
Session design:	Single
Treatment goals: (one or more of:)	● Increased psychosocial support ● Increased spiritual support ● Maintained or increased relaxation ● Increased family empowerment
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will maintain relaxation as demonstrated by an unfurrowed brow and easy, regular respirations. ● Patient will maintain relaxation as demonstrated by consistent level of awareness during music.
Details of intervention activities:	● MT plays live, improvised vocal and/or instrumental music, or patient-preferred music if MT has knowledge of this from previous sessions. ● MT matches and maintains music to match patient's respiration rate, vocalizations, or other indications of physical status. ● MT stays with patient to carefully monitor response (D.S., personal communication, May 31, 2018).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Use accompanying instruments as per patient's culture if available. ● Use language and/or lyric content (stories, symbols) as per patient's culture. ● Use musical elements (scale/tonality, rhythm, style, harmony) as per patient's culture (D.S., personal communication, May 31, 2018).
Decision rules for choices among alternative interventions (if applicable):	● If patient is 30% or higher use Music for Relaxation or Refocussing interventions
Implementation cues or tips:	Family members may find it difficult to leave the patient alone to take a break for self-care. The music therapist may offer accompanying intervention to assist family members in giving themselves permission to take a break. Family members may feel more comfortable, knowing the music therapist will stay with the patient and maintain a calm environment, playing the music of the patient/family's choice.
Case excerpts or examples:	*Elizabeth* was an elderly woman with end-stage glioblastoma. *Elizabeth's* daughter *Gail* had arrived from out of town to be with her at the hospital, and had hardly left *Elizabeth's* bedside for several concurrent days, sleeping in a chair beside the bed. The music therapist received a referral from *Elizabeth's* nurse, who explained that *Gail* was very anxious, making many requests to the team to care for her mother, who was now unresponsive. The music therapist arrived at *Elizabeth's* room just as a family friend also came to visit. *Gail* said her mother loved music, especially Elvis Presley's

	songs. The music therapist suggested that *Gail* go out for coffee with her friend, while the music therapist played some of her mother's favourite music. With encouragement from her friend, *Gail* agreed, and returned looking refreshed. *Gail* then joined in the music therapy session.

Table 5

Neuro-Palliative Care Music Therapy Intervention: Song Choice & Singing

Participant selection guidelines:	● PPS 30% or higher if patient selecting songs ● PPS 20% or lower if family selecting songs
Session design::	Single
Treatment goals (one or more of):	● Optimized pain and symptom management ● Increased psychosocial support ● Increased spiritual support ● Increased enjoyment & relaxation ● Increased sense of agency ● Increased involvement in meaningful activities ● Increased sense of optimism & hope ● Increased self-expression ● Increased family involvement & empowerment
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will demonstrate increased enjoyment by smiling during songs requested. ● Patient will demonstrate increased self-expression by choosing songs which reflect their experience. ● Patient will demonstrate increased spiritual support by verbally expressing beliefs which are reinforced by songs chosen.
Details of intervention activities:	● Offer choice of songs to patient, from a list if needed. ● If patient is unable to choose, invite family to do so. ● MT sings and/or plays requested song, encouraging patient and family to sing or vocalize also (Magee, 2013).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Request that patient or family share song(s) from their culture, if able. ● Use accompanying instruments as per patient's culture if available.
Decision rules for choices among alternative interventions: (if applicable)	If patient requests, this activity may lead to discussing and selecting music for their memorial service, celebration of life, or other event.
Directions for inclusion of essential vs. enrichment content:	● Discussion regarding the significance of the song choice for the patient and/or family deepens the experience. MT may stimulate discussion by asking what they think of when they hear this song, where the song takes them, etc. ● Specific artists are often strongly connected a particular song; MT may ask about patient's memories of a recording/artist of this song (Magee, 2013). ● Strong connections between songs and memories can make song choice a vehicle for life review. This may be structured in chronological order by asking a patient to select significant songs from different stages of their life. ● Patients who are able to participate actively may wish to choose song(s) with significant content that they wish to "dedicate" to a loved one. ● Family members may wish to choose songs to "send a message" to patients who are no longer visibly

	responsive. ● Patients or family members who are not comfortable with or not able to sing may enjoy participating by playing along on an instrument of their choice.
Implementation cues or tips:	Offering a song list or song book for patients and family members to choose from may be helpful, not all patients will be able to recall songs spontaneously.
Case excerpts or examples:	"A 35-year-old woman, Ms. Zelda, had been diagnosed with a brain tumour…she was referred to music therapy because she was extremely worried, frightened and anxious. Repeatedly, she asked the hospice staff…the same set of questions: "How will my death take place?" "Will I be alone?" "Am I going to Heaven?"…Ms. Zelda responded positively to music…and requested 60s, 70s, and 80s popular music. In her life she had used music to lift her mood…music seemed to comfort her, and she considered it a "friend" when she was lonely or sad…The music therapist attempted to validate the patient's difficult questions…on one visit the therapist brought a copy of the song *Blowin' in the Wind,* and sang with guitar accompaniment…After the music, the therapist engaged Ms. Zelda in a…discussion of the song and asked her to identify the meaning of the lyrics. After several minutes, she conveyed that the song asked hard questions and gave no answers….the therapist asked if the lyrics in the song were similar to the questions asked by the patient. The patient took a few moments, and, with a serious affect, nodded her head "yes"….After that session, Ms. Zelda stopped asking the repetitive questions, and her anxiety decreased significantly. In every music therapy session, she requested *Blowin' In The Wind*…the song served to validate her questions and comfort her in knowing that such answers were not to be known. (Hilliard, 2001, p.165).

Table 6
Neuro-Palliative Care Music Therapy Intervention: Refocussing

Participant selection guidelines:	PPS 30% and higher
Session design:	Single
Treatment goals (one or more of):	• Optimized pain and symptom management • Increased psychosocial support • Increased enjoyment & relaxation • Increased sense of agency • Increased involvement in meaningful activities • Increased sense of optimism & hope
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will indicate decreased pain perception by verbally expressing that pain has changed from 8/10 to 2/10 following intervention. ● Patient will indicate decreased dyspnea by ability to speak a full sentence in one breath following intervention.
Details of intervention activities:	● MT may ask patient to choose one or more preferred musical selections with which patient has positive associations (MT may provide live or recorded) ● MT may cue patient to breathe in tempo with music (if slow to moderate tempo) ● MT may cue patient to engage in active/targeted listening activities; E.g. Raise your hand each time you hear___. ● MT may cue patient to focus on alternate sensory input (e.g. vibro-tactile stimulation from instruments) (D.S., personal communication, May 31, 2018).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Use patient's choice of accompanying instruments as per patient's culture. ● Use patient's choice of musical elements (scale/tonality, rhythm, style, harmony) as per patient's culture. ● Use patient's choice of recorded music as per patient's culture.
Decision rules for choices among alternative interventions: (if applicable)	If patient needs more visual content to remain focussed and is not confused, use Music, Relaxation, and Imagery intervention.
Implementation cues or tips:	Patient self-report using analog scale (rating pain or other variables on a scale of 1-10) can give indication of effectiveness of intervention.

Case excerpts or examples:	"The patient [Mr. Barns] presented with a great deal of pain (reported as 8/10 on a scale of 1 to 10, with 1 being the least amount and 10 being intolerable pain). He appeared irritable, and his wife said he often became agitated with her. His wife was worried and anxious, and she chain-smoked throughout the session. Although Mr. Barns was not a particularly verbal man, he did request classic rock music and said he really enjoyed The Eagles. As the music therapist sang several songs by The Eagles (i.e. "*Take It Easy"* and *"Peaceful Easy Feeling"),* the patient closed his eyes, displayed a calm affect, and seemed more relaxed." (Hilliard, 2005).

Table 7
Neuro-Palliative Care Music Therapy Intervention: Music for Relaxation

Participant selection guidelines:	● PPS 30% or higher ● Optimal if patient is not confused ● Family participation encouraged
Session design:	Single
Treatment goals (one or more of):	● Optimized pain and symptom management ● Increased psychosocial support ● Increased spiritual support ● Increased enjoyment & relaxation ● Increased sense of agency ● Increased involvement in meaningful activities ● Increased sense of optimism & hope ● Increased self-expression
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will report sensation of decreased muscle tension ● Patient will report increased mental relaxation (decreased worrying or anxiety)
Details of intervention activities:	● MT invites patient to choose music which is significant and nourishing for them – instrumental music is preferred, moderate to slow tempo, consistent tempo, timbre, texture and volume throughout; ● MT can offer music selections if needed (live or recorded). ● MT invites/assists patient to become as physically comfortable as possible, close eyes if comfortable ● MT may encourage patient to deepen and lengthen his/her breath with verbal cues or sound of an instrument (rain stick, ocean drum, gong; Scheiby, 2005). ● MT may give verbal relaxation cues, bringing attention to various parts of the body in sequence and encouraging patient to relax. ● MT cues patient to continue to be aware of breath and listen to the music. ● MT cues patient to slowly return awareness to present surroundings when music has ended (wiggle fingers and toes, open eyes; D.S., personal communication, May 31, 2018).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Use patient's choice of accompanying instruments as per patient's culture if possible. ● Use patient's choice of musical elements (scale/tonality, rhythm) if possible. ● Use patient's choice of recorded music as per patient's culture.
Decision rules for choices among alternative interventions: (if applicable)	● If patient may become drowsy, choose Active Listening or Refocussing interventions. (D.S., personal communication, May 31, 2018).

