Music Among Family Carers of People With Life-Threatening Cancer

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Abstract

Family caregivers of people with cancer may struggle as they observe the effects of the illnesses and experience the demands of caregiving amid potential loss. In order to provide beneficial support, health care professionals need to understand factors that promote caregivers' resilience. This research explored the role of music. Twelve caregivers were recruited and data were collected through questionnaires and semi-structured interviews. Data analysis was informed by grounded theory. Six thematic findings emerged: caregivers' music backgrounds affect their cancer experiences; caregivers' use or nonuse of music is associated with how they cope with the patients' illnesses; music can help improve biopsychosocial and spiritual well-being; music can be used in caring; music may intrude; and music is recommended. Recommendations are that health care organizations providing supportive cancer care might consider offering music-based care and that health professionals may consider inquiring about caregivers' musical lives to increase their understanding about caregivers' resilience or vulnerability.

Keywords

cancer, family caregivers, music, self-care

Introduction

When diagnosed with cancer, patients receive attention from health workers and social networks as they struggle to understand its ramifications and attempt to maintain dignity and control. Family members are also adjusting, as they experience its toll on the ill person, threats to future plans and potential caring roles. When the illness is noncurative, family caregivers also report anticipatory grief encompassing heightened anxiety, depression, fear, sadness and anger, and difficulties with sleep and concentration.¹

In health care service delivery, the term "carer" (or "caregiver") typically denotes the unpaid or untrained person providing care to an ill person.² While caregivers of those with cancer are often family members, they may also encompass people close to the person, including friends.^{3,4} Caregivers provide informational, tangible, and emotional support⁵ and can enable people with advanced cancer to remain at home which is usually where they wish to be.6 The needs of caregivers of patients with cancer are widely unmet, ⁷ and their problems may include poorer quality of life, increased stress and tiredness, psychological issues (eg, anxiety, anger), and autonomic imbalance. While care at home may be challenging, caregivers also report finding satisfaction through improved communication, patient comfort, and sense of control. Formal interventions to support caregivers have improved their feelings of preparedness and competence, 11 however, few studies have included well-defined interventions. 12

Although literature is addressing issues relating to the needs of family caregivers, ¹³ there is less attention on factors affecting their endurance. ¹⁴ While often forgetting their own needs, caregivers only sometimes recognize the importance of remaining healthy, including taking a break. ¹⁴ Further examination of how caregivers deal with their care of patients with cancer is warranted in order to inform ways that health workers can support them in their role. ¹⁴ This study examines caregivers' use of music for self-care.

Music has played a fundamental role in maintaining health and well-being since ancient Egypt and Greece, ^{15,16} however, its presence within "modern" health care is less evident. ¹⁷

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Table 1. Questions/Statements Guiding Interviews

What does music do for you?

Please described music you like, dislike.

Please describe how you use music in your life.

Did your involvement with music changed when your (relative/friend) was diagnosed with cancer (and if so how)?

Does music have any spiritual connection for you?

What do you think about the sound environment in hospital?

What recommendations do you have regarding music for hospitals, other caregivers?

Is there anything else you would like to tell me about your music experiences that you think may be helpful for this study?

Please describe your experiences of music therapy, if any.

Further questions spontaneously created to extend and clarify novel descriptions about the role of music (or not) in their lives.

Music therapists are reintegrating music into health care through the creative use of music-based methods in therapeutic relationships, including improvisation, musically supported psychotherapy, and song writing.¹⁸ The positive impact of these strategies is especially evident in oncology and palliative care.¹⁹⁻²⁴ Music therapists have supported caregivers through family sessions incorporating song writing²⁵ and song sharing,²⁶ and through patient and caregiver group work.²⁷ Bereaved caregivers have reported feeling a sense of relief²⁸ and meaning through having participated in and witnessing music therapy with their dying relatives. The experience brought them joy, hope, and a sense of transcendence, connectedness, and empowerment.²⁹

People with cancer diagnoses have reported using music for self-care to promote coping³⁰ and alleviate sleep difficulties,³¹ fatigue, and pain.³² These findings indicate that patients can helpfully and spontaneously use music for self-care in ways that do not involve professional staff. There was no research found, however, on caregivers' use of music for self-care. Through understanding how caregivers use music for self-care (ie, without professional staff intervention) when caring for people who are diagnosed with cancer, health professionals may learn more about music's association with coping and may also be able to promote the efficacious use of music for self-care among other caregivers. Hence, the question guiding this study is what is the role of music in the lives of caregivers of people with life-threatening cancer (hereafter called patient, see note 1)?

