“A quiet still voice that just touches”:

Music's relevance for adults living with life threatening cancer diagnoses

Corresponding Author: A/Prof Clare O'Callaghan, c/- Caritas Christi Hospice, St Vincent's Hospital. 104 Studley Park Road, Kew, Melbourne Australia, 3101
ph: +61 3 9853 2344; fax: +61 3 9288 3399; email: clare.ocallaghan@svhm.org.au

Authors and affiliations:

A/Prof Clare C. O'Callaghan^{a,b,c,d} PhD RMT

A/Prof Fiona McDermott^e PhD

Dr Natasha Michael^b MBChB FACHPM MRCP MRCGP MSc

Dr Barbara A. Daveson^f PhD, BMus(MusThy)

A/Prof Peter Hudson^{g,h} PhD

Prof John R. Zalcberg^{b,c} MBBS, PhD, FRACP, MRACMA, FAICD

^aCaritas Christi Hospice, St Vincent's Hospital. 104 Studley Park Road, Kew, Melbourne, Australia, 3101

^bPeter MacCallum Cancer Centre, Locked Bag # 1, A'Beckett St., Melbourne 8006, Australia

^cDepartments of Medicine and Oncology, The University of Melbourne, Grattan Street, Parkville, Victoria, 3010, Australia

^dThe Melbourne Conservatorium of Music, The University of Melbourne, Grattan Street, Parkville, Victoria, 3010, Australia

^eDepartment of Social Work, Faculty of Medicine, Nursing & Health Sciences, Monash University, PO Box 197, Caulfield East Vic 3145, Australia

^fKing's College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, 6 Bessemer Road, London SE5 9PJ

^gCentre for Palliative Care Education and Research, St Vincent's & The University of Melbourne, PO Box 2900, Fitzroy, Victoria 3065 Australia

^hQueens University, Belfast, Belfast, United Kingdom

Abstract

Purpose Music has historically aided health and loss-adaptation, however, cancer patients' experience of music for self-care is not well understood. This study examines adult cancer patients' views about music's role before and after diagnosis.

Methods Constructivist approach with grounded theory informed design using convenience, snowball, and theoretical sampling. Patients from Australian metropolitan cancer and hospice settings completed demographic questionnaires and participated in semi-structured interviews. Qualitative inter-rater reliability was applied.

Results Fifty-two patients reported comparable time spent experiencing music pre-post diagnosis. Music may remain incidental, however, many patients adapt music usage to ameliorate cancer's aversive effects. Patients often draw from their musical lives and explore unfamiliar music to: remain connected with pre-illness identities; strengthen capacity for enduring treatment, ongoing survival (even when knowing "you're going to die"), or facing death; reframe upended worlds; and live enriched lives. Patients can ascribe human or physical properties to music when describing its transformative effects. Familiar lyrics maybe reinterpreted and patients' intensified emotional reactions to music can reflect their threatened mortality. Sometimes music becomes inaccessible, elusive, and/or intensifies distress and is avoided. Families', friends', and professionals' recognition of patients' altered musical lives and music-based suggestions can extend patients' use of music for self-care.

Conclusion Health professionals can support patients by inquiring about their music behaviours and recognising that altered music usage may signify vulnerability. Although commonly recommended, hospital concerts and music broadcasts need sensitive delivery. Patients' preferred music should be available in diagnostic, treatment, and palliative settings because it can promote endurance and life enrichment.

Keywords: music, cancer, music therapy, self-care, palliative care

“A quiet still voice that just touches”:

Music's relevance for adults living with life threatening cancer diagnoses

Introduction

Cancer diagnoses and treatments can overwhelm patients [1] with needs encompassing psychological, physical, information, support, and sexual domains [2]. Cancer survivors also report on-going physical symptoms and impaired daily living [3]. Thus understanding cancer patients' self-care practices can elucidate potential support interventions. Structured interviews examining 292 cancer outpatients' coping strategies found that music was the second most common self-care tool [4]. Patients use music to deal with cancer-related fatigue, pain [5], and sleep difficulties [6]. Music has also been pivotally connected with health, loss-adaptation, and social cohesion throughout the ages [7].

Music Use in Adult Life

Music is widely used during travel and physical work, and to accompany thinking, manage mood, express identity, and support reminiscence [8]. Self-selected music can distract, improve energy levels, and enhance meaning [8]. Interviews with seventeen American adults revealed broad music preferences, influences, and usages. Music enhanced: mood; work life; reminiscence; existential, social, or cultural connection; entertainment; education; and could inspire [9]. Ethnographic and interview research indicates that, rather than simply being a “stimulus”, music is also a resource appropriated by its users, affecting how people feel, view themselves, and manage their self-identity [10]. Music can also be viewed as a “medium of social order” [10^{p. 163}], for example, when transport stations use classical music to “soothe irate travellers and to disperse potential hooligans” [10^{p. 157}].

Music-Based Research in Adult Oncology

Music-based oncology research includes “music medicine”, whereby music is administered passively for therapeutic effect to a listener, or music therapy, whereby tailored music-based interventions involve assessment of client needs, ongoing evaluation, and more active music making with clients [11]. Music therapists are especially useful when people are unable to helpfully use music for themselves [10]. A Cochrane systematic review (30 oncology trials; n=1891) found significant positive effects of music medicine and music therapy on patients' anxiety ($p<0.001$), mood ($p=0.03$), pain ($p<0.001$), and quality of life ($p<0.001$) [11]. A further review (32 oncology trials; n=3191) also found significant positive effects on anxiety, depression ($p<0.001$), and heart ($p=0.02$) and respiration ($p<0.001$) rates [12]. Furthermore, qualitative and mixed methods research indicates that music therapy can enhance cancer patients' creativity,

meaning, healthy identity, social, emotional, and spiritual well-being [13], and support cancer caregivers [14].