Implementation cues or tips:	Intervention may be discontinued if patient falls asleep.
Case excerpts or examples:	"[The] patient stated her favourite types of music were light rock, popular, and light jazz…[she] reported that she listened to music on the radio every night to fall asleep, but had no experience with relaxation exercises. She requested to try "a sample" of music-focused relaxation techniques, including deep breathing, progressive muscle relaxation, autogenic relaxation…and requested "soft relaxing piano music". After the relaxation exercise, the patient discussed experiencing images of being "surrounded with support" of her family, friends and people praying for her from her church…[she] related that she was surprised that she felt "more relaxed but also more energetic" after the relaxation exercise." (Miller & O'Callaghan, 2010, p. 265)

Table 8
Neuro-Palliative Care Music Therapy Intervention: Active Listening

Participant selection guidelines:	● PPS 30% and higher ● Optimal if patient not drowsy or confused ● Family participation encouraged
Session design:	Single
Treatment goals: (one or more of:)	● Increased psychosocial support ● Increased spiritual support ● Increased enjoyment & relaxation ● Increased sense of agency ● Increased involvement in meaningful activities ● Increased sense of optimism & hope ● Increased self-expression
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will demonstrate increased expression of personal preferences by choosing music. ● Patient will demonstrate increased connection to memories and experiences though music selection. ● Patient will demonstrate increased spiritual support by choosing a piece of music from his/her spiritual tradition to share with music therapist.
Details of intervention activities:	● Patient is encouraged to choose recorded music of significance to them, particularly considering specific performers and/or recordings ● Patient is encouraged to introduce MT to this music, explain why it is significant if desired, and share the listening experience with MT. ● MT remains open to verbal and non-verbal expression of patient within the experience, may ask probing questions (D.S., personal communication, May 31, 2018).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Use patient's choice of recorded music as per patient's culture.
Directions for inclusion of essential vs. enrichment content:	● Patient may be interested to add drawing or other art media while listening.
Implementation cues or tips:	● Sound quality of listening experience is important (sufficient volume, etc.). ● Consideration of others in listening area is needed (close doors to ensure music does not disturb neighbours!).
Case excerpts or examples:	"Fred…was refusing to eat, and refused to speak to any of the staff. He was completely competent cognitively, and there was a concern that he was depressed and was trying to hasten his death…Fred had been a professional musician, having played with some of the top orchestras in the country…I brought a recording of the Haydn Cello Concerto in C, a piece that is comforting and nurturing. I entered Fred's room, introduced myself and asked if he would like some music. He nodded and whispered, "Yes." Our conversation

	was minimal up until that point, and he seemed quite withdrawn; his voice was weak and his speech was very difficult to understand. I played the music and sat close to his bedside, offering him my complete presence and attention. He closed his eyes and took in the music completely. After the music I noticed a change in his body – a greater energy and a willingness to engage with me. We had made a connection." (Dileo & Parker, 2005).

Table 9
Neuro-Palliative Care Music Therapy Intervention: Improvisation, Relaxation & Imagery

Participant selection guidelines:	● PPS 30% or higher ● Not recommended for patients who are confused ● Family participation encouraged
Session design:	Single
Treatment goals: (one or more of:)	● Optimized pain and symptom management ● Increased psychosocial support ● Increased spiritual support ● Increased enjoyment & relaxation ● Increased sense of agency ● Increased involvement in meaningful activities ● Increased sense of optimism & hope ● Increased self-expression ● Increased family involvement & empowerment
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will demonstrate increased relaxation by experiencing sensory and mental "respite" from hospital environment ● Patient will demonstrate increased engagement in meaningful activity by engaging in reminiscence with family members.
Details of intervention activities:	● Invite patient to engage in relaxation/imagery, using imagination to "escape from the hospital". Ask if they like the beach: can they remember one they enjoyed? Invite description. ● Offer patient or family member opportunity to try ocean drum. As ocean drum is played, encourage sensory image creation to complete scene: What is weather/temperature? Whom are they with? What do they hear, smell, taste? ● MT may add another instrument to enhance patient's imagery (e.g. flute or voice like a bird flying overhead) ● MT monitors response and checks in with patient to ascertain if they would like to continue to develop imagery experience or are ready to "return" (D.S., personal communication, May 31, 2018).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Incorporate patient's choice of imagery (location and other contextual variables) ● Use accompanying instruments as per patient's culture ● Use musical elements (scale/tonality, rhythm, style, harmony) as per patient's culture.
Decision rules for choices among alternative interventions: (if applicable)	● If patient expresses fear of water or negative associations with beach imagery, alternate imagery and sounds may be substituted e.g., walking in forest.
Directions for inclusion of essential vs. enrichment content:	Additional accompanying instruments may be played by family members to broaden the auditory experience, as long as overall sound level is not overwhelming to patient. (D.S., personal communication, May 31, 2018).

Case excerpts or examples:	"For visual imagery and relaxation, I use the ocean drum a lot, and I'll have someone in the family play it, or I'll play it with my elbows if I have to, or the patient can play it, and then we create images, or the patient as much as possible, creates images, of a place - usually on a beach – it might be a place they've been to…and I ask: are they alone, are they with people, can they use the 5 senses, for example, can they feel the sun on their shoulders, what do they see, what do they smell? If they're anxious or have pain, I might suggest, "Breathe in the calm, and exhale your tension or pain, imagine big waves [of breath] as you send it into the ocean." Then I use the flute as a bird overseeing this image that we've created together, I improvise something to deepen the experience, and most people find that quite lovely and relaxing and transporting, and they often say, "Oh yeah, I actually did get out of the hospital for a few minutes."(D.S., personal communication, May 31, 2018).

Table 10

Neuro-Palliative Care Music Therapy Intervention: Music for Mood Support & Alteration

Participant selection guidelines:	● PPS 30% or higher
Session design:	Single
Treatment goals (one or more of):	● Increased psychosocial support ● Increased spiritual support ● Increased enjoyment & relaxation ● Increased sense of agency ● Increased involvement in meaningful activities ● Increased sense of optimism & hope ● Increased self-expression
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will demonstrate increased self-expression by choosing music which reflects their mood. ● Patient will demonstrate increased relaxation by tapping fingers and toes with upbeat music.
Details of intervention activities:	● MT assesses patient's mood: "How are you feeling today? How would you like to feel?" ● MT may suggest using music to shift patient's mood toward their desired state. MT determines music activities most appropriate for patient's abilities, interests and energy level. ● MT may use iso principle, using improvised music to initially match and then gradually change patient's observed mood state, or ● MT may use patient's choice of pre-composed/familiar music to match patient's stated mood state, and ask patient to identify selection(s) which represents their desired state. MT may play both selections (live or recorded) and ask patient to reflect on their experience. (D.S., personal communication, May 31, 2018).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Use accompanying instruments as per patient's culture if available. ● Support inclusion of recorded music as per patient's culture if possible. ● Use musical elements (scale/tonality, rhythm, style, harmony) as per patient's culture if possible.
Decision rules for choices among alternative interventions: (if applicable)	● May employ more active or more passive music activities depending on abilities and interests of patient (e.g. instrumental improv. vs. listening) to achieve desired mood outcome.
Directions for inclusion of essential vs. enrichment content:	● May also employ physical involvement (breathing, movement) to engage patient's transition to desired mood state. ● Patient may be interested in adding drawing or other art media to add a visual representation of mood states.

Implementation cues or tips:	Mood alteration does not need to be overtly defined as goal for this intervention to be effective.
Case excerpts or examples:	"…music for mood, either matching mood, or changing mood [would be helpful], and patients can be involved in choosing the mood of the music: "Do you want something slow, do you want something lively, how are you feeling, how would you like to feel, what would be important?" So, I think that working with different kinds of music to support expression and changes in mood [could] help people cope." (D.S., personal communication, May 31, 2018).

Table 11

Neuro-Palliative Care Music Therapy Intervention: Instrumental or Vocal Improvisation

Participant selection guidelines:	PPS 30% or higher Family participation encouraged
Session design:	Single
Treatment goals (one or more of):	● Optimized pain and symptom management ● Increased psychosocial support ● Increased spiritual support ● Increased enjoyment & relaxation ● Increased sense of agency ● Increased involvement in meaningful activities ● Increased sense of optimism & hope ● Increased self-expression ● Increased family involvement & empowerment
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will maintain fine motor skills by playing keyboard. ● Patient will maintain upper extremity strength and stamina by playing tamboa with both hands.
Details of intervention activities:	● MT assesses patient's interest in improvisation and offers a choice of instruments appropriate to patient's abilities and level of functioning. ● MT demonstrates how to play instruments if required. ● MT invites patient or family member to lead, or assumes leadership role. MT may suggest all take turns leading. ● MT may/may not suggest and/or initiate a theme, structure, or organizing motif for improvisation (Magee, 2013).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Use patient's choice of accompanying instruments as per patient's culture ● Use patient's choice of image content (stories, symbols) as per patient's culture ● Use patient's choice of musical elements (scale/tonality, rhythm, style, harmony) as per patient's culture ● Incorporate folk song melodies from patient's culture as basis for improvisation, add new variations
Decision rules for choices among alternative interventions: (if applicable)	May be more accessible to patients and family members when used in conjunction with/as an extension to song choice & singing than independently.
Implementation cues or tips:	● Vocal improvisation may be added to include and support patients not capable of singing words. ● For patients who have limited strength and stamina, MT may offer instruments which require minimal movement and strength (e.g. Omnichord; Magee, 2013).

Case excerpts or examples:	"Lottie…was a woman in her mid-40's with a brain tumour… I wheeled her to the top end of the piano…she looked confused, so I gently took hold of her hands and placed them onto the keys, inviting her to play. The improvisation lasted about four minutes. Lottie begins to play with a finger from each hand in the upper register of the piano…it appears to me that her touch changes from an initial harsh brittle sound to a warmer one, where the notes are more joined together, giving a greater sense of flow and of her wanting to be a part of it – a new sense of momentum and even motivation. The improvised music, by its very nature, calls her to be part of it. Here is a woman who, at present, is having problems with the structure and grammar of speech and short-term memory. In the improvised music with me, she shows complete awareness of musical structure and grammar, and initiates repetitions of short melodic and rhythmic fragments. In music, she is able to be something different from what she is able to be outside the situation at the time." (Hartley, 2001, p. 135).

Table 12

Neuro-Palliative Care Music Therapy Intervention: Song-Writing

Participant selection guidelines:	● PPS 40% or higher ● Optimal if patient not drowsy or confused ● PPS 30% or lower if family contributing
Session design:	Variable
Treatment goals (one or more of):	● Increased psychosocial support ● Increased spiritual support ● Increased enjoyment & relaxation ● Increased sense of agency ● Increased involvement in meaningful activities ● Increased sense of optimism & hope ● Increased self-expression
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will indicate increased self-expression by identifying their emotional response to a memory. ● Patient will demonstrate increased involvement in meaningful activities by asking to share results of song-writing activity with family.
Details of intervention activities:	● Select song topic: this may be a specific memory/event the patient wishes to encapsulate, or a message to a loved one. (Magee, 2013). ● Select lyric material/source ● Select melodic material/source ● Select accompaniment
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Use patient's choice of accompanying instruments as per patient's culture ● Use patient's choice of language and/or lyric content (stories, symbols) as per patient's culture ● Use patient's choice of musical elements (scale/tonality, rhythm, style, harmony) as per patient's culture ● Adapt folk song or other song material from patient's culture as basis (re-write words or replace some [using fill-in-the-blank method], add new verses)
Decision rules for choices among alternative interventions: (if applicable)	● If patient is cognitively higher-functioning or has experience with song or poetry-writing, it may be more appropriate for patient to compose original lyrics. Music therapist may compose melody and accompaniment with or without assistance from patient, again depending on patient's interest, experience and level of functioning. ● If patient is cognitively lower-functioning (drowsy or confused), or has a specific song already chosen that they wish to modify, use fill-in-the-blank or adding-new-verses methods, retaining pre-composed melody (Magee, 2013).
Directions for inclusion of essential vs. enrichment content:	● Audio/video record or perform song live for others with patient's permission. ● Create printed lyric sheet or songbook with patient's permission.

