The spiritual meaning of pre-loss music therapy to bereaved caregivers of advanced cancer patients

LUCANNE MAGILL, D.A., M.T.-B.C.
University of Windsor, School of Music, Windsor, Ontario, Canada
(RECEIVED March 18, 2008; ACCEPTED April 26, 2008)

ABSTRACT

Objective: The aim of this study was to learn how music therapy sessions, held prior to the death of a loved one, impact spirituality in surviving caregivers of advanced cancer patients.

Method: The method of naturalistic inquiry was used to investigate the spiritual meaning of pre-loss music therapy sessions. Bereaved caregivers of seven different patients, who had been receiving music therapy through a home-based hospice program, participated in individual open-ended interviews. Interviews were recorded, transcribed, and coded. Themes were organized as they emerged.

Results: As caregivers reflected on their experiences in music therapy, they reported autonomous joy (music therapy affected the caregiver directly) and empathic joy (caregivers’ joy was based in remembering seeing the patient happy in music therapy). They also noted feelings of empowerment due to the ways they felt they had contributed in the care of the patients through music therapy. The caregivers were found to engage in processes of reflection that inspired these spiritual themes: reflection on the present (connectedness), reflection on the past (remembrance), and reflection on the future (hope). They referred to the ways that the music therapy sessions helped them find connection with self, others (through bringing their loved ones “back to life” and have a “renewal of self”), and the “beyond”; and that times in music therapy brought them happy memories and sentiments of hope. Meaning through transcendence was found to be the overarching trend in this study, as caregivers were lifted from remorse into heightened sense of meaning and gained “airplane views” of their lives.

Significance of results: Pre-loss music therapy can potentially assist caregivers during times of bereavement, as they retain memories of joy and empowerment, rather than memories of pain and distress, and find meaning through transcendence.

KEYWORDS: Music, Music therapy, Spirituality, Caregivers, Bereavement

INTRODUCTION

Advanced cancer and concomitant end-of-life issues can cause heartfelt suffering in patients and their caregivers (Hebert et al., 2007). Individuals coping with these challenges may experience physical health and psychosocial difficulties (Cherny et al., 1994, 1996; Holland, 1998; Walsh et al., 2007), as well as dilemmas regarding faith, hope, identity, and belonging (Zabora & Loscalzo, 2002; Blinderman & Cherny, 2005; Coyle, 2006; De Faye et al., 2006). Spiritual concerns tend to play a significant role in the lives of cancer patients and their loved ones during these periods of grief and loss (Breitbart, 2002; Sulmasy, 2002; Breitbart et al., 2004; Morita et al., 2004; Sand & Strang, 2006; Puchalski, 2007–2008). As spirituality is often described as a construct that goes beyond religion and is concerned with inspiration, hope, meaning, connectedness, and a transcendental way to live one’s life at a deeper level (Muldoon & King, 1995; Puchalski, 2002), it can be understood that those immersed and participating in end-stage care will inevitably face spiritual dilemmas and engage in existential inquiry.

The issues surrounding caregiving in the context of advanced cancer are well addressed in the
literature. It is understood that caregivers of these patients experience psychological distress, which often increases as the patient loses autonomy (Dumont et al., 2006). Likewise, caregivers endure multiple stressors and losses that complicate their lives and deplete resources for coping, particularly as they persistently witness the patient’s overall decline, detachment, potential loss of dignity (Chochinov, 2006), and struggles with existential meaning (Breitbart, 2002). Along those lines, caregivers often find themselves in states of perceived helplessness and isolation (Payne et al., 1999), resulting from separation from the “aliveness” of their loved ones. The literature refers to the benefits of premorbid psychosocial support for caregivers (Holland, 2002; Kissane et al., 2007–2008) and the advantages of acquiring creative measures to provide for legacy work (Chochinov et al., 2005) and life completion (Byock, 1996). Once death occurs, the process of bereavement is influenced by various factors, such as the degree of psychological preparation and preloss and postdeath psychosocial support (Corless, 2006). Other factors affect grief, such as the nature of the attachment, the mode of death, personality characteristics, and social factors (Worden, 2002). Supportive interventions, before and after death, have been found to potentially assuage feelings of caregiver guilt and enhance the ability to cope with the loss (Folkman, 1997; Kissane et al., 1998, 2006; Holland, 2002).

