

**How did Music Therapy Contribute to Patients' Quality of Life in
a Hospice and Palliative Care Setting?**

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Master of Music Therapy

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Abstract

This qualitative research explores how I, as a student music therapist, contributed to patients' quality of life (QoL) in a hospice and palliative care setting. The study principally focuses on the different music therapy and personal approaches that I used and which seemed to contribute to patients' QoL. The research was carried out at a hospice in New Zealand and I had sessions with in-patients, day hospice patients and out-patients who were all at varying stages of illness.

In this research, secondary analysis of data is used to answer my research question. The data used in this study are the clinical notes and reflexive journals that I gathered while working with 67 patients in a total of 194 sessions. Because QoL is a broad complex concept, I have chosen to use a conceptual framework suggested by music therapy theorist Even Ruud (1997) to put a structure to answering my research question. In thematic analysis, the data were both deductively and inductively analysed.

The findings describe music therapy methods, activities, strategies and techniques as well as personal approaches I employed which seemed to promote a sense of affective awareness, agency, belonging and meaning, and coherence of life in patients receiving hospice and palliative care. This study indicated that Ruud's (1997) framework has particular meaning in the context of hospice palliative care and that the framework could be extended for use in hospice and palliative care. The clinical vignette further provide an exploratory view of the use of music therapy techniques and the quality of relationships, and how both of these contributed to increasing a patient's QoL.

In the discussion, the findings are further explained in the light of other studies. In particular, 'being with' patients underpinned all of the musical and personal approaches that I made in working with hospice patients and this is evaluated as an overarching point. Although Ruud's (1997) idea of QoL was a good fit in my study, the study may suggests how his model could address ways in which affective awareness, agency, belonging and meaning and coherence of life can be supported with various music and personal approaches in the context of music therapy in hospice and palliative care settings.

Acknowledgements

I have dreamed of becoming a music therapist since I was 13, when my friend Emily suggested it as a career. Studying music therapy and writing this dissertation has been the most rewarding journey of my life. I feel I have stepped much closer to becoming practicing music therapist!

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Knock Knock

Hello

My name is Angela and I'm a student music therapist.

Introduction

This research was conducted as part of the second year of the Master of Music Therapy Programme at Te Kōkī New Zealand School of Music.

0.1. Music therapy in practice at a New Zealand hospice

My dissertation is based on the work that I did at a hospice over nine months in 2015. The hospice is situated in New Zealand and I worked approximately 24 hours per week, spread over 3 days per week. The care the hospice provided was based on its strategic mission and this was to improve patients' quality of life with respect and dignity.

The people who were under hospice care included those residing at home and those in in-patient units. The hospice also provided a programme called Day Hospice where all patients could join in, socialise with each other and participate in different activities such as musical recreation, relaxation and massage therapy. The patients were all in varying stages of illness with Palliative Performance Scale (PPS) (Appendix 1) scores ranging from 10%-60%. Not everyone was under end-of-life care and generally, the Day Hospice patients had higher PPSs than in-patients.

In the hospice, patients are admitted to the in-patient unit as their illness progresses and as their needs become more complex. The complex needs of the in-patients are treated by different medical health professionals and allied health professionals. Some patients with terminal illness stay home because they are well enough to continue living at home, be managed at home and because they wish to die at home. In some cases, patients are transferred into the in-patient unit for end-of-life care in their last days as their needs become too complex. The Day Hospice programme is open to both out-patients and in-patients. People who might benefit from meeting other people and engaging in recreational activities are invited. In this sense, the hospice is both a home and a little community for patients.

During the course of my practicum, I had opportunities to undertake clinical practice with in-patients, Day Hospice patients and patients in their own homes. In the in-patient unit, I had a ward-round each day and introduced myself to new patients. I sought their preferences for receiving music therapy. Sometimes the referrals were made by members of the multidisciplinary team. With the in-patients, I did music therapy at the bedside, in the lounge or sometimes outside on a balcony and families were often in attendance. Because the in-patients had a short prognosis of life and were under end-of-life care, I could only undertake

short-term music therapy with them.

At the Day Hospice, I greeted the patients arriving at the hospice each morning, made friendly conversation with them and determined whether they wanted to receive music therapy that day. The music therapy with Day Hospice patients was carried out in an enclosed room nearby, if no particular preference for location was indicated. Over time, some of the Day Hospice patients I worked with were admitted to the in-patient unit for terminal care and music therapy proceeded there. I was able to undertake long-term therapy with some of Day Hospice patients, form a closer relationship with them and visit them even after they died.

The outpatients were referred for music therapy by an occupational therapist, social worker and nurses. Some sessions out in the community were collaboratively done with other team-members and sometimes the team members joined in to experience music therapy with their patients.

As it is delineated above, the patients under hospice care stay at home or in the in-patient units and attend the Day group.

0.2. Research question

How did a music therapy student contribute to patients' quality of life in a hospice and palliative care setting?

My research topic stemmed from reading literature indicating that improving quality of life (QoL) is a fundamental strategic vision in hospice and palliative care. As I worked with patients with terminal illness, I observed their challenges and had an increasing desire to find out how I could help to alleviate distress and support their QoL. Because my research question is closely connected to the strategic vision of hospice and palliative care, investigating how I could contribute to patients' QoL also seemed to be a particularly relevant study to undertake.

0.3. Answering the question

This study investigates the music therapy methods, techniques and approaches that contribute to people's QoL. In the course of reviewing the literature, I found that the definition of QoL is open to some debate, and it tends to be subjective, broad and abstract (Adair, Bélanger & Dion, 1998; Cella, 1994). This means it is difficult to determine what kinds of music therapy approaches contribute to people's QoL. Therefore, a conceptual framework was used to create

a structure for my findings.

The framework used in this research is an approach to quality of life established by music therapist and researcher Even Ruud (1997). I have used his definition of QoL because to the best of my knowledge, he is the only music therapy researcher who has discussed the meaning of QoL in the field of music therapy and therefore, his suggestions seemed to me to be the most relevant to use in the context of music therapy. According to Ruud, quality is identified in four ways:

1. Affective awareness
2. Agency
3. Belonging
4. Meaning and coherence of life

In the literature review for this study, his idea of QoL is further explored. However, in my findings, I have described what affective awareness, agency, belonging and meaning and coherence of life mean specifically in the context of hospice and palliative care.

0.4. Personal inspiration

The research process embeds memories of my patients who spent their invaluable time with me in their final stages of life, and I am very grateful for their teaching and for allowing me to be present at that time in their lives. Therefore, this exegesis contains a few sentences as an introduction before each chapter and within some chapters to show memories I have of patients and to thank them.

0.5. Personal stance of the researcher

I am a 23-year-old woman who was born in Korea and immigrated to New Zealand at the age of 11. I have studied piano since I was 6 and have a Bachelor's degree in music composition. Throughout my life, I have been performing, composing and have had many musical involvements. Before I started my Master's degree in Music Therapy, I learnt to play the harp and it proved to be a very useful instrument in my practice at the hospice.

This year was my first experience of working in end-of-life care. Initially, I faced many challenges because it was not easy to deal with death as a regular occurrence in my work. I also

experienced a lot of sadness and a sense of emptiness when patients I had worked closely with died. However, all the staff, supervisors and my clinical liaison were very supportive and helped me a lot in my struggle to deal with this aspect of my work. As I gained more experience, I came to terms with death, grew to understand the nature of hospice care and had a growing appreciation of the work I did. I also believe the emotional struggle I had was not harmful because it helped me understand the feelings other patients might have had about death. Because of my own struggle, I could empathise with my patients more appropriately.

I acknowledge that I have empathy and feel a strong connection to Asians due to my own cultural identity. Therefore, in my practice, I have worked with a lot of Asians and people who were new to New Zealand. This could have given an extra focus on the cultural aspects of working with patients at the hospice.

I also have a strong Christian faith. I recognise my own risk of over-emphasising findings that are important to me in terms of my own religion and being less perceptive about other aspects of spirituality. In the process of analysis, I have tried to be open-minded about the concept of spirituality and tried to put less emphasis on religion in the light of my own tendency to over-emphasise it. I have tried to balance my thoughts but my background may have impaired my ability to have a 'real' and 'authentic' view of the data about spirituality.

0.6. Format of the exegesis

Following this introduction, the literature review provides an overview of readings relating to QoL and music therapy in hospice and palliative care, to give a background of previous research in relation to my research question. The methodology section presents the theoretical and conceptual frameworks used in this study, as well as the methods of data collection and analysis. The ethical issues involved in this study are also included. The findings are described using the framework of Ruud (1997) and the clinical vignette provides deeper insight into the use of music therapy and how relationships can contribute to QoL. In the discussion, the findings are further explained in relation to other research and I then present the overarching points, the limitations of this study, and recommendations for further research.

(After playing the guitar)

“We have railways on our fingers now!”

“You shouldn’t show your fingers to your future boyfriend Angela hahaha”

“No boys will like your fingers!” (Jokingly said)

“That’s okay. I will only show him my right hand!”

Literature review

1. Quality of life in palliative and hospice care

Improving QoL or quality of time is an integral part of hospice palliative care (Kaasa & Loge, 2003; Wittenberg-Lyles et al., 2010; Keall et al., 2015). A review of the literature provides no single definition of QoL; it is defined in a flexible manner by different people, from different perspectives and in different professions (Adair, Bélanger & Dion, 1998). To give examples, people involved in medical fields regard physical and psychological wellbeing as essential to good QoL, whereas those working in the field of sociology view cognitive and mental wellbeing as vital components of good QoL (Kaasa & Loge, 2003). Individuals have also voiced their own definitions of QoL. A Norwegian psychologist, Siri Næss suggests that QoL involves being able to engage in activities and having good personal relationships, self-confidence and a basic sense of happiness (as cited in Nordenfelt, 1991b, translated in Ruud, 1997). A nursing researcher, Tone Rustøen's (1991) view of QoL is having hope, meaning, community and identity (as cited in Ruud, 1997). Ferrans (1990) developed a commonly applied definition of QoL involving five different categories, which are: the capacity of having a normal life; happiness or satisfaction; achievement of personal goals; social utility; and natural existence. As Fowlie & Berkeley (1987) described, the meaning of QoL is “dependent on the user of the term” (p. 226).

The difficulty of defining and measuring QoL also ties into an idea raised by Nordenfelt (1991). His philosophy is that QoL is not “a set of objective criteria which must be fulfilled in order to obtain a certain level of quality of life” but a “subjective state of meaning, wellbeing or happiness” (as cited in Ruud, 1997). He has provided another lens for examining QoL, because he suggests that everybody has their own idea of what contributes to QoL and having ticks in the domains of physical, psychological, mental, cognitive, social and spiritual wellbeing does not necessarily suggest one's QoL is good. The term QoL is very blurry (Adair, Bélanger & Dion, 1998). Therefore, it is essential to know that the meaning of QoL is “dependent on the user of the term” (p. 226) and that it is both “multidimensional” and “subjective” (Cella, 1994). It is debatable how people's QoL can be measured and what it really is (Adair, Bélanger & Dion, 1998; Kaasa & Loge, 2003; Ruud, 1997; Cella, 1994; Ferrans, 1990).

The priorities in improving QoL for people in palliative and hospice care are specific and

important to consider. Steinhäuser et al., (2000) investigated the factors important at the end of life by surveying 340 seriously ill patients, 332 recently bereaved family members and 361 physicians and other care providers. The patients indicated that being mentally aware, arranging their funeral, feeling life completion, not being a burden to family/society, helping others and maintaining a relationship with God were important aspects of life. Other important attributes that were mentioned by all participants were symptom and pain management, remembering life accomplishments, having preferences for treatment, being treated as a “whole person,” and building trust with staff. It was found that what patients prioritised was different to what physicians prioritised.

1.1. A qualitative framework for reviewing quality of life in music therapy

Hilliard (2003) notes that music therapists have strong ongoing interest in assisting with QoL in palliative care. One article has provided a definition of QoL in the context of music therapy (Ruud, 1997), in terms of the following factors:

Affective awareness involves the ability to express and experience emotions and music therapy promotes this by stimulating feelings.

Agency means having control and awareness and being able to take responsibility for our own life and actions. Music-making offers choices of listening, playing and performing and by participating in one way or another, patients can make decisions, take part in actions and be responsible for their lives. As a result, the patient is rewarded with feelings of achievement, competence, empowerment and/or mastery.

The third concept, *belonging*, refers to the ability to form social networks; music can facilitate this through group music interventions where people are able to form relationships with others. *Belonging* also has connotations of feeling at home.

The last component is *meaning and coherence*. This concept entails finding meaning, purpose and wholeness of life. Music promotes these by eliciting memories or by establishing meaningful memories in the moment, ultimately helping people find meaning in their life and come to terms with life as they are experiencing it now.

2. Quality of life in music therapy in palliative/hospice and cancer care

While the primary interest of this study is in hospice and palliative care, there are notable connections with the broader field of cancer care as these have some strong overlaps in terms of the approach of the music therapist (Stanczyk, 2011). A 2015 Cochrane review that revisited 30 RCTs, involving quasi-RCTs, including 1891 participants in total, showed the positive effect of music interventions on cancer patients' QoL (Bradt, Dileo, Grocke & Magill, 2011).

Some key issues figuring in music therapy's contribution to QoL in palliative care are raised. Music therapy is beneficial for generating "immediate" therapeutic effect (Hanser et al., 2006; Krout, 2001; O'Callaghan, 2001). Because patients with terminal illness have limited lifespans, making a "timely difference" is extremely important (Krout, 2001, p. 388). Also, patients in palliative care need "things to be good now." Thus, positive effects from music provide "good quality moments" (O'Callaghan, 2001). Another reason why music therapy is beneficial for patients at the end of life is that therapeutic outcomes occur without demanding active participation or conversation from patients (Nakayama, Kiruta & Takeda, 2009; Gutsell et al., 2013).

2.1. Experimental studies on QoL in music therapy with hospice/palliative care patients and cancer patients

A randomized controlled trial (RCT) investigated the effect of music therapy specifically on QoL of hospice/palliative care patients (Hilliard, 2003). The study design balanced age and gender, recruiting 80 patients in each experimental and control group. The patients had been diagnosed as having less than 6 months to live. The experimental group received at least 2 music therapy sessions and the control group received routine hospice care.

This study used the Hospice Quality of Life Index-Revised (HQLI-R) self-report questionnaire (McMillan & Mahon, 1994; McMillan & Weitzner, 1998) to measure patients' QoL. The results of Hilliard's (2003) study showed that the experimental group had significantly higher QoL than the control group. Moreover, their QoL increased over time, even as they physically deteriorated. In particular, music therapy produced a significantly increased QoL on the psychophysiological level. This explains the effectiveness of music therapy on worry, anxiety, loneliness, anger, pain, nausea, and breathlessness. In contrast, QoL in the control group reduced over time as their health deteriorated.

A study by Wei (2014) showed improved QoL in cancer patients who participated in music therapy. The study used the Quality of Life Questionnaire-Core 30 (QLQ-C30) scale, designed for cancer patients (Fayer et al., 2001) to measure outcomes in 38 patients receiving music therapy. The scale addressed 1. Role function; 2. Cognitive function; 3. Emotional function; 4. Social function; 5. Fatigue, pain, nausea, vomiting; 6. Overall health subscale; 7. Single measurements: breathing, insomnia, appetite, constipation, diarrhea, financial difficulties. The music used was a “symptomatic soundtrack” (Wei, 2014, p. 2997) which incorporated songs associated with culture, interests and appreciation. The music intervention improved the quality of sleep and QoL although the results were not statistically significant. In a longitudinal RCT study that investigated the QoL of 80 women with breast cancer (Hanser et al, 2006), the QoL in the experimental group improved but again did not reach statistical significance. The statistical differences observed between cancer patients and hospice/palliative care might be due to differences in the stage of health (Hilliard, 2003; Wei, 2014) and the fact that the cancer patients in the studies had longer life expectancies (Hanser et al., 2006). This suggests that music may have more significance for people who are facing imminent death.

A review of 27 articles about music therapy and cancer patients indicated that music therapy can alleviate physical, emotional and social problems faced by cancer patients and promote “effective programs of rehabilitation to promote wellness, improve physical and emotional well-being and the quality of life” (Stanczyk, 2011).