	● Add patient's choice of song title and/or dedication.
Implementation cues or tips:	Call-and-response/echo song structure can encourage participation for patients who may be uncomfortable with singing.
Case excerpts or examples:	Angela was a patient…who had become quadriplegic… in the end stage of her disease…she described her anger and frustration that was resulting from her emotional and physical needs not being understood or met appropriately. [the MT] suggested that, despite her profound physical disabilities, she could be involved in active music making by writing a song…she agreed and we began to explore what kind of style and form the song could take, with [the MT] singing the line in different ways with a range of harmonies to give her some examples…Having completed the song, [the MT] prepared a recording for Angela and played it to her… She was very pleased with the result. The song's meaning and message is reflected in its simple melody and open harmonic progressions, capturing the express wishes of a dying woman who had become entirely reliant upon her professional caregivers. (Heath & Lings, 2012, p. 113-114)

Table 13

Neuro-Palliative Care Music Therapy Intervention: Composition

Participant selection guidelines:	● PPS 40% or higher ● Optimal if patient not drowsy or confused
Session design:	Multiple
Treatment goals: (one or more of:)	● Increased psychosocial support ● Increased spiritual support ● Increased enjoyment & relaxation ● Increased sense of agency ● Increased involvement in meaningful activities ● Increased sense of optimism & hope ● Increased self-expression
Treatment objectives:	Variable, dependent on patient and goals. E.g.: ● Patient will maintain fine motor control through use of instruments (piano, xylophone, Omnichord) in composition. ● Patient will indicate increased sense of optimism by suggesting they would like to share composition with family next week. ● Patient will indicate increased self-expression by stating, "This music sounds the way I feel."
Details of intervention activities:	● Select composition topic or theme: this may often be a specific memory/emotion/image the patient wishes to encapsulate, or a message to a loved one. ● MT can assist patient to select melodic material and characteristics (tonality, meter, rhythm) and notate ● MT can assist patient to select accompaniment by offering choices (harmony, rhythm) and notate by hand or with computer software ● Record or print as per patient's wishes (Magee, 2013).
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Use patient's choice of accompanying instruments as per patient's culture. ● Use patient's choice of image content (stories, symbols) as per patient's culture. ● Use patient's choice of musical elements (scale/tonality, rhythm, style, harmony) as per patient's culture ● Adapt folk song melodies from patient's culture as basis, add new variations.
Decision rules for choices among alternative interventions: (if applicable)	● If patient has previous musical experience and/or is unable to communicate verbally, Composition may be most appropriate (Magee, 2013). ● If patient has specific text s/he wishes to include, use Song writing intervention.
Directions for inclusion of essential vs. enrichment content:	● Patient's composition may be performed or recorded and shared as per patient's wishes, ensure appropriate written permission is in place.
Implementation cues or tips:	● Creative adaptations of instruments and structures may be necessary to make composition accessible e.g. using pentatonic scale, ABA form.

Case excerpts or examples:	*Anna* was admitted to the PCU with advanced cancer and brain metastases. During her first music therapy session, she was quick to reject the guitar, saying, "I don't like *that* kind of music," but stated that she had played the piano during her youth in Europe. When the MT brought a keyboard to her room, and placed it across her bed, *Anna* cautiously played a few notes. "I learned classical music," she explained, "but I loved the folk songs of my homeland most of all. It sounded something like this…" *Anna* tried a few more notes, which became the beginning of a gentle waltz. The music therapist encouraged *Anna* to continue, and *Anna* said, "I don't remember all of the tune. I wish I could teach it to my grandson. He is learning to play piano." The music therapist suggested that together, she and *Anna* could complete the tune in the traditional style, the music therapist would transcribe it, and *Anna* could share it with her grandson. *Anna* agreed, and was pleased to give the completed music to her grandson

Table 14
Neuro-Palliative Care Music Therapy Intervention: Musical Legacy Creation

Participant selection guidelines:	● PPS 40% or higher ● PPS 30% or lower if family contributing ● Optimal if patient not drowsy or confused
Session design:	Multiple
Treatment goals (one or more of):	● Increased psychosocial support ● Increased spiritual support ● Increased enjoyment & relaxation ● Increased sense of agency ● Increased involvement in meaningful activities ● Increased sense of optimism & hope ● Increased self-expression ● Increased family involvement & empowerment
Treatment objectives:	Variable, dependent on patient and goals, E.g.: ● Patient will indicate increased involvement in meaningful activity by expressing satisfaction with product of legacy recording. ● Patient will indicate increased enjoyment and relaxation by laughing more frequently during music therapy sessions.
Details of intervention activities:	● MT invites patient to consider what (memories, values, beliefs) they would like to share with, or pass on to, significant others. (This may also occur naturally as part of discussion, or be stimulated by lyric content of a song request). This could include both music and verbal content (Magee, 2013). ● If written consent to record is obtained, MT assists patient to record (audio or video) their legacy message content. Content may be spontaneous or planned, according to the patient's preference. ● MT assists patient to add live or recorded musical content, and edits recording as needed.
Suggestions for adapting content on basis of race/ethnicity, culture, language, religion or other factors:	● Use accompanying instruments as per patient's culture if available. ● Support inclusion of language and/or verbal content (stories, symbols) as per patient's culture. ● Use musical elements (scale/tonality, rhythm, style, harmony) as per patient's culture if possible.
Directions for inclusion of essential vs. enrichment content:	● This activity may become an extension of song-writing and song choice, if patient has created or selected music they would like to share. (D.S., personal communication, May 31, 2018). ● This activity may also be structured around connections between songs and memories which make song choice a vehicle for life review. A life review recording may then be structured chronologically by asking patient to select songs from different stages of their life (Magee, 2013).

Implementation cues or tips:	A written copy of CD program/liner notes, song lyrics, or other print content may be added.
Case excerpts or examples:	Casper…was 33 years old, married with a 10-month old daughter. Four months earlier he had been diagnosed with a brain tumour…and had been given a prognosis of approximately 6 months. He was a pianist but the tumour had robbed him of many of his motor skills and he was finding it deeply frustrating attempting to express himself in music…[the MT] suggested that he might write some songs as an alternative to playing the piano…As his illness progressed it became increasingly important for Casper to write a song for his daughter to, in his own words, "prove that I really did exist". The song 'Liva's Lullaby' was written and recorded in one session and became the last recording that the family have of Casper's own voice. A simple lullaby by a father for his daughter, it contains his message of love, wisdom and hope…Four years later [the MT] had the opportunity to meet Liva during a visit to the hospice…not only did Liva know the words to all of his songs, she was also able to play the melody of Liva's Lullaby on the metallophone and referred to it as 'my song from Daddy'." (Heath & Lings, 2012, p. 114-115).

Table 15
Palliative Performance Scale v. 2

VICTORIA HOSPICE

Palliative Performance Scale (PPSv2)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Instructions for Use of PPS (see also definition of terms p.59)

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.
2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.
   Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%
   Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.
   Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'
3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

Ambulation
The items '**mainly sit/lie,' 'mainly in bed,'** and **'totally bed bound'** are clearly similar. The subtle differences are related to items in the self-care column. For example, '**totally bed 'bound'** at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between '**sit/lie'** and '**bed**' is proportionate to the amount of time the patient is able to sit up vs need to lie down.

'**Reduced ambulation'** is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

Activity & Extent of disease
'Some,' 'significant,' and 'extensive' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply **'some'** disease, one or two metastases in the lung or bone would imply '**significant'** disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be '**extensive**' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, '**some'** may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. '**Extensive**' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. **Decline in activity** may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

Self-Care
'**Occasional assistance'** means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'**Considerable assistance'** means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

'**Mainly assistance'** is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'**Total care'** means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

Intake
Changes in intake are quite obvious with '**normal intake'** referring to the person's usual eating habits while healthy. '**Reduced**' means any reduction from that and is highly variable according to the unique individual circumstances. '**Minimal**' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

Conscious Level
'**Full consciousness'** implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. **'Confusion'** is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. **'Drowsiness'** implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. '**Coma**' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

Table 16
Neuro-Palliative Care Music Therapy Treatment Planning Guide (by PPS Score)

PPS Score	MT session design	Common patient & family issues/needs (Cairns, Thompson, & Wainwright, 2003)	Suggested intervention type (Dileo & Dneaster, 2005)	Suggested MT interventions
60%	Multiple	Patient: Loss of independence Family: Changes in roles	Active, Creative or Recreative	Legacy Recording Composition Song-writing
50%				
40%	Variable	Patient: Loss of mobility Increased dependence & withdrawal Fatigue Family: Stress & fatigue Withdrawal or increased presence with patient	Active, Creative or Recreative	Song choice Music for mood Relaxation & imagery Active listening Music for relaxation Re-focusing Instrumental & Vocal Improvisation
30%				
20%	Single	Patient: Physical/Symptom Management: Pain Dyspnea Restlessness Family: Anticipatory Grief Reminiscence Spiritual Support	Passive/ Receptive	Music stimulation Entrainment Family song choice & singing Family song creation
10%				
0%	-	-	-	-

Instructions Specific to Music Therapy Treatment Planning:

1. The music therapist's individual assessment of each patient and his/her needs should take precedence over any suggestions made by this treatment planning guide.
2. Each patient and family are unique. The information in this treatment planning guide contains broad generalizations which may not fit each specific case.
3. The music therapist should seek information from the patient's most responsible nurse, from his/her medical chart, and/or from team consultation/rounds to estimate the approximate PPS score of the patient if this has not already been determined.
4. Music therapy interventions recommended for patients at a lower PPS level may be useful and applicable to patients at a higher PPS level, depending on their needs and interests.
5. Music therapy treatment planning suggestions for patients above 60% PPS are not included as these patients are not generally admitted for inpatient care, and thus are beyond the delimitations of this thesis.
6. Music therapists should familiarize themselves with the PPS v.2 (see p.58) before using this guide.