Music therapy is an intervention that is used to address the multifaceted needs of cancer patients and their caregivers (Dileo & Bradt, 2005). In the care and treatment of advanced cancer patients, the music therapist holds sessions often in the presence of the caregiver(s), and it is common for caregiver(s) to witness the sessions (Hilliard, 2001; Krout, 2003; O’Callaghan, 2004; Dileo & Parker, 2005; Magill, 2006a). As caregivers experience a wide range of emotions in relation to advancing illness and as their needs are multifaceted, participation in music therapy sessions has been found to provide for a range of benefits, such as opportunities for anticipatory grieving and for the acquisition of creative strategies to mitigate distressful symptoms, improve communication, and regain a sense of life’s meaning (Magill, 2001).

Whereas it is understood that music therapy plays an important role in those contending with the end of life (Munro, 1984; Martin, 1991; Magill-Levrault, 1993; Salmon, 1993; Lee, 1995; Aldridge, 1999; O’Callaghan, 2001; Dileo & Loewy, 2005), the impact of this therapy on the spiritual realm in caregivers is less understood. There is little research that has specifically explored the spiritual influences of these sessions on caregivers in the period after the death of a loved one. This study, therefore, aimed to improve understanding regarding how music therapy sessions, held during the patient’s final stages of life, impact the caregiver’s time in bereavement. It also aimed to explore the specific aspects of spirituality, as impacted by music therapy, deemed significant by caregivers.

METHOD

The purpose of this study was to discover and describe, through open-ended inquiry, the spiritual meaning of music therapy experienced before the death of a loved one. The research method and analysis were based on naturalistic inquiry. Naturalistic inquiry involves the use of the natural setting as the source of information because the context it provides is necessary to the establishment of meaning and the determination of the significance of findings (Lincoln & Guba, 1985; Aigen, 2005). This study occurred within the natural setting, which in this case was the context of the caregivers’ experiences during their bereavement period. Another factor was the context of the interpersonal relationships. The music therapist-researcher was knowledgeable about the experiences the caregivers previously had in the music therapy sessions prior to the patient’s demise and thus was able to further understand the meaning of their reflections. The mode of inquiry was through one-on-one interviews with the surviving caregivers and also through the gathering of field notes and researcher’s journal entries. Interviews were audiorecorded, transcribed, coded, analyzed, and sorted into groupings based on shared ideas and emerging themes. Data were analyzed recursively, and saturation was attained.

Participants

Participants were those caregivers who were present in music therapy sessions with their loved ones prior to death. Caregivers were those significant others who were actively involved in the life of the patient during the course of music therapy. As this study aimed to gain an improved understanding of the impact and spiritual meaning of preloss music therapy, purposive sampling allowed for the selection of caregivers with whom there had been some reference to one or more of the underlying themes of spirituality in the sessions. These themes were: mention and/or focus on a Higher Power, God, a Higher Being, as defined by the participants; faith; the meaning and purpose of life and living; hope; transcendence, being “transported” to another realm; or nature, beauty, or infinity.
This study involved face-to-face interviews with seven adult caregivers of seven different advanced cancer patients who had been receiving home hospice care through a hospice in New York City. They included six women and one man from a variety of caregiver relationships, including two spouses, one long-time friend, one adult daughter, one niece, one long-time personal care assistant, and one sister-in-law.

Data Collection and Analysis

Data collection and analysis occurred simultaneously. Each participant was interviewed one time, and interviews ranged in length from 2 to 4 h. The interview design was open-ended, and this format was essential due to the fact that the caregivers were in a time of bereavement. The rationale was to allow the participants the time and space they needed to recollect their experiences when and as they desired. Each caregiver was initially prompted with an open-ended question, such as “What are some of your reflections on your time in music therapy and how are you coping now?” Often before the first question, the caregivers reminisced openly, sometimes grieving initially and then moving into expressions of emotions as they recalled moments of heightened communication. Tacit knowledge was attained and used during interviews, as the verbal and nonverbal communications were noted and guided the interview process. Unique explanations and perceptions were sought during data collection and analysis, for example, elucidations regarding their experiences in music therapy and the potential impact of these on the caregivers’ attitudes and abilities to cope with the loss.

In reviewing the transcriptions, several questions guided the analysis, as the aim was to explore emerging themes by delving into the caregivers’ specific areas of interest with regard to their experiences: “What are the specific salient features of their reflections?” “Which topics are they naturally addressing in interviews?” “What is the essence of their reflections?” “What meaning do these reflections have in the scope of their lives?” Transcription and analysis of the interviews began immediately following the first interview and proceeded by analyzing the transcribed interviews in detail, highlighting important ideas and themes. Each theme was then coded and recoded. Theme categories emerged across interviews.