Personal Music Use in Cancer Across the Life-Span

Qualitative research studies reveal that children with cancer and their families (n = 54) use music to promote children's coping, resilience, normality, and social-connection [15]. Adolescents' and young adults' (AYA) (n = 12) use music for endurance, identity development, hope, cathartic release, and adjustment through treatment and recovery [16, 17]. Music can also soothe, sustain, or energize cancer caregivers (n = 12) [18], while bereaved caregivers of cancer patients either use music to lessen emotional pain (mixed methods research; n = 43) [19], honor the deceased (survey; n = 50) [20], improve mood, confront grief, or avoid its saddening effects (qualitative research, n = 8) [21]. The way in which adult cancer patients use and experience music is not well understood. Swedish patients report that music can improve mood, spiritual well-being, body-mind connection, and coping (qualitative research, n = 17) [22] but further research is needed to extend development of helpful music-based care in oncology. This is the fifth and final study within a project examining "music's relevance across the lifespan" for cancer patients and their caregivers. Music's role for children, AYA, and caregivers, including the bereaved, have already been reported [15, 16, 18, 21]. This study aims to understand how music¹ is personally used and experienced by adult Australian cancer patients before and following cancer diagnosis.

Method

Design, participants, and procedure

The qualitative research design was informed by grounded theory [23] which is a constructivist research tool and now widely used in clinical research [24]. A qualitative approach is appropriate when researchers seek to understand "real life" behaviour" and constructivism asserts that perceived reality is individually, socially, and historically constructed [24]. Inclusion criteria were cancer patients over 25-years-old and diagnosed with life threatening cancer. They were recruited from a metropolitan cancer centre and a hospice ward. Exclusion criteria included marked cognitive impairment, psychiatric problems, clinically deaf, marked distress, and language skills that precluded involvement in semi-structured interviews administered in English.

Sampling was convenience, snowball, and theoretical. Theoretical sampling is a process whereby the ongoing data collected and analysed guides future sampling until no new significant data (understanding

¹ "Music" examined here focusses on recorded or live instrumental or human vocal sound.

about the research phenomenon) emerges [23]. Poster and leaflet advertisements for participants were initially placed in strategic locations in the cancer hospital and hospice. Advertisements invited patients to talk about music's role in their lives. Alongside this, CO (female first author) and hospital staff educated about the research invited patients considered to potentially provide diverse perspectives about music's role. Audio-recorded, semi-structured interviews were conducted June 2008 to November 2009 and inquired about music preferences, usages, effects, spiritual associations, music therapy experiences, and recommendations for music-based healthcare. Participants' music backgrounds and demographic data were obtained from interviews and hospital records. Hospital and hospice ethics approvals were gained and participants gave informed, signed consent.

Analysis

The inductive, comparative, and cyclic analysis was supported by data management software [25] and included: coding (researcher created labels); comparable codes condensed into categories (researcher created phrases to represent groups of codes); and comparable categories condensed into themes (researcher created labels to represent groups of categories). CO conducted interviews, transcriptions (with fieldnotes such as non-verbal gestures), and initial data analysis. Three authors (FD, NM, BD) provided inter-rater reliability [26] through reading interview transcripts, and either agreeing with and/or offering additional data interpretations which were discussed until all inter-raters were satisfied with the final presentation of results.

Results

Fifty-two patients (mean age 58 years; 30 female) with varied cancer diagnoses participated, mostly from haematology, breast, melanoma/skin and soft tissue tumor streams, 90% were Australian born. At the time of the interview, 63% had been diagnosed within the previous five years, 44% were not receiving active treatment, 38% were receiving chemotherapy and/or radiotherapy, and 19% were receiving hospice care. Thirty-three per cent of the participants were self-referred (11 female; 6 men), 40% were invited by hospital staff (9 female; 12 men), 25% were invited by CO (9 female; 4 men), and 2% (1 female) participated through snowball sampling. Further demographic details are in Table 1. Mean interview times were 68 min (SD 31.9 min; range 9-155 min). Coding, category, and thematic development are illustrated in Tables 2 and 3. Table 3 presents examples of participants' responses which informed 16 categories. Comparable categories were condensed into four themes (Table 3) which follow. Patients' music-related suggestions were summarised (Table 4).

Musical experiences are purposive or random, and encompass varied preferences, activities, and memories

Patients have used music throughout their lives to perform, learn, imagine, listen or dance to; regularly, privately, or socially (Category A1, Table 3). Music may be purposively used to accompany activities, validate, alter mood (Category A2, Table 3), or connect with one's "cause", e.g., lesbianism, and participants focussed listening on the music and/or lyrics. Some randomly (e.g., music on radio) or seldom listen to music. Music preferences similarly diverged, and included classical, folk, jazz, Broadway, spiritual, country, popular, and world-music. Many emphasized disliked music. Seventy-five percent had previously played instruments or sang, and 44% still performed. Diverse music-related memories were linked to social (77% of respondents)², entertainment (92%), performance (62%), work-life (44%), sporting (12%), spiritual (33%), and loss-related events (19%). Participants' altered music-related behaviors since diagnosis maybe associated with general life events, e.g., fewer concerts following parenthood (Category A3, Table 3).

Patients can "humanize" or "physicalize" music when describing distinctive ways in which it can enrich, transport, transform, or intrude

Preferred music can elicit helpful memories, imagery, meditation, sleep, emotions, and creative, intellectual, or aesthetic awareness. Music could uplift, invigorate, and bring relaxation, comfort, safety, companionship, pride, peace, excitement, youthfulness, happiness, love, cosiness, serenity, contentment, wonder, consolation, or solace. Music could distract from intrusive sounds, captivate, be an enjoyable journey, or enable grief expression, tension resolution, and a feeling of being alive. It could also enrich family and communal life, and support connection with significant decedents, religious practices, and deities (Category B1, Table 3).

Music's invigorating and emotional effects could linger. A 55-year-old female explained that when playing "Dirty Dancing", "we are like idiots ... singing and dancing ... forget everything ... happiness ... (for) a few hours". Music could also help some patients to "tune out", cope, "escape" to imagined places, or remember that beauty exists.

Many could not live or imagine life without music (Category B2, Table 3). Apparent dichotomous effects were also evident: Howling could comfort (Table 2). Effects could be ineffable. A 65-year-old male

² Memory descriptions were reanalysed in each participant's interview to determine frequencies of participants who reported them.

said that Mozart has “a profound effect, it’s not happiness, it’s not sadness”.

Music could also stress when not preferred or eliciting challenging memories (Category B3, Table 3). While some can ignore overheard “unpleasant” music others find it viscerally intolerable and intrusive.