Chapter 5. Discussion

The ultimate goal of this research, and thus in the development of this first-draft treatment manual, is to capture the experience of those working in neuro-palliative care in a practical way that it may be passed on to, tested, and improved upon by other clinicians. This chapter will address the limitations and challenges inherent to my thesis research, its implications for application to clinical practice, and recommendations for future research on the development of music therapy in neuro-palliative care.

Limitations

The results of this study are limited by the specificity of the intervention research to the setting and population of an inpatient neuro-palliative care program, my experience working in only one designated neuro-palliative care program, and by my inexperience as an interviewer. As I have completed only steps 1 and 2a of the intervention research method (Fraser et al., 2009), these results are also limited by the inability to test the program design which the research has developed, and by the inability to include recipients of music therapy services in the research. My biases and assumptions about the effectiveness of music therapy, generated over more than 20 years of music therapy practice including 15 years in traditional palliative care, as well as the paucity of existing literature regarding the use of music therapy in neuro-palliative care, are additional limitations.

Challenges

The challenges in this research involve the boundaries between areas of practice which overlap and become blurred as delineation is attempted. Palliative care music therapy and neuro-palliative care music therapy, rehabilitative care and palliative care, the Neurologic Music Therapy model and/or techniques) and neuro-palliative music therapy approaches and techniques: this research lies at the junction of each of these concept dyads in some ways, which makes it both exciting and uncomfortable in its lack of clarity.

As was assumed at the outset of this research, music therapy in traditional oncology-based palliative care and in neuro-palliative care have far more similarities than differences. The music therapy interventions recommended by DS for working with patients with ALS and brain tumours, based on her more than 30 years of experience, appear to be similar if not identical to those used with patients with other palliative diagnoses (as recommended by McNab, 2010).

This also proved to be true in my own practicum experience at the local neurologic hospital; I relied on the same interventions I have used in palliative care and found them to be equally effective in this new population and setting. Thus, there is little included in this neuro-palliative care music therapy intervention manual that is truly specific to patients with end-stage neurologic diseases and disorders, in terms of the interventions themselves, although the recommended method of implementation may be distinct from traditional palliative care. This may speak to the need for music therapists working in this population to have skills and knowledge specific to the clientele rather than to the music therapy interventions. It is also possible that refinement and further specification would come in the subsequent phases of Stage 2: Revision Through Expert Review, Pilot Testing, and Efficacy Trials, as reviewers could "suggest content to be added…[and] identify content that does not work in practice" (Fraser et al., 2009, p.79).

In preparing this first draft of a treatment manual for use in neuro-palliative care, it became apparent that even developing a taxonomy of interventions was a challenge. Different sources refer to the same intervention by different names, there is significant overlap between intervention procedures, and each practitioner has his/her own variation depending on his/her skill set. This is one advantage of the Neurologic Music Therapy (Thaut, 2005) approach: each intervention is clearly operationalized and has not only a very specific name, but an acronym attached to it. It is hoped that as this neuro-palliative care music therapy treatment manual is refined, the differentiations between interventions and their specific applications will also become more clearly delineated. This first draft invites additions and revisions from other music therapists.

It also seems the research question itself, "Which music therapy interventions are most appropriate for patients receiving neuro-palliative care, and their families?", presents a challenge, particularly without further specification. To determine which interventions are likely to be most appropriate, a music therapist must also determine the patient's needs and his/her stage of disability or disease. This would lead back to the framework proposed by Daveson (2008): to determine which interventions will be most appropriate, the music therapist needs to understand if the patient's goals of care are restorative, compensatory, or psycho-social-emotional. Similarly, in the framework of McNab (2010), does the music therapist want to help the patient change abilities, maintain abilities, or manage symptoms? This is where the divide between

rehabilitative and palliative care becomes apparent, or, perhaps where music therapists can find a way to bridge the gap (Magee, 2013; McNab, 2010). This is where the strength of music as our medium becomes apparent also; the same interventions can be applied to achieve more than one goal, depending on the patient's needs. However, beginning with the interventions is actually "putting the cart before the horse" as acknowledged previously: ideally the music therapist begins with the patient's needs and goals in mind, then selects interventions to address these. This is also where the divide between the often-medically-mandated objectivist stance (which requires music therapists to predict which treatments will work), and an interpretivist perspective, becomes evident. An interpretivist would be more likely to describe what has helped in a particular context, which opens other practitioners to possibilities that may be explored, rather than predicting what will or will not work in general (Baker & Young, 2016). It is my hope that this research provides the interpretivist-style invitation to further exploration.

At the recommendation of the thesis committee, this research did not include the potential application or adaptation of Neurologic Music Therapy or other rehabilitation-focussed interventions in neuro-palliative care as part of the treatment manual developed. This limitation proved to be a challenge. Although rehabilitation and palliative care seem, at first glance, to be diametrically opposed approaches to care, there may be ways which they can be successfully juxtaposed, if not integrated, in music therapy, as suggested by my research participants:

> I think palliative care is becoming a broader and longer trajectory, so we now have palliative chemo(therapy), we have palliative radiotherapy, so why not have palliative rehab? And I think even that it's not such an oxymoron, if we think of palliative care as being the maintenance of quality of life near the end of life, so that makes sense to me. I certainly have seen patients who are very somnolent, even close to semi-comatose patients, who will respond, start to sing a line of the song, open their eyes…So, we *know* that there's a physiological response, even at the end. And that really brings in Neurologic Music Therapy…that is much more rehab-oriented, and palliative care, which is much more letting go, and it brings them together…(D.S., personal communication, May 31, 2018).

I have examined only the compensatory (maintaining social roles and identity) and psycho-social-emotional (Daveson, 2008) or maintenance and comfort/affirming/symptom management levels (McNab, 2010) of using music therapy in neuro-palliative care. The

restorative (Daveson, 2008) and rehabilitative (McNab, 2010) levels of care, in which Neurologic Music Therapy (Thaut, 2005) would primarily be used, would have a different focus, and would emphasize physical and cognitive goals. This indicates an area for further research, as the literature (McNab, 2010) and the participants in this research have both identified that there is a place for rehabilitation, even within palliative care. Magee (2013) has addressed this apparent contradiction:

> Palliative models are most appropriate for the final stages and have been termed neuro-palliative rehabilitation because as the patient's neurological condition becomes more advanced, rehabilitation and palliative care approaches often overlap. This model is a useful one for music therapists to consider in order to understand the most appropriate goals of intervention and shape the intervention they offer accordingly. (p. 5)

Implications

The findings of this research indicate some suggestions which music therapists working in neuro-palliative care (whether it is specifically designated as such or not) can apply to their practice in the short term, as well as others which will require further research and development to become clinically applicable. Suggestions for immediate application to practice include:

- Use of the Palliative Performance Scale (or similar clinical tool): The music therapist may quickly and easily adopt the use of the PPS for assessment and treatment planning purposes, even if it is not currently used by the interdisciplinary team in his/her clinical setting.
- Patient and Family Education: The music therapist may educate patients' family members and friends about ways in which they can use music for the patient's well-being (outside of music therapy sessions). As this action shows potential to meet several of the identified needs of family members and caregivers in this setting and population, music therapists may consider it part of their job to actively engage family members in the use of music for patient care and self-care.
- Staff Education: Based on JG's comments about her experiences of becoming more familiar with music therapy in neuro-palliative care, the music therapist may incorporate two specific elements which increase the effectiveness of staff education regarding music therapy:

- Reminding team members of the significance of their own personal connections with music, thereby helping them to reflect on the ways in which music may benefit patients and families; and
- Inviting staff to observe music therapy sessions (ideally in person, or through case study material).

Any way in which the music therapist can increase team members' understanding of music therapy on an emotional as well as cognitive level appears to be particularly valuable in terms of garnering staff support. Staff education can also take place on an informal basis during one-on-one consultation with team members, and during team rounds. For example, the music therapist may recommend music therapy intervention when a nurse reports that a patient is experiencing dyspnea or restlessness.

An additional implication of this research is the suggestion that music therapists working in neuro-palliative care should be prepared and qualified to assist patients in working towards rehabilitative goals. As noted by the participants in this research, including rehabilitative goals in music therapy treatment for patients with life-limiting neurologic disorders may often be appropriate, and may serve to improve quality of life.

Recommendations for Future Research

Intervention research methodology clearly outlines the next steps for developing this program model for music therapy in neuro-palliative care. The remaining stages of step 2, "Revision through Expert Review, Pilot Testing, and Efficacy Trials", "Differentiation in the Practice Setting", and "Translation and Adaptation" would ideally be followed by steps 3, 4 and 5: "Refine and Confirm Program Components", "Assess Effectiveness in a Variety of Settings and Circumstances" and "Disseminate Findings and Program Materials" (Fraser et al., 2009).

Future research may also attempt to provide a better balance between perspectives on the three primary patient diagnostic categories in neuro-palliative care: stroke, brain tumour, and progressive neurologic disorders. Literature regarding the application of music therapy for patients with end-stage stroke and brain tumours appears to be currently less available than literature regarding PND, thus, this thesis may overemphasize the needs and/or possible benefits to patients with PND. Considering the needs of patients with all three diagnoses equally would yield a more comprehensive approach.

Music therapy assessment specific to neuro-palliative care is another area highlighted in this research as having potential for development. Both interview participants commented on the ability of music to assess areas of patients' functioning which are untouched by other activities or disciplines, and thereby to provide revelatory perspectives on patient's capabilities. A music therapy assessment designed for use specifically in this patient population could assist in further articulating the role of music therapy in the interdisciplinary team. This is also suggested by León, Giraldo, Restrepo, and Rengifo-Varona, (2013), in their discussion of palliative care for stroke patients:

> Establishing reliable assessments of the patient's needs is required to conduct some effective therapeutic approaches. Palliative care of patients with…CVA (stroke) symptoms requires a multidisciplinary approach, where the non-pharmacologic treatment conducted by physical, speech, respiratory, and occupational rehabilitation is as important as medicines. Teamwork is the hallmark of appropriate management in palliative care and CVA." (p.4).