Triangulation was achieved through comparing sources of data, such as the interview transcriptions, field notes, and researcher journal entries. Journal entries served to assist in sustaining self-awareness and maintaining open-endedness in grasping the meaning of the participants’ reflections on their experiences. This was an important aspect of data review, particularly in view of the preexistent therapeutic relationships. Trustworthiness was established through member checking and peer debriefing; that is, preliminary findings were presented to several caregivers in follow-up meetings and to peer palliative care health care professionals to confirm that the themes reflected their experiences.

RESULTS

Themes that emerged from the data were categorized into two areas of foci: (1) sustaining themes, themes describing their overall responses to experiences in music therapy, and (2) reflection themes, themes that described the topics naturally addressed by the caregivers (see Table 1).

Sustaining Themes

Analysis across interviews revealed that the caregivers’ experiences stirred these sentiments and characterized their overall responses. Sustaining themes were the themes that pervaded the interviews throughout a range of topics and were those overall feelings and reactions that seemed to nurture and motivate the caregivers through the illness and beyond. The two sustaining themes were (1) joy (autonomous joy and empathic joy) and (2) empowerment. Although these sustaining themes are not necessarily subsumable under the category of “spiritual experiences,” they were salient themes that

<table>
<thead>
<tr>
<th>Table 1. Overview of theme statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sustaining theme: Joy</td>
</tr>
<tr>
<td>Autonomous joy</td>
</tr>
<tr>
<td>Empathic joy</td>
</tr>
<tr>
<td>Sustaining theme: empowerment</td>
</tr>
<tr>
<td>Reflection theme: present, connectedness</td>
</tr>
<tr>
<td>Reflection theme: past, remembrance</td>
</tr>
<tr>
<td>Reflection theme: future, hope</td>
</tr>
<tr>
<td>“These times were times of great joy and pleasure.”</td>
</tr>
<tr>
<td>“I loved the music and felt uplifted by the sessions.”</td>
</tr>
<tr>
<td>“My joy was seeing him feel happy.”</td>
</tr>
<tr>
<td>“I feel happy that I was able to help and give something to my loved one.”</td>
</tr>
<tr>
<td>“In these moments, I found connection with my loved one and the greater scheme of things in my life and our lives.”</td>
</tr>
<tr>
<td>“My life has been a long and full journey. I am grateful for my loved one.”</td>
</tr>
<tr>
<td>“I am finding such peace in the music and am looking forward to doing some of the things I want to do.”</td>
</tr>
</tbody>
</table>
encapsulated their overall responses to their times in music therapy.

Joy

These times were times of great joy and pleasure.

In examining reflections on their experiences, the theme of joy prevailed throughout interviews. Although some caregivers did not use the word “joy,” the term portrays the fundamental nature of the mood that was conveyed by all caregivers and the general happiness they felt as a result of the positive effects of music therapy. The term “joy” depicts the qualitative character of their expressions. Data revealed two subthemes regarding the derivation of joy: autonomous joy, when the music affected the caregiver’s feelings of happiness directly—“I loved the music and felt uplifted by the sessions”—and empathic joy, when the caregivers’ joy was a result of witnessing the patient’s happiness—“My joy was seeing him feel happy.”

Autonomous joy. Music had a direct effect on each of the caregivers as they witnessed and participated in the music therapy sessions. They articulated wanting to be near the music and found the sounds to bring pleasure. They also referred to the internal pleasure of the presence of music and the experience of singing. This joy exemplified their personal responses of happiness and contentment resulting from the music therapy sessions:

I have been a sociologist, … a teacher, … a photographer, but what I really would have liked to do in my life was to sing… So the music always affects me, especially when the voice is involved … the pleasure of singing … so music affects me very much and I understand it can affect people in a positive way. It is liberating and also what comes out is irrational. These feelings are something you cannot describe with words. You let yourself roll. And the sounds are also pleasing and soothing … So it brings serenity and joy to everybody. … The times in music were such a brightness for me. It was a physical activity that we could engage in. We could sing the songs that we each like. So, I enjoyed it a lot for myself too.

Empathic joy. Empathic joy may be thought of as that joy a person derives from seeing someone else happy. In experiencing this form of joy, the individual tends to base his or her emotional responses of happiness on how another person may be feeling, that is, in this case, the patient. Empathic joy was a common trend across interviews and was heard in comments that reflected this thought: “The music therapy brought her happiness and therefore I felt happy.”

