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Perceptions of family members of palliative medicine and hospice patients who experienced music therapy

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Abstract

Purpose Evidence shows that music therapy aids in symptom management and improves quality of life for palliative medicine and hospice patients. The majority of previous studies have addressed patient needs, while only a few addressed the needs of family members. The primary purpose of this study was to understand family members' perceptions of music therapy experienced by a relative in palliative medicine or hospice. Patient self-reported scales and music therapist assessment of change were also investigated.

Methods Patients scored their symptoms (pain, anxiety, depression, shortness of breath, and mood) before and after music therapy sessions. One family member present during the session assessed perceived effect on the patient's pain, anxiety, depression, shortness of breath, stress level, restlessness, comfort level, mood, and quality of life. The effect on family member's stress level, quality of life, and mood and helpfulness of the music therapy session for the patient and self were studied. Recommendations about future patient participation in music therapy and qualitative comments were also solicited.

Results Fifty family member/patient dyads participated in the study. Family member perceptions were positive, with 82% of responders indicating improvement for self and patient in

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stress, mood, and quality of life; 80% rating the session as extremely helpful; and 100% of 49 recommending further music therapy sessions for the patient. Patients reported statistically significant improvement in pain, depression, distress, and mood scores.

Conclusions Family members of patients in palliative medicine and hospice settings reported an immediate positive impact of music therapy on the patient and on themselves. More research needs to be conducted to better understand the benefits of music therapy for family members.

Keywords Music therapy · Palliative medicine · Hospice · Family

Introduction

Over the last 25 years, there has been an increase in research regarding the effectiveness of music therapy with palliative medicine and hospice patients. Sites have included cancer centers [1–3], palliative medicine programs [4–15], and hospices [2, 3, 6, 7, 10, 12, 14–20]. Of primary interest to many researchers is the effect of music therapy on symptom management and addressing patients' physical, emotional, cognitive, psychological, spiritual, and social needs. According to the literature, music therapy has positively affected physical symptoms such as pain [1-13, 15-18, 20], fatigue [3, 5, 10-13, 20], shortness of breath [6, 8, 10, 11, 16, 20], and discomfort/tension [1-6, 9-15, 20]. It also has been beneficial in treating emotional symptoms such as anxiety [1, 3-12, 16,17, 19, 20], anger [5], depression/sadness [2, 3, 5, 6, 8, 10–13, 19], fear [5, 11], quality of life [3, 5, 8, 9, 12, 13, 15, 16, 20], mood [1-6, 8, 12, 13, 15, 20], and stress/distress [1, 3-5, 7, 11-13, 16, 19, 20].

End-of-life themes often emerge around unfinished business [4-7, 12]; life review [2, 4-6, 12-18]; guilt/remorse/regret [3-5, 7, 10, 12, 13]; memories/reminiscence [1-6, 11, 12, 16-20]; grief/loss/bereavement [2-7, 10-12, 14, 17-21]; suffering [5-7, 11]; spirituality [2-7, 10-12, 15, 20]; and identifying the meaning and purpose of one's life, suffering, and death [2-4, 6, 7, 10-15, 17, 20, 21]. These themes are commonly addressed in music therapy through the music, the interventions, and the relationship. Interventions include such things as music listening, singing, song choices, musical life review, memory sharing, instrument playing, improvisation, lyric analysis, song discussion, music-assisted relaxation, and songwriting [2-5, 8, 11, 13, 15-19, 22]. Patients may also address coping [1, 3, 5, 6, 11-13, 15-17, 20, 21], courage [4], healing [7], hope [2-4, 6, 10-12, 14, 15, 17, 20, 21], hopelessness/helplessness [11], isolation [5], support [3], and resilience [3]. Music therapy is also effective in helping patients express feelings [2-7, 9-16, 18, 20, 21] and in improving communication with friends and family [1-6, 9-15, 20]. According to Byock [22], there are four phrases that may need to be said at the end of life in order to mend relationships and provide well-being. These include "please forgive me," "I forgive you," "thank you," and "I love you" [22, p. 3]. They can be addressed in music therapy by focusing on forgiveness, reconciliation, and peace [6, 7, 12]; the completion and closure of relationships [2-7, 10-13, 15, 19, 20]; and expressing thanks, gratitude, and love [4, 7].

