

Full-Length Article

Comfort, Connection and Music: *Experiences of Music Therapy and Inter-Active Listening on a Palliative Care Unit*SarahRose Black¹, Camilla Zimmermann², Gary Rodin²¹Princess Margaret Cancer Centre, Kensington Hospice, University of Toronto, Toronto, Canada²Princess Margaret Cancer Centre, Global Institute of Psychosocial, Palliative and End of Life Care, University of Toronto, Toronto, Canada**Abstract**

Music therapy in palliative care aims to provide psychosocial support, assistance with pain and symptom management and opportunities for life review and legacy work. Although there have been a variety of studies conducted on the effects of music therapy in palliative care facilities, there is a gap in research examining the experience and feasibility of music therapy on acute palliative care units within cancer care settings. This qualitative study explored the lived experience of inter-active listening (IAL), an individualized music therapy in which the therapist plays music or sings while the patient engages through listening, for 9 inpatients on a palliative care unit. The study found that a receptive music therapy referred to as IAL was associated, in cancer patients in an acute palliative care unit, with increased emotional and spiritual well-being and a greater sense of connection to self and others. Further research into specific effects of various music therapy intervention styles is warranted.

Keywords: *music therapy, palliative care, inter-active listening, comfort, connection.*

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Introduction

Music therapy is a dynamic, interpersonal and multi-faceted process in which a trained therapist uses music in a variety of forms to promote, maintain, and restore mental, physical, emotional, and spiritual health [1]. This therapy may be delivered in various ways, including but not limited to: improvisation, in which music is created spontaneously to meet the needs of the patient [2,3]; receptive music therapy, in which the patient listens to music provided by the therapist [4,5], and composition, in which the therapist helps the patient to produce lyrics, melodies or original songs [6,7]. The experience of individualized music therapy involves a therapeutic relationship in which there may be intimate and powerful moments of catharsis, self-expression and connection [6,8]. The benefits of music therapy may be derived from the comfort of familiar music styles, the verbal and nonverbal processing of the musical experience, and life review/legacy work [9,10].

Over the past several decades, music therapy has become recognized as a valuable addition to interdisciplinary palliative care in hospitals and hospices throughout the world [11-15]. Studies have shown that music therapy may help to alleviate physical, emotional, and spiritual suffering [16-18], support pain management [19], reduce anxiety [20], increase self-awareness [17] and engage patients in legacy work [9,21]. A number of studies conducted on the impact of music therapy on patients on palliative care units (PCUs) have shown that it can result in increased well-being, relaxation, and decreased tension [17,19,22,23]. Although studies have been conducted on music therapy in hospice and palliative care settings [9,18,20,24,39], none have involved receptive music therapy alone. Previous studies have typically examined a combination of interventions including receptive music therapy, 16 song-writing techniques [9], lyric analyses [17], and improvisational techniques [16].

Traditional receptive music therapy, in which a participant listens to music and responds musically, verbally or in another modality [6], has been used in a number of settings, including palliative care, cardiac rehabilitation, psychiatric care and geriatrics [4]. Inter-active listening (IAL) music therapy is a technique based on the principles of receptive music therapy, and was developed by the researcher to be particularly suitable for patients with advanced disease [5]. IAL differs from traditional receptive music therapy in

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that IAL focuses on the patient’s responses as the primary source of information regarding how to proceed musically. Although a traditional approach takes this into account, it may not always acknowledge the participatory role of the patient. IAL considers patient responses as essential to the intervention’s direction, yet can be undertaken with patients who are less capable of active participation. The therapist observes the patient’s physiological state (e.g. breathing patterns) or verbal requests (e.g. song preferences) which can be incorporated into later sessions. Depending on the patient’s responses, the therapist may verbally explore various emotional reactions, and use these as an opportunity for discussion with the patient.

Objective

The present qualitative study was conducted to examine the lived experience of IAL with patients on an acute PCU in a comprehensive cancer centre, and to test its feasibility and impact on patients in this setting.

Methods

Research design

This study was based in qualitative phenomenology in order to capture participants’ lived experience of IAL music therapy. The research design encompassed open-ended phenomenological semi-structured interviews. Questions were pre-arranged however the exact phrasing of each question was left open to adapt to and suit each interviewee. Each session consisted of a primary intervention (IAL), during which time the music therapist produced live music with keyboard, voice, singing bowl, and/or ocean drum while the participant listened but was not playing. Semi-structured interview questions were administered by the therapist to each participant following the intervention, addressing their physical, emotional and spiritual experiences during the session(s). The therapist provided time for participants’ open-ended reflection, as well as time to sit in silence after each musical piece. All sessions were audio-recorded, and verbal dialogue and musical aspects were transcribed. A qualitative content analysis, including session transcription and thematic analysis was used to identify themes and subthemes. Basic demographic and medical information was recorded at the time of recruitment. The study was approved by the Research Ethics Board of the University Health Network.