2.2. Challenges in measuring QoL

QoL measurement tools have been established to address “multidimensional health-oriented concepts” (Kaasa & Loge, 2003). In one music therapy study that specifically measured patients’ QoL, the Hospice Quality of Life Index-Revised (HQLI-R) self-report scale was used (Hilliard, 2003). This scale has the following facets:

- a) *Functional*: daily activities, social life, ability to concentrate, ability to enjoy activities
- b) *Psychophysiological*: aspects relating to anger, pain, nausea, sex life, worry, anxiety
- c) *Social/spiritual*: meaning in life, physical contact, family support, relationship with God

However, self-report scales have challenges because patients are potentially stressed and often

cognitively affected due to medication and the progression of their disease. Therefore, self-reports may arise from impaired perceptions of self (Kaasa & Loge, 2003). Moreover, the fluctuating biological processes that patients undergo impede the reliability of reported physical functioning rates (Kaasa & Loge, 2003). Another challenge to the use of the scales is that the spiritual aspects included in the scale insufficiently indicate the spiritual needs that music therapists address (Hilliard, 2003).

As Lipe (1991) explained, defining or implementing music therapy with patients who have health impairments becomes difficult due to lack of communication and the fact that different people have different needs. Therefore, the importance of redefining “quality of life” and unifying different ideas into one definition of QoL, specific to context, has been raised (Lipe, 1991, p. 102).

There has been much qualitative research on the use of music therapy with patients in hospice and palliative care and more quantitative studies are called for because such findings have more reliable generalisability (Hilliard, 2005b) However, qualitative studies are advocated in the context of music therapy because the meaning of music can be only found in qualitative perspectives with dying people (Krout, 2003; Magill, 2009).

3. Music therapy approaches and methods in hospice/palliative care

Music therapy techniques used in palliative care can be largely divided into 4 categories; “receptive, creative, recreative and combined” (Clements-Cortés, 2015).

Receptive	Creative	Recreative	Combined
Music listening	Songwriting	Instrumental playing	Music and movement
Song choice	Instrumental-	Singing pre-composed-	Music and other arts-
Lyric analysis	improvisation	songs	experiences
Entrainment	Vocal improvisation	Conducting music	Musical life review
Music and imagery	Toning		Musical autobiography
	Song dedications		
	Music/song legacies		

Receptive music therapy is especially common in end-of-life care because patients often becomes too unwell to be active participants (Gutgsell, 2013; Clements-Cortés, 2015; Leow,

Drury & Poon, 2010; Krout, 2003). However, the effectiveness of music therapy is not affected because music therapy recipients can benefit from music therapy at “any level of participation” and no prior knowledge of music is required (Pawuk & Schumacher, 2010; Gutgsell et al., 2013; Nakayama, Kikuta & Takeda, 2009).

O’Callaghan (1996a) studied songwriting in palliative care. Songwriting involves choosing topics, brainstorming and grouping ideas, choosing keys, rhythms, preferred moods, melodies, accompaniments, titles and recording the final product. This enables patients to express emotions and articulate thoughts (O’Callaghan, 1996a; Whittall, 1991). Additionally, the recording can be a transitional object for family or loved ones, or a musical gift (Whittall, 1991; Magill, 2009). O’Callghan (1996a) found that 39 patients in palliative care expressed self-reflections that included compliments, memories, and reflections about significant others (including pets), opinions about adversity, imagery and prayers in 64 songs analysed.

A further study by O’Callaghan (2008) found that lullaby and lament music had comforting qualities for patients. The researcher introduced the term “lullament” because qualities such as love, care, hope, and sleep expressed in *lullabies* and qualities such as crying, loss, grief and sadness evident in *lament* songs validate the patients’ sadness as well as happiness, a sense of attachment as well as detachment, and give nurturance as well as support to their anticipatory grief. These two contrasting colours of music are important in supporting “seemingly paradoxical phenomena” prominent in the lives of palliative care patients. The “lullament” effect can be conveyed through *improvisation*, *songwriting* and *listening*. Typical songs of the “lullament” genre are *Rock a Bye Baby* and *Swing Low Sweet Chariot*.

Life review is seen as one of the important interventions for hospice palliative care patients (Wlodarczyk, 2009). In music therapy intervention, a musical life review involves reflecting on memories of the past and this is especially beneficial in helping patients deal with spiritual and existential issues (Keall et al., 2015; Sato, 2011; Wlodarczyk, 2009). This intervention is different from reminiscence because life review involves an ‘evaluation’ process that enables patients to work through and resolve internal/emotional issues (Keall et al., 2015; Sato, 2011). On the other hand, reminiscence is defined as a simpler process that recalls meaningful memories of the past to give powerful and pleasurable experiences to patients (Keall et al., 2015; Sato, 2011; Wlodarczyk, 2009). Because life review takes “reminiscence to a deeper

level,” patients may be more inclined to reach resolution of conflicts and a sense of completion of life (Keall et al., 2015, p. 748).

3.1. Music therapy goals and specific methods

Music therapy methods are used in hospice palliative care to meet 1) *physiological goals*: improving symptom management, encouraging physical activation; 2) *psychologic goals*: encouraging emotional expression, decreasing anxiety, isolation and depression, normalizing life, reinforcing identity and supporting issues regarding death and dying; 3) *social goals*: supporting communication, and a sense of belonging; 4) *cognitive goals*: providing multi-sensory stimulation, increasing alertness, improving coping strategies, enhancing the effectiveness of other treatments; 5) *spiritual goals*: supporting internal issues, spiritual exploration and validation and giving hope; 6) *goals for families or caregivers*: providing coping skills, communication and bereavement support (Pawuk & Schumacher, 2010; Munro & Mount, 1978; Hilliard, 2003; 2005a; Krout, 2001). The goals are oriented according to the needs, desire, strengths, capabilities and areas of musical stimulation of patients (Hilliard, 2003).

One music therapy method can address different goals simultaneously. Songwriting can prepare for one’s funeral and can also be a medium for emotional expression (Pawuk & Schumacher, 2010; Hogan, 2003). Relaxation can give spiritual help by bringing people to a new awareness (O’Callaghan & McDermott, 2004) and perception of symptoms and agitation can also decrease (Gutgsell, 2003; Pawuk & Schumancher, 2010). Patients’ choice of songs not only uplifts their mood but facilitates emotional expression and can lead them to a realm of peacefulness (Hilliard, 2001). With the same principle applied, different music therapy methods can be used to address a single goal (Gallagher et al., 2006).

Goals	Goal-directed interventions
Promote positive behavioural activation by engagement with music Elicit memories and sharing the memories Discussing meanings of songs or general discussion of thoughts Participating in breathing, muscle relaxation / imagery Making personalized music and preparing for funeral	Providing live music / instrumental playing Musical life review / Song choices Verbal processing / Lyric analysis Music-assisted relaxation / Entrainment Compiling CD / choosing songs or song-writing

Specific methods are found to have specific benefits. In live music playing, an intimacy

between patients and music therapists can be created. Also, playing live music allows the practitioner to make changes in musical elements such as tempo, rhythm and dynamics to meet patients' needs (Hilliard, 2005a; Gallagher et al., 2006). Song choices can empower patients through decision making, and respecting their choices. They also guides patients' inner thoughts that are reflected in their choice of music (Magill, 2009). Therefore, singing songs of their choice is a way for patients to express and have their feelings validated (Hilliard, 2005a). Musical reminiscence, life-review and asking open-ended questions offer patients "a moment to reflect upon significant events in their lives and also validates the meaningfulness of their life experiences" (Hilliard, 2005a, p. 49) or "restore connections" to past times (Magill, 2009). Imagery in music involves incorporating words in improvised music that gives comfort to patients (Hilliard, 2005a). This is different from imaging to music which involves picturing images in the mind without any verbal input. Imaging to music also has the effect of creating transcendence (Aldridge, 1995; Lipe, 2002). Often, imagery happens without effort from the patient during soothing, meditation-like music (Maroon, 2004). Family-centered music therapy helps patients create meaningful moments where families can communicate their love via songs and play instruments together to strengthen family bonds (Krout, 2003; Hilliard, 2005a). Therapists can offer relatively easy-to-play instruments such as an omnichord or autoharp to distract patients from pains and increase their feelings of self-worth (Hilliard, 2005a). In lyric analysis, patients can express their feelings with their song choices in the third person (Hilliard, 2005a). Music parody involves personalizing lyric to a pre-composed song for emotional expression (Hilliard, 2005a). Other involvements of music therapists include participating in special occasions such as birthday parties or weddings with music, planning for funerals, and participating at funerals by providing music (Hilliard, 2005a).

3.2. Possible benefits of the literature review

The studies cited provided limited explanations about how and why certain interventions were used. In music therapy, the protocols music practitioners use are based on evidence from literature, training/experience, patients' needs and preferences (Stanczyk, 2011; AMTA, 2010) and therapists' assessments (Stanczyk, 2011). Although knowledge continues to develop about what interventions to use to address specific goals (Gallagher et al., 2006; AMTA, 2010), the music interventions outlined in this review of the literature suggest possible ways of using music to address different goals.

4. Different aspects of health addressed by music therapy in hospice/palliative care

Patients in hospice/palliative care can experience “total pain” (Saunders, 1967; Tassinari & Maltoni, 2009). This means they can experience complex and multiple problems or pain arising from the physical, psychological, financial and spiritual domains (Hilliard, 2003). Despite the fact that hospice and palliative care aims to provide “total care” (Tassinari & Maltoni, 2009) with holistic approaches, patients indicated their unmet needs in terms of emotional, psychological (Rainbird et al., 2009), psychosocial and spiritual needs, isolation, communication with staff, loss of autonomy, control and activities, in addition to pain and symptom management (Ventura et al., 2014; Davies, 2004).

Music therapy can be beneficial because it addresses multidimensional aspects of health and treats the “whole person” (Hilliard, 2003; Clark, 2014) as well as focusing on areas that other professionals do not address (Hilliard, 2004). The literature reviewed indicates what aspects of health music addresses, which may be improved with music therapy. This includes the effect of music on physical, emotional, social, spiritual, cognitive and psychophysiological wellness.

4.1. Pain and symptom management

The associations between neurology, biology and music are being investigated to create a deeper understanding of how music serves as medicine. According to Lane (1992, 1993) music helps pain because musical vibrations change emotional responses to pain by producing decreased muscle tone, blood pressure, respiratory rate and pulse rate (as cited in Halstead & Roscoe, 2002), generating increased levels of dopamine (Zatorre & Salimpoor, 2013), causing distraction (O’Callaghan, 1996b) and changing brain waves and affecting gastric movement in nausea (Halstead & Roscoe, 2002).

A 2011 Cochrane review of music therapy at the end of life shows music interventions have moderate pain-reducing effects. Gutschell (2013) found that therapist-guided autogenic relaxation and live music significantly decreased pain levels. The music therapist verbally led muscle relaxation and breathing exercises and asked patients to imagine a safe place in order to help patients use all five senses. Instruments such as drum and harp were used, and music was improvised in the Mixolydian mode. “Light classical” music that patients were unfamiliar with or other pieces that patients described to be relaxing were played. The reason for using unfamiliar music was not specified. However, it has been suggested that unfamiliar music is

ideal for relaxation as it avoids triggering memories and senses (Hollis, 2010).

The iso-principle is defined as matching patients' breathing or mood to lead them in a desired direction. Thus, live music has been found to be effective in reducing pain when compared with pre-recorded music (Lee, 2005). Other factors such as reduction in isolation due to the therapist's presence, the energizing effect of music, and the comforting quality of voice, facial expressions and body language all contribute to changing patients' moods, and their perception of pain (Lee, 2005). This concurs with the finding that pain and symptoms can be alleviated with "emotional, cognitive and interpersonal responsiveness to music" (AMTA, 2015).

With music therapy, patients have been found to experience improvements in areas such as pain, shortness of breath and body movement (Gallagher et al., 2006), agitation (Hilliard, 2001) and relaxation (Krout, 2001; Gallagher et al., 2006). However, music was not favoured as a primary source of pain and symptom relief for some patients (Leow, Drury and Poon, 2010).

4.2. Psychosocial and emotional needs

Patients in end-of-life care have many emotional issues, such as anger, fear, sadness, depression, denial, hopelessness, anticipatory grief and spiritual concerns (Black, 2012; Hilliard, 2005a). Music therapy alleviates these emotional problems, helping with patients' mood, emotions and spiritual needs.

In a quantitative study by Nakayama, Kiruta & Takeda (2009), conducted in Japan, songs requested by patients and songs of their era were played to investigate the effect of music therapy on s-cortisol levels/stress levels and mood in 10 hospice patients. Music therapy decreased s-cortisol levels/stress, anxiety and depression, and increased feelings of refreshment and excitement.

An empirical data that reviewed 11 music therapy studies in palliative or hospice care from 1986 to 2005 demonstrated that music therapy could have positive effects on levels of pain, physical comfort, fatigue, energy, anxiety, relaxation, mood, spirituality and QoL (Hilliard, 2005b).

Qualitative studies have provided deeper insights into the effects of music therapy. In a study on the multidisciplinary perspectives of music therapy (O'Kelly & Koffman, 2007), it was found that music therapy helped patients in the emotional, physical, social, environment,

spiritual and creative domains. Emotionally, music helped people with expression and awareness and facilitated emotional catharsis. Physically, music therapists working collaboratively with physiotherapists improved patients' movements, making them more organised. Socially, music brought groups and families together. Environmentally, music uplifted or relaxed mood. Spiritually, music had a transcending effect. Lastly, creativity in music had synergistic effects because "creative experiences in music therapy were considered as 'satisfying and fulfilling', 'exciting', 'transformative' and 'confidence building'. These experiences were also considered as successful in providing motivation to pursue other creative activities, and were capable of enhancing the effectiveness of other treatments" (O'Kelly & Koffman, 2007).

However, according to O'Callaghan (2001), emotional help may elicit both positive and negative emotions, not necessarily desirable memories. Physically, patients could sometimes better endure treatments with the altered sensory and somatic experiences achieved through music. Socially, patients' social positions embedded in memories could be reaffirmed. Spiritually, patients may gain new awareness with an altered sense of reality through imagery in response to music. It is, however, important to note that music is not a helpful agent for some patients.

In a study by Leow, Drury and Poon (2010), five hospice patients' experiences of music therapy were investigated using face-to-face interviews. Firstly, music mirrored inner feelings, including improved mood, happiness, and distraction from adversity. Secondly, music served as a bridge or connection. Patients connected to themselves, the past, music, and comfort. Thirdly, music was a therapeutic medium. Patients felt enjoyment and comfort, and were happy to have had the music therapist as a companion. Lastly, barriers to music were identified. As patients' health deteriorated, music no longer seemed important and playing instruments could be disappointing. Sometimes, listening to music was hard but in those times, patients felt holding an instrument could give comfort. Some patients were afraid of playing instruments incorrectly.

The meaning of music to patients in pre-loss sessions was sought from caregivers (Magill, 2009). It was found that music gave peace and joy from past memories, inspired feelings of love and affection, and that live music touched patients deeply, and soothed and touched

distressed hearts.

4.3. Spirituality

People at the end of life have questions related to existential issues such as “what is the meaning of life?” (Aldridge, 1995). Spirituality is an umbrella term that encompasses purpose, meaning, hope, creativity, identity, transcendence, God and personal relationships (Wlodarczyk, 2007; Aldridge, 1995; Lipe, 2002). Spirituality also stands for “heightened emotions” (Marom, 2004). It is an essential part of human life (Hepburn & Krout, 2004), strongly related to health, and good QoL (Wlodarczyk, 2007).

Spiritual wellbeing can be supported with music (Aldridge, 1995; Lipe, 2002; O’Callaghan & McDermott, 2004; O’Callaghan, 2014). When patients engage in musical experiences, their selves are reawakened in realizing another musical purpose and by gaining new perspectives in “doing” music (Aldridge, 1995). This is a way in which patients’ normal ways of thinking, being and experiencing are challenged. This means they transcend or move out from their original way of living, imagining, and experiencing, stepping into previously unknown awareness (Lipe, 2002; O’Callaghan & McDermott, 2004).