The majority of studies have focused on the effectiveness of music therapy for the patient. However, hospice and palliative medicine focus on patient- and family-centered care. For the purposes of this study, family is defined as whomever the patient identifies as family, including friends, caregivers, and spiritual care personnel [1–8, 10–21, 23]. Studies have illustrated the beneficial effects of music therapy in addressing patients' and families' needs related to anxiety, [11, 13, 14, 17, 21]; meaning, hope/hopelessness, and coping [17]; confusion and dementia [17]; and anticipatory grief, saying goodbye, letting go, and pre-loss bereavement [3, 4, 7, 17]. Further studies have investigated family members' depression/sadness [2, 3, 7, 10, 13, 17, 20, 21], fatigue [3, 11, 13], mood/emotions [2, 3, 5, 7, 10, 11, 21], quality of life [2, 11, 21], stress [2, 6, 7, 11–14, 19–21], satisfaction [3, 16], and relaxation/comfort [2, 3, 5, 10-13, 17, 21]. It is also important to provide opportunities for families to express caring to their dying relative [3, 7, 10-12, 20]; to provide calm for the family before and after the death [12]; and to note family members' facial expression [8, 20], body movement [8, 20], and verbalizations [8, 13, 20].

Along the patient's trajectory of illness, there are many changes in roles, self-esteem, identity, and dignity [11, 23]. These may additionally be impacted by the stage of the cancer and the family's current developmental stage [23]. Newly forming and young families may have more difficulties coping than aging families [23]. Families at all stages need to be educated on the stages of illness, as well as what to expect at the end of life [6, 7].

Music [1-3, 5, 12] and specifically music therapy [1-15, 12]17-19, 21] have been effectively used to address the needs of patients in palliative medicine and their families. The literature describes these experiences, the importance of the music utilized, the role of the music therapist, and goals and interventions [1-16, 18-21]. Interventions include the creation of musical autobiographies [5], song legacies [3, 5], and recordings for patients and families [2, 3, 5, 6, 10–12]. The music therapist can use music to create a comforting, peaceful space as the patient transitions from life to death [3, 4]. Families are invited to participate in the session and to use music to express things to the patient [2-5, 7, 8, 10-15, 17-21]. It is interesting to compare family members' perceptions of the music therapy experience with that of the patient [2, 16, 18, 20, 21]. While several studies have been published regarding the use of music and/or music therapy with families, the outcomes have not included quantified and detailed family members' perceptions of the effect of music therapy on the patient.

The main goal of this study was to identify the benefits of music therapy in palliative care and hospice settings, through the collection of data from patients and their families. In our setting, we use the term hospice to represent someone that has a prognosis of 6 months or less to live and is receiving end-oflife services at home, in a nursing home, or in an inpatient hospice care facility. Palliative medicine, on the other hand, may include hospice patients, but this service focusing on symptom management can be utilized from diagnosis through end of life. In our case, palliative medicine patients were seen on an inpatient, 23-bed palliative medicine unit. It was hypothesized that music therapy would have a positive effect on patients' self-reported scores of mood, pain, anxiety, depression, and shortness of breath. It was also hypothesized that family members would perceive music therapy as effective for treating the patient's symptoms, stress, restlessness, comfort, and quality of life. Finally, it was hypothesized that families would identify music therapy as having a positive effect on their stress, quality of life, and mood.

Methods

Subjects

This study was approved by the Institutional Review Board (IRB) at the Cleveland Clinic. All procedures followed were in accordance with the Helsinki Declaration of 1964 and its later amendments or comparable ethical standards [24]. Patients admitted to the Harry R. Horvitz Center for Palliative Medicine; followed by its physicians; or served by the Cleveland Clinic Center for Connected Care hospice in

homes, nursing homes, or inpatient hospices were eligible to participate.

We attempted to recruit 100 palliative medicine and/or hospice patients' family members using the following inclusion criteria: present during the entire music therapy session; at least 18 years old; and able to speak, read, and write English. Patients were asked if they would participate in a music therapy session; however, they were not asked whether family members could be approached for study involvement. Only one family member per patient was recruited. If several met the criteria, one was identified by those present to complete the survey. A participant information sheet was provided and reviewed with the family member. His/her willingness to complete the survey was deemed consent to participate. A waiver of written informed consent was granted by our IRB.