Methods

Sample and Recruitment

People caring for someone with life-threatening cancer were eligible. Purposive sampling was used: people considered able to share stories about music's relevance in their caring role were invited to participate. These included people who had previously described music's significance, or lack of significance in their lives to maximize variation in the sample. The first author's previous music therapy clinical experiences in a 94-bed comprehensive cancer center and 36-bed hospice in Melbourne, Australia, informed some invitations. The first

author also invited staff coworkers, patients, and family members associated with these hospitals to ask caregivers for their permission for the first author to contact them, when they believed that the caregivers would be able to contribute helpful information about their use of music. Caregivers could also self-refer after reading information posters (see note 2). Human Research Ethics Committees at Peter MacCallum Cancer Centre and St Vincent's Hospital, Melbourne, approved the research.

Methods

The study encompassed a constructivist research approach that reflects the understanding that people's interpretations of their world differ according to their backgrounds.³⁴ The grounded theory research design was selected because it is an approach through which phenomena can be explained by analysing participants' interpretations.³⁵ It has also been previously used in music and medicine^{36,37} and music therapy research,^{38,39} including oncology.⁴⁰ Grounded theory also allows the use of multiple and varied data sources.³⁵

Caregivers completed a brief music demographic questionnaire (see note 3), which asked where and how often they listened to music before and since the patient was diagnosed with cancer and whether they had ever performed music. They also partook in an audio-recorded semi-structured interview. Questions and statements to elicit reflections about music's role are in Table 1. The predominantly inductive, iterative, and comparative data analysis involved textual coding, grouping comparable codes into categories, and grouping comparable categories into themes. Funding restrictions limited sampling time, therefore the potential for data saturation (as needed for theory development) was unknown. Grounded theory may inform studies in which data analysis ceases upon thematic development of the findings.⁴¹

The first author conducted, transcribed, and initially analyzed the interviews with data management software assistance. A qualitative inter-rater reliability process promoted interpretive rigor. Two other authors read the transcripts and the initial analysis and provided feedback which was integrated into the final analysis. The three authors agreed upon the final representation of the findings.

Sociodemographic profile. Of the 12 adult caregivers who participated in the research, 10 lived in a large city and 2 in country areas. Ten were female. Interviews were conducted between May 2008, and April 2009. One caregiver was aged at least 70, 7 aged 45 to 69, and 4 aged 21 to 44. Relationships to the patient included 5 wives, one female partner, 2 mothers, and one each of father, daughter, son, and friend (who described the patient as "my sister"). Eight lived with the patient and another had lived with the person during treatment. In all, 5 cared for people aged from midteens to 44 years, 4 cared for people aged 45 to 69, and 2 cared for someone at least 70 years (one person's age was unknown). Time since cancer diagnosis ranged from 6 months to 10 years.

Four were initially invited to participate by patients who were involved in related research. Two responded to hospital posters. Four were invited by cancer hospital staff and 2 were invited by the first author. Eight caregivers who were also invited to participate declined or expressed interest but did not follow-up.

Overview of music interests. A total of 6 respondents stated that they chose to listen to music "now" every day, 4 listened a few times a week, one listened less than once a week, and one seldom listened. Before the cancer diagnosis, 7 chose to listen to music every day, 2 a few times a week, 2 about once a week, and one "seldom." Three people listened to less music "now," and 2 listened to more music "now." People had regularly listened in the car (11), home (11), work (one), and live music venue (one). Since the diagnosis, one wife listened to less music at home and live music venues, and another wife had stopped paid employment and listening to music there. Five had previously played instruments (piano, flute, or guitar) or sung in public. Two had hearing loss. One was minor but another needed hearing aids to appreciate music. Interview length averaged 58 minutes (SD 9.1 minutes). A caregiver's letter received after their interview was also used as data with permission.