Setting

Recruitment occurred from December 2012 to November 2013 on the PCU at the Princess Margaret Cancer Centre, University Health Network, Toronto, Canada. This is a 12-bed inpatient unit, with an interdisciplinary team that provides

pain and symptom management as well as psychosocial and emotional support. The average length of stay is 11-12 days and approximately half of the patients are near the end of life [25]. This study began at the time of initiation of the music therapy program on this unit.

Participants

Recruitment was conducted through purposive sampling, and informed consent was obtained from either the participant or a caregiver. In addition, participants were required to have had no prior experience with music therapy (see Table 1). Of 16 patients approached, 9 (56%) agreed to participate in the study; one participant asked to receive the treatment but declined study participation. Three patients refused to participate: two felt they were too physically ill to engage and one initially consented but then retracted consent, as he was scheduled for discharge. Recruitment was terminated when saturation of themes was achieved.

Table 1. Information on participant demographics and session quantity in order of recruitment.

Participant	Sex	Age	PPS% at Point of Recruitment	Primary Cancer Site	Number of IAL Sessions
1	Female	79	40	Unknown	3
2	Female	64	30	Colon	7
3	Male	68	50	Breast	5
4	Female	41	20	Breast	1
5	Male	55	30	Pancreatic	3
6	Female	52	30	Ovarian	3
7	Female	72	40	Endometrial	3
8	Female	46	40	Ovarian	2
9	Male	59	30	Liver	1

PPS: Palliative Performance Scale; ratings may range from 0 to 100%, with lower scores reflecting declining physical performance status. A PPS score of 50% indicates an inability to do any work (e.g. job-related), and evidence of extensive disease. A PPS score of 40% indicates that time is spent mainly in bed, with an inability to do most activity, and extensive disease present. 30-10% scores further indicate significant and extensive disease progression with reliance on assistance and limited to minimal oral food/drink intake [38].

IAL: Inter-active Listening music therapy

Intervention

IAL is predominantly non-verbal, and uses music as the primary catalyst to establish rapport and to develop a therapeutic relationship with the music therapist. The therapist plays, sings, or provides music in some form while the participant listens; the participant may interact non-verbally or verbally and further interventions are based on participants’ responses [5]. The therapist provided all music via an electronic keyboard (Yamaha Piaggero NP-V80, Tibetan singing bowl, ocean drum, and/or vocalizations

depending on participant preferences, which were determined in a pre-session assessment. Music was chosen based on this pre-session assessment, which specifically included questions regarding the participant’s mood, current physical and psychosocial state (e.g. pain level, distress level), and musical preferences. This intervention was developed to accommodate all stages of disease and allows for a wide range in the degree and nature of participation. It is inter-active in that participants choose music for the therapist to play, and attention is paid to their verbal responses (e.g. commenting on the way the music made them feel) or non-verbal responses (e.g. a slowing in respiration rate or an unfurrowing of the brow, possibly signaling physical relaxation).¹⁹ The IAL model reframes the traditional receptive strategy by considering all dimensions of the client/participant’s responses.

Music therapy session design

Initially, the music therapist/researcher explained both the concept of music therapy and the research study, highlighting that the patient would be welcome to engage in the intervention even if they chose not to participate in the study. If a patient consented, the music therapist explained that she would play or sing based on that participant’s musical preferences, or improvise based on a word or a sentence the participant gave her about how they were feeling. If the participant was non-verbal (unable to communicate verbally) or actively dying, the music therapist would ask family members/friends about musical preferences. A semi-structured interview followed the music therapy session, during which the music therapist asked questions about the participant’s overall experience of music therapy in the context of the inpatient PCU. Family members were invited to be present during the sessions depending on the participant’s preference. If family members were present during the interviews (as they were in 7 of the 9 participants’ sessions), they were invited to be included in the interview. There were no substantial differences noted between sessions when family was present or not. There was no pre-determined number of sessions (they ranged from 1 to 7); duration of participation in sessions was determined by researcher and participant and in all cases, sessions were terminated when the participant left the PCU or when they died. The mean length of sessions was 34 minutes, and the range was 15 to 65 minutes.