Sessions/procedures

A board-certified music therapist (MT-BC) conducted music therapy sessions with patients and families. These sessions included patient-preferred music, as well as interventions such as music listening, singing, choosing songs, playing instruments, engaging in music-assisted relaxation techniques, analyzing song lyrics, and writing songs. Once the session was completed, a copy of the music therapy family survey (Appendix) was given to family members who were encouraged to complete and return it within 24-48 h. They sealed it in an envelope and anonymously returned it to the unit secretary, nurse, or music therapist via mail or in person. All envelopes were opened during data analysis to further ensure anonymity. Study data were collected and managed using REDCap (Research Electronic Data Capture) electronic data capture tools hosted at Cleveland Clinic's Quantitative Health Sciences Department [24].

Data collected

Family members

The music therapy family survey (Appendix) was developed by our team specifically for this study from an initial pilot of 10 patients and family members. This pilot helped to establish content validity while improving the format and questions; and the recommendations from the participants were incorporated into the final instrument [25]. The identified family member was asked to complete the survey in order to assess the effect on nine variables as better, same, or worse; to provide recommendations regarding further music therapy sessions; and to rate the helpfulness of the session for patient and self on a 0–5 scales where 0 = not helpful at all and 5 = extremely helpful.

Patients

Data routinely collected according to the standard music therapy protocol were extracted from the patient's electronic medical record, with the approval of the IRB. This included referral source, reason for referral, goals, interventions, selfreported symptom severity, and observed behavior changes. Six patient-reported variables were scored before and after the session, five on a 0-10-point numeric rating scale (pain, anxiety, depression, shortness of breath, and distress) and mood on a 0-4-point scale based on the Rogers' Happy/Sad Face Assessment Tool [26]. The music therapist scored five behavior variables on a 0-3 scale before and after the session (facial, body movement, sleep, vocal, and verbal). This scale was based on the Nursing Assessment of Pain Intensity [27] and the Riley Infant Pain Scale [27]. For all scales, higher scores represented worse results. Some responses to the scales were unable to be obtained due to patients being unresponsive, nonverbal, or minimally responsive; not rating symptoms; sleeping; giving a verbal response instead of a numeric response; or having dementia and unable to give a valid response.

Statistical analysis

Descriptive statistics were generated. Score changes from preto post-session were analyzed using the paired *t* test. A *p* value lower than 0.5 was considered statistically significant. No adjustments were made for multiple comparisons since this is an exploratory study.

Results

Although we hoped to obtain data on 100 family members, only 50 completed the survey before the end of the funding period. Six patients/families were offered music therapy but declined. Forty-six (46) family members identified their relationship to the patient. These relationships included children (43%) and spouses (33%), as well as caregivers (13%), parents (7%), siblings (2%), and friends (2%). For 54% of family members, this was their first experience with music therapy. Forty-three percent of the sessions were with palliative medicine patients, and 57% were with hospice. Forty-three percent of the sessions and 41% were follow-up (16% missing data).

Referrals came from a variety of sources, such as social workers (31%), nurse case managers (17%), physicians (15%), nurses (9%), certified nurse practitioners (6%), music therapists (6%), and other sources (16%). Top reasons for referral, in order of frequency, were family requested, anxiety, coping, family support/comfort, pain, and self-expression. Session lengths averaged 51 min and ranged from 30 to

90 min. In 56% of the sessions, the music was chosen by a combination of the patient, family, and/or music therapist; in 18%, the patient alone chose the music; in 16% the music therapist; and in 10% the family.

Change in patient scores (Table 1)

Patient scores, either self-reported or assessed by the music therapist, are summarized in Table 1. Score changes from preto post-session are described and were analyzed using the paired t test. There were significant reductions (improvements) in pain, depression, distress, and mood. Music therapist assessment of facial behavior and vocal behavior improved from pre- to post-session.