When patients transcend the moment, they are transported “beyond ordinary awareness” (Salmon, 2001) to a place where a richer sense of self can be experienced in “meaning, relatedness, humour, nourishment, acceptance, love, faith, beauty, hope, understanding, creativity and awareness” (p. 145). Often in this process, patients express deep sorrow and grief, achieve peace, find resolution of problems and find a meaning and purpose in life in their deeper exploration of self and self-realisation (2001).

Transcendence is a way of reaching out for new awareness and it is a way of achieving hope, a vital component of a good QoL (Aldridge, 1995). Spiritual exploration is particularly important for people at the end of life because that new sense of consciousness maintains a sense of wellbeing which otherwise may be compromised by physical and psychosocial matters (Aldridge, 1995).

4.3.1. Research on spirituality

Renz et al., (2015), used meditation music, imaging to music, relaxation, prayer and had conversations about dreams or existential experiences to investigate spiritual experiences of

transcendence in 251 patients with advanced cancer. The patients experienced God or a spirit and in the spiritual experience, they reported feeling an altered awareness of body, reduction in pain and anxiety, increased acceptance of death and illness, and gained new spiritual identity. Spiritual or heightened emotional experiences included a sense of freedom, peace, warmth, protection and hope. The same outcomes were found in patients with diverse religious affiliations and in atheists.

Wlodarczyk (2007), investigated the effect of music therapy on spirituality of patients in hospice as measured by self-report. In the study, the researcher used approaches including choosing songs, singing, improvisation, songwriting, life review, music for prayer or worship, and making “gift songs.” The goals were to facilitate relaxation and communication, alleviate mood, decrease isolation and pain, give spiritual support, solve emotional issues and increase QoL. The study was done in ABAB structure in which the patients received 30 minutes of music therapy, followed by 30 minutes of non-music visits. The design was counterbalanced with a BABA structure for 5 patients. The results indicated that more discussions about spiritual issues were stimulated by music therapy, and patients’ spiritual wellbeing scores significantly increased on music days.

A mixed-method RCT study investigated the effect of music therapy on spirituality in 17 cancer patients (Cook & Silverman, 2013). The music therapist sang patients’ preferred music or suggested relevant songs with guitar accompaniment and measured improvements in finding meaning, peace and faith. Quantitatively, peace and faith scores were significantly higher in the music therapy group than in the control group. The score for meaning did not reach significance. Qualitatively, patients reported feeling closer to God and having their mood lifted.

In a case study by Hilliard (2001), a 35-year-old woman was anxious, frantic and worried about how her dying process would take place, whether she would be in pain, and where she would go after death. The music therapist aimed to reduce anxiety and validate her thoughts. Lyric analysis was done on the song *Blowin’ in the Wind* (Dylan, 1963). The lyrics “the answer my friend is blowin’ in the wind” clarified that the answers she desired are beyond human knowledge. The song also communicated she was not the only one who did not know the answer; the composer did not know it either. The song helped the patient come to terms with her questions about death and it comforted her. The song helped her not just emotionally but

spiritually by providing comfort with respect to existential pain and unresolved questions about life.

Although research has shown improvements in aspects of spirituality as a result of music therapy, it has been observed that “potential mechanisms of change are difficult to conjecture” and one reason for this is that all patients have different needs (Wlodarczyk, 2007). Music therapy helps patients in many different ways, depending on the nature of the individuals involved (Cook & Silverman, 2013).

4.4. Collaborative work

Nowadays, collaborative working models such as interdisciplinary or multidisciplinary approaches are growing (Renick, 2012). Music therapists therefore tend to work within multidisciplinary or interdisciplinary teams to provide alternative or complementary therapy in hospices (Hilliard, 2003; Demmer, 2004; Hilliard 2004; Mansky & Wallerstedt, 2006). Music therapists address the same physiological goals as medical practitioners to reduce symptoms such as pain or nausea, work with counsellors and social workers to support family and counselling sessions, or with chaplains to facilitate spiritual wellness (Hilliard, 2003; Krout, 2004). Further collaborative work is done with home health aides, massage therapists for relaxation, art therapists for creative experiences and bereavement coordinators for memorial services (Krout, 2004). Studies have revealed that within the alternative and complementary treatments provided in hospice, music therapy is the most popular with patients (Demmer, 2014)

Collaborative work is effective because music therapy addresses multidimensional needs in patients (Hilliard, 2003; 2001; Hilliard, 2014; Hogan, 2003). Bruscia (1998) noted that music therapy is “transdisciplinary in nature” which means “music therapy is not a single, isolated discipline with clearly defined and unchanging boundaries. Rather it is a dynamic combination of many disciplines” (p. 6). This statement supports the concept that music therapy addresses multidisciplinary goals and caters for patients’ multidimensional needs (O’Kelly & Koffman, 2007; Hilliard, 2003; Clark, 2014).

Studies have found that music not only addresses multidisciplinary goals but also provides motivation and increases the efficacy of other treatments that patients receive (O’Kelly & Koffman, 2007). Some patients have indicated that music gives “confidence and tools” in dark times and makes suffering “manageable” (O’Callaghan et al., 2014, p. 1042). This supports the

idea that music stimulates internal resources that provide coping mechanisms, treatment compliance and motivation, without necessarily receiving external support to manage health-related difficulties (Wei, 2014; MacDonald, Kreutz & Mitchell, 2012; O’Kelly & Koffman, 2007).

4.5. Music therapy with families

“The work of hospice is best realized when we allow families to come together and share meaningful moments during the end-of-life transition” (Krout, 2003).

In Krout’s (2003) study, the therapist used songs that had meaning for families. The songs sung included music that patients enjoyed, songs from patients’ favorite genres, and significant songs for families. Sometimes the therapist followed families’ leads, used silence appropriately, and repeated meaningful lyrics. During singing, family members came together, sang together, compassionately touched the patient, attentively looked at the loved one and whispered to “let go.” The music provided comfort to the family and on a “psychosocial and spiritual level.” In patients’ last hours, music therapy facilitated communication, family connection, reminiscence of special moments, and enabled “meaningful release” to happen.

Another study also showed that music therapy facilitated families’ caring behaviours (Savage & Taylor, 2013). The music therapist sang the family’s choice of songs, well-known songs, light classical pieces or improvised music with voice and guitar, responding to cues, responses, and memories elicited by the family. The music was gentle, simple and the therapist allowed silence to enter for “moments of silent reflection” (p. 90) and to give comfort (Savage & Taylor, 2013; Krout, 2003). The pre- and post-test design revealed the creation of a musical milieu enabled families to openly express their emotions through caring behaviours. The behaviours noticed were attentive looking, crying, moving closer to the patient, smiling, compassionate touching, verbally expressing love, singing for the patient, kissing, massaging and sleeping close to the patient. The songs sung in family-centered music therapy facilitated intimate connection because songs seemed to be “personally meaningful” for families (Savage & Taylor, 2013).

Connectedness and intimacy in relationships is facilitated in music therapy (Savage and Taylor, 2013; Krout, 2003). This makes “relationship completion”, “healing”, and “improved appreciation for the value of one another’s lives” between families and loved ones easier (Dileo

& Parker, 2005). Compassionate gestures and emotional connection are important for dying people because it is a meaningful therapy for them that medical interventions do not address (Anstey, 1991; Morris et al., 1986).

4.6. Music therapy supporting the dying process

According to Hogan (2003), people go through four different stages of death: vulnerability, stabilization, intensive physiological pain and unresponsiveness.

Music therapy helps people when they are vulnerable. Song choice and composing songs helps people to express their feelings (Magill, 2009; Hogan, 2003; Hilliard, 2005a). A case study showed that a patient wrote and recorded a song about the “good old days” to express love and gratitude to his brother (Hogan, 2003).

Music therapy helped patients to stabilise using musical life review. By recalling past experiences, identity is restored and the coherence of life can be seen (Aldridge, 1995; Hogan, 2003). Important moments can be re-experienced through reminiscence. Listening to music that recalls the past facilitates the experience and it further has the effect of reducing anxiety, the need for medication, and helps patients sleep better (Hogan, 2003).

In stages 3 and 4, playing familiar music is recommended as recognition of music can give comfort, mental lucidity and identity (Aasgaard, 2001; Hogan, 2003). Music also can help physiologically with the use of the Iso-principle/entrainment which brings down respiratory rate and reduces anxiety (Lee, 2005). Further relaxation can be induced by playing predictable chords, lowering pitch and humming, which gives a sense of “warmth, security, and structure” (Hogan, 2003). Some case studies have shown that soothing music gradually slowed down the speed of breathing and reduced agitation, breathlessness and restlessness in a dying patient (Hogan, 2003; Hilliard, 2001).

4.7. Personalising music to connect with a patient’s essence

Aasgaard (2001) documented the emergence of love, friendship and normalcy in patients’ end-of-life experiences with music therapy. These arose from family-based music therapy, building relationships with patients, and identifying the strengths of patients to maintain a healthy ‘artistic side’ in them. As Magill (2009) noted, music therapy highlights personal traits, personalities and a sense of self, which may be subdued due to illness.

In one case study, the researcher (Aasgaard, 2001, p. 180) sings a song to a dying boy. The boy who was lying in bed becomes more playful and looks for his blanket which was needed for the musical play. After the research describes the case, he ends with these words:

“I cover Peter’s head halfway with his sheet, sing the song with a brittle lyre accompaniment, and remove the sheet most carefully at the end. Peter smiles for a second, but shortly after he closes his eyes again. He dies the next morning.”

In this example, the explanation of the case itself explains the therapeutic moment. As reported by Krout (2003), there is a difficulty in quantifying data from studies done in music sessions with hospice/palliative care patients. This is because insight into the deep meaning of music sessions with patients is only possible in the descriptions or stories of music therapy.

5. Summary of literature review

Quality of life is an umbrella term, defined differently from different perspectives. In research studies, different QoL scales have been used to assess patients’ QoL and there are some challenges in using these tools in hospice/palliative care. Nonetheless, the use of tools has revealed that music therapy increases QoL in hospice/palliative care patients, and cancer patients. In music therapy with people at the end of life, music therapists use a wide range of methods and techniques. However, explanations of why and how these are used are sparse.

In terms of health and music therapy, I have looked at what aspects of health music therapy addresses. These include studies that have examined the emotional, physical, social, cognitive, spiritual and psychophysiological domains of health. Pain issues received a particular focus and spiritual issues and family times are especially important at the end of life. Therefore, music relating to spiritual issues and family times were also reviewed, in addition to how music assists the dying process at the very end-stage of life.

“It was nice to hear you sing...”

Methodology

Introduction to qualitative research

The purpose of qualitative research is to develop knowledge, understanding and explanations in a specific social context as a means of improving social phenomena (Guba & Lincoln, 1994; Flinders & Mills, 1993). I worked both as a student researcher and a student music therapist, reviewing practice with patients in hospice/palliative care. Hence, the data was generated from genuine interactions in a social context (Richards, 2015) and the “meanings” developed from the data (Willig, 2013; Wheeler & Kenny, 2005) were evaluated in relation to my engagement and experience with the patients. This project therefore was a practice-based inquiry involving a process described as ‘clinical data-mining,’ which generates “evidence-informed” findings (Epstein, 2001; 2012; O’Callaghan & Barry, 2009). As Master of Music Therapy students are encouraged to develop non-intrusive approaches, I have used clinical records gathered routinely to answer aspects of my research question. This allowed me to deepen my understanding of my work and proceed with research that was low in ethical risk.

6.1. Secondary analysis of data

Secondary analysis of data was used to determine what techniques, strategies and approaches seemed to help patients’ QoL. In secondary analysis, researchers reuse “pre-existing data” to implement new questions and make new findings (Heaton, 2008). The data used in my research was originally gathered for clinical purposes and to provide references for my work. Self-collected data (Heaton, 2008) was re-assessed to generate knowledge embodied in my clinical experiences.

6.2. Constructing a theoretical framework

Qualitative evaluation is “grounded in an interpretivist philosophical inquiry framework” (Flinders & Mills, 1993). Therefore, my research employed this framework to shape my ‘philosophical, epistemological, methodological, and analytical approach’ and provide a rationale for the findings (Grant & Osanloo, 2014).

Theoretical framework

A theoretical framework supports “one’s thinking on the problem and analysis of data” (Grant & Osanloo, 2014). This study was grounded in constructivism. The idea of constructivism is

that realities are connected to one's subjective experience of the world and therefore, a phenomenon has multiple layers of meaning (Guba & Lincoln, 1994; Edwards, 1999). Because I was both student practitioner and researcher, the knowledge I generated is obviously context-bound, and can be understood only with reference to the interactions and through the lens of the student researcher. However, the knowledge formulated could potentially add new interpretations on pre-existing knowledge (Guba & Lincoln, 1994).

Conceptual framework

Identifying a conceptual framework provides a "specific direction" to research conducted within a theoretical framework (Grant & Osanloo, 2014). As mentioned on page 7 of this exegesis, Ruud's suggested definition of QoL. This was used as the conceptual framework to structure the way the study was conducted and analysed.

However, an acknowledged limitation is that this framework is not specific to the context of hospice/palliative care.

6.3. Personal reflexivity

I was the student researcher as well as the student music therapist. This means that I took part both in documenting the practice and in analysing the data. I was aware of my inclination to wish to prove that my musical approaches were effective. However, I recognise that QoL is very subjective and I could only determine it from patients' commentaries and observing how they were affected by music therapy. There was a danger of over-interpreting the importance of what I saw. However, in my analysis I have tried to be faithful to what I saw, what I perceived, and what I thought.

Although I have tried my best to look at my data with a "third person" overview, my own subjectivity necessarily permeates the practice and the analysis. I attempted a number of ways of acknowledging this, using a reflective journal as self-inquiry, and using my supervision experience and notes with my music therapy supervisor and clinical liaison adviser to expand and extend my perceptions. However, it must be acknowledged that the data itself was created using my thoughts, interpretations, understanding and involvement in the music therapy provided.

6.4. Data collection

The data was recorded in four ways:

- Clinical notes/ supervision notes
- Reflective journal
- Pre-composed songs
- Songs co-composed with patients

Supervision notes, reflective journals and songs provided further interpretations, analyses and thoughts that extended from the clinical notes. All this material contained information about both musical and personal approaches I made, as well as therapeutic processes that occurred in each session. In other words, supervision notes, journals and songs added another layer of interpretation and helped me analyse each music session from a multi-directional viewpoint by acknowledging ignorant views, biased thoughts and any unfair judgments (Richards, 2005).

6.5. Data gathering

The data covered the period from 2 February, 2015 to 31 August, 2015. I continued to review sessions and reflective materials until I was satisfied that no different ideas were being developed and that *data saturation* had occurred. A total of 194 sessions with 67 different patients who consented to participate in music therapy were reviewed and analysed.

6.6. Data analysis

The data was analysed using thematic analysis. In thematic analysis, reoccurring themes or patterns in data are identified, analysed and reported (Braun & Clark, 2006). The patterns capture details that are highly relevant to the research question and generate meaning from it. The data related to the therapeutic meaning of each music session developed knowledge, understanding and explanations about possible methods, techniques, and approaches that students/music therapists can use as a means of improving their practice in hospice and palliative care settings. Thematic analysis was very fitting in my study because “thematic analysis can be placed within a constructivist paradigm, where ideas, values, or perceptions are assumed to be variously construed by participants, and all viewpoints (including the researcher’s) are acknowledged and included” (Ghetti et al., in press).

The following steps show the processes my research involved, based on guidelines provided by Braun and Clark (2006).

1. Familiarising myself with my data

In this process, I read my clinical notes and reflective journal. Then I electronically recorded my data into a Word document. Typing the notes enabled me read the data again and to become very familiar with it.

2. Generating initial codes

I highlighted points that seemed closely linked with my research questions and formed initial codes. This process involved inductively analysing data whereby I generated idea(s) emerging from the data (Appendix 2). Sometimes, more than one code arose from some highlighted points.

3. Allocating codes under Ruud's (1997) idea of QoL

Because I used Ruud's construct in my research, I deductively analysed the codes and allocated them to his four categories: affective awareness, agency, belonging and meaning and coherence of life (Appendix 3: step 3).

4. Searching for themes

When the codes were categorised, I sought for recurring patterns within each category of Ruud's idea of QoL. In this process, I grouped codes which had similar meanings (Appendix 3: step 4). This process was not clear-cut. Sometimes, I had to form new groups/themes, reallocate codes into different groups/themes and even move codes to a different category of Ruud's ideas.