The caregivers unanimously talked about this aspect of the times for them, and described, in their own words, the joy and happiness they felt in seeing their loved ones happy, relaxed, and smiling. This was a striking theme and signified a sense of deep concern for the patients’ well-being and their own sense of relief at not seeing the patient in pain, discomfort, agitation, and sadness. These memories stood out as significant moments for them, and they all experienced some form of emotion, ranging from tears to laughter, as they recalled seeing these positive responses in sessions. The caregivers conveyed that feelings of joy seemed to assist them in preparing for the eventual death of their loved ones in that they knew the patients had moments of contentment and peace before dying. Empathic joy, then, seemed to help sustain them through the death and during bereavement:

Music helped me because of the effect on him, not so much as the effect on me. Of course, I love to hear music, but this was a special occasion in which music had a different meaning. … In this case I was with him. … He [patient] was going back to being himself, like when he was singing, … which was typical when he was happy, and so I was happy too because I saw something of him that I thought had disappeared completely … and he was happy and so I felt happier then too.

Empowerment

I feel happy that I was able to help and give something to my loved one.

A second sustaining theme that prevailed was empowerment. The caregivers each described the relief, comfort, and fulfillment that they felt in being able to bring pleasure, as well as allay some of their loved one’s distress. These experiences seemed to be helping them cope during these final stages and during bereavement. The feelings of empowerment they attained in, and as a result of, music therapy helped reduce their own sense of helplessness and facilitated their preparedness to let the patient “go in peace,” as one participant stated:

I was able to help give her the pleasure of music in the sessions and was able to give back to her the way she gave to me for so long. It was hard to see her in pain. Our singing brought her peace and comfort and I could smile and laugh again. … For me it brought me a sense of peace that I helped her in this way and did bring her something.
She really did thank me for arranging the music therapy.

Narratives described caregiver feelings of great happiness, comfort and overall relief as they experienced and recalled the longer lasting effects of their times in music therapy. The data demonstrated that these sustaining themes aided the caregivers in feeling strengthened and uplifted as they progressed through the illness and into bereavement.

Reflection Themes

Analysis also revealed spirituality-laden themes that were sorted according to processes of reflection, that is, reflection themes, that categorized the naturally emerging areas of concentration on which caregivers commonly focused during the interviews. These three areas of foci were unanimously recurring across interviews: reflections on the present, the past, and the future. A further analysis of transcriptions revealed these themes: (1) reflection on the present: connectedness; 2) reflection on the past: remembrance; and 3) reflection on the future: hope. The caregivers ruminated on the present, including their current state, as well as the meanings of their “in the moment” experiences with the patient in sessions; their lives in the past, with and/or without the patient; and on the future. These processes of reflection seemed to guide them into understanding the gestalt of their lives and were processes that were described as having been inspired by the music therapy sessions.

Connectedness

In these moments, I found connection with my loved one and the greater scheme of things.

Caregivers collectively referred to the theme of connectedness. Connectedness in palliative care is understood as a concern with the experience of relationship, for example, intrapersonal, interpersonal, and transpersonal (Reed, 1992). It pertains to the search for a holistic view of one’s life in relation to self, others, and the infinite (Chao et al., 2002; Edser & May, 2007). People coping with the end of life tend to seek for life and relationship completion through relatedness with past, present, and future (Byock, 1996).

Caregivers’ comments indicated an interest in three areas of connectedness. These three subthemes emerged, then, as (a) connectedness with self (patient-self—observing the patients’ self-connections—and caregiver-self—caregiver’s identity with and subjective awareness of self in the larger schema of their own lives); (b) connectedness with others (their sense of connection with the patients and significant others and experiencing deeper communion with them in sessions); and (c) connectedness with the “beyond” (their own sense of connection with the infinite, a supreme dimension, or the “beyond,” through references to God, angels, and previously deceased loved ones).

Connectedness with self: patient-self and caregiver-self. Patient-self: The caregivers were intrigued by the power of music therapy to help restore the patient’s connection to the patient-self and referred to two aspects of this theme: the patients were brought “back to life” and had a “renewal of self.” The majority of caregivers found that the sessions tended to help revitalize and reawaken their loved ones, and conveyed the significance of these unequivocal responses. Coming back to life and having a renewal of self were striking themes that often signified their being able to partake in interactions and being able to see glimpses of their personalities, attributes, and strengths once again. Across interviews, caregivers commented on their observations of seeing loved ones display personal traits in music therapy sessions that had otherwise been absent during this stage of illness. The implications of this trend are significant, as caregivers were given opportunities to communicate with and re-view the patients’ qualities. Patient-self connections seemed to serve to assist them in gaining a deeper understanding of the overall purpose and value of the patients’ lives:

In the beginning it was a great surprise and pleasure when the first time you came, and he was kind of comatose; he was with his eyes closed and he was not speaking, and you started playing and his lips started moving and then he starts singing, with a very soft voice, but he became alive again, and before he was not communicating with anyone; and more and more than in the other days, his voice was much stronger and he was obviously enjoying it tremendously, which was an incredible surprise because he was very passive and kind of like in a coma, detached with no response. He was remembering more of his life, because in his life... he liked to sing “Goody, Goody” and others. I never heard them before and knowing that they were coming after 50 years of just being inside him and noticing he was also left more alive after singing and was not falling into his coma; he was awakened. The effect was lasting also. So this was the first great impression, seeing someone who comes back to life. He was not half dead anymore. Because of those times, I can remember him again,
with his personality, and can remember him as a living person.