Categorical assessment of music therapy and its helpfulness (Table 2)

In order to be more similar to family member assessments, patient difference and music therapist-rated difference scores were categorized according to whether the score after the music therapy was better (score decreased), same (score unchanged), or worse (score increased) than the pre-session score. This data is summarized along with family-rated data in Table 2. The number of missing responses is noted as not rated, but they were not used to calculate percentages. The helpfulness of music therapy is shown as frequency counts and percentages and as mean and standard deviation. None of the family members indicated that any scale got worse. Family members perceived improvement in the patient ranging from 71% for pain to 98% for anxiety and considered the music therapy experience to be extremely helpful to the patient in 82% (Fig. 1). Family members' perceived selfimprovement of 83% for quality of life, 92% for mood, 94% for stress/distress; and 84% considered the music therapy experience to be extremely helpful (Fig. 2). Forty-nine family members indicated that they would recommend another music therapy session for the patient, and one did not respond. The exact 95% confidence interval (CI) for the recommendation is 100% (49/49), 95% CI 92.8-100%. If one assumes non-response means non-recommendation, then recommendation is 98% (49/ 50), 95% CI 89.4-99.9%.

Qualitative results

The most common reasons patients and families chose the music for the session were the meaning of the songs; enjoyment for the patient; familiarity and memories; and the music's soothing, calming, and/or comforting effect. Participants cited the music's importance as something they and the patient would like that would help them relax, cheer them, comfort/ soothe them, or decrease their stress and/or anxiety.

When asked to identify their expectations of music therapy, 19% of the family members identified no expectations; 17%

Table 1 Change in patient scores

Scale	Number	Mean	SD	p value
Pain (scored 0-	-10)			
Before	26	2.6	2.7	-
After	24	1.7	2.1	-
Change	24	-0.9	1.9	0.024
Anxiety (score	d 0–10)			
Before	23	2.0	2.1	-
After	21	1.3	1.4	-
Change	21	-0.7	1.9	0.08
Depression (sc	ored 0-10)			
Before	19	2.4	3.0	-
After	18	0.9	1.4	-
Change	18	-1.4	2.1	0.010
Shortness of b	reath (scored 0-10))		
Before	18	1.8	2.4	_
After	14	1.2	1.7	_
Change	14	-0.4	1.3	0.25
Distress (score	d 0–10)			
Before	20	3.1	2.6	_
After	21	1.3	1.5	_
Change	18	-1.9	1.9	< 0.001
Mood (scored	0-4)			
Before	27	1.3	1.3	_
After	27	0.7	0.8	_
Change	27	-0.7	1.2	0.007
Behavior: facia	al (scored 0-3)			
Before	50	0.7	0.5	_
After	50	0.4	0.5	_
Change	50	-0.2	0.6	0.010
Behavior: mov	vement (scored 0-	3)	010	01010
Before	50	0.1	0.4	_
After	50	0.1	0.1	_
Change	50	-0.1	0.2	0.26
Behavior: slee	n (scored $0-3$)	011		0120
Before	4	13	1.0	_
After	8	0.9	1.0	_
Change	4	0.0	0.0	_
Behavior: voca	al (scored $0-3$)	0.0	0.0	
Before	47	0.7	0.5	_
After	47	0.7	0.5	
Changa	47	-0.1	0.5	0.033
Rehavior vorb	τ	0.1	0.5	0.055
Refore	35	0.6	0.7	_
After	35	0.0	0.7	—
Change	33	0.0	0.7	- 0.22
Change	33	0.0	0.2	0.32

thought the patient would enjoy it and provide happiness; 15% thought it would be relaxing; 9% expected it to be calming, peaceful, soothing, and comforting; 4% thought it