Many participants ascribed music with human, organic, physical, or transforming properties. Individuals described their music “relationship”, or how music “touched”, “hugged”, “held”, “connected”, “contained”, “dragged”, “pulled”, “doesn’t betray”, goes “through your veins”, gave a voice, or was a “savior”. Music could also be a “part of” patients; “gateway to culture”; “cruel mistress”; soul; “like meeting a person”; and transport or carry patients elsewhere (Category B4, Table 3).

When dealing with cancer, music can: be a lifeline; support biopsychosocial and/or spiritual life; remain an incidental presence; be avoided; or is elusive

Although cancer patients apparently experienced comparable amounts of music following diagnosis (Table 1), and preferences often remained constant, music was often used, reacted to, and interpreted in ways which ameliorated cancer’s aversive effects. Familiar music could reflect a continuity of the pre-diagnosis person or prompt helpful identifications (Category C1, Table 3). The diagnosis could also intensify music-related distress: “Horrible” emotions evoked by music associated with a 36^a-year-old³ female’s deceased grandmother were “five times as much now”. Music’s effect, however, could remain incidental: a 53-year-old male said that music never “stirred” him and was infrequently listened to.

Many described more discerning and intense musical reactions associated with heightened awareness of threatened mortality, such as “listen(ing) to a busker a bit more”. Unfamiliar music genres could be explored: A 42^a-year-old female rationalised that cancer “fast forwarded” and condensed her creative life “like a concertina”. Some patients found that specific music helped with cancer stressors while long standing preferences continued in “normal” life. Others changed from varied to specific music preferences. A 40-year-old female stopped listening to music associated with former employment because it elicited related loss. More music was used by some patients as it remained accessible unlike other hobbies. Neural damage, musical hallucinations, breathlessness, immunosuppression, fatigue, and cancer related tinnitus or distortion could also make music listening or performing difficult.

Music could empathise, reassure, distract from fear, remove sadness, and be a friend (Table 2). Music’s nonjudgmental and unconditional attributes were especially valued (Category C2, Table 3).

³ To differentiate comments from patients with same age and gender, ^{a, b, c} are used.

Sometimes patients purposively used music to alter their mood. When the 65-year-old wants “escapism” she, “put(s) Queen on” (and) “might get over it, start to feel happy again.” Music could also affirm, encourage, and expand awareness. A 76-year-old female said music, “brings me back to who I am ... the success that I’ve made with my life ... I feel self-worth has come back.” One patient, however, admitted that music distracted from overdue disease monitoring.

Lyric identifications were empathic and potentially useful for communication. Listening to “Hero” reinforced a 36^b-year-old female’s optimistic spirit and she “played” it to girlfriends to communicate feelings. Identifications with musicians who had cancer could also inspire (Category C2, Table 3).

Some patients described spiritual connections with music: it could enable peace (Category C2, Table 3); reflect faith (Table 2); and a 52-year-old female considered that “visual flashes” during piano improvisation were “little flashes of heaven.” One Catholic patient, however, avoided hymns associated with a punishing God and death.

Many used music during treatment and diagnostic procedures to relax, help sleep, enjoy, motivate, reduce pain, or quicken or mark time. One 38-year-old female danced to music daily, adding, “It gives me a sense of ‘I’ve accomplished something’”. Her IV pole became her “dancing partner” during isolation treatment. Another 67^a-year-old female’s fatigue reduced after visualising herself as a famous singer. A 70-year-old female said, “when I’ve got a lot of pain I ... listen to music ... I can really imagine I’m back skiing ... I just move myself away from it so I don’t feel the pain”.

Music could also elicit helpful interactions with staff, other patients, and families, or separation/privacy in hospitals through headphone use. Music interests could still be shared between a 67^b-year-old female with word-finding difficulties and her husband. One 36^c-year-old female, however, felt alienated when staff forgot her radiotherapy music playlist. Live music in hospital could elicit feelings of being “cared for” or discomfort: A 67^c-year-old female “burst into floods of tears” and “was in such shock” when a familiar song was overheard during chemotherapy treatment. Music could also repel: after chemotherapy a 64-year-old female discovered and repetitively listened to Schubert’s String Quartets. While the patient said they were her “lifeline” she added that they “drove (her) daughter out of home.” Re-experiencing music associated with treatment in the recovery phase can remain beautiful, affirming, and comforting, or is avoided: a 40-year-old grieved that a favourite album, Gomez, was “tarnished” following its use during diagnostic scanning.

Some patients described periods of less or non-music use related to access problems, changed lifestyles, and cancer's emotional, physical, and chaotic effects. Music could be elusive: for some time one patient had tried but could not listen to any of his large music library (Category C3, Table 3). A 37-year-old female with disease-related headaches also had a "strong passion" for music but needed silence during stem cell transplant and had since found that music could overwhelm. All had returned to music, through self-talk, antidepressants, and/or adaptation, e.g., one composed music with computer assistance when unable to play saxophone. Some did not need nor miss music during hospitalizations as they were busy, imagined music, or feared its "contamination".

Many patients described how music helped transform "dark" and "black" cancer experiences into relaxed and enlightened states (Category C4, Table 3). Six believed that music was essential for survival (Category C5, Table 3) while others described how music enabled healing and health. Many also reflected on how music helped, or would help adaptation following treatment. One 37-year-old female had already achieved something on her "to do list" by singing, "I will Survive" in a karaoke bar and added, "it's not about not dying ... because you're going to die ... my goal is ... I will survive, or just to live it." Alternately, one 66-year-old male speculated that pain related to not achieving musicianship success would end if he died, and another 76^a-year-old male feared that cancer pain would impede his busking livelihood. People also appeared comforted when anticipating music during anticipated health decline or their funerals (Category C6, Table 3).