Transcripts were condensed into 589 codes, 13 categories, and 6 themes. Themes and statements informed by the categories, codes, and text follow. Caregivers' quotes are included in italics to illustrate.

Theme 1: caregivers' music backgrounds affect their cancer experiences. Caregivers were distressed by the patients' cancer diagnoses as they faced uncertain futures and often had altered roles or life plans. Their musical backgrounds often affected their use of music in their caring roles, or for self-care, as indicated in the following quotes:

I wasn't aware until he got sick at how important (music) was for me....I put them on my little ipod and I'd go to bed and that would... settle me down the night. (wife)

I was pulling out my old favorite (after daughter's diagnosis) and I know they were self-soothing...I'd had (used it for) bad hip pains....

One caregiver described music's negligible effect throughout her life, and another caregiver's background apparently intensified music's association with loss, mitigating its potential for self-care:

I completely lost interest in music listening probably for 8 or 9 months (after husband's diagnosis)...my father adored music and he died...I was 11 and so we didn't have any more music...I suspect on an unconscious level there's that association too.

Theme 2: caregivers' use or nonuse of music is associated with how they cope with the patients' illnesses. Caregivers' favorite music included popular songs from the 50s to contemporary. They also favored varied genres, including jazz, blues, sacred,

classical, and/or silence. When patients were diagnosed, the preexisting preferences for music did not change for the caregivers, however, their musical behaviors sometimes did. Four said they listened to less music (see note 4). One wife was "so stressed . . . I couldn't even cope with the music . . . I was carrying everything . . . because all (he) could do was just survive." Recently, though, her husband went on a holiday with a friend and, she said, "the first thing I started to do, I went back and put music on." Another young wife used selected music to help her deal with emotions related to her husband's deterioration:

I think you're always grieving for the life that could have been, that we don't have....Mum would go, "Ooh you've been listening to that song ("Your Sympathy," by Mika, see note 5) again," because I'd be all upset (after visiting husband in hospital). "Yeh, but it helps"...just release a lot of emotion that had gone on for the day and I'd have my cry and then I'd be ok again.

This music was turned off, however, if she did not want to connect with the emotion:

Having this new treatment...every single night he's here (home) and it's ok...I don't sort of feel the need to listen to music any more to make me cry...I don't want to go back to feeling depressed all the time...I need things that will lift me up...just sort of a fast beat and jumpy.

Two caregivers also described being more selective with the instrumental music that they were listening to since the diagnoses. One preferred low sounds because high pitches reminded of chemotherapy pumps. One wife used rainforest music and Pachelbel's Canon in D to help her get to sleep. Unexpectedly though, the Canon occasionally overwhelmed and she needed to turn it off.

Two caregivers were listening to more of the patients' music preferences because of the time spent with them. Four caregivers described comparable music behaviors since before the cancer diagnosis, however, one "became critical of my sound machine and it became imperative that we replace it." Three caregivers also said that unfamiliar music was enjoyed more now. Two speculated this was because it did not have emotional connotations, and another believed this was because it was loud and quick (i.e., Mahler's First Symphony), rather than slow and "wistful." One mother tried to remain connected with "emotional" music:

(Listening to favorites songs from the 60s)...sometimes...the words will set me off, or sometimes I have to turn off the radio-(because it) makes me cry.... If I'm with others it doesn't happen...maybe it's good that it gets it out of me. (After I feel) not better...I'm sort of down and then it's like a wave...you can't be happy during this time....(But I still listen to music) because you can't stay away from the emotion...you've got to be strong.

Increased stress related to caring and worry could also make the process of tracing and organizing music for self-care difficult, as evident in this example:

While she was going through treatment... I was just struggling hard to find calming music... like a male choir or a Tibetan (humming sound)... but was too busy and I was too stressed to try and locate it. (mother)

Theme 3: music can help at biopsychosocial and spiritual levels, and can enable connectedness with the patient. All caregivers believed that music was helpful, encompassing emotional, physical, communicative, supportive, empathic, affirming, transformational, cathartic, distractive, or stabilizing elements, at minor to profound levels. Music was selectively used to alter thoughts and increase productivity, as evident in the following:

Soothing music I just find really stops my mind from just straining in a place where I don't want it to go. . . . I'll be more productive. (son)

I can think this thinking's about (husband) off (see note 6) and ... just enjoy the music and get on with the job I am doingwhen you need to think ... you can switch it off and it doesn't answer you back. It doesn't give advice ... it's just a great comfort.