of the effects of music therapy

Scale	Self-report	Self-report or music therapist		Family for patient		Family for self	
	N	%	N	%	N	%	
Pain ^a							
Better	9	37.5	25	71.4	Not applicable		
Same	13	54.2	10	28.6			
Worse	$\frac{2}{2}$	8.3	0	0.0			
Anviety ^a	20	-	15	_			
Better	9	42.9	43	977	Not apr	licable	
Same	10	47.6	1	2.3	rior application		
Worse	2	9.5	0	0.0			
Not rated	29	-	6	-			
Depression ^a	-	20.0	25				
Better	7	38.9	37	94.9	Not app	licable	
Same Not roted	11	61.1	2	5.1			
Shortness of breath ^a	32	—	11	—			
Better	2	14.3	23	88.5	Not apr	licable	
Same	10	71.4	3	11.5	riet upp		
Worse	2	14.3	0	0.0			
Not rated	36	-	24	-			
Stress/distress ^a							
Better	11	61.1	37	92.5	45	93.8	
Same	22	38.9	3	7.5	3	6.2	
Not rated Mood ^a	32	-	10	_	2	-	
Better	13	48 1	42	93 3	44	91.7	
Same	11	40.7	3	6.7	4	8.3	
Worse	3	11.1	0	0.0	0	0.0	
Not rated	23	_	5	-	2	-	
Facial ^b							
Better	13	26.0	Not applicable		Not applicable		
Same	34	68.0					
Worse Movement ^b	3	6.0					
Better	3	6.0	Not appl	icable	Not and	licable	
Same	46	92.0	riot appi	liedole	Not applicable		
Worse	1	2.0					
Sleep ^b							
Same	4	100.0	Not appl	icable	Not app	olicable	
Not rated	46	-					
Vocal	0	10.1	NT-41		NI-4	1	
Somo	9 26	19.1	Not appl	licable	Not app	incable	
Worse	2	43					
Not rated	3	_					
Verbal ^b							
Better	1	3.0	Not appl	icable	Not applicable		
Same	32	97.0					
Not rated	17	-					
Comfort	Not applica	bla	44	02.6	Noton	liashla	
Same	Not applica	bie	44	93.0 6.4	Not app	nicable	
Not rated			3	-			
Quality of Life			-				
Better	Not applica	ble	40	87.0	40	83.3	
Same			6	13.0	8	16.7	
Not rated		1 0 10	4	-	2	-	
Music therapy experi	ence: was it he	lptul?	0	0.0	0	0.0	
0 = not at all	Not applica	DIE	0	0.0	0	0.0	
2			1	2.0	1	2.0	
3			0	0.0	2	4.0	
3.5			ĭ	2.0	$\overline{0}$	0.0	
4			7	14.0	5	10.0	
5 = extremely			41	82.0	42	84.0	
Mean (S.D.)			4.8 (0.6)		4.7 (0.7)	

^a Patient self-reported

^b Music therapist observed/reported

would bring back pleasant memories; and the remaining 36% stated a variety of other reasons. Sixty-three percent of patients had a positive verbal response, indicating they enjoyed and/or benefited from the session: and the other 37% either did not indicate how they felt or were unable to respond. Although 13% of family members did not have a definitive response, 87% had a positive response to music therapy. Family members used a variety of words to describe the experience such as relaxing, soothing, peaceful, uplifting, calming, beautiful, comforting, enjoyable, fun, pleasant, spiritual, exciting, good, hopeful, joyful, and wonderful. One family member wrote, "my gratitude to those who search for ways to improve end of life care in any possible manner; it is a difficult period to find comfort", and another wrote, "I think that music therapy should be considered in every hospital." No negative comments were documented on the surveys.

Discussion

To the best of our knowledge, this is the first study to assess in a standardized manner family members' perceptions of the effects of music therapy on their relative in palliative medicine or hospice settings. Positive changes in pain, depression, and distress scores were statistically significant after the music therapy intervention. Although improvements in anxiety and shortness of breath were reported, they did not reach statistical significance. Based on the literature, the effectiveness of music therapy in addressing these symptoms has had mixed results. This study also demonstrated that music therapy had a significant effect on patients' mood, as well as benefit confirmed through facial expression and vocalizations, which is consistent with our previous research [8].

The patient self-reported results are consistent with a previous study published by our group with palliative medicine patients, which also showed statistically significant changes in pain and depression and improvements in anxiety and shortness of breath after participating in a music therapy session [8]. In the current study, the average length of sessions was 51 min, whereas in the previous study, it was 27 min. One possible reason for this is the inclusion of hospice sessions which may last longer than many palliative medicine sessions. This may be due to the fact that most palliative medicine patients are extremely ill when they are in the hospital and have limited energy, whereas many hospice patients are not acutely ill and may have more energy. However, the average length of palliative medicine sessions was also higher. This may be due to the needs of patients who participated in this study, the presence of family members, and/or the different approaches between music therapists. Many times after rapport is built with patients in the initial session, it is common for the sessions to increase in length, which may be the case as 41% of the session were follow-ups.