Although music therapy treatment is not specifically mentioned in the above, it has potential to make a valuable contribution in neuro-palliative care. A music therapy assessment specific to neuro-palliative care would also add a much-needed missing chapter to the included treatment manual, which thus far, focusses solely on interventions.

Additionally, it is recommended that future research further investigate the role of music therapy (including Neurologic Music Therapy) in neuro-palliative rehabilitation, as recommended by McNab (2010), rather than separating the rehabilitative and palliative stages, which seems an artificial delineation. Integrating the two within a continuum of care will ideally result in better outcomes for patients. As indicated by the results of this research, music therapy has potential to address several of the areas of holistic care outlined by McNab, particularly symptom control, communication interventions and psychosocial support.

During her research interview, DS reflected on the implications of the advancement of music therapy into neurology and neuro-palliative care. These reflections, from the wise perspective of a veteran Canadian palliative care music therapist, draw attention to the many unanswered questions which remain in new areas of research and practice:

> I've been thinking…about the great work that music therapists do, on the one hand, and the tendency for a lack of recognition on the other hand…there's been an explosion of

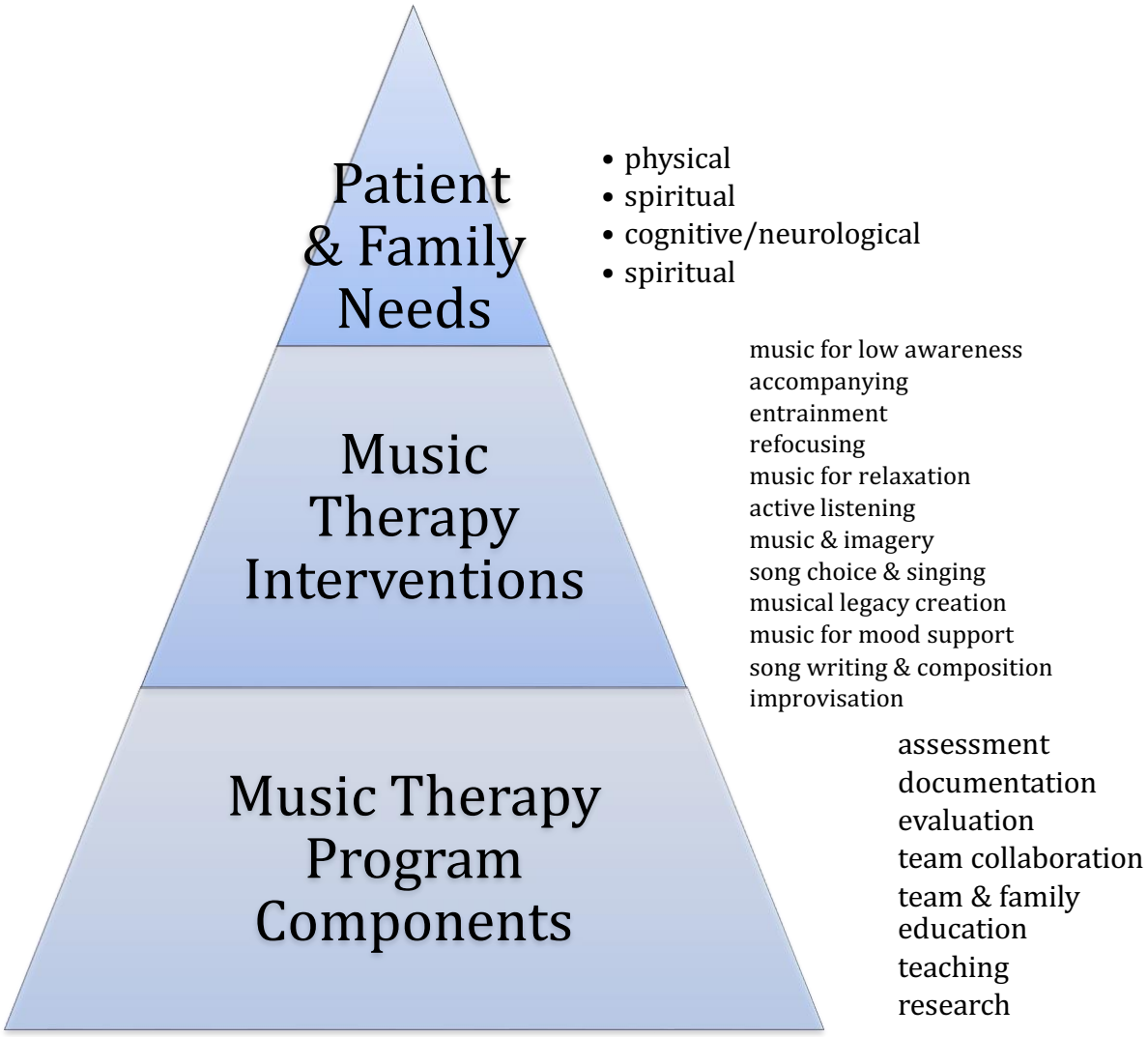
> research, but I think we need more evidence…we need more education, we need people at the Master's-and-beyond levels, so I think these are things we need to keep advocating… but I'm wondering…so that music therapy could really take its place in neurology, (which has a lot of brainy people, so to speak)…and be recognized, and more fully accepted, what would that take and how would we get there? Who needs to know, what evidence do we need…what do we need to be doing? How do we take our place at the table? Let's not be the nice people who are doing nice things with nice patients… How do we let other people know that it [music therapy] has a basis, that it's been proven…or shown to make a difference, and that it's not only anecdotal. I think we have to collaborate…(DS, personal communication, May 31, 2018).

Perhaps this comment reveals an area of profession research which invites further investigation: the workings of interdisciplinary collaboration itself, and how partnerships with other professions may strengthen the evidence base for music therapy in neurology (Magee & Stewart, 2015) and neuro-palliative care.

Conclusion

Coming full circle to review my three research questions, it is interesting to note that their answers could build on one another to create an overall program structure. This could be represented in a simple pyramid diagram:

Figure 5.1. Neuro-palliative Care Music Therapy Program Structure



This diagram represents the way in which the essential elements of a music therapy program for neuro-palliative care (including music therapy assessment, evaluation, teaching, research, staff education, team consultation, documentation, and resources) provide a foundation. When these are in place, the music therapist is provided with a structure within which to create high-quality, client-focussed music therapy interventions (including music stimulation for low awareness states, accompanying, entrainment, refocussing, music for relaxation, active listening, music and imagery interventions, song choice, musical legacy creation, music for mood support, song-writing, composition, and instrumental or vocal improvisation). High-quality music therapy interventions, in turn, support the needs of neuro-palliative care patients and families (in physical, cognitive/neurological, psychosocial and spiritual domains), allowing them to reach

their goals of care (improved quality of life and decreased suffering). The needs of patients and families are the highest priority, therefore are at the top of the pyramid (and are not of lesser importance although they appear smaller in size).

In a broader sense, these three elements also represent my experience of being a music therapist in palliative care. Throughout my 20+ years of music therapy practice, it has been the trust and collaboration of team members which has supported me, and the graceful perseverance of patients and family members which has inspired me to reach higher in my practice. In the middle of these has been music, creating connections between the multiple layers of human experience: between self and others, past and present, this life and beyond. It is these musical (and neural!) connections which, as a music therapist, I am privileged to share with patients and families in (neuro)palliative care.

References

Academy of Neurologic Music Therapy. (2015). *Neurologic music therapy training institute: Course handbook.* Fort Collins, CO: Academy of Neurologic Music Therapy.

Aldridge, D., Schmid, W., Kaeder, M., Schmidt, C., & Ostermann, T. (2005). *Functionality or aesthetics? A pilot study of music therapy in the treatment of multiple sclerosis patients.* Complementary Therapies in Medicine. 13(1). 25 -33. doi: https://doi.org/10.1016/j.ctim.2005.01.004

Baker, F., & Roth, E. A. (2004). Neuroplasticity and functional recovery: Training models and compensatory strategies in music therapy. *Nordic Journal of Music Therapy, 13*(1), 20-32. doi:10.1080/08098130409478095

Baker, F., & Young, L. (2016). The relationship between research and practice. In Wheeler, B. and Murphy, K. (Eds.) *Music therapy research* (3rd ed.). (pp. 26-36). Dallas: Barcelona.

Boersma, I., Miyasaki, J., Kutner, J., & Kluger, B. (2014). Palliative care and neurology: Time for a paradigm shift. *Neurology*, *83*(6), 561–567. http://doi.org/10.1212/WNL.0000000000000674

Bradt, J., & Dileo, C. (2010). Music therapy for end-of-life care. *Cochrane Database of Systematic Reviews,* (1) doi:10.1002/14651858.CD007169.pub2

Brain Tumour Foundation of Canada. (2017). Brain tumour facts. Retrieved from https://www.braintumour.ca/2494/brain-tumour-facts

Cairns, M., Thompson, M., & Wainwright, W. (2003). *Transitions in dying and bereavement*. Baltimore, MD: Health Professions Press.

Clements-Cortex, A. (2016). *Voices of the Dying and Bereaved.* Dallas: Barcelona Publishers.

Dallara, A., & Tolchin, D. (2014). Emerging subspecialties in neurology: Palliative care. *Neurology, 82*(7), 640-642. 10.1212/WNL.0000000000000121 Retrieved from http://n.neurology.org/content/82/7/640.abstract

Fraser, M. W., Richman, J. M., Galinsky, M. J., & Day, S. H. (2009). *Intervention research: Developing social programs*. New York, NY: Oxford University Press.

Daveson, B. A. (2008). A description of a music therapy meta-model in neuro-disability and neuro-rehabilitation for use with children, adolescents and adults. *The Australian Journal of Music Therapy, 19*(1), 70-85. doi: Retrieved from https://0-search-proquest-com.mercury.concordia.ca/docview/1465832?accountid=10246

Davis, G., & Magee, W. L. (2001). Clinical improvisation within neurological disease: Exploring the effect of clinical improvisation on the expressive and interactive responses of a patient with Huntington's disease. *British Journal of Music Therapy, 15*(2), 51-60.

Davis, K. (1998). To never surrender: Music therapy in the fight against multiple sclerosis. *Canadian Journal of Music Therapy/Revue Canadienne de Musicothérapie, 6*(1), 20 - 34.