Family, friends, and professionals can help patients to extend or recover music's helpful effects

Patients could find memories of significant people triggered by music comforting. Music-based support provided by families, friends, teaching, and health professionals could also help patients to use music for self-care. They could: suggest or give music; share dancing, listening, performing, or music discussions; teach; help patients attend music venues; and adapt bands to enable patients' involvement. They also sometimes recognized that patients needed help when their musical lives altered and assisted them to reconnect with music (Table 2; Category D1, Table 3). Twenty (6 male) participants had experienced music therapy (10 with CO). Music therapy, including live familiar music: improved mood, relaxation, peacefulness, and enjoyment, reduced isolation and symptoms; enabled imageries of memories or enriching locations; and distracted from treatment or another dying patient's noisy breathing. Through assisting patients' song-writing music therapy connected families, and one 67^c-year-old female added that singing

and guided music imagery, “helped me to remember my love of music and its importance in our lives” (Categories D1-3, Table 3).

Discussion

The various ways in which music was used, avoided, or remained incidental amongst the 52 patients in this study provide insights into how cancer patients privately deal with diagnoses, and how others in informal and formal care networks support them through music. Patients often draw from musical lifetime experiences or explore unfamiliar music to: remain connected with healthy identities; strengthen capacity for enduring treatment, recovery, or facing death; feel supported, understood, and affirmed; find altered ways of viewing and dealing with upended worlds; continue living enriched aesthetic lives amidst health fragmentation and restoration; and survive. Families', friends', and professionals' recognition of patients' altered musical lives and music-based suggestions and support can also extend patients' use of music for self-care.

As reported elsewhere, many cancer patients found that music improves mood, healing, self and spiritual awareness [22], energy, and pain relief [5, 6], and their music therapy reactions, including symptom relief and family connection, also reinforced positive oncologic research outcomes [11, 13, 28]. The ten patients who received music therapy from the interviewer may have censored their responses to not offend, however this was unlikely because their responses were similar to those who received music therapy elsewhere. The findings also compare with four earlier studies in this “music’s relevance in cancer across the lifespan” project [15, 16, 18, 21] (n=138) in that music usage was often adapted or reinterpreted to ameliorate cancer’s distressing effects. Furthermore, across all studies some patients and caregivers with strong music attachments lost some, or all, of their musical connections through their illness experience because it: overwhelmed their senses; reminded of aversive symptoms/treatments [15]; became inexplicably unreachable or inaccessible despite efforts to play [16] or listen (Category C3, Table 3); or was purposively avoided because of emotional evocation and internal chaos identified with cancer-related loss [16, 18, 21]. Ways that family and health professionals can help patients reconnect with music were highlighted in this study, however it may not always be possible. As a 17-year-old cancer patient said in the AYA study, “I still want music in my life ... I just, I don’t know how to get it back” [16]. Importantly, altered musical behaviours in people affected by cancer may signify underlying vulnerable states hence health professionals are encouraged to inquire about their musical lives during need assessments.

Most patients in this study were nonetheless supported by music, possibly explained by music's activation of neural regions and connections involving arousal, pleasure, and opioid transmission more extensive than language [29], and its aestheticism which is associated with healthy psychobiological transduction [30]. While non-referential qualities [31], multiple meanings [32], and identifications [16, 22] associated with music are already recognised foundations for its therapeutic effect, the findings suggest that patients' human, physical, or "transporting" projections onto music are also important devices for coping. The findings support deNora's view that music's power to soothe is derived from both the musical "stimulus" and the way that it is appropriated [10]: when no-one understands, music can have an identity, express what's needed, and be dialogued with. It could also be a tool for accessing and enlightening "dark" intrapsychic worlds and "moulding" emotion (Category C4, Table 3). This affirms Winnicott's view that music can be a transitional phenomenon which mirrors and affirms one's sense of self, and thereby enables creative awareness [33]. Apperception of familiar music is an ongoing creative experience [34] which can reflect and transform cancer's adverse effects. The 34-year-old female's song title question, "Who's going to make the gravy?" (Table 2) mirrored fears about her young family, affirmed her anguish, permitted crying, and enabled personal strength.

Music can be a vehicle for "touching" (Table 2) and externalising wrenching states too intense to verbalise [35]: it can allow those experiencing devastating loss a "safe place" where emotions can dominate [36]. Arguably, music appeals because of ontological properties shared with cancer. Cancer can be symbolically represented by music experiences in ways that language cannot represent: both can be unpredictable, elusive, mysterious, and nonverbal experiences which "inhabit" body and psyche. Cancer is usually life threatening; Music is almost instantly lost [37]. Music can therefore touch, "understand", and alter cancer's effects. It can be a "virtual" means of constructing and expressing emotion in real time [10]. Music can bring harmony from dissonance; order from chaos; resolution from tension; contain and release. As one patient said, music held her internal "thrashing around" before she could let it go. It may also offer hope for survival because it continues through being reproducible in the "mind's ear" [37]. In connecting with healthy physiological processes and life memories [37], music can help maintain continuity of pre-illness identities [10], allow imagining in life beyond cancer, and render life worth living (Table 4).

Limitations and Recommendations

Given that most respondents in this study had music performance backgrounds, the findings' broader applicability are limited. To increase understanding of music's relevance when dealing with cancer further

theoretical sampling is recommended which includes people who do not have extensive music backgrounds, who continue to avoid music, and who are from diverse cultural backgrounds. Patient declines to participate in the research and their reasons were not recorded: this information could have elucidated understanding about music's possible deleterious effects and is recommended in future research. Patients most interested in music may also be more likely to participate when hearing about this kind of research.

Given the profound ways that music can help cancer patients, consideration of participants' suggestions for music-based care is considered an imperative (Table 4). Importantly, patients should be offered preferred music in treatment and ward settings. Music in public hospital areas is commonly recommended (Table 4), however, this study also found that music can occasionally distress. The use of music in cancer settings requires careful and sensitive consideration and further research on music avoidance in oncology is warranted [38] to inform hospital music-based programs sensitive to patients' needs.

Conclusion

Adult cancer patients use music as a lifeline, emotional support, vehicle to reduce symptoms, or tool to assist with living and anticipating a quality life. While patients usually adapt music usage and interpretations to deal with cancer's aversive effects, some find that music is elusive or needs to be avoided because of intensified emotional evocation or symptom related memories. Through sensitive communication and practical assistance, family and staff caregivers may help patients' recovery of aesthetic and supportive music engagement. Health professionals can validate patients' whole person (beyond patient) identities and potentially extend their endurance and coping by inquiring about music used in self-care, offer additional support if patients' altered music usage signifies distress, and enable patients' control over music exposure in diagnostic, treatment, and follow-up care. In sum, music is encouraging, accompanying, and enriching the lives of many cancer patients enduring treatment, dealing with survivorship, or transitioning from corporeal existence. Patients' preferred music should therefore be available in cancer care, and further investigation of ways to extend music's therapeutic power is warranted.