Another caregiver explained these thoughts regarding “coming back” in music therapy in such a subtle and gentle way as to allow for final communications to occur:

And while I had a hesitation about kind of bringing my mother back, I wanted to let her go; when you came and played, she came back to us enough. It didn’t seem disruptive to her leaving. It was a very gentle kind of coming back. I feel she was only back on this level of music, was aware that the younger granddaughter was present, but she didn’t have to completely wake up and come back to full living. This was an important time for my niece to be in touch with her grandmother this way.

Caregiver-self: The caregivers made references to their own personal connections with themselves within the content of interviews. These moments of self-acknowledgement and self-affirmation were important to the caregivers, as they were able to perceive their own inner strengths and attributes and gain an enhanced sense of meaning as they reflected on their roles and the larger themes in their own lives. At times these references occurred as they discussed the music in sessions, their musical journeys in life, their personal strengths and interests, or thoughts pertaining to new or refreshed perceptions regarding their lives apart from the patient. Often interviews shifted to these self-reflections, signifying a “coming back” to self again, reconnecting to self and the life experiences that had brought satisfaction and fulfillment. These caregiver-self connections were salient themes across interviews:

I have seen the effect of the music in my work on the foundation. I was in a village that I went to and the effect was on the children that I saw… It was very rare that I would sing to someone, and I knew all those folk songs, before even him [patient], and it was not something I was singing usually, so music affects me very much. I hear more music now. There are times now when I wake up in the night with a song in my head. If I want to relax I put on music. Our times in music therapy have helped me be in touch with myself and my love for music and singing more. The music has helped bring the best out of me.

Connectedness with others. Connectedness with others was a predominant theme in this study, as caregivers unanimously made references to their thoughts and feelings regarding revived interrelatedness. Most commonly these statements emerged in descriptions regarding connection and communication with the patients in, around, and following the music in sessions. In addition, the caregivers referred to sentiments of intimacy with others present in sessions:

This was the only way of communication and activity, doing something together. In the music, we were doing something together, which was a better level also, involving feelings and all these memories that he had. When you came and sang, he opened his eyes and he smiled at me and we sang, and the songs were so old that he knew the words and he would sing…. In the music, we were together again and doing something together. Also, it was a really positive thing that finally my son and I were able to share something with him with you, that we could sing with him, do something along with him. Before we were doing something but he was very passive and he was not responding. For the first time… we were doing together something with him. And after you left, he kept singing.

Connectedness with the “beyond”. The third prevalent connectedness theme was association with the “beyond.” Caregivers indicated this by using various terms and focusing on an existence beyond this world. This connection was described in words such as “God,” “faith,” “angels,” “moving on to another place,” and feeling the presence of deceased loved ones. References were made to music and its potential to act as a medium through and by which a relationship to this realm could be made. Experiencing communion with this domain seemed to inspire faith, offer support, and to instill a deeper and clearer sense of meaning for them:

When I heard the music, I heard the angels with us and felt like I was talking to God. I knew she [patient] was seeing her loved ones as we sang, even though they were somewhere beyond us. I know she is happy and in peace in that place now…. In the last four nights, she [patient] was reaching a lot in the night, and really struggling and reaching, really clear that she was trying to go somewhere … and it really seemed to me that my mother could see things. She would say, “Do you see a face?” And when you [music therapist] and I sang “Wayfaring Stranger,” I could sing all those names of people who are no longer alive to her to help her “go home.”

Connectedness emerged as a prominent feature of this study. Caregivers consistently reported the
significance of the times in connectedness with their loved ones, particularly the profound manner in which music therapy sessions served to inspire their loved ones back to life and build momentous pathways of communication and rapport between them. They poignantly illustrated the difficulties in witnessing decline and loss of “livingness”: “The pain is to see the person decline and lose the best. The real pain is to see the person losing his personality, losing the best aspect of his personality. It is very painful.” At the same time, they explicitly described the striking impact of music therapy on patients’ responses. These reaching and revitalizing qualities of music therapy stood out as being some of the most memorable features in that they could again observe and access the “living” essence of their loved ones. Experiences in connectedness seemed to help them let go and prepare for death while leaving them with images of faces, eyes, and voices filled with smiles, laughter, and songs. The caregivers also expressed feeling supported by the presence of the music therapist, as well as the connections they had with their perceptions of the beyond. They all referred to the joy they felt in regard to these experiences.