Dileo, C., & Parker, C. (2005). Final moments: The use of song in relationship completion. In C. Dileo, & J. V. Loewy (Eds.), *Music therapy at the end of life* (pp. 43-56). Silver Spring, MD: Jeffrey Books.

Downing, G. M., & Wainwright, W. (Eds.). (2006). *Medical care of the dying*. Victoria: Victoria Hospice Society.

Elman, L. B., Houghton, D. J., Wu, G. F., Hurtig, H. I., Markowitz, C. E., and McCluskey, L. (2007). Palliative care in amyotrophic lateral sclerosis, Parkinson's disease, and multiple sclerosis. *Journal of Palliative Medicine, 10*(2), 433-457. doi:10.1089/jpm.2006.9978

Fraser, M. W., & Galinsky, M. J. (2010). Steps in intervention research: Designing and developing social programs. *Research on Social Work Practice, 20*(5), 459-466. doi:10.1177/1049731509358424

Fraser, M.W., Richman, J.M., Galinsky, M.J. and Day, S.H. (2009). *Intervention research: Developing social programs.* New York: Oxford University Press.

Gallagher, L. M., Lagman, R., Walsh, D., Davis, M. P., & LeGrand, S. B. (2006). The clinical effects of music therapy in palliative medicine. *Supportive Care in Cancer, 14*, 859-866. doi:10.1007/s00520-005-0013-6

Glasziou, P. (2015). Music in hospital. *The Lancet, 386*(10004), 1609-1610. //0-dx.doi.org.mercury.concordia.ca/10.1016/S0140-6736(15)60640-7 Retrieved from https://0-search-proquest-com.mercury.concordia.ca/docview/1725692810?accountid=10246

Graham-Wisener, L., Watts, G., Kirkwood, J., Harrison, C., McEwan, J., Porter, S., . . . McConnell, T. H. (2018). Music therapy in UK palliative and end-of-life care: A service evaluation. *BMJ Supportive & Palliative Care, 0*10.1136/bmjspcare-2018-00510

Hartley, N.A. (2001). On a personal note: A music therapist's reflections on working with those who are living with a terminal illness. *Journal of Palliative Care, 17(3),* 135-141.

Heath, B. & Lings, J. (2012). Creative songwriting at the end of life and in bereavement. *Mortality, 17(2)*, 106-118. doi: 10.1080/13576275.2012.673381

Hilliard, R.E. (2001). The use of music therapy in meeting the multidimensional needs of hospice patients and families. *Journal of Palliative Care, 17(3),* 161-166.

Hilliard, R. E. (2005). Music therapy in hospice and palliative care: A review of the empirical data. *Evidence-Based Complementary and Alternative Medicine, 2*(2), 173-178. doi:10.1093/ecam/neho76

Hilliard, R. E. (2005). Enhancing quality of life for people diagnosed with a terminal illness. In C. Dileo, & J. V. Loewy (Eds.), *Music therapy at the end of life* (pp. 19-24)

Howland, R. H. (2016). Hey mister tambourine man, play a drug for me: Music as medication. *Journal of Psychosocial Nursing & Mental Health Services, 54*(12), 23-27. //0-dx.doi.org.mercury.concordia.ca/10.3928/02793695-20161208-05 Retrieved from https://0-search-proquest-com.mercury.concordia.ca/docview/1850758026?accountid=10246

Killoran, S. (2012). *Palliative patients' experiences of the Bonny Method of Guided Imagery and Music.* (Unpublished MA Creative Arts Therapies). Concordia University, Montreal.

Krout, R. E. (2001). The effects of single-session music therapy interventions on the observed and self-reported levels of pain control, physical comfort, and relaxation of hospice patients. *American Journal of Hospice and Palliative Care, 18*(6), 383-390. doi:10.1177/104990910101800607

Krueger, H., Koot, J., Hall, R.E., O'Callaghan, C., Bayley, M., & Corbett, D. (2015). Prevalence of individuals experiencing the effects of stroke in Canada: Trends and projections. *Stroke*, 46, pp. 2226-2231. Doi: 10.1161/STROKEAHA.115.009616

León, M. X., Giraldo, L. F., Restrepo, J., & Rengifo-Varona, M. L. (2013). Palliative care in patients with chronic non-oncological diseases. *Techniques in Regional Anesthesia and Pain Management, 17*(1), 2-6. doi:10.1053/j.trap.2013.09.006

Magee, W.L. (2013). Adults with neurodegenerative diseases. In Allen, J. (Ed.), *Guidelines for Music Therapy Practice in Adult Medical Care: Chp. 9.* (pp. 2-218). Dallas: Barcelona.

Magee, W. L., & Davidson, J. W. (2004). The effect of music therapy on mood states in neurological patients: A pilot study. *Journal of Music Therapy, 39*(1), 20-29.

Magee, W. L., & Davidson, J. W. (2004). Music therapy in multiple sclerosis: Results of a systematic quantitative analysis. *Music Therapy Perspectives, 22*(1), 39.

Magee, W.L. & Stewart, L.E. (2015). The challenges and benefits of a genuine partnership between music therapy and neuroscience: A dialogue between scientist and therapist. *Frontiers in Human Neuroscience*, *9,* doi:10.3380/fnhum.2015.00223/full

McNab, E. (2010). Music therapy in progressive neurological disease: A neuro-palliative rehabilitation perspective. *Australian Journal of Music Therapy, 21*, 59-76. Retrieved from http://0-search.ebscohost.com.mercury.concordia.ca/login.aspx?direct=true&db=psyh&AN=2010-19410-007&site=eds-live

Miller, D. M., & O'Callaghan, C. (2010). Cancer care. In D. Hanson-Abromeit, & C. Colwell (Eds.), *Music therapy for adults in hospital settings* (pp. 217-298). Silver Spring, MD: American Music Therapy Association.

Neuman, W. L. (2006). Analyzing qualitative data. In W. L. Neuman (Ed.), *Social research methods: Qualitative and quantitative approaches* (6th ed., pp. 457-489). Needham Heights, MA: Allyn & Bacon.

Oliver, D. (2014). Palliative care for people with progressive neurological disease: What is the role? *Journal of Palliative Care, 30*(4), 298-301.

Public Health Agency of Canada. (2014). Mapping connections: An understanding of neurological conditions in Canada. Ottawa: Public Health Agency of Canada. Retrieved from https://www.canada.ca/content/dam/phac-aspc/migration/phac-aspc/publicat/cd-mc/mc-ec/assets/pdf/mc-ec-eng.pdf

Robinson, M. T., & Barrett, K. M. (2014). Emerging subspecialties in neurology: Neuro-palliative care. *Neurology, 82*(21), e180-e182. doi:10.1212/WNL.0000000000000453

Scheiby, B. (2005)."Dying Alive" - A transpersonal analytical music therapy approach for adults with chronic, progressive neurological diseases. In C. Dileo, & J. V. Loewy (Eds.), *Music therapy at the end of life* (pp. 171-188). Cherry Hill: Jeffrey Books.

Schmid, W., & Aldridge, D. (2004). Active music therapy in the treatment of multiple sclerosis patients: A matched control study. *Journal of Music Therapy, 41*(3), 225-240. Retrieved from https://0-search-proquest.com.mercury.concordia.ca/docview/223555299/abstract/275AD2DF854544F2PQ/1?accountid=10246

Steele, M. (2005). Coping with multiple sclerosis: A music therapy viewpoint. *The Australian Journal of Music Therapy, 16*(1), 70--87. Retrieved from https://0-search-proquest-com.mercury.concordia.ca/docview/1463188?accountid=10246

Thaut, M. (2005). *Rhythm, music, and the brain: Scientific foundations and clinical applications*. New York: Routledge. Retrieved from http://www.loc.gov/catdir/toc/ecip059/2005006731.html

Veronese, S., Gallo, G., Valle, A., Cugno, C., Chiò, A., Calvo, A., Rivoiro, C., & Oliver, D. J. (2015). The palliative care needs of people severely affected by neurodegenerative disorders: A qualitative study. *Progress in Palliative Care, 23*(6), 331. doi:10.1179/1743291X15Y.0000000007

World Health Organization. (2017). Palliative care. Retrieved from http://www.who.int/cancer/palliative/definition/en/

World Health Organization. (2018). Neurological disorders. Retrieved from http://www.who.int/features/qa/55/en/

CERTIFICATION OF ETHICAL ACCEPTABILITY
FOR RESEARCH INVOLVING HUMAN SUBJECTS

Name of Applicant:	Kirsten Davis
Department:	Faculty of Fine Arts \ Music Therapy
Agency:	N/A
Title of Project:	A Music Therapy Program Design for Neuro-Palliative Care
Certification Number:	30009547

Valid From: May 07, 2018 To: May 06, 2019

The members of the University Human Research Ethics Committee have examined the application for a grant to support the above-named project, and consider the experimental procedures, as outlined by the applicant, to be acceptable on ethical grounds for research involving human subjects.

Dr. James Pfaus, Chair, University Human Research Ethics Committee

Appendix B
Participant Recruitment E-mail

A Music Therapy Program Model for Neuro-palliative Care

Hello, my name is Kirsten Davis. I am a Master's student in the MA Creative Arts Therapies (Music Therapy option) program at Concordia University, and recently completed a practicum in your facility. My faculty supervisor in Charles-Antoine Thibeault, MTA, MA, of Concordia University. I am seeking medical professionals specializing in neuro-palliative care who work with patients and families at end-of-life to volunteer to participate in one 60-75 minute interview (by phone, videoconference, or in person) about their experience of working with this population and the potential applications of music therapy therein. The aim of this research is to develop a music therapy program design for later testing and implementation in neuro-palliative care.

A foreseeable benefit of participating in this research is a sense of satisfaction from contributing to the development of specific music therapy programming, which will in turn develop a little-researched area of the field and expand treatment options for this population. Potential risks or harms that could arise for participants as a result of this research are minimal, with an inconvenience of time spent for the interview and data review, and possible use of internet conferencing applications (such as FaceTime or Skype) as the only known factors. There is a risk that participants may be identifiable given the specific nature of the population and the uniqueness of the neuro-palliative care program, however, there may also be some benefit to being identified as participants. Thus, participants will be given a choice as to how much of their personal identifying information is included in the findings, and how much is altered.

Due to the limited scope of this project, only English-speaking members of the neuro-palliative care team at the local neurologic hospital, or consultants thereto, will be eligible to participate in the interviews. If you are interested, please contact me directly at Kirsten.davis@mail.concordia.ca. Please feel free to contact me, or my research supervisor, with any further questions.