5. Defining themes

When the codes were coherently grouped together, I defined the theme of the group. I made sure that each theme represented the codes (Appendix 3: step 5).

6. Understanding the themes as a whole

When all the themes were generated, I captured the real "essence" of the grouped codes (Rickson, 2015). In other words, I evaluated what the themes represented and what these

said about the effect of music therapy on the patients' QoL (Appendix 4).

7. Producing a scholarly report

6.7. Ethical issues

As a student music therapist, studying for a Master of Music Therapy degree at the New Zealand School of Music, I abided by the Code of Ethics for the Practice of Music Therapy in New Zealand (Music Therapy New Zealand, 2012) and the Code of Ethical Conduct for research teaching and evaluations involving human participants (Victoria University of Wellington).

I used secondary analysis of practice data, which means that participants did not do anything different from normal music therapy. Therefore, this kind of case study or theoretical research is considered to be lower risk than active research involving participants. Informed consent was sought for developing a clinical vignette of practice as part of the exegesis (Appendix 8). No participant was under pressure to give consent, as any people engaged in music therapy at the hospice could be approached. I also informed participants of the purpose, procedures, risks and benefits of the research and other factors that could influence their decision to participate.

In storing data and publishing the exegesis, pseudonyms were used to protect participants' privacy. The name of the facility was not used to further maintain the anonymity of the patients. However, there still was a chance of participants and the facility being identified. Although I made every effort to protect patient privacy, participants and their families were made aware of the possible risks.

During the course of the clinical practice, I had a consultation with a Maori adviser to ensure that Maori culture was respected and to improve my work with Maori patients.

Permission to carry out the research was obtained from the facility as well as Victoria University Human Ethics Committee (Human Ethics Approval: #22131).

(Angela sings in Samoan)

“Tele i ’a O Le Sami~

Tele fo ’i la ’au o le vao

Tele manu felelei i le lagi

Tele teine a fatasi~

Ai sili ai oe o la ’u pele~

La lalelei o Samoa~”

“Mate ... ma.. what’s the lyric here again please?”

“It’s Mate maia o lau tupua Angela”

“Mate maia loo too a~”

“No. Mate maia o lau tupua Angela”

“Mate maia lapo tua~”

“MATE MAIA O LA’U TUPUA! hahaha”

“Mate maia lopotoa~~~~~”

Findings

Tables 1 to 4 summarise different musical and personal approaches I made in addressing the four important aspects of QoL, which are affective awareness, agency, belonging, and meaning and coherence of life.

Specifically, music stimulated the underpinning facets of the four important aspects of life. The facets of the important aspects of life that make up each theme (affective awareness, agency, belonging and meaning and coherence of life) are represented in sub-themes under each theme. Different music therapy methods, strategies and techniques that I used to improve patients' QoL are described in the findings. The clinical vignette further provides an illustration of how music techniques are used and how the techniques and the relationship I formed with the patient both contributed to the patient's QoL.

Affective awareness

QoL indicator	Methods	Activities	Strategies	Techniques
Music therapy supported patients to become more alert through:	Re-creative Receptive	Playing instruments Listening to live music	Employing specific technology/software and hardware Using familiar music	Providing physical support
Music therapy supported patients to become more aware through:	Receptive Receptive	Listening to improvised live music Listening to improvised live music	Visualisation Creating relaxing music	Slower tempi, gentle strum, use of mode, recurring melodic motifs, glissando, humming
Music therapy supported patients to have emotional changes through:	Receptive Receptive Creative Receptive	Listening to live music Listening to theme-based-improvised live music Collaborative theme-based improvisation Listening to live music	Uplifting music Choosing a theme Choosing a theme Using pt's favorite music	Syncopation, accents, dotted rhythms, thick texture, faster tempi and louder dynamic Creating music that enhances pt's chosen theme Creating music that enhances pt's chosen theme
Music therapy supported patients to emotionally comforted and validated through:	Receptive Creative	Lyric analysis Songwriting Performing the written song	Talking about lyrics Writing lyrics and choosing musical elements Having audiences	Using scores or have lyrics printed out Performing song to close friends

	Receptive	Listening to live music	Emphasising meaningful lyrics	Changing accompaniment, volume, tempo and repeating
	Creative	improvisation	Choosing instrument	Matching dynamics, style, mood, providing pedal note, play in sync, following and leading
	Receptive	Silence		
Music therapy supported patients to become more relaxed through:	Receptive	Listening to live music	Employing stringed-instruments	Stroking and humming in downward gesture
Music therapy supported patients to become more satisfied:	Receptive	Listening to improvised live music	Choosing a theme or musical genre	Creating music that enhances pt's chosen theme or genre
	Creative	Collaborative theme-based improvisation	Choosing a theme	Creating music that enhances pt's chosen theme

Table 1. Summary of findings: affective awareness

Theme 1: Affective awareness

Definition of the theme

In the context of this study, supporting affective awareness encompasses processes that help patients become more alert, and aware of how they feel at this challenging stage in their lives, and how music and relating can provide emotional comfort.

7.1. Increasing alertness

While working with patients who were confused, there were moments that seemed to indicate that they were becoming more alert. Instrumental playing was involved and at the patient's bedside, I used a piano application downloaded on my electronic device and located it where they could comfortably view it. I carefully moved their fingers across the keyboard, helping them tap on the right keys to play the melodies of their favorite songs. The device was a useful tool because it was not heavy to hold, and the screen responded sensitively to even gentle touch, which could be challenging on real instruments. As patients engaged in playing, their eyes widened; they looked attentively at the screen and one patient gave herself a thumbs-up after the music finished. It seemed that the patients were becoming mentally more lucid as a result of the musical stimuli.

There were moments in my work when patients who were normally unresponsive or had low responsivity seemed more aware during music sessions. At their bedsides, I offered music listening by singing recognisable songs such as their favourite songs; those of their era, and from their favourite artists and genres. I used those, thinking that music could evoke memories, images and act as a stimulus for senses or feelings. While I sang, some patients subtly opened their eyes, started blinking slowly, verbalised undistinguishable words, smiled and some started singing along with me.

7.2. Facilitating different awareness

7.2.1. Transcendence

When working with a number of patients, I understood that they had some spiritual experiences in which they felt they transcended their current challenging situations. In *musical visualisation* which involved imaging in response to improvised music, I asked people to create a picture in their mind to music. Some examples included reports of "rivers running through," "Celtic landscape" or hearing "church bells." I also often improvised what I perceived to be *relaxing*

music on the reverie harp. This was usually played slowly with gentle slow stroking in musical modes such as the pentatonic scale, using recurring melodic motifs, glissandi and humming. On a number of occasions, people spontaneously reported sounds of “wind blowing on the cliff” and pictures such as “sun opening up” that occurred to them during and after the music. People seemed emotionally affected by the images they saw and showed excitement at being taken somewhere different in their imaginations.

7.2.2. Facilitating emotional change

Patients became aware of new feelings after they experienced emotional changes following being involved in music. Initially, they reported to feeling bored, depressed, worried, anxious, reserved, apathetic or lethargic. During and after music, people described themselves as feeling “uplifted,” “shiny” and “happy.”

Patients had idiosyncratic perceptions of what uplifting music is. For some patients, playing live music with syncopation, accents, dotted rhythms, a thick texture and singing reasonably loud and fast made them feel more uplifted. They were observed to be moving their feet rapidly, moving their legs up and down, and sometimes made remarks such as “(I) feel like dancing.” However, some other patients showed actions such as lifting their hand up, waving it from side to side, and moving their fingers rapidly to gentle and delicate music I played. Such music was slower, quieter and had a more sparse texture. It seemed that music played with a higher energy level than the patients’ own sometimes had the effect of leading patients’ moods to where the atmosphere of the music pointed.

In *theme-based-improvisation* and *collaborative-theme-based-improvisation*, I improvised or collaboratively improvised music based on the patient’s chosen theme. Asking patients to choose a theme helped them express and receive the kind of feelings they needed, which their theme could inspire. An example of a theme is “pulling down heaven and knocking on heaven’s door.” I played the harp and glockenspiel by incorporating glissandi, staccatos and trills in my music to produce celestial, heavenly and angelic sounds which enhanced the sound of the theme the patient requested. Sometimes patients played collaboratively by choosing an instrument. They reported feeling better, “shiny,” smiled or clapped after responding to the mood and emotion encompassed in the theme.

Playing people’s favourite music, genre, instrument, music from their favorite composer and

music from their own culture, led to patients reporting that they felt “happy,” which might encompass other emotions such as feeling touched, moved, pleased or a sense of bittersweetness. I asked patients or their families for a song that is meaningful and favored by the patients. In knowing patients’ musical taste, I also chose music by their favourite composer and in their favourite style to increase a sense of positivity in the challenging times they were facing. Sometimes after the music, they appeared chirpier, smiled, joked more, and appeared more boisterous.

Some patients were physically unable to verbalise their experience of feelings and could not explicitly express the emotions they were experiencing. Moreover, sometimes patients seemed to experience emotions that were difficult to put into words. These undefinable emotions include feeling “mixed emotions.” Other expressions of their feelings included: “music touches deep in my heart;” “I get lost in the music;” “music takes a life of its own” and “music is taking me to a lala land.” These descriptions are not quite specific, but I got a sense that they were capturing strong feelings with their words.

As patients experienced an emotional change, they became increasingly aware of how they felt. The emotional changes suggest that they had not only become more aware of their feelings but also had become aware of the resolution of their emotional issues.

7.3. Providing comfort

7.3.1. Emotional expression and validation

Emotions such as frustration, anxiety, anger, sadness and fear were prevalent in patients who were in hospice/palliative care. Different musical approaches helped patients to release or express feelings and feel emotionally validated. Emotional expression and validation occurred together because I supported their expressed emotions both explicitly, and implicitly.

Lyric analysis involved talking about a character who experiences similar feelings to the patient’s in a song that I introduced or they chose. I sometimes prompted this process by asking “what do you think the song means?” It was also useful to have a score or lyrics printed out for both me and patient to read and discuss together. People could express their own feelings by talking about the lyrics in the song, and feel validated in hearing that others had also experienced the same troubles. To enhance the validation, I listened to them attentively, responded by nodding and making eye-contact when appropriate and sang the song to be with

patients' emotions so they felt heard and knew their hardship was shared. To one patient who was facing death, singing a song about a person who "cannot do anything now" seemed to comfort him; he asked me to sing the same song in every music session until he passed away. The song he asked for was *Lilli Marlene* (Dietrich, 1973).

In *songwriting*, patients expressed their feelings by writing lyrics. Afterwards, they chose musical elements such as key, rhythm, tempo and melody to enhance the meaning of their lyrics, and the expression of their message. Sometimes, I chose suitable musical elements for patients to help them feel understood, and supported when I sang back the lyrics they wrote with music that enhanced their feelings. Patients could also feel validated by *performing the song* to Day Hospice patients who could empathetically embrace and understand each other's feelings.

Patients could also indirectly express their emotions by choosing songs they want to listen to both live and from recordings. Sometimes, music of the patients' choice seemed to communicate their inner feelings, thoughts and psyche. For instance, a patient chose a song called 'I believe I can fly' and it seemed that his feelings about wanting to be free, or expecting to be free after death, were expressed through the song. I validated patients' feelings by playing the song on electronic devices or by playing it live.

Lyrical affirmation not only involves singing patients' chosen songs but also emphasising lyrics that contain powerful messages or that patients can particularly sympathise with. Sometimes, while they listened to certain lines of a song, they became tearful, had a fixed gaze, sang along with particular lines, or did not sing but appeared to be listening very attentively. I could affirm some of the seemingly meaningful lyrics by changing accompaniment style, volume or tempo and using repetition to accentuate some lines of songs that appeared to be meaningful.

Improvisation involved creating free-style music by choosing an instrument and this seemed to facilitate patients' expression of emotion. Patients often seemed to choose an instrument that could express their internal thoughts and I chose an instrument that would best support the timbre that the patient's instrument made. Then, I created a similar-sounding musical milieu where patients felt enabled and safe to freely make the music they wanted to make. For this, I matched the dynamics, style, and mood of patients' music, whether it was gentle, loud, busy, or simple. It seemed that different feelings, thoughts and emotions were expressed at every moment in patients' music and sometimes in their facial expressions. I validated their emotions

moment by moment by *holding and containing*¹ patients' feelings by playing pedal notes (grounding sounds) under patients' music, synchronising with patients' music, following patients' leads, and leading patients to support and embrace their feelings. Sometimes, I made eye-contact with patients or smiled when they smiled, to be with their emotions.

Sometimes, I found allowing *silence* to be very powerful. I let silence enter to unite with patients' unspoken feelings when patients said no words. I matched their sound, which was silence, to recognise, understand, acknowledge and support their feelings by being with their silence. In silence, I felt I met patients on the same emotional level and I felt that I was "being with" them and with their feelings. Sometimes, I used silence instead of music to recognise their emotional distress that was not expressed verbally but silently.

7.3.2. Facilitating relaxation

At times, patients' anxiety seemed to subside as they became more relaxed by the music. I *strummed* stringed-instruments such as the harp or guitar gently downwards or hummed melodies with downward gestures, stroking their hands very gently. I did this to convey a feeling of patients' minds being stroked, and tension brought down. While I played music in this manner, some patients closed their eyes, breathed slower, stopped frowning, and fell asleep.

7.3.3. Providing Satisfaction

Patients' emotional needs could be met with *collaborative/theme-based-improvisation*² and by offering the *patients' preferred musical genre*. Patients' *preferred musical genres* were played to provide feelings that were missing or needed in patients' lives to counterbalance their current mood. Musical genres such Baroque music seemed to counteract the complexity of life with its homophonic structure³ that gives a feeling of life falling perfectly together, like the music. Other genres such as jazz seemed to create more dynamism in life, with animated rhythms making the moment more spirited. By using music in different styles, the atmosphere could be changed, emotional needs could be met and patients could sometimes experience restored emotions.

¹ "Cradling" and holding tightly to patients' emotions for thought process to safely happen (Ogden, 2004).

² Explained above in the 3rd paragraph of emotional change section.

³ Different lines of music are played together at a constant beat. The music sounds straight, consistent, clean and easy.

Twinkle Twinkle Little Star
How I wonder what you are
Up above the world so high
Like a diamond in the sky
Twinkle Twinkle Little Star
How I wonder what you are

Agency

QoL indicator	Methods	Activities	Strategies	Techniques
Music therapy supported patients to have more possibilities in life through:	Receptive	Choice making	Ask pts' preferences for receiving music therapy	
Music therapy supported patients to have more preferences and alternative ways of engaging in life through:	Receptive	Choice making	Suggest different music interventions	
Music therapy supported patients to self-care for their emotions through:	Re-creative	Playing instruments	Choosing score	Color-coding scores and instruments, using alphabet stickers
	Creative	Collaborative theme-based improvisation	Choosing a theme	Creating music that enhances pt's chosen theme
Music therapy supported patients to manage nausea through:	Receptive	Listening to improvised live music	Employing melodic instruments	Consistent rhythm, tempo and dynamics, playing triads
	Receptive	Listening to live music	Employing cultural music	
Music therapy supported patients to manage restlessness and breathlessness through:	Receptive	Entrainment	Matching to pt's breathing rate or mood	Decreasing tempi and volume

Music therapy supported patients to manage pain through:	Creative	Collaborative theme-based improvisation	Selecting pain as a theme	Creating music that enhances pt's chosen theme
	Receptive	Listening to improvised live music	Visualisation	Relaxing-style music
	Receptive	Listening to live music	Employing songs with pictorial lyrics	Employ accompaniment to elicit pictorial sounds
	Receptive	Listening to improvised live music	Creating relaxing music	Decreasing tempi and volume, descending musical gestures
Music therapy supported patients to manage pain through:	Receptive	Listening to improvised live music	Employing clear and distinct sound	Monophony, slow tempi
	Creative	Songwriting		
	Receptive	Choosing songs		
	Receptive	Organising music performer		
Music therapy supported patients to continue family care through:	Creative	Songwriting		
	Creative	Instructive-music-therapy	Giving teaching resources	
	Combined	Action and music	Helping pt to be in the center	
Music therapy supported patients to continue to help others through:	Re-creative	Giving a leader/provider role	Employing electronic devices	

Table 2. Summary of findings: Agency

Theme 2: Agency

Definition of the theme

In the context of music therapy in hospice/palliative care, agency encompasses feeling responsible for one's life by making choices and decisions, taking actions, having a sense of involvement and being in control of life. The sub-themes that arise in agency are creating possibilities, enabling preferences and alternatives, management and continuation.