Remembrance

My life has been a long and full journey. I am grateful for my loved one.

The second reflection theme occurring in the data was the caregivers' review and reference to the past. This theme of remembrance was a prominent across-interview feature of this study. The caregivers were drawn, on their own initiative, to recollect life events and reminisce about times with and apart from the patient. Their reflections were commonly inspired by the memories evoked through the songs in sessions and the broader connections these songs had to their lives. They reviewed the salient moments in music therapy, a process that seemed to assist them in feeling the joy and empowerment they articulated so clearly. Remembrance, then, seemed to facilitate the process of grief and the discovery of meaning in their overall lives.

The reflections in the interviews were centered on memories relating to the music:

But when he was happy he would sing “What a Friend We Have in Jesus.” And I remember we were once at the sea in Greece, sitting in front of the Temple of Adur. It was very nice, and he started singing this song, the first time I heard it. And also Joan [step daughter] heard it. Again, we were on vacation and there was the beautiful landscape, and he started singing. In our times with you [music therapist] he wanted to sing this song together again.

At times, the caregivers ruminated on their childhoods and other memorable life events:

It [the music] is something that has me very connected to my mother [patient]…. Most people had very negative messages, everybody except me. We came from a very loving home. We had good lessons. We had a lot of freedom. We were respected. I had a good childhood. I had good parents, consistent parents…. Every day my mother had a great day. She sang daily and enjoyed whatever she did. So, there’s what she showed me.

Other contemplations pertained to the events surrounding the actual death. In the following, a caregiver spoke about her words to the patient before she died:

[I told her] I love you and whatever is your decision, I’m with you. I’ve been with you all the times so whatever you want.” … She looked at me and she smiled and I got closer and she gave me a kiss…. She never said “I want to die” until that day. So I respected that. But I am so glad I had the chance to tell her this. We then played her that song we always sang with you [music therapist].

Remembrance occurred frequently throughout the interviews. Through such reflections, caregivers seemed to be acknowledging their lives and finding deeper existential meaning of their living-through-loss experiences. Remembrance was most frequently motivated by the memories of times in music therapy, as the impact of the profound effects of the music inspired them and led them to further life review.

Hope

I find a place of peace in the music and am looking forward to doing some of the things I want to do now.

The third reflection theme emerged as the caregivers considered the future and thoughts pertaining to hope. Hope has been defined as an inclination toward something that we do not know (Aldridge, 1995) and an inner power directed toward enrichment of “being” (Herth, 1990). In facing difficult life circumstances, hope can be a coping strategy that can help caregivers look beyond the current state of affairs. Hope also involves an expectation and going beyond the visible facts and may be seen as a motivating force to achieve inner goals (Saudia et al.,

Several caregivers described the sense of hope experienced as a result of the music therapy, as the “transporting” effects of music were comforting and “rejuvenating.” As per the caregivers, the patients waited eagerly for upcoming sessions and described these futuristic inclinations in interviews:

It was something that she [patient] was waiting for. She would say: “When is the next time she [music therapist] is coming?” And she couldn’t wait until the next time that you were coming for the music. When we sang with her with you [music therapist], she would be in such places of joy and peace.

In other cases the caregivers referred to thoughts pertaining to the beyond in the context of hope:

I am sure she is next to God. No doubt. And we will put the words of that song we sang with you on her head stone: “You are the wind beneath my wings.”

Throughout the study, reflections on hope were commonly directed primarily toward their own personal lives. For example, several participants were thinking about specific goals and plans for themselves:

I am looking forward to doing things that I want to now. Music, yoga. I am also debating between poets to read now. I have never been able to do that easily and my mother loved “The Leaves of Grass.” I have decided to read this. She [her mother/patient] really liked this… It is to carry on with living.

Reflections on hope were present in the interviews in these various ways. Caregivers were integrating their pasts and present with an orientation toward the future. These references to the future and hope seemed to portray the participants’ readiness to move on with their lives.