Some caregivers wondered about how the music they loved could make them feel sad, and how they sometimes desired silence. They may have also thought that these responses were unusual. A mother's selective use of music for headaches after her daughter's diagnosis also illustrated music's potential to soothe:

... sacred music, ... classical arias, Ave Maria ... Morriconi's oboe. I found that a great way to release emotion, have a good cry ... (music) was a unique private way to acknowledge and release it.

Music-based strategies that caregivers used to feel in control and enhance quality of life or to promote sleep included listening to selected music, actual or imagined singing, and dance or relaxation techniques. A partner of a newly diagnosed patient said:

I get worked up, my heart races occasionally and I have anxieties...singing to myself...regulates my breathing and everything...I'll start singing a song in like triple time...and I'll slowly, slowly, slow down...it kind of does calm me.

Caregivers could also feel connected with the patient through shared music listening or dancing, or comforted through knowing that such connection would remain, even if the person died, as the following examples highlight:

They were long days...when (patient with glioblastoma) wasn't well enough to really do anything...we didn't have to sort of talk the language, we could just listen to it and it was very soothing...the music seemed to take it over and just make it tolerable. (friend)

When I bought that CD I've thought...whenever mum dies I'll be able to listen to the music and I'll remember her. (daughter)

Four described music as company or supportive friend, reducing isolation or helping with an alternating sense of "anticipatory grief" and optimistic future when the disease was episodic. One mother described how music supported when it was "almost a burden" being with other people. Others said:

(Listening to radio is) sort of keeping to yourself but a bit different because I still let go of all of the emotion...there does seem to be some level of understanding...almost feels like a friend singing a song. (wife)

It's a very confused state to live in ... you feel as though you've got to prepare yourself and you feel guilty for doing so ... so you put on piece of nice music and try and forget it (or) ... debrief yourself ... it's just a very useful comfortable tool ... a good friend. (wife)

Anticipated use of music was also associated with hope and comfort:

I just always hoped I would have the chance to get (music) back or for how it used to be. (wife)

Music gives me joy, it gives me confidence and it's good for me to practice ... singing ... it keeps a sort of hope alive that I might do something musically again. (wife)

It is comforting knowing (music's) there and I just chose to not really access it. (daughter)

Music's connection with the caregivers' spirituality was either nonexistent or expressed through hope, belief, relief, peace, calm, beauty, validation, or God's presence. These attributes could help caregivers' coping, as evident in the following:

(Music) is like transformation into another world. It's relaxation. It's a spiritual connection. It's an emotional broadening, emotions at times that's hard to express or communicate...it leaves a lovely feeling,...it's just like something's touching my heart and I need to get it out somehow. (mother)

One respondent's spirituality was experienced when she felt "at one" with nature sounds that matched her mood. Others were drawn to either lyrics or traditional musical elements and their associations, as illustrated in these respective examples:

There's one (song) that's called, "Dedication" and it's saying we're dedicated to God and... "we'll live or die,"...I think that's what's kept me going is my faith. (wife)

When (daughter) was diagnosed I went (to synagogue) that first Saturday...some of the tunes...elevate me...and I sat there crying a lot...I needed to be in the familiar sounds...I believe that God is helping us through it Something about the tunes. A great and powerful God...the words are very much secondary.

One person described sacred music as "an expression of God in the universe." She found, however, that sacred music did not offer her solace because it was too emotional. Other caregivers also said that specific characteristics of music were disliked

("angry, noisy" and death metal) or sad and frightening (adagios, violin, minor keys, certain voices and chord progressions).

Many caregivers specified that live music was enjoyed because it could affect them differently or intensify the emotional experience. One favored, and two seemed just as content with, recorded music. While most of the helpful effects described were from the purposive selection of recorded music, live music was also sometimes sought for its comfort (as in the earlier synagogue music example).