Acknowledgments

The authors thank the 52 people who shared their stories for this research.

Clare O'Callaghan's contribution was enabled through a National Health and Medical Research Council (NHMRC) postdoctoral fellowship in palliative care (2008-9).

Conflict of Interest

The authors had no conflict of interest in this study. They all had full control, that is, access to all primary data, and agree to allow the Journal to review the data if requested.

References

1. Duffy JD (2011) The clinical psycho-oncology assessment. In: Duffy JD, Valentine A (eds) MD Anderson manual of psychosocial oncology. The MacGraw Hill Companies, New York
2. Sanson-Fisher R, Girgis A, Boyes A, Bonevsk B, Burton L, Cook P (2000) The unmet supportive care needs of patients with cancer. *Cancer* 88:226-237
3. Brearley SG, Stamatakis Z, Addington-Hall J, Foster C, Hodges L, Jarrett N, Richardson A, Scott I, Sharpe M, Stark D, Siller C, Ziegler L, Amir Z (2011) The physical and practical problems experienced by cancer survivors: A rapid review and synthesis of the literature. *Eur J Oncol Nurs* 15:204-212. <http://dx.doi.org/10.1016/j.ejon.2011.02.005>
4. Zaza C, Sellick S, Hillier, L (2005) Coping with cancer: What do patients do. *J Psychosoc Oncol*, 23:55-73
5. Williams PD, Balabango AO, Manahan L, Piamjariyakul U, Ranallo L, Laurente CM, Cajucom L, Guela D, Kimbrough M, Williams AR (2010) Symptom monitoring and self-care practices among Filipino cancer patients. *Cancer Nurs* 33:37-46. <http://dx.doi.org/10.1097/NCC.0b013e3181b0f2b4>
6. Williams PD, Piamjariyakul U, Ducey K, Badura J, Boldts KD, Olberding K, Wingate A, Williams AR (2006) Cancer treatment, symptom monitoring, and self-care in adults. *Cancer Nurs* 29:347-55
7. Dissanayake E (2006) Ritual and ritualization: Musical means of conveying and shaping emotion in humans and other animals. In: Brown S, Vogelstein U (eds) *Music and manipulation: on the social uses and social control of music*, Berghahn Books, Oxford and New York, pp. 31-56
8. Sloboda J, Lamont A, Greasley A (2009) Choosing to hear music: motivation, process and effect. In: Hallam S, Cross I, Thaut M (eds) *The Oxford handbook of music psychology*. Oxford University Press, Oxford, pp 431-440
9. Crafts S, Cavicchi D, Keil C (1993) *My music: And the music in the daily life project*. Wesley University Press, London
10. DeNora T (2000) *Music in everyday life*. Cambridge University Press, Cambridge
11. Bradt J, Dileo C, Grocke D, Magill L (2011) Music interventions for improving psychological and physical outcomes in cancer patients. *Cochrane Database of Systematic Reviews* 2011(8), 1-73. Art. No.: CD006911. DOI: 10.1002/14651858.CD006911.pub2

12. Zhang J, Wang P, Yao J, Zhao L, Davis MP, Walsh D, Yue GH (2012) Music interventions for psychological and physical outcomes in cancer: a systematic review and meta-analysis. *Support Care Cancer* 20:3043-3053. <http://dx.doi.org/10.1007/s00520-012-1606-5>
13. O'Callaghan C (2009) Objectivist and constructivist music therapy research in oncology and palliative care: An overview and reflection. *Music and Medicine* 1:41-60
14. Burns DS, Robb SL, Phillips-Salimi C, Haase JE (2010). Parental perspectives of an adolescent/young adult stem cell transplant and a music video intervention. *Cancer Nurs* 33:E20-E27. doi: 10.1097/NCC.0b013e3181d4b671
15. O'Callaghan C, Baron A, Barry P, Dun B (2011) Music's relevance for pediatric cancer patients: A constructivist and mosaic research approach. *Support Care Cancer* 19:779-788. <http://dx.doi.org/10.1007/s00520-010-0879-9>
16. O'Callaghan C, Barry P, Thompson K (2012) "One of my friends": Music's relevance for adolescents and young adults with cancer. *Support Care Cancer* 20: 687-697. <http://dx.doi.org/10.1007/s00520-011-1104-1>
17. Ahmadi F (2009) Hard and heavy music: Can it make a difference in the young cancer patients' life? *Voices: A World Forum for Music Therapy*. <https://normt.uib.no/index.php/voices/article/viewArticle/345/269>. Accessed October 15 2013
18. O'Callaghan C, Hudson P, McDermott F, Zalcberg J (2011) Music amongst family caregivers of people with life threatening cancer. *Music and Medicine* 3:47-55.
19. Vale-Taylor P (2009) "We will remember them": a mixed method study to explore which post-funeral remembrance activities are most significant and important to the bereaved people living with loss, and why those particular activities are chosen. *Palliat Med* 23:537-544. <http://dx.doi.org/10.1177/0269216309103803>
20. Castle J, Phillips WL (2003) Grief rituals: Aspects that facilitate adjustment to bereavement. *J Loss Trauma*, 8: 41-71
21. O'Callaghan C, McDermott F, Hudson P, Zalcberg P (2013) Sound continuing bonds with the deceased: The relevance of music, including preloss music therapy, for eight bereaved caregivers. *Death Studies* 37:101-125. <http://dx.doi.org/10.1080/07481187.2011.617488>