DISCUSSION

Although issues surrounding caregiving at the end of life are well substantiated (Glajchen, 2004), and although research has documented the benefits of music therapy in cancer and palliative care (Hilliard, 2003; Dileo & Bradt, 2005), the spiritual meaning of preloss music therapy to surviving caregivers in bereavement has been less understood. The findings of this investigation concur with research to date that clarifies caregiver issues in advanced stages of cancer, in that the caregivers in this study described the challenges they faced preloss. Similarly, the findings in this study support the work of other authors who have reported the relevance of music therapy in addressing complex and multifaceted needs of patients with advanced cancer and their families (Aldridge, 1999; Hogan, 1999; Burns et al., 2001; Magill, 2001, 2006b; Barrera et al., 2002; O’Callaghan, 2004; Dileo & Bradt, 2005; Wlodarczyk, 2007). Moreover, the results shed further light on the potentialities for the use of this modality to assuage symptoms of caregiver suffering and provide for moments of healing and closure.

The significance of the potential for music therapy to retrieve and revive meaningful communication during these final stages of life has been documented (Gardner, 1999) and was highlighted in the current study. Bright (1988) reports that “for many families it is only through music that they see a restoration of the person they once knew…” It is the change from an active involved person to an apathetic one, that families find most distressing, so that to provide an environment in which the personality… is restored, even if only for a few minutes, is a source of joy to the family” (pp. 53–54). There is a common tendency among family members, facing the death of a loved one, to struggle with alterations in patient responsiveness. Restoration of meaningful communication prior to death can mitigate feelings of guilt and remorse and can allow for opportunities for relationship completion and preparation for death (Byock, 1997; Dileo & Parker, 2005; Hirai et al., 2006).

The caregivers in this study described the long-lasting impressions these sessions had on them, such as the joy and empowerment they experienced in times of interaction and singing, impressions that left them with memories of humanness in the midst of deterioration and decline. These findings illustrate some of the potential prospective values of music therapy during the end stages of illness.

Meaning through Transcendence

Analysis of the overall findings revealed an overarching theme: meaning through transcendence. Meaning through transcendence may be understood as an overall process that evolved over the course of time for the caregivers in this study. During the hours spent in music therapy and then during bereavement, as they reflected on times in music therapy, the caregivers seemed to be “lifted” into moments of increased appreciation and understanding of the personal value of their relationships with others and the value of their lives as a whole. They seemed to gain augmented perspectives of meaningful life experiences, facilitated through their music-centered reflections on the present, past, and future.
Meaning through transcendence, then, occurred within and across the caregivers’ experiences. The caregivers reported remembering the moments of intimacy in sessions with love, joy, and feelings of empowerment, finding grounding in knowing that they helped provide for moments of peace and happiness prior to death. They repeated words of gratitude for the gift of these moments that brought them a sense of fulfillment.

The concepts of transcendence and meaning are well understood in palliative care literature. When faced with the challenges of illness and suffering, there is a tendency to search for ways to transcend, go beyond the struggles and challenges at hand. Transcendence, then, may be seen as a lifting into new or increased understandings and a shift into expansion of self (Aldridge, 2000). Meaning, or having a sense that one’s life has meaning, involves the belief and understanding that one is fulfilling a unique role and purpose in a life that is a gift, a life that comes with a responsibility to live up to one’s full human potential, and by doing this, is able to achieve a sense of peace, happiness, and also transcendence through being connected to something greater than oneself (Breithart, 2002).

Although search for meaning tends to occur during the end stages of illness and during bereavement (Doyle, 1992; Lethborg, et al., 2008), what was unique in these cases was the milieu of the music therapy sessions. Music, in an overall capacity, seemed to act as a catalyst, facilitating transcendence out of despair and into heightened moments of awareness and connectedness. It is well known that music stirs memories and is an access into the lower context to achieve new perspectives both for the loved one ... and the family caregiver” (Gardner, 1999, p. 82). It is also known that music engages cognition, mobilizes emotions, and inspires imagery (Salmon, 2001; Dileo & Bradt, 2005). Aldridge (1995) maintains that music enables end-of-life patients to transcend, “to extend beyond the immediate context to achieve new perspectives ... when they are encouraged to maintain a sense of well-being in the face of imminent biological and social loss” (p. 107). Likewise, Lee (2005), states that “the eloquence of music to provide a non-verbal path of meaning in the face of loss is a transcendent phenomena of the greatest proportions” (p. 149). Moreover, music provides form to what may appear chaotic and can offer an important aspect of spirituality, namely hope (Aldridge, 1995). The regularizing and stabilizing influence of music can bring a mood of order to what otherwise may seem to be an uncontrollable time of flux and chaos (Aldridge, 1995). In addition, the multidimensional nature of music may facilitate transcendence due to its potential to reach a multitude of domains simultaneously (Magill, 2006b). Transcendence, then, was one of the primary fundamental aspects of their overall experiences in music therapy, providing the means through which they could each experience joy and empowerment and could attain some form of connectedness, remembrance, and hope, all factors potentially leading to enhanced life meaning.