Data collection

Prior to each session, the study purpose and confidentiality protocol were explained, and descriptive demographics were recorded. Physical performance status was rated (by the medical chart) using the Palliative Performance Scale (PPS) [38], ratings may range from 0 to 100%, with lower ratings reflecting declining performance status. This data was collected in order for the researcher to have a basic understanding of the potential for participants to engage

verbally in sessions. One music therapist conducted all 28 sessions (SRB). Following each session, the music therapist/researcher made in-depth field notes to reflect on aspects of the sessions for later cross-analysis with the audio-recorded data.

Data analysis

Following data collection, inductive qualitative content analysis was used, which allowed for categories and codes to emerge through a coding scheme, informed by Strauss and Corbin’s coding model [26]. The inductive content analysis also allowed for the researchers (the music therapist and two research team members, both experienced clinicians with expertise in psychosocial oncology within palliative care) to make replicable, valid inferences from the data within their contexts, in order to provide new insights and a framework of knowledge based on emergent themes [27,28,29]. The coding process included session transcription, summarization of each session using narrative/ethnographic writing, bracketing and clustering units of meaning to form themes, extracting general and unique themes, and translating descriptive material into essences. These steps were followed by a cross-case analysis, comparing themes, and by the writing of reflections on the themes, triangulated with journal entry data. Additionally, the researcher/therapist engaged in data review for triangulation purposes with the two research team members/co-authors and with two music therapy colleagues. Finally, the themes were synthesized into a final description.

Results

Primary themes

The two primary themes identified within each session were connection and comfort (Table 2).

Table 2. Summary of IAL Musical Choices for each Participant

Participant	IAL Musical Descriptors
1	Improvisation (major keys, arpeggiated major 7 th and 9 th chords, between 60-80 BPM) with keyboard based on verbal mood descriptors from participant (“looking back, sadness, reminiscence”), Pre-written songs as requested by participant (Harold Arlen: Somewhere Over the Rainbow, 1939; Hugh Williams: Red Sails in the Sunset, 1935); Pre-written songs were sung by therapist/researcher in soprano range.
2	Improvisation (major keys, gospel-style chord progressions and vocalizations in soprano range) with keyboard and ocean drum based on participant’s breathing patterns (slow tempi, 60 BPM or less), Pre-written songs as requested by participant and family member (Newton: Amazing Grace, 1779, Scriven: What a Friend We Have in Jesus, 1855, Boberg: How Great Thou

Art, 1885). Pre-written songs were sung by therapist/researcher in soprano range; participant's daughter also sang.

- 3 Improvisation on keyboard (major and minor keys, arpeggiated chords and pop-style chord progressions, moderate tempo, 80-100 BPM) based on verbal mood descriptors ("calm, peaceful, nostalgic") from participant and family member, Pre-written songs sung by therapist/researcher in soprano range, as requested by participant and family member (McCartney: In My Life; Armstrong: What a Wonderful World). Participant's wife sang along at times.
- 4 Improvisation (keyboard; minor keys, as well as major chords with major 7ths and 9ths and 11ths, both solid and arpeggiated; slow tempo, 60 BPM or less) based on verbal mood descriptors from participant ("quiet, relaxing").
- 5 Improvisation (vocalizations in soprano range along with keyboard accompaniment by therapist/researcher in major and minor keys, primarily oscillating chord progressions and melodic lines in treble end of keyboard; moderate tempo, 80-100 BPM) based on verbal mood descriptors from participant and family members ("relaxing, easy, quiet").
- 6 Improvisation based on participant's breathing patterns (keyboard; major and minor keys, as well as vocalizations; stepwise melodies with vocalizations in a soprano range accompanied by solid chords on keyboard, slow tempo, 60 BPM or less).
- 7 Improvisation based on participant's breathing patterns (keyboard; major and minor keys, as well as vocalizations; stepwise melodies with vocalizations in a soprano range accompanied by solid chords on keyboard, slow tempo, 60 BPM or less).
- 8 Improvisation based on verbal mood descriptors from participant and family member ("hopeful") with keyboard; major keys, sustained vocal tones with movement in arpeggiated keyboard harmonies, moderate tempo, 80-100 BPM.
- 9 Improvisation based on participant's breathing patterns with keyboard, sustained chords in major keys (slow tempi, 60 BPM or less)

Participants commented directly on the sense of connection they felt while listening to the music provided by the therapist. When participants were asked about this experience, they indicated that they had felt one or more of the following: a connection with themselves and their experiences of their illness (e.g. a chance to examine and reflect on their own journeys); a connection with those in the room with them (family members and friends); and a connection to the music and the music therapist. Participants commented that music provided the opportunity for reflection on their situation, which led to a sense of connectedness with their own feelings about themselves, their experiences, their loved ones' experiences, and to the future. The following quotation from a participant illustrates this sense of connection: "I feel more aware of this moment, of myself, of my illness, of my wife. The music is sort of bringing it all together, connecting all the parts" (Participant 2).