22. Ahmadi F (2013) Music as method of coping with cancer: A qualitative study among cancer patients in Sweden. *Arts & Health: An International Journal for Research, Policy and Practice* 5:152-165. DOI: 10.1080/17533015.2013.780087.
23. Corbin J, Strauss A (2008) *Basics of qualitative research 3e: Techniques and procedures for developing grounded theory*. Sage, Thousand Oaks
24. Kuper A, Reeves S, Levinson W (2008) Qualitative research: An introduction to reading and appraising qualitative research. *BMJ* 337: 404-407. <http://dx.doi.org/10.1136/bmj.a288>
25. ATLAS V.5.5.9 (2009) ATLAS.ti Scientific Software Development, Berlin
26. Kitto SC, Chesters J, Grbich C (2008) Quality in qualitative research: Criteria for authors in the submission and assessment of qualitative research articles for the Medical Journal of Australia. *Med J Australia* 188:243-246
27. O'Callaghan C (2010) The contribution of music therapy to palliative medicine. In: *The Oxford Textbook of Palliative Medicine* (4th ed.), In: Hanks G, Cherny N, Christakis N, Fallon M, Kaasa S, Portenoy R (eds) *The Oxford Textbook of Palliative Medicine*, 4th edn. Oxford University Press, Oxford, pp 214-221
28. Cassileth B, Vickers A, Magill L (2003) Music therapy for mood disturbance during hospitalization for autologous stem cell transplantation. *Cancer* 98:2723-2729
29. Levitin DJ (2006) *This is your brain on music* Atlantic, London
30. Kleinman A (1997) "Everything that really matters": Social suffering, subjectivity, and the remaking of human experience in a disordering world. *Harvard Theological Review* 90:315-335
31. Feld S (1994) Communication, music and speech about music. In: Keil C, Feld S (eds) *Music grooves*, University of Chicago: Chicago, pp. 77-94
32. Levitin DJ (2008) *The world in six songs: How the musical brain created human nature*. Dutton, New York
33. Winnicott DW (1971). *Playing and reality*. Routledge, London
34. McAdams S (1984) The auditory image: A metaphor for musical and psychological research on auditory organization. In: Crozier WR, Chapman AJ (eds) *Cognitive processes in the perception of art*. North-Holland, Amsterdam, pp 289-323
35. Stein A (2004) Music, mourning, and consolation. *J Amer Psychoanalytic Assoc* 52:783-811

36. Saresma T (2003) "Art as a way to life": bereavement and the healing power of arts and writing. *Qual Inq* 9:603-620
37. Stein A (2007) *The sound of memory: Music and acoustic origins*. American Imago, Baltimore, 64:59-86.
38. Lamont A, Greasley A (2008) Musical preferences. In: Hallam S, Cross I, Thaut M (eds). *The Oxford handbook of music psychology*. Oxford University Press, London, pp 160-168

Table 1 Participants' baseline characteristics

	Females (n= 30)	Males (n = 22)
Age (years)	58 (SD 17.4)	58 (SD 13.0)
Origin		
Australia	27	20
Other ^a	3	2
Diagnosis		
Haematology	7 (23.3%)	8 (36.4%)
Breast	13 (43.3%)	
Melanoma/skin	3 (10%)	4 (18.2%)
Soft tissue	2 (6.7%)	5 (22.7%)
Others ^b	5 (16.7%)	5 (22.7%)
Time since diagnosis		
< 1 year	8	5
1-5 years	9	9
> 5 years	13	8
Treatment status		
Living at home/no current treatment	15 ^a	8
Inpatient/receiving treatment	5	4
Outpatient/receiving treatment	5	6
Hospice inpatient	1	2
Day hospice patient	4	2
Location of Interview		
Home	9	4
Hospital	20	16
Cafe	1	2
Music Background		

Currently play musical instrument, sing	12 (40%)	11 (50%)
Previously played instrument, in choir, music theatre	10 (33.3%)	6 (27.3%)
None	8 (26.7%)	5 (22.7%)
Major City (> 100,000)/ other	25/5	19/3
Frequency of music listening before diagnosis		
Every day/few times week	24 (80%)	20 (90.1%)
About once a week or less	2 (6.7%)	0
Seldom or never	4 (13.3%)	2 (0.9%)
Frequency of music listening now		
Every day/few times week	27 (90%)	20 (90.9%)
About once a week or less	2 (6.7%)	1 (4.5%)
Seldom or never	1 (3.3%)	1 (4.5%)

^a Italy (1), Germany (1), Latin American (1), UK (2)

^b lung (1), colorectal (2), prostate (4), gynaecological (1), brain (2)

^c The participants volunteered after reading information flyers placed in strategic locations.

^d One patient got permission from another patient to recommend her to the researcher.

Table 2 Excerpts from a 34-year-old female's interview illustrating coding and the categories they informed (categories listed in Table 3)

Codes and Categories they Informed	Text Segments from Interview
Inspired by radio song "music in me" to come for radiotherapy and to "sod off cancer" (Informed Categories A1, A2, C2, Table3)	<i>(Patient's baby was) 4 months old, ...^a. I was traumatized because I know I was going to have ...this awful radiotherapy stuff ... I was really ill, but I still had a little bit of energy and I remember this song came on the radio ... (singing): "But when the night is falling and you cannot find the light, If you feel your dreams are dying, hold tight, You've got the music in you". And that song, I hear it now and it just makes me go, yeh, I have, I've got the music in me, and I'm just going to you know, sod off cancer, you're not taking me. (singing) "Don't let go, you've got the music in you, One dance left, this world is going to pull through, Don't give up, you've got a reason to live...."^b</i>
Put on and able to express how feeling through gravy song: could knock down brick wall and cry (Informed Categories A1, A2, C2)	<i>When I came down to city, I had only been here a couple of weeks and I was staying by myself ... that's when depression kicked in, so on went Paul Kelly (musician) didn't it, "Who's going to make the gravy?" (song title) ... that's how I felt, you know, I'm locked away from all my family and my friends and you know, who's going to make the gravy? ...</i>
Gravy song was a comfort, friend, understood (Informed Categories B4, C2, Table 3)	<i>And here I am lying on the floor just howling, crying my eyes out to that song that song understood how I was feeling ... it was a comfort, it was a friend, it was a shoulder to cry on, even though I was by myself ... I was crying because those lyrics and the tune had allowed (me) to express how I was feeling and it knocked down part of a brick wall that I had built up around about myself. I'll be right ... I'm strong. Ugh. Ugh. But it's ok to cry, it's ok.</i>

Cancer deepened how appreciated music; reignited music passion lost before illness (Informed Category C1, Table 3)