Sincerely,

Researcher:

Kirsten L. Davis, MTA
Department of Creative Arts Therapies
Concordia University
1395 Blvd. Rene Levesque Ouest
Montreal, QC H3G 1M8
Email: Kirsten.davis@mail.concordia.ca
Phone: 250-480-8727

Faculty Research Supervisor:

Charles-Antoine Thibeault
Department of Creative Arts Therapies
Concordia University
1395 Blvd. Rene Levesque Ouest
Montreal, QC H3G 1M8
Email: Charles-antoine.thibeault@concordia.ca
Phone: 514-333-8989 xt. 527

If you have any questions regarding your rights as a research participant, you may contact Karen Gregg, Research Ethics Coordinator: Karen.Gregg@concordia.ca 848-2424 ext 7481.

Appendix C
Participant Consent Form

INFORMATION AND CONSENT FORM

Study Title:

A Music Therapy Program Model for Neuro-Palliative Care

Researcher: Kirsten Davis, MTA

Researcher's Contact Information:

Kirsten.davis@mail.concordia.ca (250)480-8727

Faculty Supervisor: Charles-Antoine Thibeault, MTA, MA

Faculty Supervisor's Contact Information:

charlesantoine.thibeault@concordia.ca (514)333-8989 ext. 527

You are being invited to participate in the research study mentioned above. This form provides information about what participating would mean. Please read it carefully before deciding if you want to participate or not. If there is anything you do not understand, or if you want more information, please ask the researcher.

A. PURPOSE

The purpose of the research is to develop a specialized music therapy program to support the psychosocial, physical, and spiritual needs of patients who are receiving end-of-life care due to brain tumours, severe strokes, or other end-stage diseases and disorders of the brain and nervous system, and their families.

B. PROCEDURES

If you participate, you will be asked to participate in your choice of an individual or dyad interview, 60-75 minutes in length, regarding the unique needs of patients receiving neuro-palliative care and their families, and your recommendations for future applications of music therapy with this population. You may receive interview questions in advance, if desired, to allow time to reflect on the topic and prepare your responses. If you express interest in participating, the researcher will contact you to provide a written informed consent form for your review, and to arrange a mutually convenient interview time, location and method (in-person, phone, or videoconferencing). The researcher will use an in-depth, semi-structured interview format which will begin with a set of specific questions but will also allow your unique

knowledge to emerge and be explored. You will also be invited to ask questions and express any concerns you may have.

After the researcher has transcribed and coded the interview data, you will be asked to review the themes extracted from the interview transcript to confirm accuracy. At this time, you will have the opportunity to make any changes you wish to the intended content and/or meaning of your interview statements.

In total, participating in this study will take 1.5 - 2 hours (60-75 minutes initial interview + 30-45 minutes member checking and reply time).

C. RISKS AND BENEFITS

You might face certain risks by participating in this research. These risks include a risk of your being identified, due to the impossibility of complete anonymity in reporting of this research interview data, as this is a unique clinical setting and a niche area of practice. There could also be a risk of discomfort if reporting negative opinions of music therapy to the researcher.

Potential benefits include making a contribution to strengthening music therapy research literature specific to neuro-palliative care. Recognition of the hospital, its neuro-palliative program, and its neuro-palliative team as being supportive of music therapy could also be of benefit. Receipt of research findings following completion of the study may benefit you, as these findings may be used to strengthen your understanding of the applications of music therapy, your clinical practice, and the facility's music therapy program in the future.

D. CONFIDENTIALITY

The researcher will gather the following information as part of this research: your medical opinion and perspective regarding the unique needs of patients who are receiving end-of-life care due to brain tumours, severe strokes, or other end-stage diseases and disorders of the brain and nervous system, and their families, and the ways in which music therapy may theoretically address these needs.

The researcher will not allow anyone to access the information, except people directly involved in conducting the research. The researcher will only use the information for the purposes of the research described in this form.

The information gathered will be coded for analysis. This means that the information will be identified by a code. The researcher will have a list that links the code to your name.

The researcher will protect the data by:

1) Using a handheld Zoom H2 digital recorder to audio-record interview data on a password-protected SD card.
2) Transferring interview data within 12 hours from the SD card to the researcher's password-protected MacBook Pro laptop, then backing up to password-protected external hard drive and thumb drives. Data will not be saved to the iCloud. Following the data transfer, the SD card will be reformatted, so all interview data will be erased.

3) Being the only person to have access to and passwords for the storage devices above. The storage devices will be kept in a locked cabinet in the researcher's home when not in use.

4) Transcribing the recordings within 1 month into Word documents. These will also be saved to a password-protected external hard drive and thumb drives. Data will not be saved to the iCloud.

The researcher intends to publish the results of this research. Please indicate below whether you accept to be identified in the publications:

[ ] I accept that my name, identifiers and the information I provide appear in publications of the results of the research.

[ ] Please do not publish my name, or other identifying information specified below as part of the results of the research:

_____

The researcher will destroy the information after the thesis has been defended, accepted by the committee, and deposited in the Spectrum online research repository.

F. CONDITIONS OF PARTICIPATION

You do not have to participate in this research. It is purely your decision. If you do participate, you can stop at any time. You can also ask that the information you provided not be used, and your choice will be respected. If you decide that you don't want the researcher to use your information, you must tell the researcher before June 15, 2018.

There are no negative consequences for not participating, stopping in the middle, or asking the researcher not to use your information.

G. PARTICIPANT'S DECLARATION

I have read and understood this form. I have had the chance to ask questions and any questions have been answered. I agree to participate in this research under the conditions described.

NAME (please print) _____

SIGNATURE _____

DATE _____

If you have questions about the scientific or scholarly aspects of this research, please contact the researcher. Their contact information is on page 1. You may also contact their faculty supervisor.

If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or oor.ethics@concordia.ca.

Appendix D: Participant Research Interview Questions

Nurse Clinician Participant Research Interview Questions:

(questions indicated in italics are those actually discussed during the interview)

1. It is often said that "hearing is the last sense to go" at end-of-life. Is there any neurological basis to this statement?
    a. If so, how could a music therapist employ this knowledge to a patient's (and their family's) greatest benefit?
2. *Please tell me about an experience you've had (prior to this music therapy practicum) with a patient and family receiving neuro-palliative care, in which music (not necessarily music therapy) was significant.*
    a. *Please tell about this experience in as much detail as possible.*
    b. *If yes, what seemed impactful (in a positive or negative way) for the patient, the family, and yourself about the role of music in that patient's care?*
3. *You generously agreed to accept this (first) music therapy practicum in your (neuro-palliative care) program.*
    a. *What outcomes were you hoping for?*
    b. *How did you think that music therapy might support the goals of neuro-palliative care?*
4. *In my understanding, yours is the first neuro-palliative care program in Canada. As specialists in this patient population, how you would describe the:*
    a. *physical symptoms & needs of neuro-palliative care patients?*
    b. *psychosocial needs of NPC patients?*
    c. *spiritual needs of NPC patients?*
    d. *How are these different from the needs of "traditional" palliative care patients?*
    e. *In your opinion, could music therapy potentially address patients' needs in neuro-palliative care? If so, which ones*?
5. *In my understanding, patients receiving neuro-palliative care fall into 3 broad diagnostic categories: stroke, brain tumour, or progressive neurologic disease. How might the treatment goals of neuro-palliative care be different for each of these diagnoses?*
    a. *Are there any factors which could contraindicate the use of music therapy for patients with these diagnoses? For example, is there anything specific to the way that patients' ability to process music might be affected neurologically by their lesion or disease process?*
6. *As a physician or a nurse clinician, you have many resources at your disposal to support patients and families (medications, other therapies, social work support, volunteer services…).*
    a. *What would motivate you to refer a patient/family to music therapy?*

b. *What outcomes would you hope to see from MT?*

7. NPC patients have precious, extremely limited time and energy. In your opinion, what returns/benefits could MT offer that would make it worthwhile for NPC patients to invest their limited time and energy in MT sessions?
8. As a part of an interdisciplinary team approach to neuro-palliative care, what might MT offer to patients and families that other therapeutic approaches don't?
9. As a newcomer to NPC in an inpatient hospital setting, how could a music therapist best integrate his/her service within the team approach?
10. *Are there any comments, recommendations, or questions you would like to add regarding the development of a music therapy program for neuro-palliative care patients and their families in an interdisciplinary, inpatient hospital setting?*

My thesis research questions are:

- What are the components of a music therapy program for patients and families receiving neuro-palliative care?
- Which music therapy interventions are most appropriate for patients receiving neuro-palliative care, and their families?
- Which patient/family needs and goals can music therapy address in the neuro-palliative care setting?

Although I will not be asking these research questions directly during the interview, I am including them as it might be helpful for you to have a general sense of the purpose of my inquiry.

Thank you in advance for participating ☺

Music Therapist Participant Interview Questions

(Questions indicated in italics are those actually discussed during the interview.)

1. It is often said that "hearing is the last sense to go" at end-of-life. Do you know if there is any neurological basis to this statement? Have you observed this to be true?

If so, how could a music therapist employ this knowledge to a patient's (and their family's) greatest benefit?

2. Please tell me about an experience you've had with a patient and family receiving neuro-palliative care (palliative care for a brain tumour, stroke, or progressive neurologic condition), in which music (not necessarily music therapy) was significant.

Please tell about this experience in as much detail as possible.

If yes, what seemed impactful (in a positive or negative way) for the patient, the family, and yourself about the role of music in that patient's care?