Theme 4: caregivers can use music and music therapy to support the patients, which can bring caregivers relief. Caregivers described how pleased and relieved they were when they helped the patients through supporting their use of music, as evident in the following:

She's been part of a musical community...so we just put all of our energies, making sure that she was participating (when going through cancer treatment) making sure that's what she really wanted to do....It was enormous, absolutely enormous relief...she's able to emotionally express herself through the music, and then hearing other types of sounds around her, I think that was protective, nurturing, nourishing, kind of healing, healing the spirit. (mother)

I don't know what's on his MP3 player...if he needs his battery recharged (in hospital) he'll just ring one of us (children) up...he's always got his headphones on...(otherwise) he'd be going mad. The fact that he's not crawling up the walls makes me feel good. (son)

There were times when he would be extremely distressed because he was in pain...and it didn't work all the time but quite often, if I put (Viennese Waltzes) on...that would help him get through it. (wife)

Finally, music therapy, which was experienced by three caregivers, enabled relaxation, escapism, and/or enjoyment and was observed to be helpful for others.

They were like in a little prison cell (in hospital) and everything's revolved around everyone's sickness, and (music therapist) would come in and it was just like fresh air....We had something else to talk about that wasn't sickness....It was just wonderful. (wife)

Theme 5: caregivers found that music may intrude. One caregiver observed that music was occasionally too hard for the patient to listen to early in the diagnosis:

When she was sick ... it was still mum but it wasn't mum ... she was a different person (who stopped listening to music) and so now (she has resumed music listening) ... it's like she's got her life back and a big part of that is the music.

Furthermore, the support that music provided one patient elicited his wife's fear:

Music for (husband) is like breathing ... That's one of his ways for unwinding and for being creative ... There have been nights where it's seven nights a week (he's composed music) ... A lot... is very wistful ... I just say to him, ... "please don't play that one," because I know it's about his journey but ... "What if he does die and I'm on my own?"

Theme 6: expanded use of music was recommended for oneself and other caregivers. Caregivers recommended that hospitals offer and promote more age-appropriate music programs for patients and visitors and offered many suggestions for individuals' self-care. There were, however, divergent views about public music in hospitals. These are clarified in Table 2. The interview also increased some caregivers' impulse to further explore their relationship with music, as evident in a letter received after the interview:

I was thinking ... "Why is it I don't listen to music?" Keeping music at arm's length had helped me keep all my sadness at arm's length as well. ... I am going to open my heart to music more, especially the feeling-music, and so what if it makes me cryIt's obviously something I just need to do now. ... I was scared of it. But it is so beautiful, and I'm so glad I have had this epiphany. (daughter)

Discussion

Health care service providers need to understand and strengthen what caregivers find as "essential and meaningful" to help them continue their roles. He while music's presence profoundly sustained some caregivers of patients with "grotty" (see note 7) cancer diagnoses, music was elusive for others because caregivers did not have enough time to listen or because music was too confronting to bear. Some caregivers' valiant efforts to comprehend and endure the enormity of their loved one's threatened lives were reflected in their struggles to listen to music; however, they expressed hope that music would "return," or were comforted from knowing that music was available.

Some caregivers oscillated in what music they listened to and when they listened. In bereavement, the maintenance of "continuing bonds" is identified as an adaptive process of engagement and disengagement as a new connection with the lost person is constructed⁴⁴ and the dual-process model of coping states that this process oscillates between confronting and avoiding grief tasks. 45 A comparable process of alternately confronting and seeking refuge from losses and fears was evident in some of these caregivers' use of music. They may have found particular music confronting because it carried sad and frightening connotations of their loved one's vulnerability, embodied in lyrical identifications, musical sonorities, and memories. At other times, caregivers used music as a diversion. Such relief is important when dealing with the constant hardship of uncertainty and threatened loss. People found refuge in either familiar or unfamiliar music. Music also contained, providing a "place" for being with fraught emotions and

Table 2. Caregivers' Recommendations About Music for Organizational and Self Care