Played guitar, bought keyboard and started singing regularly once got voice back (Informed Category C1, Table 3)

Terrified of losing voice but people invalidated by saying “you’re alive” (Informed Category C4, Table 3)

Finds music a quiet still voice from God that touches without judging, unlike people who pat on back when don’t understand (Informed Category C2); Puts music on when feeling judged (Informed Category C2, Table 3)

Radiotherapists played “Can’t get you out of my head” – became song for all radiotherapy and dialogued with lyrics and tapped feet: was helpful (Informed Categories C2, C4, Table 3)

The cancer experience has ... maybe deepened my emotions, ... I appreciate music now. ... it’s almost reignited a passion that I had probably lost before I had cancer. I’d stopped playing my guitar really and I hadn’t really sang that much and, um, but after this you know I picked up my guitar again. I bought a keyboard you know and I started singing regularly once I got my voice back. I mean I was traumatized by that. ... Never mind my hair I can get a wig but I can’t get a wig voice. ... “Oh never mind you’ll be alive” people said to me.

(Music) comes from God... it’s a quiet still voice that just touches ... without having to judge you, without having to you know pat you on the back when it doesn’t understand, I mean it is, it’s identity ... They are still telling me how I should feel but I just ... switch off and put my music on. (Radiotherapists) put it on and after I heard it, I went, “That’s my music for when I have radiotherapy”, ... (singing) “Can’t get you out of my head”, and because I had head and neck cancer, ... I would just lie there, I’m tapping my feet (foot taps) ... something I would never normally listen to ... and I thought yes, this radiotherapy will, this will get you out of my head you stinking tumor

^a “...” indicates omission of textual data and the end of a sentence. “...” indicates the omission of text within a sentence.

^b By the band, “New Radicals”

Table 3 Themes, categories, and textual examples which inform them

Themes & Categories	Text
Theme A. Musical experiences are purposive or random, and encompass varied preferences, activities, and memories.	
A1. Music involvement can comprise solo or shared, unfamiliar or familiar listening, performance, imagery, composition, discussion, education, and movement	<i>The most music I every listened to was about 12 months after (husband) died ... I listened to "Abide with me" mostly and cried ... I found it comforting (83 yo,^z female)</i>
A2. Widely varied musical exposure and likes and dislikes are experienced purposively or randomly.	<i>When my cancer returned it wasn't a good time for me, I went into a very traditional city church where I could just sit and let the high standard of music wash over me (62 yo, male)</i>
A3. Diverse musical lives before cancer diagnoses, and altered musical life after diagnoses can be developmental	<i>Having a 2-year-old daughter means we are always listening to playschool tapes ... you ... become a bit naive to what's being played on the radio (29 yo, male)</i>
Theme B. Patients can "humanize" or "physicalize" music when describing distinctive ways in which it can enrich, transport, transform, or intrude.	
B1. Music's effects can be ineffable yet incidentally to profoundly enrich personal, communal, and/or spiritual life, through it's validation and physical, emotional, imagery, creative, cathartic, aesthetic, intellectual, and connective effects	<i>"Song 2" by Blur ... exhilarating ... yelling Wahoo and it's just about, I don't know ... but the sound to me, everything is great and it's about exuberance of life, like standing on a mountain and yelling "Whoo hoo" ... I immediately feel happy (40 yo, female)</i> <i>My brother started molesting me when I was about 11 ... God gave me the gift with the piano to be able to let my emotions out on that (52 yo, female).</i>

- B2. Music can intensify the sense of life integral to existence or identity *I find God through my singing because through my singing I feel peacefulness ... It keeps you alive ... I'm in heaven ... if I didn't have music in my life what would I live for? (52 yo, male)*
- B3. Music can elicit stress when non-preferred or in adverse contexts *It makes me cry. I remember things. ... I don't like it at all but I'm stuck with it (76^b yo, male)*
A lot of music aggravates me, ... the doof, doof doof (77 yo, male)
- B4. Music's transmutative power is reflected in its ascribed anthropomorphic and physical properties and capacity to transport *It was a saviour, ... I was too tired ... but I could put on a CD ... I was achieving something (68 yo, male)*
It's mostly transported you go ... it's just a thrilling quality ... when you get somebody performing a musical piece (61 yo, male)

Theme C. When dealing with cancer, music can: be a lifeline; support biopsychosocial and/or spiritual life; remain an incidental presence; be elusive; or is avoided

- C1. Music experience may remain consistent following cancer diagnosis or shift, alongside one's musical preferences, reactions, competencies, tolerance, opportunities, and relationships: this usually but does not always support coping *I was listening to this music before the treatment ..., during the treatment, and I'm enjoying listening to the music again after the treatment and it's kind of a continuity of me ... there's something validating me in all of this because it's kind of part of me so I identify with that ... (I) feel good even if it was reflecting sad moods, it kind of validated the sad moods (44 yo, male)*
I use to love listening to "Everything Hurts" and I never knew what the words were ... (now) I feel sad. (55 yo, female)
- C2. Music may ameliorate cancer related stressors associated with diagnostic/treatment procedures through its physical, emotional, cognitive, and/or spiritual effects and identifications: this music may be liked or avoided later. *Ave Maria which I listened to over and over again during my first chemo Now it instantly takes me back to that ... I was petrified ... I was just bawling and I had this song blaring in my ears and I just kind of shut out the world and got lost in Ave Maria I listen to it now. ... I still kind of feel ... the beauty ... it helped me kind of make peace. (37 yo, female)*
(Pathology results were) not at all what we expected ... but the

music contained all that ... (the) round shiny CD ... is a container, it's like a pill, it's like here you go, I focus for you ... it sort of gives creativity to your thoughts but contains them as well so it really held the fear, ... that made it manageable. ... Music connected with that sad, petrified bit of me, ... it empathized, ...gave me a valid place to be, ... sat with me without asking any questions, ... reflected how I felt. (47 yo, female)

Michael Brecker (saxophonist) ... went through pretty much what I'm going through ... you see his strength ... he wasn't going to let it beat him, and in the end it killed him ... (but) it was either going to be that or nothing. (41 yo, male)