3. *You initiated this (first) music therapy practicum in the neuro-palliative care program.*
   a. *What outcomes were you hoping for?*
   b. *How did you think that music therapy might support the goals of neuro-palliative care?*

    c. *In your opinion, could music therapy potentially address patients' needs in neuro-palliative care? If so, which ones?*

4. In my understanding, patients receiving neuro-palliative care fall into 3 broad diagnostic categories: stroke, brain tumour, or progressive neurologic disease. How might the treatment goals of neuro-palliative care be different for each of these diagnoses?
5. Are there any factors which could contraindicate the use of music therapy for patients with these diagnoses? (headache, tinnitus…)
6. *Which music therapy interventions are used most frequently used in "traditional" palliative care music therapy sessions?*
    a. *Could these interventions also be applicable in neuro-palliative care music therapy?*
7. NPC patients have precious, extremely limited time and energy. In your opinion, what returns/benefits could MT offer that would make it worthwhile for NPC patients to invest their limited time and energy in MT sessions?
8. As a newcomer to NPC in an inpatient hospital setting, how could a music therapist best integrate his/her service within the team approach?
9. *My first research participant mentioned the possible combination of palliative care and rehabilitation, and this is mentioned in music therapy literature also. Have you ever observed functional improvements though music therapy when working with a neuro patient in palliative care?*
    a. *Do you see this as possible – rehab even in PC?*
10. *How or in what ways do the interventions you use with patients in palliative care change, as the patients' conditions decline toward EOL?*
    a. *How does your focus in sessions change?*
    b. *Do the goals of MT change as patients' condition decline toward EOL*?
11. *As a new music therapist (or a music therapist new to working with the neuro-palliative population), would you find it helpful to have a tool which classifies music therapy interventions by patients' functioning levels, to guide you in deciding how to work with patients according to their needs?*
12. *Are there any comments, recommendations, or questions you would like to add regarding the development of a music therapy program for neuro-palliative care patients and their families in an interdisciplinary, inpatient hospital setting?*

My thesis research questions are:

- What are the components of a music therapy program for patients and families receiving neuro-palliative care?
- Which music therapy interventions are most appropriate for patients receiving neuro-palliative care, and their families?
- Which patient/family needs and goals can music therapy address in the neuro-palliative care setting?

Appendix E: Permission and Application to Use PPS

VICTORIA HOSPICE

EDUCATION & RESEARCH
T: 250-370-8283
F: 250-370-8172

June 5th, 2018

Kirsten Davis, MTA
3810 Wilkinson Road
Victoria, BC V8Z 5A2
Email: kdavis@shaw.ca

Dear Kirsten,

Victoria Hospice has granted permission for you to use the Palliative Performance Scale v2 (found on our website at http://www.victoriahospice.org/health-professionals/clinical-tools) as you specify in your application (*attached*), for non-commercial use only.

This permission is subject to the following conditions:

- The complete PPSv2 chart will appear with complete instructions for its usage.
- A credit line will appear in the immediate area of the table and will include: Copyright Victoria Hospice Society, BC, Canada (2001) www.victoriahospice.org
- Permission is granted for non-exclusive English rights only

For permission to use the PPSv2 in other languages, materials or forms, please contact me again with specific requests.

Please do not hesitate to contact me if you have any further questions: **250-370-8719** or **Helena.Daudt@viha.ca**

All best regards,

Helena Daudt, PhD
Director, Education and Research
Victoria Hospice

Appendix E: Permission and Application to Use PPS

From: Kirsten Davis Slamet <kdavis@shaw.ca>
Sent: Sunday, June 10, 2018 12:48 PM
To: Daudt, Helena
Subject: Re: Permission to use PPS for my thesis?

Hi again Helena,
Further to my request re: the PPS…I am also wondering if there is a version of the PPS table in Word that I can use? The reason for this is that I'd like to add (as a sub-table or inset) a section which would contain additional information for music therapists about session design, patient participation level, and recommended music therapy interventions. For my thesis this will be for patients PPS 10 - 60%. I can create this myself, but if there already a Word version I can start from it will of course be easier :)
I will be including the full PPS first as well - not just the expanded one, and explaining how it is used.
If not, no problem, just thought I'd check…no point in reinventing the wheel as they say! If you have questions please let me know.
Thanks much!
Kirsten

On Jun 5, 2018, at 1:41 PM, Daudt, Helena <Helena.Daudt@viha.ca> wrote:

Hi Kirsten
Thank you for this official request;-). I am copying Taylor on this so she can prepare the letter and send it to you (Taylor, please, use this email as backup to this request).
To cite the PPSv2 you should use the Medical Care of the Dying book reference:
Downing, G. M., & Wainwright, W. (Eds.). (2006). Medical care of the dying. Victoria Hospice Society, Learning Centre for Palliative Care. Chapter Pain-assessment, pg 120-121.
And I love your thesis idea.
Cheers
Helena

-----Original Message-----
From: Kirsten Davis Slamet [mailto:kdavis@shaw.ca]
Sent: Tuesday, June 05, 2018 9:32 AM
To: Daudt, Helena
Subject: Permission to use PPS for my thesis?

Hi Helena,
I'd like to ask for official permission to use the PPS as part of my thesis :)
My concept is basically the same as what I described to you when I asked permission to use it for my class presentation - except that my thesis is specific to neuro-palliative care, so the context is more specific. I'll be using the PPS to outline a model for music therapists, which will help them to choose music therapy interventions according to a patient's level of functioning.
I'm also wondering: when I am referring to the PPS in my paper, which is the best reference to use? I know there have been many articles published about it, and several different versions, so I want to make sure I am using the most appropriate and up-to-date one.

Thanks, Kirsten

Appendix F: Request to Correct Use of PPS Originally Submitted (September 9, 2018)

VICTORIA HOSPICE

November 23rd, 2018

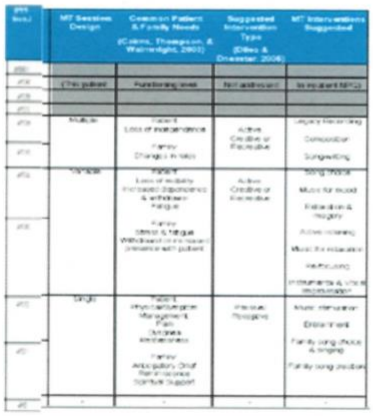
Concordia University, Montreal
Music Therapy, Creative Arts Therapies (MA)
Advisory Committee – Kirsten Davis Slamet

Dear Committee

Ms Davis has requested permission to use the PPSV2 in her thesis and was granted permission as per the attached letter. The conditions are stated on the letter.

Our understanding was that there would be a section, beside the PPS tool, which would contain additional information for music therapists about session design, patient participant level, and recommended music therapy interventions. The figure on the thesis does not conform with the permission letter as it presents only few columns of the PPSv2 tool plus the additional section.

Our suggestion would be to offer the PPSv2 tool as an appendix or within the thesis (whatever you prefer) and present, as part of the thesis, an alternate figure (similar to the one below). This figure should **not** be called "modified PPSv2" as it is not the case. The PPS scores are used as a guide to propose the suggestions for music therapists.



Thank you very much for your consideration.
Regards

Dr Helena Daudt - Director, Education and Research

3RD FLOOR RICHMOND PAVILION, 1952 BAY STREET, VICTORIA BC V8R 1J8
WWW.VICTORIAHOSPICE.ORG | Charitable Registration Number 87440-9964-RR0001

(See next page for magnified version of above table).

PPS Level	MT Session Design	Common Patient & Family Needs (Cairns, Thompson, & Wainwright, 2003)	Suggested Intervention Type (Dileo & Dneaster, 2005)	MT Interventions Suggested
100%				
90%	(This patient	Functioning level	Not addressed	In inpatient NPC)
80%				
70%				
60%	Multiple	Patient: Loss of independence Family: Changes in roles	Active, Creative or Recreative	Legacy Recording Composition Song-writing
50%				
40%	Variable	Patient: Loss of mobility Increased dependence & withdrawal Fatigue Family: Stress & fatigue Withdrawal or increased presence with patient	Active, Creative or Recreative	Song choice Music for mood Relaxation & imagery Active listening Music for relaxation Re-focusing Instrumental & Vocal Improvisation
30%				
20%	Single	Patient: Physical/Symptom Management: Pain Dyspnea Restlessness Family: Anticipatory Grief Reminiscence Spiritual Support	Passive/ Receptive	Music stimulation Entrainment Family song choice & singing Family song creation
10%				
0%	-	-	-	-

Appendix G: Resources for Facilitators:

Handout Materials for Family Members & Caregivers

Caring for Your Loved One with Music

The sounds of the hospital can be unfamiliar at best and upsetting at worst.
You can help to make it more relaxing and healing for your loved one.

Research shows that music keeps the brain active, and reduces pain and anxiety.
Physicians, nurses and music therapists recommend that patients bring their own music to the hospital to benefit from its healing properties.
(Glasziou, 2015, Howland, 2016)

Please provide a music player (CD player, iPod, or other) for your loved one.
Please ensure that your loved one can control the volume and music selections,
And/or that instructions are left for staff for its use.
If bringing headphones or earbuds, please ensure that they are wireless.
Please label all items with the patient's name.

What kind of music should I provide?

Whatever is most familiar to your loved one! What would they enjoy?
Relaxing nature sounds, such as wind, birds, ocean waves may also be helpful,
IF these are familiar and pleasant to your loved one.

You can share music during a visit!

You can sing familiar songs with or for your loved one.
Familiar voices are always best, even if your loved one is not able to respond.
You are also welcome to bring instruments!
(Just be considerate – close the door before starting the concert.)
This is a great way to involve children and help them feel comfortable here.

Would you or your loved one enjoy music therapy?

To create personalized songs, memory recordings, or jam sessions, or
to find how music therapy can support spirituality, symptoms, and emotions,
Request a music therapy visit through your loved one's nurse,
Or call music therapist _____ at _____

Appendix H: Resources for Facilitators:

Handout Materials for Nursing Staff & Other Neuro-Palliative Care Team Members

Caring for Your Patient with Music

The sounds of the hospital may be anxiety-provoking and agitating to patients.
You can help to make it more relaxing and healing for your patients.

Research shows that music stimulates diffuse brain activity,
and may reduce pain and anxiety.
(Glasziou, 2015, Howland, 2016)

Please ask family members to provide a music player (CD player, iPod, or other) for your patients.

Please ensure that your patient can control the volume and music selections.
Headphones or earbuds should be wireless for safety purposes.
Please ask that family members label all items with the patient's name.

What kind of music should my patient listen to?

Whatever is most familiar! If the patient or family are not able to make suggestions, gentle instrumental music is preferable to vocal music (singing).
Relaxing nature sounds, such as wind, birds, ocean waves may also be helpful,
IF these are familiar and pleasant for your patient.

You can share music during care!

When using recorded music, please ensure that the music is the patient's choice,
and is adjusted to an appropriate volume level.

Would you or your loved one enjoy music therapy?

To create personalized songs, memory recordings, or jam sessions, or
to find how music therapy can support spirituality, symptoms, and emotions,
Request a music therapy visit:
Call music therapist (name) at _____