	Organizations Providing Support for Cancer Patients and Caregivers
Public music	People have divergent views about public music in hospitals. One was adamant there should be no music because it would give the message that they were "trying to cheer you up." Others thought live music would break monotony. One recommended instrumental chamber music (eg, Bach and Vivaldi) at a volume "where you don't necessarily identify the piece" to mitigate the hospital's "deathly silence."
Music libraries	Should be available so that patients and caregivers can download music onto mp3 players. CDs and DVDs including stories about composers and talking books, should be available. This is especially important for those too stressed to bring music from home.
Aversive procedures	Sound equipment should be available to help people through aversive procedures such as stem cell collection, in age-appropriate ways. Staff caregivers may need to be proactive in offering music to people who may be hesitant to ask for help.
Music samplers	Music samplers (ie, sound tracks of varying music types) could be available to assist people's exploration of suitable music.
Free tickets	Offer free tickets to live music (and theater, etc) to patients and/or caregivers when possible. They help people feel "cared for," "normal," distracted, and "self-soothed." Financial strains associated with cancer can reduce capacity to pursue live music interests. Even if people can afford tickets, they may be too busy to plan and organize getting them. Offer free tickets sensitively, especially to teenagers who "don't want to be a charity case (or) stand out," for example, through someone "cool" associated with a youth cancer support organization, or a Web site. Also, when organizing groups of young people with cancer to go to a concert venue, some may not want to socialize with the others but may feel comfortable going to the same venue.
Grants	To support music interests (eg, instrumental purchases) because cancer can be a "big thing" financially as caregivers may need to stop work.
Software	Offer composing and music mixing software for patients and caregivers to use in hospital
Instrument making	Offer music instrument making workshops, eg, harp and drum making.
Web sites	Provide Web sites to explain music's helpful effects.
Shared music support groups	Offer music-based support groups away from and in the hospital, for example, meditation, choir, and music and exercise. This was recommended by someone who said, "You feel very lacking in support yourself." Choice of location is important. While one carer found a support group in the hospital too confronting (because of the unwell and older people present), another found the same group helpful. Caring for others
Use music	"Bring music into it as much as you can find out what they love most." Include recorded and live music concerts and music therapy.
Headphones	Provide mp3 players with complete ear cover headphones in hospitals to block out sounds like people coughing and "throwing up."
Be sensitive	One suggested introducing music by opening with, "I have found music a very important part of my life. Do you feel like trying it in yours? another person has used it as a good friend." Start with what was liked in the past and then introduce the new music for exploring its effects.
	Self-care
Follow what your mind and body is telling you Close your eyes when you listen For release, find a song	"Gravitate to music that's going to lift you up If you need to be soothed, try to find some soothing music that suits you and also a hot bath candles around." "That's part of blocking it out, you're in a different place." "Find a nice piece of music that helps you release as well and just let it all out and have a cry because it doesn't hurt to have a cry."

enabled some to continue productive tasks, release emotion, and "move on." Importantly, music's capacity to support was associated with caregivers' individualized choice of what and where music was heard.

Research on music in the everyday life of British and American city dwellers, ⁴⁶ which found that music enabled the regulation of self (self-care) elucidates this study's findings. In the city dweller study, music was a building material of "subjectivity," a resource for identifying "how one feels" and conceptualizing this as knowledge.

One may grow tense and relax as the music does.... To play music as a virtual means of expressing or constructing emotion is also to define the temporal and qualitative structure of that emotion, to play it out in real time, and then move on. In this sense, music is both an instigator and container of feeling. 46(pp57-58)

Comparably, the caregivers in this study used music to contain as well as to release emotions and also to help alter their moods. Furthermore, music's effect arose from ways that people engaged with and interpreted music, and placed it within their sociohistorical contexts. Husic is a device for remembering and constructing who one is, putting one in touch with their capacities, and generating future identity structures. Hence, while familiar music structures may have provided

some caregivers with a sense of coherence in a chaotic and uncertain context, it is understandable that "wistful" music, resonating with a possibly frightening and even unimaginable future, became unlistenable.

While musical sonorities were most important for some people, the lyrics were vital for others. Because there is a "compression of meaning" in lyrics, listeners are invited to interpret their own meaning. Music's power to convey understanding and validation is contained within its capacity for multiple interpretations of meaning alongside neurochemical release triggered by music listening. Music's comforting properties may have also been vicariously experienced by caregivers as they observed how it supported those with cancer. This was also evident in music therapy research with bereaved caregivers. Page 28,29

Limitations

These findings were exploratory rather than saturated and further studies are needed on caregivers' music experiences to broaden understanding of music's potential role in their self-care. The findings still offer, however, important considerations for health professionals, as follows.