Comfort

The word "comfort" was used frequently by participants and by their family members who were present. One participant noted she was "comforted by the familiarity" of the music (Participant 5), and another participant stated that he was "so comforted" when discussing memories brought up by the songs that were played (Participant 8). All participants and/or their family members or caregivers requested songs with which they were familiar. The sense of familiarity within the music was a source of emotional comfort for all of the participants, as was discussed in the follow-up interviews. One participant stated "that song brings me back so long ago, to a time when things were simpler, easier, and it's comforting" (Participant 1).

Subthemes

Each primary theme had three subthemes. Subthemes that fell under the primary theme of connection were gratitude, nostalgia, and spirituality. Subthemes that fell under the primary theme of comfort were symptom relief, relaxation and love.

Subthemes of Connection

Gratitude

The participants often indicated gratitude, speaking about feeling "lucky" and "grateful" that they could experience music therapy in the hospital, with one participant stating: "The music makes me feel at peace, I feel lucky. I am such a lucky man" (Participant 3). Another participant spoke about feeling "grateful for the people I am able to share my final days with" (Participant 9). Three participants did not use the words "grateful" or "lucky" but expressed gratitude by saying "thank you" frequently, at various times in their music therapy process with the therapist.

Nostalgia

Connection

A sense of nostalgia was apparent for all participants, as each of them and/or their family members told stories of their past. One participant recalled: “I remember all of my kids, lying on their tummies, watching the Wizard of Oz. Those were good days.” (Participant 1). Six participants requested music that reflected their past experiences, usually from a particular era. Nostalgia was manifest through narrative.

Spirituality

For all participants, an aspect of spirituality emerged during the session(s), often as the final prominent point of discussion or reflection. Five participants spoke openly of God and their faith in God; two participants mainly wanted to hear the music therapist play hymns and spiritual songs, with one stating “I feel God’s presence in the music, play another hymn for me” (Participant 5). One participant spoke of feeling “greater powers at work” in her disease trajectory, and said she “trusted the process of what was about to come” (Participant 1). Although one participant was non-verbal, her sister, who was present during the session, reflected on a sense of spirituality in the participant’s life.

Subthemes of Comfort

Symptom relief

Most participants were in physical discomfort during moments of their sessions, and six verbally self-reported that their pain had eased slightly as a result of listening to the music. One participant initially stated that his most pressing issue was ongoing nausea; after five minutes of IAL at the bedside, he stated “I feel ease, I feel relief. I’m much less nauseous than I was five minutes ago. Can you keep playing?” (Participant 7).

Relaxation

Seven participants verbalized their physical sensations of relaxation, and all nine participants showed signs of physical relaxation, noted by the researcher in the recorded observational data. Several participants’ dropped their shoulders and unfurled their brows, while others took deep breaths and sighed audibly. One participant stated: “Calm, it’s a certain calm that comes over me, suddenly my whole body is relaxed, and the nausea is gone, such a relief” (Participant 4).

Love

Five participants spoke of love for a spouse, one spoke of love for a sibling, and three spoke of love for their children. When asked about what was most prominently on his mind after listening to the music therapist play the keyboard, one participant said, “Love. Love is what is on my mind. Love in all its forms, it’s so strong, I feel it so much right now” (Participant 6).

Table 3. Summary of primary themes and subthemes followed by related quotes from participants.