8.1. Creating possibilities

Patients could choose between two different possibilities. They could decide to receive or decide not to receive music therapy. In music therapy, they could either participate actively (e.g. singing) or receptively (e.g. listening). These possibilities enabled patients to make choices, be in control of their lives and take part in life in other ways of their choosing.

8.2. Enabling preferences and alternatives

Finding a preferred way of living facilitates action, participation and involvement in life. Therefore, I explained every musical activity I offered, to widen the scope for patients to find preferences and possible ways of taking action. The interventions I offered and which they could participate in were *singing, music listening, journeying music, music-cued-conversation, music visualisation, verbal discussion, socialisation, music-based relaxation, character sensitization, reminiscence/life review, composition, instructive music therapy, performances, recording music, improvisation, leading sessions, personal thought processes, family-based music therapy and planning for funerals.*

Sometimes challenging moments arose when patients were no longer able to participate in music therapy as they used to. In these cases, I provided alternative ways that could help patients maintain their participation in life. For instance, when a patient could no longer sing, I offered instruments so patients could continue 'singing' in a different way. At other times, other preferred interventions were sought from patients. In these ways, patients could maintain their participation in the music therapy sessions.

8.3. Management

Personal care is one of the fundamental ways of being responsible for our lives. In hospice palliative care, patients lose much of their independence and can feel impotent or

disempowered. I helped patients to feel some independence again by providing ways to take care of themselves.

8.3.1. Emotional self-care

In *instrument playing*, I offered music scores to patients so they could choose and play what would “sound good” to them, in times of emotionally difficulty. In other words, they played instruments to take care of their own emotions through their own action. To enhance emotional self-care, I made instrumental playing easy by reforming instruments and scores. This involved sticking alphabet stickers on the keyboard and making scores by writing alphabets, or colour-coding glockenspiels and making colour-coded scores. I also made my own lap harp scores that can be placed directly under the strings with dots indicating which strings to pluck. With the instrumental playing made easy, patients could play music that gave them positive feelings without having difficulty playing the instruments. Patients who engaged in this activity seemed to be distracted from anxiety, found pleasure from playing music like “a true musician,” and looked excited or relaxed as they played music.

Collaborative theme-based improvisation invited patients to choose a theme that created the kind of feeling they needed or wanted to hear. After selecting a theme, they created music based on the theme. Patients could self-cater for their emotional needs by playing music for themselves and also with my support in enhancing the sound of their chosen-theme. Sometimes, the music was *recorded* so the patients could continue listening to the music they had created that supported their emotional needs in their own time, outside music sessions.

8.3.2. Management of symptoms

When patients needed physical and emotional comfort, they chose to receive music therapy and listen to music, in the hope of making themselves “feel better.” The patients seemed to engage in listening because sometimes, physical or emotional changes occurred during or after music therapy. Listening to music was a way the patients could gain comfort, and restore a sense of independence and responsibility for themselves when they were experiencing pain and other symptoms.

When I tried *improvisation* for patients experiencing nausea, I played melodic instruments to counterbalance patients’ possible feelings of fluctuation and to stabilise their sensations. I kept rhythm, tempo and dynamics consistent, and improvised by playing simple triads such as CEG

or FAC to create a containing sound. Sometimes, I noticed patients' retching decreasing with less vomiting and increased calmness. A patient even vocalised to music and seemed to be self-managing along with music I provided. The patient asked me to play music for a longer period of time.

There were moments when vomiting, or buildup of gastric fluids was uncontrollable for some patients. However, in one example, upon hearing *music from her own culture*, a patient smiled gently, turned her body towards me and closed her eyes in her bed. The music seemed to remind her of a home and create a comforting atmosphere because even when she became nauseated, she asked that the music be continued because it sounded "beautiful" and "relaxing." It seemed that music made the nausea less troublesome, not because the nausea improved but because the situation seemed better with an altered perception of here and now.

For patients who were restless and experiencing shortness of breath, I tried *entrainment* to induce calmness. In entrainment, played instruments by matching to patients' breathing rate and gradually slowing down my musical playing, inducing slower and deeper breathing. However, for a lot of patients who were breathing unevenly, entrainment was difficult. Therefore, I entrained by matching the mood or atmosphere and decreased the volume and tempo to create tranquility, peace and induce deeper rest. Some patients breathed more evenly, with reduced body movements.

8.3.3. Pain management

Pain management is included under the category of agency because music therapy offered listening and other music interventions that hospice patients could engage in to manage their own pain and be responsible for themselves.

In *collaborative-theme-based-improvisation*, music could be improvised by selecting pain as a theme. Patients could express their experiences of pain by freely improvising on instruments. Patients hit percussive instruments hard, made sweeping motions with a mallet as if they were sweeping out illness, and verbally said "shatter illness." In this way, patients gained control over their illness and managed their pain by terminating the illness in their imaginations. I matched the patients' music to enhance the sound of shattering pain and to create a safe musical space where patients could feel enabled to play as they desired.

Visualising to music helped patients ease pain. Sometimes, images were evoked while patients

listened to relaxing music and music seemed to distract patients from their pain as they imaged and described what they saw. The patients seemed able to transcend the pain-experience moments in their imaginations⁴. Sometimes, I sang music that had strong pictorial lyrics such as *Raindrops Keep Falling on my Head* (Thomas, 1969) which can easily provoke images in patients' imaginations. I also accompanied in a way that supported the lyrics. For instance, I played the notes of each chord separately in staccato to suggest the sound of raindrops. During music, patients closed their eyes and seemed to be calm and peaceful. Some reported they "felt better" after a session. Records seem to indicate that some required less pain relief after music therapy.

Improvising music in a relaxing-style involved responding to patients' pain, expressed by frowning or moaning. In the moments when patients experienced pain, I slowed down the music, played more gently, strummed the harp in a downward motion and played descending arpeggios quietly. I played in this manner to give a feel of tension subsiding as well as to help patients combat adverse pain stimuli, experienced both physically and emotionally, through the soothing quality of the music. Some patients' facial expression were eased, some fell asleep patient indicated to have felt "pain free" after deep relaxation to music. However, some patients showed no distinct indications of having their pain eased. At other times, I played improvised melodies by making each note sound distinct and clear, to interfere with painful stimuli that patients were experiencing. It was important to play in monophonic structure⁵ and slowly, to give enough space between notes to prevent the music from overstimulating patients. On one occasion, a patient stared at the instrument I was playing and seemed distracted from pain.

8.3.4. Planning for funeral

Towards the end of life, patients could continue to be responsible for their lives by planning for their funerals. Some patients thought organising their own funeral was a "good idea" and showed much interest and were actively involved in music sessions. Organising a funeral involved writing songs, choosing songs and organising performers. I could help patients to be involved in managing their experiences, and it was a way that patients could continue having

⁴ This relates to transcendence in affective awareness

⁵ A single line of music played without accompaniment. The music very simple and easy to listen to

an involvement in their life until the very end.

8.4. Continuation

8.4.1. Family care

Most of the patients in hospice/palliative care were parents/grandparents who had children and family to look after. I helped them to help their families in different ways. Offering *songwriting* helped patients write lyrics that gave their family knowledge, important learning and wisdom. Some included ‘obeying rules,’ or religion-based teachings. Some patients also wrote songs to give as special gifts to family.

In *instructive music therapy*, I taught patients musical knowledge and passed on teaching strategies and resources for them to teach their own children. This was not only a way that parents could help their children with their education but also a way of spending time with children when patients became physically restricted.

Lastly, parents with young babies could continue child-rearing even when they became physically limited by singing lullabies with my music accompaniment, or by singing together with me. However, if a patient lost their voice or was unable to sing, I sang the lullaby by moving out of the baby’s field of view while the parent performed hand actions such as jiggling hands to the song ‘Twinkle Twinkle Little Star.’ By supporting parents’ hand motions while the baby watched the parent, nursing the baby was still possible when looking after a baby in other ways became challenging.

8.4.2. Helping others

I tried giving patients a *leader role* by asking them to play music with their iPad or radio in music sessions. This was a new initiative I created in my work. I offered this to put them in the role of provider rather than patient. Although patients had the leading role, I maintained the therapist’s stance by actively listening to their music and asking “who sings this song?” to enhance the role of a provider. As I expressed much interest and pleasure in their choice of music, they enthusiastically chose other music from the iPad, shared their knowledge of the songs and even made me copies of their music. It seemed they enjoyed being the facilitator or a producer. This seemed to be an effective way of increasing the worth of their actions and making them feel responsible to a great degree for entertaining others with their music, and actions.

Amazing grace
How sweet the sound
That saved a wretch like me
I once was lost
But now I am found
Was blind but now I see

Belonging

QoL indicator	Methods	Activities	Strategies	Techniques
Music therapy actively supported family's togetherness through:	Re-creative Creative Combined Re-creative	Playing instruments Improvising solo part Family-remiscing to music Performing with family	Employing families' choice of song Singing names Employing recognisable songs Choosing music and instruments	 ABA structure Prompting conversation
Music therapy passively supported family's togetherness through:	Receptive	Listening to live music	Employing family's choice of songs or love songs	Sitting at a distance, playing in a relaxing-style
Music therapy both actively and passively supported family's togetherness through:	Re-creative Combined Re-creative	Singing to pre-composed songs Family-remembrance to music Singing and playing instruments to pre-composed songs	Withdrawing my musical presence Withdrawing my musical presence Providing more active music	Gradually singing softer and providing accompaniment only Active listening Increasing volume, changing accompaniment style, matching to family's tempo
Music therapy supported family's togetherness through:	Receptive	Silence		

Music therapy supported patients to become connected to their country through:	Receptive	Listening to live music	Employing cultural music	Singing in pts' first language, cultural songs, playing cultural instruments
Music therapy supported patients to become connected to their home through:	Receptive	Listening to live music	Employing songs that remind pts of their home	
Music therapy supported patients to become connected to their spirituality through:	Receptive	Listening to live music	Choosing songs that remind pts of their deceased family	
	Receptive	Listening to live music	Employing music from pts' religion	
	Re-creative	Singing	Employing music from pts' religion	
	Receptive	Listening to live music	Employing songs about heaven	
	Re-creative	Singing	Employing songs about heaven	
	Creative	Collaborative theme-based improvisation	Choosing heaven as a theme	Matching to pts' expression of heaven

Table 3. Summary of findings: belonging

Theme 3: Belonging

Definition of the theme

In the context of my study, belonging also implies a sense of connection. Music therapy can help patients feel a sense of belonging or connectedness to the aspects of life and spirituality. These aspects of life include family, country and home, and all patients had different spiritual beliefs. A sense of belonging inevitably provides supportive emotions such as a sense of affection, home, security and safety.

9.1. Aspects of life

9.1.1. Including family

Active approach

An *active approach* involved facilitating active interactions. I facilitated family-based instrumental playing, singing, music-based reminiscence and sometimes created a small performance for families' loved ones. I took this active role when families showed openness to active engagement, as indicated by initial family dynamics, their vocal tone, facial expressions and verbal requests.

In family instrumental playing, I invited families to play instruments to their chosen songs and to do a solo improvisation within an ABA musical structure. The A parts were played by all family members and the B part was the solo improvisation part. I cued the solo part by singing a person's name to invite them to do a solo improvisation. I used the ABA structure because families could have a musical experience together in the A parts and be listened to, feel embraced and appreciated by everyone when playing solo.

In music-based reminiscence, I played recognisable songs such as families' favourite songs; those played in family events, and those chosen by them. Then I led the conversation by asking questions such as "how is the song meaningful to your family?" Sometimes, families started conversations without my prompting. In this intervention, families could share the memories elicited by music and revisit family times in their memories, together as a family again.

Family performances, by family members for their loved one, were a moving experience for all family members because the patient could receive a special gift and the family could give something meaningful to them, expressing their love. I asked patients' families to choose a

song to sing for their loved one and instruments to play with and privately practiced with them. Their choice of songs included their own favourite songs, patients' favourite songs or those containing meaningful messages such as *When You're Gone* (Lavigne, 2006). Sometimes, families had an impromptu performance without any preparations.

Passive approach

Taking a *passive approach* was another way of enhancing families' connectedness. I sang at a softer volume and played instruments peacefully. For instance, I played the harp at a slower tempo and sang gently with harp and guitar accompaniment. The songs I sang include families' choices, generic songs and songs about love such as 'I'll Always Love You,' and 'I will leave this world loving you.' Often, families seemed to be affected by the mood created by the music because they compassionately and affectionately touched their loved ones when the music began. For instance, they moved closer to the patient, stroked their face or arms, massaged them, held hands or compassionately looked at each other. It seemed that music facilitated love, affection and compassion during these family times. I used this approach when working with families whose loved one was facing imminent death or when family members were having a quiet moment together or to facilitate a relaxing time for the family. I supported their final time, or their quiet time, by creating comfort in the atmosphere. Sometimes, I sat at a distance from the family to maintain their feeling of togetherness.

In the *passive approach*, I also asked family members to make a song choice to sing for their loved one. They often chose songs that contained the kinds of messages they wanted to convey. The song choices often consisted of themes of love, courage, thankfulness and reunion in the future. Even when families were not interacting actively, music brought the family to the same emotional level and they could be emotionally connected in listening to the same music.

Appropriate withdrawal / Intervention

Sometimes I changed my approach from *active to passive*. This happened when I tried to facilitate family time. When families were actively involved in singing in response to my active approach, I gradually withdrew from singing and only provided musical accompaniment so the family could hear each other's voices better and have some moments of family time, feeling genuine family togetherness. I also took this approach sometimes to help patients be more aware of the family's presence. When families joined in singing, I stopped singing and only

provided guitar accompaniment so the patient could hear family voices more clearly, recognise their presence, and feel close. Likewise, in reminiscence, when families started to actively talk about their shared memories, I stepped back, remained silent and actively listened to allow this active interaction.

Sometimes, I changed my approach from *passive to active*. While singing and playing instruments, some families appeared reserved at first but gradually became energetic as more family members joined in singing. I changed the style of my approach to match to the growing enthusiasm of the family and to actively support their time together. This involved increasing the volume of the music, changing the accompaniment style from arpeggios to strumming, and matching the family's tempo.

Silence

The use of *silence* seemed to bring families together quite powerfully. However, this needed to be a sensitive intervention. When families are actively engaged in music, a moment of silence seems to connect everyone together in listening to the 'same empty space'. However, when a loved one is imminently dying, families often do not speak and emotionally seem much affected by music which connects families in listening. Therefore, silence in such moments sounds abrupt and uncomfortable and seems to break the connectedness.

9.1.2. Country

There were moments in my work when I thought patients were feeling connected to their homeland and country. I sang songs in patients' own languages, played their cultural songs and played instruments that reminded them of their homeland. When this music was played, patients would share information about their hometown, recall memories, and sometimes just listen, looking very restful and comfortable. The music seemed to help some patients envision their homeland, feel connected to home and created a sense of being at home again.

Sometimes, patients requested music from their culture when they were physically and emotionally distressed. It seemed that music associated with their culture and homeland conveyed a sense of comfort and of being at home. Feeling connected to one's country and feeling at home was important to patients in hospice and palliative care because music is one of the limited ways that patients can feel at home. This was especially important for people whose homeland is outside New Zealand, who did not have family members here in New

Zealand and had limited ways of feeling at home.

9.1.3. Home

Some patients became tearful and looked very sad when they were listening to songs that reminded them of home. The music I sang and played included songs they listened to at home and other songs about home such as 'Home on the Range' and 'Country Road Take Me Home.' Because some patients were under terminal care, they were never going to go home again. Therefore, music seemed to connect patients to a sense of longing for home, and embraced and comforted them in their experience of longing for home and family, and of loss.