The fact that 57% of the sessions were conducted in hospice influenced results such as referral source, reason for referral, and possibly patient verbal response. Social workers (31%) and nurse case managers (17%) were the largest sources of referrals. Previous studies also noted high referrals from social work, and since nurse case managers assess the hospice patients, it is no surprise that they are also a frequent referral source. The top reason for referral was family request for the service. This was most frequently found in the data for hospice patients. The high percentage (38%) of patients with no verbal response is largely due to the fact that many patients were unresponsive or had limited to no verbal communication. These instances occurred more frequently in the hospice sessions. One reason may be that dementia can affect patients'







Fig. 2 Family assessment of helpfulness of MT for self

verbal responses, and many of the hospice patients had some form of dementia.

A majority of family members rated the session as extremely helpful for themselves, as well as for their patient. In addition, a significant majority rated the patient's as well as their stress/ distress level, mood, and quality of life as better after music therapy. In the majority of sessions, the patient, family, and music therapist chose the music together. As noted previously, family members undergo a lot of stress, anxiety, fatigue, varied emotions, depression, and sometimes poor quality of life when they are caring for a relative who is receiving palliative medicine or hospice care [3-6, 8-10, 13, 15-22, 24-26, 28-31]. They also experience anticipatory grief, as well as unfinished business or things that they want to say to the patient before it is too late [4, 6, 7, 10, 13, 18, 21, 25, 30]. All of these elements underscore the importance of having family members present and demonstrate the level of interaction and rapport that occurred between the patient, family, and therapist.

The three most common words used to describe the music therapy experience were "relaxing," "soothing," and "peaceful." These words were also reflected in why the particular music was chosen as many stated their reasons as the music being relaxing, comforting, and peaceful. The most common reason for choosing specific music was that it was the patient's favorite music, which supports reports that a patient's preferred music is what will be the most effective for him/her [28–30].

There are some limitations to this study. One is that the music therapist collected the patient self-reported data pre- and postsessions; therefore, the findings could have been biased. It is possible that patients could respond positively in order to please the therapist, in spite of the therapist's attempts to remain objective. Although the practice of having the music therapist collect the pre- and post-session data is not the most objective for research purposes, it is how clinical practice is conducted. The family questionnaires, however, were sealed by the family member and were not opened by, or shared with, the music therapist.

Given the exploratory nature of the study, p values were not adjusted for multiple outcome comparisons with the understanding that this could increase the number of false-positive 1775

results. Missing data is another limitation. Many of the patient variables were only recorded on about half of the individuals. The average length of stay on the palliative medicine unit is approximately 2 weeks; therefore, the patient may only be seen once or twice. However, those in hospice may receive weekly music therapy sessions for months. Due to this higher frequency, hospice patients often equate music therapy with feeling better, and because they often report the same information over many weeks or months, they often come to a point in time where they do not want to complete the preand post-scales. There are also times that it is not appropriate to utilize the scales such as if there is difficulty developing rapport, if the patient is reluctant to answer, if the patient is confused, and if the patient indicates that he/she is not exhibiting the symptoms.

Although designed based on widely used scales, our assessment tools have not been validated, and what constitutes a clinically significant change has not been established. We are planning future validation studies against previously validated scales. While our findings are encouraging, further research is needed to investigate the duration of the effect of music therapy, as well as the effectiveness of specific interventions in addressing specific goals. Since the patient and family are all highly affected by the patient's illness, there needs to be more research on the benefit of music therapy for palliative medicine and hospice patients and their families.

Conclusion

The majority of patients and families who participated in this study indicated that music therapy was helpful in addressing their physical symptoms. In addition, mood, quality of life, comfort, and stress were noted to improve. Family members recognized the helpfulness of music therapy for the patient and for their own experience; therefore, it is important to include family members in music therapy sessions. Since music therapy had a significant effect on symptoms such as pain, depression, and distress and since it was beneficial for both patients and their family members, music therapy has the potential to represent a valuable asset to hospice and palliative medicine programs.

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Compliance with ethical standards This study was approved by the Institutional Review Board (IRB) at the Cleveland Clinic. All procedures followed were in accordance with the Helsinki Declaration of 1964 and its later amendments or comparable ethical standards.

