

RESEARCH | PEER REVIEWED

## The “Palliative Soul”: Music Therapy, End of Life Care, and Humanizing the Patient

Zoe Tao<sup>1\*</sup>

1 Southwestern Medical School, Dallas, University of Texas

\*zoetao1@gmail.com

Received: 4 March 2018 Accepted: 15 March 2019 Published: 1 July 2019

Editor: Marisol Norris Reviewers: Leigh Jenks, Amy Clements-Cortes

### Abstract

This qualitative research project features semi-structured interviews on perspectives of humanistic care with Spanish physicians and therapists who have worked in or are familiar with music therapy and end of life care, disciplines that identify themselves as centering humanistic values in patient care. The purpose of the study was to have the thirteen music therapists and physicians elaborate on their perceptions regarding humanistic patient care and synthesize common elements from their interviews. A grounded theory approach was used to construct and derive themes among interviewees, and a narrative method of analysis was used to highlight salient philosophies of care and moments of conversation with clinicians. Building off of the interviews, this article explores how artistic engagement in end-of-life contexts sets up avenues for spiritual, psychosocial, and medical care. This “palliative soul” approach to patient care illuminates how health professionals may humanize patients at the end of life: leaning in to experiences of suffering with intention and an open ear, approaching patients in anticipation of their potential spiritual, emotional, and psychosocial needs, defining suffering, wellbeing, and effective clinical intervention through the patient’s voice, thinking actively about their own biases and shortcomings in care, and overall seeing the beauty and humanity in people both within and despite their arrival at end-stage disease. Lastly, this article discusses how even outside the context of end of life care, health professionals may broadly adopt the “palliative soul” and incorporate the needs of patients and their relational networks into clinical practice.

**Keywords:** *music therapy, end of life care, community, psychosocial care, spiritual care*

### Introduction

This research highlights perspectives of care shared among Spanish physicians and therapists who have worked in or are familiar with music therapy in end-of-life care settings. The study features significant themes and concerns that arise at the end of life and how music therapy may address the emotional, spiritual, and psychosocial dimen-

sions of care for dying patients. This project explores possibilities of integrating the “palliative soul” into medical practice more broadly, whether one works directly with patients at the end of life or otherwise.

The term “palliative soul” comes from a Spanish internist who I had the privilege of speaking with about his career caring for incarcerated patients. Somewhere in our conversation, he stated, “I arrive at the conclusion that us doctors have to have a palliative soul,” words that stuck with me as I formulated this article. In the context of this project, I elaborate on the “palliative soul” to describe an approach to delivering care that defers to the voices of patients and their loved ones in defining states of suffering and wellbeing, sees patients as more than their illness, addresses spiritual, emotional and psychosocial needs, allows for patient agency in co-constructing routes of healing, and practices reflexivity regarding the personal baggage clinicians bring into clinical encounters.

In recent years, medical humanism has taken root as a movement toward patient-centered care, emphasizing values such as patient dignity and autonomy (Hartzband & Groopman, 2009). Art modalities such as literature, the visual arts, and music have been utilized in medical educational settings as tools for teaching humanism, with several educators citing music’s emphasis on values such as fostering relationships, expressing emotions, and promoting human dignity as its relevance to medical training (Hanes & Newell, 2003; Janaudis, Fleming, & Blasco 2013; van Roessel & Shafer, 2006).

While researchers in the intersections of music and medicine have frequently noted that medicine, especially medical education, can benefit from engagement with music listening and performing, few studies have attempted to gauge the personal and professional insights of individuals whose careers have encompassed exposure to both music and medicine. Music therapy has been cited as providing humanizing qualities to medical settings, assisting palliative care teams in meeting patients’ holistic needs (O’Kelly & Koffman, 2007). A qualitative study on the personal and clinical experiences of music therapists who have survived cancer and work with cancer patients illustrated that self-awareness and addressing such holistic needs – spiritual, emotional, and physical – were integral parts of clinical practice (Lee, 2016). Likewise, the World Health Organization (2018) defines palliative care as an integration of medical, psychological, and spiritual dimensions of care. As music, medicine, and end of life care comprise disciplines cited for their humanistic attributes, it was suspected that music therapists and physicians involved with music therapy and end of life care might have profound personal and professional insight into putting medical humanism into practice. This study provides a window into the perceptions of four Spanish physicians and nine music therapists on how we might engage with medical humanism in our individual practices.

## Palliative care in Spain

The overarching practice of palliative care is based on physical suffering’s connection with existential, emotional, psychosocial, and spiritual distress (Brennan, 2017). According to *Spirituality in the Clinic* by the Spanish Society of Palliative Care (SECPAL), the philosophy of palliative care holds to the belief that care is only adequate if it attends to multiple dimensions of a person’s needs (Benito, Barbero, & Dones, 2014). While palliative care is not synonymous with end-of-life care, which is the focus of this study, the philosophy of palliative care informs much of end-of-life care.