C3. Music experiences may lessen during cancer illness because of access problems, and/or music's emotional evocation, preciousness, or stress inducing properties; however patients can reconnect with music

I love Annie Lennox ... it was so sad, it told of how she lost a baby and everything ... I had to stop listening to that for ages ... it's too close to what could be happening to me. (55 yo, female)

I was trying to get to the music but I was still, I couldn't cope with anything, I was so afraid ... it's amazing how you lose your confidence (57 yo, male)

C4. Music can help patients to be in and emerge from darkness

("Having to stop life" is) very, very black, ... you're there alone first, ... then you let the music come to you, and then you use the music to help you be there and really stew about in it. It's like a good stock, ... the pain of before you start to cry, ... like sort of thrashing around like waves ... all held within before anything's released ... (and) getting up and feeling oh, I'm ok ... moving from really anxious to relaxed. (47 yo, female)

It gives you the confidence and tools to go to that dark place ... to mould that emotion ... construct something musically and then express that ... get to the light by going down there. (41 yo, male)

C5. Music can be essential for dealing with cancer and its treatments

It's been like a spark that's helped me to tap into something that's helping to keep me alive. (67^o yo, female)

Music is my be and end all, you know that this is going to help me

heal. (38 yo, female)

C6. Contemplating music in one's future treatment, life, or funeral can be hopeful, interesting, or challenging
(After chemotherapy) I've really got to track down some 80s music ... that happiness and optimism and energy ... engage with movement and music and life again. (42^b yo, female)
As I get sicker my attention span will fall, movies will decrease so it will be easier to sort of escape through music than through movies. (40 yo, female)

Theme D. Family, friends, and professionals can help patients to extend or recover music's helpful effects

D1. Others can support cancer patients by providing and sharing music experiences or through being thought about when experiencing music
A home help lady ... said "Are you in pain now?" and I said, "Yes," and she said, "... Why don't you lie down and put on some relaxing music?" ... it really helped. (42^a yo, female)
The head radiotherapist said to me, "I knew you weren't well because you weren't bringing music anymore", ... and the radiotherapists were ... softly encouraging and ... helped me ... (and then) I was bringing in music again. (44 yo, male)

D2. Music therapy was supportive and elicited positive emotional, physiological and imagery reactions, helped family interaction, and witnessing its effects on others was also positive
(The music therapist played "Clair de Lune") ... I lost myself in the music ... I felt like I was in some beautiful grass in the Serengeti ... where you know everything's fine (34 yo, female)
They'll pick me up if I try and rush through (when singing the playsong the patient composed for her children) ... (I'm) connected, ... it's something that's theirs ... they feel very special about their song (38 yo, female)

D3. Music therapy could help patients to connect with music's helpful qualities, sometimes when music use had ceased – this could empower and motivate
You sort of give up, everything's too hard even just to switch it (music) on but (music therapist) came along and we didn't have to do anything, s/he just sort of got us involved, just nice to relax (57 yo, male)

^zyo = years old. NB. Small letters with ages separate patients with the same age/gender.

Table 4 Cancer patients' music-related recommendations

For Cancer Patients' Self-care

Everyone responds differently to different kinds of music: be open and explore different types to find what best helps relaxation and imagery of favourite places.

Bring music to treatment to make time quicken, reduce boredom, and promote relaxation.

Use music to help you think of good things in life and release stress.

Try putting your hands on your diaphragm and taking deep breaths with relaxing music.

Use music to motivate exercise. Pick a song. Dance to it once a day. Dance crazily like no-one is watching and belt it out so that you can be energized and not worry.

People should sing more together.

Parents should write songs with the music therapist so that your children can know how you feel about them in the future.

Listen to music you can empathise with and which has an affirming message. Use music that brings pleasure. Consider also using music that lets you be sad.

If you have lost track with your music find a way to reconnect with it; seek out music which makes your heart sing and you feel alive. Lay in bed and listen.

People without any music interest should start by listening to Enya and then Mozart to find "works" because "music can make people feel that life is worthwhile." (65 yo, male)

Be open to how music can make you smile.

For Professional Health Carers

Live quiet music in hospital wards, waiting areas, day treatment centre, and hospice to break up the day. Short time-frames (e.g., 10 mins). Suggested genres: classical, Boston pops, Spanish, waltzes. Suggested instruments: piano, cello, guitar, flute, string group, adult and children's choirs. (NB. one patient said he would prefer silence).

Broad music audio and DVD libraries in hospitals, and availability of radios. Suggested genres: spiritual, Disney, Enya, pop, meditation, world music, jazz, birdsong.

Allow patients to download music from electronic libraries. Teach MP3 player usage. Include stories about musicians. Make music available in treatment areas and for diagnostic procedures. Ensure good

quality sounds systems are available. Radiotherapists should offer to shift volume before leaving the bunker or patients should have a manual control.

Clip-on devices for audio equipment so that patients can listen to music when walking with IV poles.

Musical instrument library for patient borrowing.

Offer sampler CDs/playlists with varied short pieces (3-5 minutes each) to help people explore helpful music.

Music interest and support groups, e.g.s., drumming, choir, music lessons.

Music with hand massages.

Financial assistance for concerts; free tickets (especially after treatment).

Music recording channels at bed/chair-sides (as on planes).

Counsellors need to consider music in clients' lives: talking about music can be as cathartic as listening;

understanding how patients are relating to music can be an assessment tool.

Extend music into meaning making therapies.

Suggestions for recorded/piped music in wards were inconsistent (positive and negative views): choice is needed.

Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:

O'Callaghan, CC;McDermott, F;Michael, N;Daveson, BA;Hudson, PL;Zalcberg, JR

Title:

"A quiet still voice that just touches": music's relevance for adults living with life-threatening cancer diagnoses

Date:

2014-04-01

Citation:

O'Callaghan, C. C., McDermott, F., Michael, N., Daveson, B. A., Hudson, P. L. & Zalcberg, J. R. (2014). "A quiet still voice that just touches": music's relevance for adults living with life-threatening cancer diagnoses. SUPPORTIVE CARE IN CANCER, 22 (4), pp.1037-1047. <https://doi.org/10.1007/s00520-013-2059-1>.

Persistent Link:

<http://hdl.handle.net/11343/283330>