Primary Themes:	Connection	Comfort
	“When I hear the music, I feel so present, so connected to my wife. I’m here. I’m leaving but I’m here now. With her.” (Participant 8)	“The music is so soothing, like, everything will be ok even if I’m not here. There’s a lot of reassurance and comfort in that.” (Participant 3)
Subthemes:	Gratitude	Symptom Relief
	“I’m just so overwhelmed, so grateful for everything I’ve been able to do and experience.” (Participant 6)	“The pain just let go for a moment. I don’t know how or why, but during the music the pain wasn’t as bad.” (Participant 7)
	Nostalgia	Relaxation
	“I remember sitting with my kids, watching them sing along to this song years ago. They were so happy. I was so happy.” (Participant 1)	“Calm, it’s a certain calm that comes over me in the music, suddenly my whole body is relaxed, and the nausea is gone, such a relief.” (Participant 6)
	Spirituality	Love
	“Gospel music, that’s when I feel the most at peace, when I hear that Gospel music. Can you keep playing?” (Participant 2)	“Love, that’s what the music brings up, an overwhelming feeling of love. And that feels like the most important thing right now.” (Participant 3)

Discussion

IAL was found to be a highly acceptable intervention for all participants. Although the number of therapy sessions administered ranged from 1 to 7, all participants displayed or reported benefit in terms of their psychological and physical well-being.

The two primary and six subthemes identified were consistent in the data. The primary themes (connection and comfort) have been described previously [12,16,20,30]. Previous studies of music therapy have reported relief of pain and nausea relief [19,31,32], a sense of spirituality and a connection to a religious figure or faith tradition [30,33] and a sense of relaxation through music [5,16]. While themes of love, gratitude and nostalgia have been written about in essential palliative care music therapy texts [34], they have not

previously been found to emerge in qualitative studies of participants' lived experiences.

This study is unique in its consistent portrayal of the experiences between participants, which may, in part, be due to the consistency in intervention style. The intervention (unique to this study) and subsequent qualitative analysis allowed for the music to be catered to each participants' individual though somewhat similar needs. In contrast to some studies with similar settings and designs [17,31] the music therapist/researcher was able to adapt musical styles (improvisatory as well as pre-composed songs) and elements (tempo, rhythms, dynamics) to the patients' individual needs, and the music was consistently live (not pre-recorded) at the bedside. This may have been a significant factor in the consistency of outcomes and emergence of themes, in that the adaptation of the music to the individual may have allowed for further and more in-depth exploration of themes that had arisen (e.g. spirituality as a theme prompted more songs about faith in some participants).

The results of this study demonstrate the impact and feasibility of IAL for patients with advanced cancer on a PCU. Despite variability in clinical status, all participants reported or appeared to demonstrate benefit from IAL. Some participants were very close to death (e.g. Participant 4 received the IAL intervention several hours before her death), and others went on to live for approximately two more months, but all participants were able to participate in the intervention. Some participants spoke a great deal, while others remained mostly quiet.

Because IAL does not require participants to be verbal, this form of music therapy is suitable for inpatients who suffer from substantial impairment in mobility, cognition, and communication capacity [5,12]. It may be equally suitable in other settings where patients have advanced disease [35,36]. IAL draws attention to the therapeutic relationship that develops, even with patients with advanced disease, and allows for greater participation and interactivity with patients who are less ill and more able to actively engage. Regardless of a participants' ability to communicate verbally, IAL can support the process of palliative and end-of-life care as this intervention appears to enhance a sense of connection and comfort, including an easing of physical distress for some, and it evokes reflection in patients related to their personal history.

A limitation of this study is that the music therapist had a dual role as both provider of music therapy sessions and primary researcher [37]. This dual role, common for music therapists who engage in research, may affect the participant's comfort level with offering negative feedback, and participants may have responded differently had they been interviewed by a third party. However, the close proximity to and engagement of the music therapist might have enhanced her observations and her understanding of the patients' experiences. Other limitations of generalizability of this study are its small sample size and that it was conducted on a single

PCU at one cancer centre. The diminished capacity of some participants to respond verbally may also limit data validation. Although member checking was attempted in all interviews through summarizing the session and information gathered, some participants were unable to engage in this process due to their low PPS score and inability to communicate verbally. However, in one case, a participant's daughter requested to view the data results when the study was complete; these were shared at the conclusion of the study, and feedback was provided by the daughter that the study accurately described her mother's experiences during the IAL sessions.

Conclusions

The present study supports the value of IAL music therapy in providing emotional comfort and nonverbal connection to individuals with advanced disease, including those who are unable to communicate verbally or who have diminished levels of awareness or consciousness. IAL is unique in that it takes into account both verbal and nonverbal communication, making it feasible to deliver at end of life. This study points to the impact of bedside music therapy and IAL in supporting and caring for many aspects of an individual's emotional well-being. Further research is needed to determine its impact in other settings and other patient populations.

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