Aspects of the music therapy experiences were found to act in a comprehensive manner toward enhanced meaning. The music may be thought of as the motivator, stirring emotions and cognitive processes, opening channels for communication, and linking thoughts to images and memories. The role of the music therapist provided the supportive presence that offered encouragement, interaction, and exploration. The presence of music and the music therapist seemed to play key roles in facilitating transcendence, the lifting in sessions that resulted in feelings of joy and empowerment. Joy and empowerment also acted as sustainers, helping provide an impetus for moving forward through times of great difficulty. The processes of reflection on the present, past, and future seemed to assist the caregivers in making sense of the course of their lives and the events therein. These reflective processes seemed to inspire broader, airplane view perspectives on their lives, affording them a sense of fulfillment in knowing that the lives of their loved ones and their own lives had and do have value and meaning.

Analysis of Music Therapist–Researcher Role

The music therapist–researcher role was taken into consideration in the study design and implementation. It was conceived that the presence of the music therapist as interviewer may influence authentic communications. Procedures for the researcher were implemented, such as journal entries and field notes, to ensure an ongoing self awareness and mindful regard of preconceived notions regarding lived experiences. In review and analysis of data, it seemed that the presence of the music therapist as researcher facilitated discussions, as the caregivers had a developed sense of trust and community with the music therapist–researcher. Caregivers seemed to relate freely and readily as they described feelings and areas of reflection, as they knew that this researcher was intimately aware of the moments significant to them. It is possible that this preexistent
relationship stirred reminiscence, as caregivers focused quickly on feelings and memories of times spent together with the loved ones. This familiarity, however, seemed to facilitate a thorough reflection on their experiences in music therapy and on the impact those moments had on them during bereavement. Although the dual music therapist–researcher relationship was found to be a beneficial aspect of this study, it is possible that it could at times be a limitation as well. Therefore, researcher procedures that include personal exploration through journal entries and field notes are recommended in order to reserve presumptions and prior determinations. The design of this study allowed for the relationship between caregivers and the music therapist to continue into bereavement, a result that seemed to offer them opportunities to process grief and receive support from a familiar health care provider.

Limitations

This study had some limitations. It was a small study with seven participants. A larger study would allow for opportunities to learn the viewpoints of more caregivers. After seven interviews, a saturation of data occurred, as emergent themes were consistently recurring. Thus, study sample seemed sufficient. Nevertheless, a larger study would allow for the potential discovery of more themes of significance. Another possible limitation of this study is that the participants were at varying stages of bereavement, ranging from 2 to 9 months postdeath. Although this did not seem to affect the themes, as the themes were consistent across interviews, a study focusing on the meaning of the music therapy experiences at different stages of bereavement may be informative. In addition, whereas this study sought to examine the experiences of caregivers in bereavement, future research to look at the meanings as perceived by the patients would provide music therapists the opportunity to understand the spiritual views of patients during end-of-life stages.

CONCLUSION

The findings in this study illustrated that preloss music therapy can assist caregivers during bereavement. As described throughout the narratives, sessions with their loved ones provided for moments replete with joy, pleasure, and fulfillment rather than sorrow and lamentation. For the caregiver, the value of such moments, when considered from a whole-life perspective, is remarkable. Experiencing a loved one come back long enough in episodes of intimate communication in music therapy to be with loved ones again can have lasting impressions. These moments can allow for relationship completion, lead to healing, and inspire improved appreciation for the value of one another’s lives. Such healing generally proceeds into the future, from generation to generation, as dying can take on new associations and meanings.

It is understood that care of the caregivers has long-lasting ramifications, potentially providing for healthy outcomes of grief and bereavement. This study demonstrates the intrinsic value of music therapy in this arena, as the caregivers described the ways in which they, along with their dying loved ones, were able to transcend their suffering and acquire deepened meaning through their musical connections and reminiscences. They reiterated the comfort they felt in knowing that they helped prepare the path for a peaceful death through the provision of music therapy, a milieu within which there were moments of shared songs, stories, and smiles. During the end stages of illness and beyond, the essence of the value of music therapy may be viewed as a gift beyond measure.

ACKNOWLEDGMENTS

The author thanks the following people: the caregivers who participated and the patients and staff of the Cabrini Hospice, New York City, New York; the faculty of New York University, Barbara Hesser and Kenneth Aigen, and also Jimmie Holland, M.D., of Memorial Sloan-Kettering Cancer Center, for their advice and support; and these colleagues: David Aldridge, Nessa Coyle, and Cheryl Dileo, for their suggestions, contributions, and support.

REFERENCES