Conflict of interest The authors declare that they have no conflict of interest

Appendix Music therapy family survey

 Relationship to Patient: □ Spouse □ Child 	□ Significant Ot □ Friend	her	 Parent Caregiver 	□ Sibling □ Other:
2. Were others present durin	g this music therapy	v session?	Yes 🗆 N	0
3. If yes, how many were the	ere (other than the p	atient and the	nusic therapist)?	
4. Was this your first exposu	ure to music therapy	? 🗆 Yes	□ No	
5. How did the music therapy Please check the appropria	y affect your family ate response below:	member (the p	atient) during th	is music therapy session?
	Better	Same	Worse	Not Applicable
a. Pain				
b. Anxiety				
c. Depression				
d. Shortness of Breath				
e. Stress level				
f. Restlessness				
g. Comfort level				
h. Mood				
i. Quality of life				
j. Other	□ (i.e. nausea, vomi	ting)		
6. How did the music therap Please check the appropria	y affect you during t ate response below: Better Sa	his session? me Wo	orse Not Appl	icable
a. Stress level]		
b. Quality of life]		
c. Mood		[
7. Who chose the music? (C □ Patient	heck all that apply) □ Family	Music T	herapist	Other

Please complete the following sentences, if applicable:

8. My family member picked the music used in this session because:

9. I picked the music used in this session because:

11. What were your expectations of music therapy (if any)?_____

12. Did today's music therapy session meet your expectations? \Box Yes \Box No \Box NA

13. Please use up to 3 words to describe your experience with music therapy:

14. On a scale of 0 to 5, where 0 = not helpful at all and 5 = extremely helpful, how would you rate the music therapy experience for yourself?

15. On a scale of 0 to 5, where 0 = not helpful at all and 5 = extremely helpful, how would you rate the music therapy experience for family member?

 $\Box 0 \quad \Box 1 \quad \Box 2 \quad \Box 3 \quad \Box 4 \quad \Box 5$

16. Would you recommend that your family member receive music therapy again? \Box Yes \Box No

17. What else would you like to share about this experience in music therapy?

Location:
Pall Med
Hospice – Home Nursing Home Session Type: Initial Follow Up

References

- 1. Hanser SB (2006) Music therapy to enhance coping in terminally ill, adult cancer patients. In: Dileo C, Loewy JV (eds) Music therapy at the end of life. Jeffrey Books, NJ, pp 33–42
- O'Callaghan CC, McDermott F, Hudson P, Zalcberg JR (2013) Sound continuing bonds with the deceased: the relevance of music, including preloss music therapy, for eight bereaved caregivers. Death Stud 37:101–125. doi:10.1080/07481187.2011.617488
- O'Callaghan CC, McDermott F, Michael N, Daveson BA, Hudson PL, Zalcberg JR (2014) "A quiet still voice that just touches": music's relevance for adults living with life-threatening cancer diagnoses. Support Care Cancer 22:1037–1047. doi:10.1007/s00520-013-2059-1
- Clements-Cortes A (2011) Portraits of music therapy in facilitating relationship completion at the end of life. Music Med 3:31–39. doi:10.1177/1943862110388181
- Clements-Cortes A (2015) Development and efficacy of music therapy techniques within palliative care. Complement Ther Clin Pract S:1744–3881. doi:10.1016/j.ctcp.2015.04.004
- Dileo C, Dneaster D (2006) Music therapy at the end of life: state of the art. In: Dileo C, Loewy JV (eds) Music therapy at the end of life. Jeffrey Books, NJ, pp xix–xxvii
- Dileo C, Parker C (2006) Final moments: the use of song in relationship completion. In: Dileo C, Loewy JV (eds) Music therapy at the end of life. Jeffrey Books, NJ, pp 43–56
- Gallagher LM, Lagman R, Walsh D, Davis MP, LeGrand SB (2006) The clinical effects of music therapy in palliative medicine. Support Care Cancer 14:859–866. doi:10.1007/s00520-005-0013-6
- Gutgsell KJ, Schluchter M, Margevicius S, DeGolia PA, McLaughlin B, Harris M, Mecklenburg J, Wiencek C (2013) Music therapy reduces pain in palliative care patients: a randomized controlled trial. J Pain Symp Manag 45:822–831. doi:10.1016/j. jpainsymman.2012.05.008
- Krout RE (2006) The use of therapist-composed song in end of life music therapy care. In: Dileo C, Loewy JV (eds) Music therapy at the end of life. Jeffrey Books, NJ, pp 129–140
- Magill L (2008) The conjoint use of music therapy and reflexology with hospitalized advanced stage cancer patients and their families. Palliat Support Care 6:289–296. doi:10.1017/S1478951508000436
- Miller DM, O'Callaghan C (2010) Cancer care. In: Hanson-Abromeit D, Colwell C (eds) Medical music therapy for adults in hospital settings: using music to support medical interventions, American Music Therapy Association, MD, pp 217–306
- O'Kelly J (2008) Saying it in song: music therapy as a carer support intervention. Int J Palliat Nurs 14:281–286
- Stewart K, Silberman J, Loewy J, Schneider S, Scheiby B, Bobo A, Scott-Moncrieff S, Beckford B, Salmon D (2006) The role of music therapy in care for the caregivers of the terminally ill. In: Dileo C, Loewy JV (eds) Music therapy at the end of life. Jeffrey Books, NJ, pp 239–250
- Wlodarczyk N (2007) The effect of music therapy on the spirituality of persons in an in-patient hospice unit as measured by self-report. J Music Ther 44:113–122. doi:10.1093/jmt/44.2.113