9.2. Aspects of spirituality

Some patients seemed to feel a sense of security from thinking that they would have a place to stand or to belong to after death. This seemed to arise from their spiritual beliefs and their belief in 'spiritual beings.' They talked about meeting God or deities, reuniting with deceased family members and being in heaven.

I was responsive to individuals' belief systems to support their spirituality. To support some patients' belief in reuniting with deceased family members, I played songs that patients requested. These included songs that had been played at family members' funerals, songs that identified their family and songs that contained "messages" to deceased family members such as 'I'll Always Love You.'

Supporting some patients' belief in meeting their God/gods or deities involved playing and/or singing a wide range of religious music such as Catholic hymns, Christian worship songs and accompanying Hindu patients' religious chanting by playing percussive instruments to provide a beat. Sometimes, patients and families sang together, worshipped their God/gods or deities, prayed or just listened.

Heaven could be thought of as a sense of 'home' - a place that some patients believe they will go to after death. Supporting their spiritual belief involved listening to patients talking about heaven, sharing people's song choices that involved lyrics about heaven, and singing songs together about heaven to paint an image of heaven in their minds. Such songs included 'Swing Low Sweet Chariot' and 'Dancing in the Sky.' Collaboratively improvising music based on the theme of heaven was also done to create a little "heavenly space" around patients by matching

my music to patients' musical expressions of heaven. This sometimes helped patients feel sure of the existence of their 'home.'

Some patients seemed to indicate they were connected to their spirituality by listening to music with their eyes closed, singing together or verbally reporting "they (deceased family members) hear me from up above." I supported their spiritual beliefs which seemed to connect patients to a place or people in the afterlife and give a sense of security and safety.

“You’ve provided us a special memory”

Meaning and coherence of life

QoL indicator	Methods	Activities	Strategies	Techniques
Music therapy supported patients to have a meaningful moment by connecting to past through:	Receptive	Musical reminiscence	Employing music that are cultural; famous; requested; and played at special events	Asking questions
	Receptive	Musical reminiscence	Employing unfamiliar music	
Music therapy supported patients to find meaning and coherence of life by connecting to past through:	Combined	Musical life review	Employing music that are cultural; requested; associated with time/person; and special events;	Asking questions or using photos
	Receptive	Listening to live music	Employing lullabies; cultural song; those requested by families or patients	
	Receptive	Musical life review	Journeying memories	Playing music patients remember from childhood to senescence
Music therapy supported patients to fulfill wishes in the present time through:	Receptive	Watching and listening to live music performance	Choosing music pts desire to watch being performed	
	Re-creative	Instructive music therapy	Choosing a piece pts want to play or that helps them learn music	Arranging difficult music and making it easy to play

	Receptive	Organising music for funeral	Choosing performer, instrument and music	
Music therapy supported patients to have new experiences in the present time through:	Re-creative	Performance	Gathering audiences	Organising event with other staffs
	Receptive	Watching and listening to live music performance	Using instruments that are new to pts	
	Combined	Having music at the wedding		Collaboratively working with other staffs
Music therapy supported patients to restore lost musical-self in the present time through:	Re-creative	Instructive music therapy		
	Re-creative	Performance		Organising event with other staffs
	Re-creative	Listening to CD	Compiling CD for pts	Including songs pts identify with
Music therapy supported patients to find a meaning and coherence of life by connecting to future through:	Re-creative	Musical analysis	Employing contrasting music	Using ABA structure
	Combined	Making a transitional object	Video-recording music sessions	
	Creative	Making a transitional object	Songwriting	

Table 4. Summary of findings: meaning and coherence of life

Theme 4: Meaning and coherence of life

Definition of the theme

In the context of my study in hospice and palliative care, the meaning and coherence of life involves having a meaningful moment, a sense of meaning, purpose, fulfilment and peace with life. This happens by connecting to past, present and future.

10.1. Past

10.1.1. Reminiscence

In reminiscence, hospice patients were helped to recall memories. Recalling the past helped the patients have some pleasurable experiences and therefore, they could have a meaningful time, here and now.

Both the pre-recorded and live music I used in reminiscence included patient's requests, cultural songs, famous music from particular eras and music they listened to at special events. The music recalled beautiful moments they had with family, memories made at work and moments they might have taken for granted in the past. Sometimes, I facilitated reminiscence by asking "what does the music remind you of?" For instance, when I sang a famous song of a patient's era – in the hope of making a connection in the patient's memory - the song recalled a memory of the patient's daughter dancing to the song when she was little. The patient shared that "she was so cute in her tutu" and imitated the movement her daughter did with her arms. The patient seemed glad to have thought about the special memory. By recalling memories, some patients could be helped to have a quality moment by re-experiencing the feelings experienced in their memories.

Once, when I played music of an unfamiliar genre to a patient, it seemed that the mood, emotions and the atmosphere the music created elicited a particular memory, unexpectedly. The patient indicated she recalled a special childhood memory and she seemed excited about recalling what she did not realise she had remembered.

10.1.2. Musical life review

In hospice palliative care, many patients who are preparing for death undergo spiritual and existential crisis. Musical life review does not involve mere memory recall; it helps patients think about their life, deeply. In life review, I made several different approaches to help people

find meanings in their recalled memories which might help them resolve their existential conflicts.

The use of music, music-cued conversation and photos

Musical life review can happen by providing both pre-recorded and live music, and incorporating music-cued conversation and photos. The music I used in life reviews included cultural songs, music closely related to a particular time or to a person, songs played at family gatherings, at home, in special events; and those they requested. When I played those songs, some patients seemed to respond powerfully to music that tied into their memories of hometown, past events, family and religion. Some patients initiated conversation after listening to music and at times, I initiated verbal discussions by asking “may I ask you how you relate to the music” and “what does this music mean to you?” to help them search for meanings in the memories that could resolve their internal issues. Some music sessions involved viewing patients’ photos that had been taken at certain places at certain times.

To give an example, a patient who was finding living life with terminal illness meaningless listened to music that recalled his memory of marrying his wife. He said that “marrying her was the best thing happened in my life” and continued to talk about his wife, describing her as “caring and loving.” Despite the fact that his life with terminal illness was challenging, music seemed to help him find meaning in his life and restore the value of his life by recalling a meaningful and memorable event. In another example, a patient was experiencing a sense of loss and disappointment because she had to stop travelling, which was her passion in life. Upon listening to music that recalled her memories of travel experiences and as she looked at her photos taken in different countries, she expressed she was “lucky” to have been to all those places. Although she could no longer follow her passion, she seemed to make meaning of life from her memories of travelling. As reported by her husband, she became more sociable and “happy.” In musical life review, memories provided meanings and messages that could help resolve patients’ internal conflicts. As a result, some people seemed to feel a sense of relief, resolution and satisfaction with life and their verbal, facial and behavioural expressions improved.

The use of music only

In the hospice environment, not all patients were verbal or could engage in conversation due

to shortness of breath. Some chose not to engage in conversation because they “just do not want to talk.” However, music therapy seemed to help patients find meaning in life and ease their internal crises even without initiating conversations. As noticed, upon singing lullabies, cultural songs, songs played at other people’s funerals and those that were family’s and patients’ requests, some patients expressed emotions that they were holding in, started to talk to other people after neglecting everyone for days, and some were observed to come to a peaceful state after showing agitated behaviours. Music that was associated with their homeland, the last birthday party they had, deceased family members and their memory of being the mother or the father of a newborn seemed to speak powerfully about existential aspects of life to dying patients. During and at the end of the music, some patients appeared to be more restful, peaceful or more vibrant and became a “different person” as reported by family and doctors of one particular patient.

Journeying memories

Sometimes, I helped to stimulate ‘journeying memories.’ This involved recalling or suggesting songs from the oldest memories patients could remember, and then moving from childhood to adolescence, adulthood and senescence. This presented a panorama of memories. By reminiscing about each stage of their life, patients could realise that memories and meaning were continuously generated throughout their life, and that they had lived a full and contented life. Sometimes, negative memories were elicited and at those times, I either listened to patients talk about those memories if they were willing to, or moved on to other music. Journeying created a complete picture of the patient’s life and a sense of wholeness and a completion of life.

10.2. Present

10.2.1. Fulfilling wishes

When patients fulfilled a life-long wish or a new wish, the meaningfulness of their life seemed to be deepened. I performed music some patients had wanted to watch live, and helped some to play an instrument they had wished to play for a life-time. The latter happened in *instructive music therapy* or in *improvisation*, where they could learn about, or explore music, playing freely with my support. In instructive music therapy, it was important to teach songs that could be easily learnt to help patients feel they had achieved their dream. At times, I arranged songs

that patients wanted to learn, to make them easy to play. Once, a patient asked me to play music at her funeral. She specifically asked me to play the harp and before she died, she chose the harp music she wished me to play at her funeral. This was a special request and was the last thing I could help the patient with. Fulfilling wishes seemed to mean a lot to patients because they often remarked “you made my day,” became excited, and sometimes seemed relieved.

10.2.2. New experiences

Music therapy provided new experiences that helped to tick off things on patients’ “list of things undone.” These included organising patients’ own musical performances at Day Hospice and playing instruments that patients never encountered in real life, such as the harp, which reportedly “is not an everyday instrument.” Once, I participated by playing music at a patient’s wedding held at the hospice. The types of experiences they had, and the fact that they had new experiences, seemed to enhance the meaning of life. Patients showed satisfaction, pleasure and joy in their new memories and new achievements. In the continuation of living, new life encounters, and the fulfilment of wishes, meaning and continuity of life can be found.

Offering new experiences to patients involved working with other staff members. Assembling audiences, preparing a stage and bringing audience and performers together for an event would have been impossible for me to organize by myself. Working with an occupational therapist, Day Hospice coordinators, and nurses made the events possible and added meaning to patients’ remaining time.

10.2.3. Restoring lost musical-self

When people are terminally ill, engaging in everyday life becomes challenging, and eventually they can no longer engage in the same way they previously did, due to both psychological and physical impairment. For patients who had been involved with music in their past, I helped in a number of ways, including: regaining musical knowledge lost as a result of brain cancer; creating a stage at Day Hospice for those who were music performers in the past; and reawakening musical passion and possibilities by compiling a CD of the music that patients enjoyed listening to and playing in the past. One patient spontaneously started recalling and singing music contained in the CD, and was motivated to “get the gears out again.” When living life became difficult, and when patients developed an emotional wall between their present self and their past self, thinking they would never be able to live as they did in their past time,

instructive music therapy, performance, instrument playing, and reminiscence helped them find their lost self, their past self and ways of continuing to live meaningful life in the here and now.

10.3. Future

10.3.1. New life

Sometimes, patients found meaning in life by looking into the future and imagining finding happiness and life again after death. One patient interpreted music as life-death-life. Meeting God or deities, and the prospect of living again in heaven or a higher place with deceased family members were what made life coherent and meaningful; life was seen as a “cyclic form.” It seemed that listening to and analysing the musical ABA structure helped patients find meaning and coherence in life, and even the meaning behind hard times and death. This was strongly associated with ‘hope’ as patients foresaw positives in this challenging time of life.

Using an ABA structure, I improvised section A in patients’ preferred style and key, and in the B section, I improvised contrasting music in a different style and key. After that, part A returned. In response to the music, patients noted that they felt ‘pleasure-displeasure-pleasure’, or felt ‘happy-sad-happy’.

One patient realised that the meaning of life is to experience hardship sometimes but that “there is meaning behind sadness and life will become happy again.” The patient foresaw happiness, and happiness behind sadness with music that was improvised in a “happy-sad-happy” style.

10.3.2. “To be remembered in a pleasant way”

In my journal, I wrote that ‘in music therapy, sometimes the patients are not seen as patients but as people who are living life, enjoying the moment, and engaging in music activities.’

In the videos and photos of patients taken in music sessions, patients are seen as people enjoying instrumental playing, singing and listening to music rather than people who are experiencing illness. Also, in gift songs written by patients for their family, patients are remembered as a person who gave a special gift. The ‘transitional objects’ such as videos and songs, which take the patients’ place, represent the way patients can be remembered in the most pleasant way, which is how they want to be remembered.

How is your family?

Oh they are very good 😊

Your daughter?

😊 She helped me bring my shoes this morning

11. Clinical vignette

My contribution to all four categories of QoL

Introduction

This vignette describes music therapy work with a 49-year-old Indian woman, named Lilly. She was a Hindu lady who lived with her husband and daughter after immigrating to New Zealand and who spoke English as her second language. She had been diagnosed with breast cancer and was a Day Hospice attendee who participated in music therapy once a week. She was fully ambulant, and was expecting to undergo chemo and radiation therapy because of recurrence of the cancer.

Initially, I met her at a hospice outing. I volunteered as a daily buddy and accompanied her for the day. A rapport was formed as we socialised and enjoyed a shared experience. On the day, I also had an opportunity to introduce myself and the work I do in detail. Lilly showed particular interest in songwriting and joined the session the following week.

I worked with Lilly once a week and had 9 sessions in total. This vignette explains the music therapy techniques and approaches I used, the relationship I formed with Lilly and how both of these contributed to all four components of QoL (Ruud, 1997).

Dear family

Lilly expressed her desire to write a song for her family as a gift. She reported the full support, care and unconditional love she had always received from her family. Therefore, she wanted to express her love and gratitude so they would know her feelings even when she passed away. The song *Dear family* expresses her feelings and it was planned to be dedicated to her husband on their wedding anniversary which was the week after the first music session.

In the process of songwriting, Lilly could express her feelings both verbally and through planning lyrics. She talked about her past life, how well her family treated her and how she felt about that. I listened attentively, and conceptualised possible ideas for the song in my head. When she finished talking, we brainstormed possible ideas together on paper. The key ideas that arose were “hard times,” “full family support and care,” “thankfulness,” “unconditional love” and “I love you.” Lilly further added “when I’m not here, you will know that I love you and thank you.”

Because the wedding anniversary was very close, I finished up the songwriting by incorporating the words Lilly had expressed and adding musical elements to the lyrics. I aimed to create musical elements that supported Lilly's message, to enhance its meaning. I also aimed to validate her emotions when I sang back the song that communicated her feelings the following week. The song had a lyrical melody in a moderate tempo so the lyrics could be heard as Lilly was speaking them. The overall mood of the song was mellow and warm, to convey Lilly's love.

"The song is too sad"

A week later, Lilly listened to the completed song very attentively and after few seconds of silence she said "I liked it. Thank you." However, the week after her wedding anniversary, she indicated that she had not given the CD to her husband and that she never would. Apparently, one of her friends who listened to the song before Lilly gave it to her husband thought the song was too sad. Diana said that she wanted to make her family happy. It seemed that she valued her family's happiness more than her own expression of feelings.

The song was performed to the Day Hospice patients, as Lilly wished. Lilly did not feel able to sing to the crowd. Therefore, I sang the song for her to support her by indirectly expressing her feelings and at the same time, validating her feelings with the words she expressed and what they meant to her. While I sang, Lilly became very tearful. I thought the music performance was beneficial for her because she could express the feelings that were deep inside her heart safely to her close Day Hospice group members, staffs and me who could warmly empathise with her. Moreover, sharing her sadness also seemed beneficial because she normally put a smile on her face, when in reality she was likely to be emotionally troubled during such a difficult time. Although the song was not given to her family, her choices were respected and this song helped her express and release her feelings, as well as being able to share and be understood, recognised and embraced by other people who care about her.

Dear my daughter

Lilly and I wrote another song for her young daughter's birthday present. The process involved brainstorming ideas, writing lyrics, changing the order of the lyrics, and choosing the melody and musical style. As Lilly was writing the lyrics, she was excited about preparing a gift for her daughter and reported that her daughter was her "life." This song was the result of Lilly's

long contemplation of the lyrics and she added more words even after the songwriting was finished. It seemed that she had lots to tell to her daughter. Although the daughter is too young to understand the message now, Lilly believed that “she will understand the meaning of the song when she grows older.”

The song gives both explicit and implicit messages from Lilly. The lyrics explicitly show praise, compliments, the positive sides of her daughter, prayers to God, and how she foresees their future together and that her daughter is her “life.” Implicit messages are love, apology, sadness and Lilly’s wishes to be together with her daughter for a long time and her hope for the daughter to be a ‘good girl’ as she is now, even in the future.