Practice Recommendations

Oncology staff and other organizations providing supportive cancer care services may consider implementing caregivers' recommendations for music as a supportive modality (eg, music libraries, instrument making; see Table 2). Health professionals may also inform other caregivers about ways in which music has been found helpful by caregivers in this study (eg, using music to trigger emotional release or uplift; the use of music with patients; see Table 2). Furthermore, the findings can be used to reassure distressed caregivers who are unable to listen to music that others have also had this experience, and that it may be only temporary.

Caregivers' descriptions about their musical lives may offer important insights into how they are managing their caring role, or their vulnerability, therefore health professionals may consider inquiring about their use of music. When caregivers are too busy in their "caring" to nurture themselves with music, health professionals may support their access to recorded or live music experiences. Caregivers who avoid music because it elicits high levels of distress may also be offered further psychotherapeutic support.

Conclusion

(Music) is like a best friend. . . . it'll always be there. (wife)

Twelve caregivers described how they used and/or avoided music when caring for people with cancer diagnoses, and how their music experience was often associated with the patient's illness trajectory. Music therapy, while experienced as helpful by 3 caregivers, is unfortunately not widely available for

patients with cancer and their caregivers. The findings, however, reveal that some caregivers' use of music is an important part of how they deal with their caring role, and prompt suggestions for how other caregivers can find further relief and support through music. Caregivers also shared many ideas that may help oncology staff and other health professionals to establish music-based supportive care and to enhance their communication of helpful strategies and information about music which could potentially sustain other caregivers in their roles.

This study found that music soothed, sustained, energized, and/or confronted the caregivers as they dealt with caring. Some regretted having little time for music or avoided specific music because of sad associations. It was always hoped, however, that music's life-enriching presence would return. While our life repertoire of music will always accompany us, some music needs to be "archived" when too painful to bear. When one wants and is able to, one can return to their elusive music in a new life context. While the music will continue to honor the sadness, it will also hopefully inspire a strengthened sense of one's capacity for moving onward.

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Appendix A

The following lists the likely sources of songs mentioned by participants in the text.

- "Ave Maria." Many composers have set this Christian prayer to Mary, the Mother of God, to music. Widely known versions include those composed by Bach, Gounod, and/or Schubert. Accessed September 28, 2010, from http://en.wikipedia.org/wiki/Hail_Mary.
- "Dedication." This was, presumably, "Christian Dedication" from the Worldwide Association of Jehovah's Witnesses. Accessed September 28, 2010, from http://www.jw.org/index.html?option=QrYQZRQVNZHFVP.
- "Mahler's First Symphony." Gustav Mahler, Symphony No. 1 in D ("Titan").
- "Morriconi's oboe." This was likely "Gabriel's Oboe" by Ennio Morricone. Accessed September 28, 2010, from http://en.wikipedia.org/wiki/The_Mission_(soundtrack).
- Pachebel's Canon in D. This is known as "Canon in D Major," composed by Johann Pachelbel.
- "Your Sympathy," by Mika. Accessed September 28, 2010, from http://www.metrolyrics.com/your-sympathy-lyrics-mika.html.

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Notes

- The word "patient" here is based on the Shorter Oxford Dictionary meaning "a person receiving or registered to receive medical treatment." 33(Vol II, p2123)
- Posters were general requests for people to talk about music's relevance when affected by life-threatening cancer as part of a broader study on music's role in cancer experience.
- The Music Demographic Questionnaire was designed by the first author and inspired by Table 2 in Wang et al.⁵⁰
- 4. This does not necessarily contradict the questionnaire finding where 3 said they listened to less music now: the questionnaire asked whether they listened on a day-to-day level, rather than an amount within the day.
- See Appendix A for likely sources of songs mentioned by participants in the text.
- 6. This meant music helped her to stop thinking about her husband.
- Adjective meaning "unpleasant" which was used by a wife respondent.

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