- Burns DS, Perkins SM, Tong Y, Hilliard RE, Cripe LD (2015) Music therapy is associated with family perception of more spiritual support and decreased breathing problems in cancer patients receiving hospice care. J Pain Symp Manag 50:225–231. doi:10.1016/j. painsymman. 2015.02.022
- Hilliard RE (2001) The use of music therapy in meeting the multidimensional needs of hospice patients and families. J Palliat Care 17:161–166
- Krout RE (2003) Music therapy with imminently dying hospice patients and their families: facilitating release near the time of death. Am Journal Hosp Palliat Care 20:129–134. doi:10.1177 /104990910302000211
- Magill L (2011) Bereaved family caregivers' reflections on the role of the music therapist. Music Med 3:56–63. doi:10.1177 /1943862110386233
- Savage R, Taylor EJ (2013) Hospice family caring behaviours during music therapy. The New Zealand J Music Ther 11:81–103
- O'Callaghan CC, Hudson P, McDermott F, Zalcberg JR (2011) Music among family carers of people with life-threatening cancer. Music Med 3:47–55. doi:10.1177/1943862110390821
- 22. Byock I (2014) The four things that matter most: a book about living, 10th anniversary edition. Atria Books, New York
- Veach TA, Nicholas DR (1998) Understanding families of adults with cancer: combining the clinical course of cancer and stages of family development. J Couns Dev 76:144–156
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG (2009) Research electronic data capture (REDCap): a metadatadriven methodology and workflow process for providing translational research informatics support. J Biomed Inform 42:377–381
- Creswell JW (2009) Research design: qualitative, quantitative, and mixed methods approaches, 3rd edn. Thousand Oaks, Sage Publications, Inc
- 26. Rogers A (1981) The assessment of pain and pain relief in children with cancer. In: Third world congress on pain of the international association for the study of pain, Edinburgh, Scotland, September 4–11, 1981, Abstracts. Pain 11, Suppl 1: S11
- Schade JG, Joyce BA, Gerkensmeyer J, Keck JF (1996) Comparison of three preverbal scales for postoperative pain assessment in a diverse pediatric sample. J Pain Symp Manag 12:348– 359
- Davis WB, Thaut MH (1989) The influence of preferred relaxing music on measures of state anxiety, relaxation, and physiological responses. J Mus Ther 26:168–187
- Rentfrow PJ, Gosling SD (2003) The do re mi's of everyday life: the structure and personality correlates of music preferences. J Pers Soc Psychol 84:1236–1256
- Salimpoor VN, Benovoy M, Longo G, Cooperstock JR, Zatorre RJ (2009) The rewarding aspects of music listening are related to degree of emotional arousal. PLoS One 4:e7487–e7500
- World Medical Association (2016) WMA Declaration of Helsinki: ethical principles for medical research involving human subjects. Retrieved from www.wma/net/en/30 publications/10policies/b3