This song is a gift as well as a transitional object that will help to represent Lilly. The song will symbolise the time that Lilly and her daughter spent together, Lilly’s everlasting love and how happy she was to have her daughter in her life.

The importance of trust and a sense of safeness

In my relationship with Lilly, she had two different roles. Lilly not only was receiving therapy from me but sometimes she showed a strong motherly side to me. I felt that when Lilly offered me life lessons, showed concern for my own health and gave feedbacks on my therapeutic approaches. This is one of the pieces of advice that she gave me.

“Angela, ask patients about their family, positive past times and their interests. Past memories are really important to cancer patients. Go and ask that to inpatients today. Then they will like you more and you will become a better therapist.”

Sometimes, I faced role confusion when she sounded like a carer. I sometimes wondered why she would say that and whether I had failed to form a therapeutic boundary with her. However, it is important to note that she also opened up her vulnerable sides. She sometimes cried, expressed her concerns, sorrow, frustration and anger and allowed me to see and help her with her sorrow and emotional pain. In contemplating my dual role with her, I realised that the reason why she could sometimes be the carer as well as a recipient of therapy was not because I had not formed a safe therapeutic relationship with her but because I had built a trust with her and she felt safe to be both a mother and a patient, as she was. Because of the sense of trust and safety in our therapeutic relationship, Lilly could feel safe to be both a recipient of care and a

normal 49-year-old female who was not always taken care of by other staff and family, but a person who was still able to help others. In this relationship, I was a normal 23-year-old, who has a mother of Lilly's age, but still was able to support Lilly because she trusted me as a student music therapist.

What Lilly expressed

This is what Lilly expressed that I think is important for all clinicians and student/music therapists to know. From time to time, frustration, sadness and anger arose from people treating patients only as a cancer patient.

“I am not just pain, blood pressure, breathing and medicine and sometimes ... people seem to forget about that”

In the light of what Lilly had expressed, asking patients more about their life, self, family and acknowledging their different identity as a person than a patient seemed crucial.

Quality of life

This work is related to all four categories of QoL (Ruud, 1997). In songwriting and songwriting performance, Lilly could express her feelings and feel validated by others listening to her message. By writing a song for her daughter, she was meaningfully involved in life and continued her family care in a very special way. A sense of belonging was generated by connecting with Day Hospice friends during performances and with her family as she was involved in writing songs for them. Preparing a song gift for her daughter, who is her “life,” enhanced the meaning of her life and helped her be remembered meaningfully by her daughter.

The therapeutic relationship I formed with Lilly added another layer to her quality of life. In terms of agency, Lilly could continue to help others - in this case it was me - and feel she was still capable of living a life as a typical woman. In terms of belonging, Lilly made a social connection with me. In terms of meaning of life, writing a song together was a meaningful task that Lilly and I did collaboratively. Lastly, in my opinion, the most prominent emotion experienced was trust. Trust was what enabled her to show her vulnerability, express her feelings and let me participate in making the precious gift for her daughter.

“I’m glad I’ve found someone to help me”

“I see the light through the dark tunnel”

Discussion

12.1. Summary of findings

In this study, I have evaluated how music therapy contributed to patients' QoL using the framework of Ruud (1997). In the context of hospice and palliative care, all categories of QoL, which are affective awareness, agency, belonging and meaning and coherence of life, had slightly different colours to how Ruud described them.

Various music therapy methods, activities, strategies and techniques were used to contribute to hospice patients' QoL. The patients could engage in any or all of receptive, creative, re-creative and combined music therapy interventions. The research findings show different musical and personal approaches that I made as a music therapy student to improve hospice patients' QoL towards their end of life.

In terms of affective awareness, expressing and experiencing emotions were important but having patients' feelings expressed and validated seemed crucial. Moreover, affective awareness encompassed spiritual awareness. The meaning of agency could be defined as Ruud (1997) described it in the context of this study. Music therapy provided manageable, creative and possible ways that patients could engage in life. Therefore, patients' sense of agency could be maintained and restored. In terms of belonging, patients could be with families in a meaningful way and feel at home. In particular, in the context of this study, belonging also entailed connectedness and connectedness is what helped patients feel they were with family, at home, and even connected to spiritual entities that existed in their belief systems and memories. Connectedness was important because what patients experienced in the past could not happen again in reality. The meaning and coherence of life seemed very important because finding meaning and a purpose in life resolves existential crises that people often face at the end of life. Patients found what had made their lives worthwhile by finding the meaning and value of their lives in the past, present and future. Finding meaning in life could help patients feel a sense of completeness, satisfaction and fulfillment in life.

Ruud's idea of QoL

Ruud's (1997) framework as used in my research created a structure for answering the research question. One concern I had in using this framework was that it is not specific to the context of hospice palliative care, albeit it is specific to the context of music therapy. However, in the light

of the definitions of QoL suggested by other health professionals, Ruud's framework does address all of the multidimensional needs of patients in the physical, emotional, social and spiritual domains which affect life quality for patients at the end of life (Hilliard, 2003; 2005b; Saunders, 1967; Tassinari & Maltoni, 2009; Clements-Cortés, 2015).

12.2. Discussions about affective awareness

Therapists' stances

When working with patients with terminal illness, I not only made music with them but I sometimes smiled or cried with patients, patted their backs or held their hands. Some studies suggested that patients' emotions can change not only because of music but also because the presence of therapist reduces a sense of isolation (Lee, 2005; Bailey, 1983) and the facial expressions and body language that music therapists use in music sessions give both implicit and explicit messages to patients that are emotionally meaningful (Bailey, 1983; Munro & Mount, 1978). Therefore, it is not only the use of music that contributes to changing patients' moods and emotions but the "presentation" of music (Bailey, 1983).

Listening to music

It is apparent that the receptive method of music therapy was commonly used with patients with terminal illness in my research (Gutgsell, 2013; Clements-Cortés, 2015; Leow, Drury & Poon, 2010; Krout, 2003). In a hospice setting, many patients could no longer physically engage in life activities that could change their mood and emotions and make differences at each moment. However, listening to live music can stimulate emotional changes without demanding active participation from patients (Pawuk & Schumacher, 2010; Gutgsell et al., 2013; Nakayama, Kikuta & Takeda, 2009).

The importance of emotional expression

Patients under hospice and palliative care often put on a "brave face" in order not to be a burden to their families (Ventura et al., 2014; Steinhauser et al., 2000). Sometimes, patients' vulnerability was revealed when families left, before or during music therapy. When patients showed indications of sadness and the need for emotional comfort both verbally and non-verbally, I supported the safe expression of their emotions. Because patients sometimes hide their feelings and try to be brave when situations in hospice care are also hard for them,

supporting them with emotional expression and validation seems important.

Emotional responses

Alertness and awareness seem to occur together, because sometimes patients became more alert, having previously been unresponsive. This may be because music touched the patient deeply and awakened his/her senses. One explanation for the increased alertness may be the stimulation of memories or images that are associated with music (Salmon, 2001). Personally, and especially because I was new to working at the hospice, seeing patients becoming more alert was a surprise and sometimes it was a surprise for the staff as well. One staff member commented that it is not common for unresponsive patients to become alert and “not everyone can bring people to consciousness.” When patients gain a bit more lucidity, their quality of time is increased because being mentally aware is reported to be an important factor for patients under palliative care (Steinhauser et al., 2000).

Benefit of improvisation

Improvisation allowed emotional expression and validation to occur without requiring patients to speak about their feelings (Nakayama, Kikuta & Takeda, 2009). As Bunt and Hoskyns (2002) noted, “music therapists are fortunate in having the medium of music as a means of ‘sounding out’ what we have heard and what our patients are trying to communicate to us.” Likewise, patients’ music that projected their feelings, mood and psyche in improvisation were safely expressed, understood and supported in the process of music making. Improvisation was particularly useful because it validated feelings that patients sometimes did not recognise for themselves but that were latently embedded.

Affective awareness and spirituality

Some patients seemed to undergo spiritual experiences during music therapy. This is because the patients transcended the moment with a different consciousness (Aldridge, 1995; McClean, Bunt & Daykin, 2010), became awakened (Magill, 2007) and experienced peace, spirit and energy (Renz et al., 2015; Magill, 2007; McClean, Bunt & Daykin, 2010; Cook & Silverman, 2013). As Ruud (1998) explained, music connects people to a ‘transcendental space’ and people can transcend the moment, emotional pain and suffering and move into moments of better experience (Aldridge, 1995; McClean, Bunt & Daykin, 2010; Magill, 2007; O’Kelly &

Koffman, 2007).

12.3. Discussion about agency

The importance of being independent

For patients under hospice palliative care, being independent and taking care of one's life is an important factor for having a better QoL (Morris et al., 1986; Steinhauser et al., 2000). Patients can restore their sense of responsibility by managing their physical and emotional struggles, which reduce life quality, via their own actions (Steinhauser et al., 2000; Davies, 2005). Music therapy helps patients to continue taking care of family and other people, and to take part in preparing for their own funeral. In the light of the findings of Steinhauser et al. (2000), these are important because patients with terminal illness have indicated that arranging their funeral and helping others are important factors in achieving a better quality of life.

“Synergistic” effects of music

Music therapy gave terminally ill patients different ways to engage in their life to restore responsibility. Feeling able to take care of one's life facilitates a sense of empowerment, confidence, competence and self-belief (Ruud, 1997). According to O'Kelly and Koffman (2007) pointed out, music therapy has a “synergistic” effect (p. 238) that gives patients confidence and motivation, which enhances the efficacy of other treatments. During the course of my practicum, two Day Hospice patients I worked with were discharged from the hospice service because they had recovered from their illness to a great extent. In the music sessions I had with them, I noticed confidence growing in them. The comments they gave in music were “I'm Mozart” or “I did it!” with the fist clenched. It seemed that the confidence was generated from noticing their achievements and the positive results that their efforts yielded them. The sense of confidence and self-belief could have affected their attitude, mindset and compliance with respect to other treatments (O'Kelly & Koffman, 2007).

Regarding pain and symptoms

Pain and symptom management is one of the most important care plans in hospice and palliative care (Morris et al., 1986; Rousseau, 1995; Steinhauser et al., 2000; Davies, 2004). At first, pain and symptom management did not seem to belong to agency because patients could not do much to manage their pain and symptoms. Although that was the case, listening to music,

choosing instruments that they thought would help them, and making the decision to participate in music therapy and listen to music was a way that they could provide some input to their own treatment. Therefore, although their actions might have felt insignificant or small, they were doing the best they could to find a better means of looking after their health. Patients receiving palliative care experience lowered self-control but music therapy can restore patients' sense of self by helping them manage their own pain (Gutgsell et al., 2013).

12.4. Discussion about belonging

Compassionate touch in families

In my work, the majority of music therapy sessions happened with families. Often, I noticed that music therapy had a strong tendency to draw out families' compassion for their loved ones in the form of gentle touching (Krout, 2003; Savage & Taylor, 2013). The compassionate touch seems important for hospice palliative care patients because this facilitates communication between families when patients feel "out of touch with self and others" and experience depression, withdrawal and isolation (Magill, 2007). Magill (2007) comments that "music reaches beyond words and touch, builds bridges of communication and helps restore unity" (p. 178). Also, the bonding between self and others is important to patients because it gives a sense of security and safety which has therapeutic qualities (Mount, Boston & Cohen, 2007; Anstey 1991).

Connecting to spirituality

In music therapy, some patients were helped to be connected with spiritual beliefs which included God/gods or deities, deceased family members and heaven. Connecting patients to their faith or reassuring them of their faith is important because it reinforces their belief of being looked after by whatever gives them faith. (Magill, 2007). In times of suffering, having faith and hope provides a coping strategy (Aldridge, 1995; Magill, 2007; Lipe, 2002; O'Callaghan & McDermott, 2004).

Helping patients connect to their religious faith seemed particularly important because maintaining a relationship with God is an important factor that improves patients' QoL (Steinhauser et al., 2000). Moreover, experiencing God/gods' or deities' presence relieves pain, fear and gives a sense of warmth, protection, freedom and peace to palliative care patients (Renz et al., 2015). Sometimes, music provided a means for spiritual practices such as prayer

and praise (Magill, 2007) and this is an important way of providing spiritual care for palliative care patients because praying helps them release anger, pain, sadness and emotions deep down in their “heart, mind and spirit” (Best, Butow & Olver, 2016; Magill, 2007).

12.5. Discussion about meaning and coherence of life

The difference between reminiscence and life review

Reminiscence and life review both use past memories as a medium for therapy but have different therapeutic effects and goals (Keall et al., 2015; Sato, 2011; Burnside & Haight, 1992). Reminiscence recalls powerful and significant events from the past to give pleasant moments to patients, here and now (Keall et al., 2015; Sato, 2011) and to improve their QoL (Keall et al., 2015). On the other hand, life review “is more of an evaluative activity involving examination, addressing and resolving or rectifying conflict if able” (Keall et al., 2015, p. 748). This intervention involved specific techniques and strategies to ease patients’ existential conflicts. For instance, life review helps patients at the end of life find meaning and purpose in life (Aldridge, 1995) and make sense of life (Wlodarczyk 2009; Sato, 2011) and feel a sense of completion, satisfaction, wholeness of life and peace (Burnside & Haight, 1992; Keall et al., 2015). Life review is an important nonpharmacological therapy that alleviates existential or spiritual pains that arise towards the end of life (Wlodarczyk 2009; Keall et al., 2015).

Musical life review

In hospice palliative care, other health professionals provide different kinds of interventions such as dignity therapy or meaning-making intervention to help patients review their lives to resolve existential conflicts (Keall et al., 2015). These interventions involve talking, and musical life review in my practice also sometimes involved verbal discussions. However, verbal discussions have challenges because patients who are in their final stages of life have a high risk of fatigue, shortness of breath and cognitive impairment (Sato, 2011; Keall et al., 2015). Although there are no specific methods used in musical life review, musical life review is still possible without initiating conversation, by playing music that recalls powerful memories that have messages to tell patients about life (Sato, 2011).

Transitional objects

Patients at the end of life wonder how they will be remembered after death and whether they

will be remembered as they want to be remembered (Włodarczyk, 2009). In the video-recordings of music sessions and gift songs which were prepared as legacies, patients could be remembered as creative beings despite having terminal illness and as people who were still living the moment – which is how they want to be remembered (Mount, Boston & Cohen, 2007). In gift songs patients could be remembered as people who could “still love” others (p. 377); a loving mother, father, daughter or son, which is how they want to be remembered.

Spirituality and meaning and coherence of life

Finding meaning and coherence in life contributes to patients’ spirituality because resolving existential pain is an important factor for spiritual wellbeing (Aldridge, 1995; Magill, 2007; Best, Butow & Olver, 2016). As Włodarczyk (2007) said, “though there are differences in the definitions and conceptualizations of spirituality, the same themes, such as the search for meaning in one’s life, often recur” (p. 114).

12.6. Spirituality and QoL

Magill (2007) states ‘Spirituality, then, is this search for meaning in times of distress; is the search for faith, hope and inspiration; is the human tendency to transcend to places, times and concepts that convey the magnitude of life and creation; and is the search for connectedness with self, others and that which lies beyond’ (p. 173).

The student music therapist could use various music therapy methods, activities, strategies and techniques to contribute to hospice patients’ QoL. Most prominently, each suggested idea of QoL (Ruud, 1997) had some connections to spirituality. Patients’ QoL was helped with music in the domains of emotional awareness, agency, belonging and meaning and coherence of life (Ruud, 1997) and spiritual properties such as transcendence, faith, hope, peace, connection and meaning-making were all elicited and enhanced (Magill, 2007; Aldridge, 1995; Lipe, 2002). Therefore, it seems that music therapy can contribute to patients’ QoL as well as their spiritual wellbeing.

12.7. ‘Being with’

Although I used various music therapy and personal approaches to help patients have the best quality of life, ‘being with patients’ seemed to be the most fundamental approach that underpinned all of the other steps that I made in working with patients in hospice palliative

care.

According to Bunt & Hoskyns (2002), therapists need to ‘be with’ whatever feelings and emotions patients experience for therapeutic processes to unfold. They also acknowledge that being with the patients’ feelings can be intensely discomfoting (p. 36).

This passage is highly relevant to my experience of working as a student music therapist in a hospice. In working with patients, it was essential to ‘be with’ patients’ death-related thoughts and only by accepting and understanding patients’ death could I help them with their difficulties, sufferings, goals and wishes related to death. Being with patients involved accepting, understanding, empathising and sympathising with their feelings, psyches, emotions and thoughts (Magill, 2007) and helping them in their journey to the very end of life with a genuine heart. When working with patients at the end of life, “being with a person is as important as ‘doing’ something for them” (Roger, 2015).

12.8. Limitations

This research has some limitations. Because patients in hospice care were sometimes unresponsive and unconscious, assessing the value and relevance of the therapeutic approaches was difficult. Also, the usefulness of the techniques and approaches could only be assessed in the light of the Ruud’s concept of QoL.

Moreover, it was hard to discern whether some of the patients’ physical and verbal responses in music therapy were affected by music or other physical and psychological responses to biological processes. Also, my ability to effectively reflect on sessions and write notes and journals, which I used as the data for this study, gradually improved over time and therefore, I may have omitted some essential information from the early sessions I conducted.

12.9. Recommendation

In this study, one patient unexpectedly recalled memories of her past in response to music that she had never heard before. It may be useful to undertake a study that investigates the extent to which familiar and unfamiliar music can elicit latent memories.

Overall, Ruud’s (1997) category seemed to be a good fit in my study. However, it would be helpful to investigate how else QoL can be defined in the context of music therapy and what other music therapy approaches can help patients in hospice and palliative care.

Conclusion

The study investigated how I, as a student music therapist, contributed to the QoL of patients receiving hospice and palliative care. The main focus of this research was to investigate what music therapy techniques, methods, strategies and approaches could contribute to patients' QoL. In order to establish how my different approaches contributed to patients' QoL, I had to have a structure which could pinpoint 'how' and 'why' my approach can be said to have contributed to people's QoL. For this reason, I used Ruud's (1997) concept of QoL as my conceptual framework for this research. According to Ruud, music therapy can contribute to people's life quality by improving their capacity to be aware of their emotions (Affective awareness), have control, choice and responsibility for life (Agency), have social networks and feel at home (Belonging) and find meaning, purpose and coherence of life (Meaning and coherence of life). I used clinical notes and reflective journals as my data and used secondary analysis of data to find out 'what I did' and 'how that related to' all four aspects of life that make up people's QoL. My findings describe what approaches, both musical and personal, stimulated facets of life that underpin all four concepts in Ruud's framework. The important aspects of life (expressed in Ruud's four concepts of QoL) are depicted as a theme in the findings and the processes that underpin these important aspects of life are depicted as sub-themes in my findings. It needs to be noted that the sub-themes, which are important aspects of life, and the music approaches used, were "context-bound" (Edwards, 1999) and understood through my own 'lens'. I found that Ruud's definitions of the constituents of QoL had particular "colours" in the context of hospice and palliative care. Therefore, some extensions to Ruud's concepts were applied to address ways in which affective awareness, agency, belonging and meaning and coherence of life can be supported with various techniques and approaches in the context of music therapy in hospice and palliative care settings. Some of the techniques that I used were pre-existing and some were newly initiated in my practice. The clinical vignette describes the use of music therapy techniques in detail and how it contributed to all four categories of QoL. The vignette also describes how my relationship with the patient added another layer to her QoL. In the discussion, the findings are further explained in the light of other studies. In particular, 'being with' patients seemed to underpin all of my musical and personal approaches that I made in working with hospice patients.

“I’m glad I met you in my life Angela”

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Palliative Performance Scale (PPSV2) version 2

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)

- 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.
- 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 precedence' (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 'total care.'
- 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.
- 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.

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February 22, 2016

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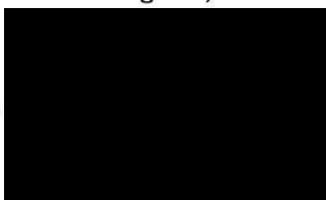
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Appendix 2 – Deductive analysis and initial coding

<p>As observed, in the beginning of the music session, the father (patient) watched his baby girl who was in her little cradle. I sat further away from the family not to interrupt their togetherness and to respect their time together. At that moment, it seemed appropriate to sing nursery rhyme for the baby girl. By sitting further away from the family, I sang Twinkle Twinkle Little Star with the guitar accompaniment. As observed, the father mouthed the lyrics (he is no longer able to produce sound with his vocal cord) and did hand actions to the song by opening and closing his hands like “a star.” I followed the pace of the father’s hand movements and mouth movements. The father constantly looked at the baby, the baby had a fixed eye gaze on her father or his father’s hand actions while I provided music outside the baby’s scene. It seemed that the baby enjoyed watching her father and the father also seemed to enjoy doing music for his daughter.</p>	<p>Sitting at a distance to maintain family’s togetherness</p> <p>Ill patient continues child care</p>
<p>The patient was interested to see the harp and asked me to play the harp for her. I improvised the harp in a relaxing style by playing glissandi, matching to the patient’s breathing pace and allowing silence to avoid overstimulation of sound. As I started playing, she closed her eyes. Sometimes, tapping of her foot observed. After improvising for about 10 minutes, the patient opened her eyes and indicated that she visualised “sun opening up” and heard “wind blowing on the cliff.” She said it with some excitement. It seemed that when she had her eyes closed during music, she felt being at somewhere different, outside the hospice environment.</p>	<p>Relaxing-style music helps patients transcend the moment</p>

Appendix 3 – An example of the steps 3, 4 and 5

Step 3: Affective awareness

Step 4: Group 1 / Theme 1

Step 5: Increasing alertness (step 5)

Instrumental playing brings more awareness

Patients seem more awakened with familiar music

Step 4: Group 2 / Theme 2

Step 5: Emotional expression and validation

Singing songs validate patients' death-related thoughts

Patients express feelings in song-writing

Performance of composition tells story to others

Improvisation helps patients release their feelings

Improvisation holds, contains and validates patients' feelings

Song-choice reflect patients' mind

Repeating lyrics that seems meaningful

Using silence to let patients know they are heard

Step 4: Group 3 / Theme 3

Step 5: Facilitating relaxation

Relaxing-style music helps with anxiety

Step 4: Group 4 / Theme 4

Step 5: Providing satisfaction

Plays musical style that contrasts to patients' current situation

Step 4: Group 5 / Theme 5

Step 5: Transcendence

Relaxing music evoke creative visualisation

Step 4: Group 6 / Theme 6

Step 5: Emotional change

Uplifting mood by changing elements of music

- Idiosyncratic perceptions to live music

Theme-based-improvisation provokes specific feelings

Patients smile to cultural music

Cultural music makes patients “happy”

Patients feel “shiny”

Patients experience indescribable feelings

Appendix 4 – Example of the step 6

Step 6: Essence - Increasing alertness

Instrumental playing brings more awareness

Patients seem more awakened with familiar music

Step 6: Essence - Providing comfort

Theme: Emotional expression and validation

Singing songs validate patients' death-related thoughts

Patients express feelings in song-writing

Performance of composition tells story to others

Improvisation helps patients release their feelings

Improvisation holds, contains and validates patients' feelings

Song-choice reflect patients' mind

Repeating lyrics that seems meaningful

Using silence to let patients know they are heard

Theme: Facilitating relaxation

Relaxing-style music helps with anxiety

Theme: Providing satisfaction

Plays musical style that contrasts to patients' current situation

Step 6: Essence - Facilitating different awareness

Theme: Transcendence

Relaxing music evoke creative visualisation

Theme: Emotional change

Uplifting mood by changing elements of music

- Idiosyncratic perceptions to live music

Theme-based-improvisation provokes specific feelings

Patients smile to cultural music

Cultural music makes patients “happy”

Patients feel “shiny”

Patients experience indescribable feelings

Appendix 5 – Consent form for facility



Te Kōkī New Zealand School of Music

VICTORIA UNIVERSITY OF WELLINGTON, PO Box 600, Wellington 6140,
New Zealand

Phone +64-4-463-5369 **Email** music@nzsm.ac.nz **Web** www.nzsm.ac.nz

Research question

How does music therapy contribute to people's quality of life in a hospice/palliative care setting

Research permission letter

Dear whom it may concern

My name is Angela (Ah Young) Jeong and I am a music therapy student at New Zealand School of Music, Victoria University, Wellington. The research I wish to conduct for my thesis involves looking at how music therapy contributed to patients' quality of life. I will be analysing my own musical techniques and strategies to answer my research question. This project will be conducted under the supervision of Dr. Sarah Hoskyns.

I am hereby seeking a formal consent to conduct my research with the clinical notes and reflective journal gathered from the work I did in (-----) Hospice.

I have provided you with a copy of my research proposal. If you require further information, or clarification on my research process, please don't hesitate to contact me or my supervisor. If you feel you have obtained sufficient information about my research, please send me a written consent form within 10 days if possible please.

Yours sincerely,

Angela Jeong

Appendix 6 – Information sheet for vignette



Te Kōkī New Zealand School of Music

VICTORIA UNIVERSITY OF WELLINGTON, PO Box 600, Wellington
6140, New Zealand

Phone +64-4-463-5369 Email music@nzsm.ac.nz Web www.nzsm.ac.nz

Information Sheet for vignette

How does music therapy contribute to people's quality of life in a hospice/palliative care setting?

My name is Angela (Ah Young) Jeong, and as a part of my second year course in Masters of Music Therapy of New Zealand School of Music, I have carried out my practicum in (---) Hospice for three days each week from February.

As a part of music therapy program, I am doing a research about the work that I have done with patients and families in this facility. I am interested in how music therapy can contribute to patients' quality of life in hospice and palliative care setting. My research project focuses on the techniques, methods, approaches and strategies that I have utilised in working with patients and families in (----) Hospice. The purpose is for me to learn from my work, to improve my own practice and potentially to provide useful information for other music therapists or music therapy students who also work in hospice or palliative care setting in New Zealand.

I am writing to ask your permission to use data that was collected as part of my clinical practice, and which relates to you and music therapy work done with you. This will be included in a clinical vignette section of my exegesis. Data, includes clinical notes and my reflective journals. The data will be stored in my laptop and securely protected with a password. After the project is completed, I will return the data to the facility or to Victoria University of Wellington where it will be stored for a period of ten years until being destroyed.

Anonymity will be protected whenever possible. Every information that might identify the location or the name of (-----) Hospice and patients' name will all be removed.

You are under no obligation to give permission for your data to be used for research purposes. If you decide to allow it to be used, you have the right to:

- Ask any questions about the study at any time until it is completed;
- Provide information on the understanding that your name will not be used unless you give permission to the researcher
- Be given access to a summary of the project findings when it is concluded

Please also note that this project has been reviewed and approved by the New Zealand School

of Music Postgraduate committee. The Victoria University of Wellington Human Ethics Committee have given generic approval for music therapy students to conduct studies of this type. The music therapy projects have been judged to be low risk and consequently, are not separately reviewed by any Human Ethics Committees. The supervisor named below is responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research, please contact the supervisor or, if you wish to raise an issue with someone other than the student or supervisor, please contact Associate Professor Susan Corbett, the Chairperson of the Victoria University of Wellington Human Ethics Committee.

Please take time to consider this request, and feel free to contact me or my research supervisor if you have any questions about the project.

If you are willing for me to use your data in my research, please complete the attached consent form.

Appendix 7 - Consent Form for Resident/Patient



Te Kōkī New Zealand School of Music
VICTORIA UNIVERSITY OF WELLINGTON, PO Box 600, Wellington
6140, New Zealand
Phone +64-4-463-5369 Email music@nzsm.ac.nz Web www.nzsm.ac.nz

Consent Form for Resident/Patient

How does music therapy contribute to people's quality of life in a hospice/ palliative care setting?

1. I understand that Angela (Ah Young) Jeong is writing a book about music therapy done in hospice
2. I understand that the book will be presented to Victoria University lecturer as a part of Angela Jeong's training
3. I know that the book will be available for other people to read
4. I have had a chance to ask questions about this project and I am happy with the answers
5. I know that real names will not be used in the book
6. I have had enough time to think about whether information about my music therapy sessions can be included in the book
7. I give consent for information about my music therapy sessions to be included in the book

(Yes / No)

I _____ hereby give consent for information about my music therapy sessions to be used in this project.

Signature _____

Date _____

Project explained by _____

Appendix 8 - Consent form for visiting music therapist



Te Kōkī New Zealand School of Music

VICTORIA UNIVERSITY OF WELLINGTON, PO Box 600, Wellington
6140, New Zealand

Phone +64-4-463-5369 Email music@nzsm.ac.nz Web www.nzsm.ac.nz

To. Visiting music therapist / music therapist supervisor

Hello Alison. I am Angela (Ah Young) Jeong who is studying Master's degree in Music Therapy in New Zealand School of Music. I am researching about how I can contribute to patients' quality of life in hospice and palliative care setting. I am using secondary review of data and the permission to undertake this research was approved by Victoria University Ethics Committee.

During the course of my research process, I have found my notes and journals that I have collected are inevitably related to what we have discussed in supervision times. My reflections on my work also stem from my learning that I obtained from your teaching. Some of the notes gathered also include what we have discussed on the days I had my assessment. Your teachings and careful thoughts about myself and my work also did not stop there but they were the first stepping stones to all other thoughts and reflections that I had and gathered in my journals and notes.

Therefore, I thought it is important to ask you if I can use some of the notes and journals which are closely related to our supervision and discussions. Please feel free to discuss with me other questions that arise about my research and/or about giving permission to use the materials in my research. I have included the information sheet and if you feel you have obtained sufficient information about my research and the use of the notes and journals, please sign the enclosed form.

Appendix 9 – Information sheet



Te Kōkī New Zealand School of Music
VICTORIA UNIVERSITY OF WELLINGTON, PO Box 600, Wellington
6140, New Zealand
Phone +64-4-463-5369 Email music@nzsm.ac.nz Web www.nzsm.ac.nz

Information Sheet

How does music therapy contribute to people's quality of life in a hospice/palliative care setting?

My name is Angela (Ah Young) Jeong, and as a part of my second year course in Masters of Music Therapy of New Zealand School of Music, I have carried out my practicum in (----) Hospice for three days each week from February.

As a part of music therapy program, I am doing a research about the work that I have done with patients and families in this facility. I am interested in how music therapy can contribute to patients' quality of life in hospice and palliative care setting. My research project focuses on the techniques and strategies that I have utilised in working with patients and families in (----) Hospice. The purpose is for me to learn from my work, to improve my own practice and potentially to provide useful information for other music therapists or music therapy students who also work in hospice or palliative care setting in New Zealand.

I am writing to ask your permission to use data that was collected as part of my clinical practice, and which relates to you. The research method will be secondary analysis. Data, including clinical notes, my reflective journals and notes from meetings will be analysed to answer the research question. The data will be stored in my laptop and securely protected with a password. After the project is completed, I will return the data to the facility or to Victoria University of Wellington where it will be stored for a period of ten years until being destroyed.

Anonymity will be protected whenever possible. Every information that might identify the location or the name of (----) Hospice and patients' name will all be removed.

You are under no obligation to give permission for your data to be used for research purposes. If you decide to allow it to be used, you have the right to:

- Ask any questions about the study at any time until it is completed;
- Provide information on the understanding that your name will not be used unless you give permission to the researcher
- Be given access to a summary of the project findings when it is concluded

Please also note that this project has been reviewed and approved by the New Zealand School of Music Postgraduate committee. The Victoria University of Wellington Human Ethics

Committee have given generic approval for music therapy students to conduct studies of this type. The music therapy projects have been judged to be low risk and consequently, are not separately reviewed by any Human Ethics Committees. The supervisor named below is responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research, please contact the supervisor or, if you wish to raise an issue with someone other than the student or supervisor, please contact Associate Professor Susan Corbett, the Chairperson of the Victoria University of Wellington Human Ethics Committee

Please take time to consider this request, and feel free to contact me or my research supervisor if you have any questions about the project.

If you are willing for me to use your data in my research, please complete the attached consent form.

Music therapy Student:

Name: Angela (Ah Young) Jeong

Mobile:

E-mail: jeongange@vuw.ac.nz

Research Supervisor:

Name: Sarah Hoskyns

School: **Te Kōkī New Zealand School of Music**

E-mail:

Thank you

Angela Jeong

Music Therapy Student

New Zealand School of Music