Discussions of death and dying also have deep roots in religion and culture. Spain’s religious consciousness is largely of Catholic influence, although people of older age experience this to a greater extent than adolescents or younger people (Olarte, Núñez, & Guillén, 2001). Additionally, Catholic spirituality has been associated with an external center of control, in which the events of one’s life are attributed to external forces; in an end-of-life healthcare context, religiously-oriented patients see these external forces as divine, with God being responsible for health and wellbeing (Olarte,

Núñez, & Guillén, 2001). This implies that psychosocial and spiritual suffering at the end of life in a Spanish medical context tend to be seen as less internally and individually dependent and more externally and collectively dependent. While this connection between external divine control and adverse medical circumstances is not explicitly stated in the clinician interviews, it may help contextualize the importance health professionals in Spain attribute to spiritual wellbeing.

## Music therapy in end of life care

Difficult emotional circumstances encountered at the end of life come with a critical need for self-expression and self-disclosure. As MD Anderson Palliative Care Artist-in-Residence Marcia Brennan stated in *Life at the End of Life*, our culture often cannot bring itself to look directly at dying subjects, leading to the social and physical marginalization of individuals at the end of life (Brennan, 2017). Death is commonly perceived as undesirable, unthinkable, and a subject to be relegated to the shadows. Pilar Arranz, a Spanish palliative care psychologist, stated, “in the Western world it is not common to confront death face to face” (As cited in Benito, Barbero & Dones, 2014, p. 77). In this sense, music therapy in end of life care can provide a professional avenue by which clinicians can face death and find the human amidst difficult circumstances, making “otherwise abstract issues vividly concrete and discussable” (Brennan, 2017, p. 50). In fact, music therapists on interdisciplinary palliative care teams have become increasingly common in recent years (Clements-Cortes, 2016). Empirical studies of music therapy in palliative care settings have found that music therapy techniques can successfully reduce patients’ pain perception, enhance perceived quality of life, reduce symptoms of anxiety and depression, enhance mood and self-esteem, assist with reconnecting to one’s identity, and facilitate communication with others (Clements-Cortes, 2016).

Ultimately, the motivation for undertaking this project is based on an interest in what common ground, both personal and professional, clinicians who are affiliated with work in music therapy at the end of life may share in fulfilling many of the ideals of medical humanism. I hypothesized, pre-interviews, that these physicians and therapists, based on both their proximity to complex suffering and healing through the creative arts, would stand out for their focus on patient subjectivity in generating their own professional voice, centering their careers on seeing and caring for multiple dimensions of a human being.

## Method

### Project Setting

This project was conducted at El *Instituto Música, Arte y Proceso* (the Institute of Music, Art and Process, or IMAP) in Vitoria-Gasteiz, Spain. IMAP is a multidisciplinary institution that focuses on using music in a diverse array of medical and therapeutic contexts. Currently, IMAP is in the process of pioneering what may be the first formal hospice facility in Spain outside of a hospital or home service context. IRB Approval was granted by Rice University for completion of this study, as IMAP does not have an IRB or equivalent review board.

### Participants

Participants of this project were music therapists and physicians who either performed or were exposed to music therapy in end-of-life care. Clinicians were recruited via snowballing techniques in which known candidates who meet criteria were asked directly for their participation (Patrick, Pruchno, & Rose, 1998). The clinicians did not all incorporate music therapy into their healthcare practices; rather, they were affiliated in some way with music therapy, whether it be (a) participating in IMAP’s *vivir con voz propia* (“living through your own voice”) program, a community program that

**Table 1.**

Breakdown of clinician interviewees by profession, context of end-of-life care practice, and population of patients served. Table serves to highlight the diversity of clinical practice among the interviewees rather than draw conclusions regarding the impact of clinical experience on interview content.

Professional training	Contexts of end of life care experience	Populations of patients attended
music therapist, psychologist	private hospital, intensive care unit	adult/geriatric
music therapist, psychologist	home hospice service, private hospital, oncology unit, senior home residence	adult/geriatric
music therapist, nurse	private hospital, pediatric oncology unit, palliative care unit	pediatric, adult/geriatric
music therapist, nurse	private hospital, palliative care unit	adult/geriatric
music therapist, music teacher	private hospital, palliative care unit, home hospice service	adult/geriatric
music therapist, music teacher	government-funded senior home residences	adult/geriatric
music therapist	private hospital, palliative care unit	adult/geriatric
music therapist	private hospital, palliative care unit	adult/geriatric
music therapist, social worker	private hospital, palliative care unit	adult/geriatric
palliative care physician (family practice)	home hospice service	adult/geriatric
palliative care physician (family practice)	private hospital, palliative care unit	adult/geriatric
palliative care physician (internal medicine)	private hospital, palliative care unit	adult/geriatric
palliative care physician (internal medicine)	public hospital, palliative care unit, prison care	adult/geriatric

seeks to promote hospice and palliative care through the music therapy institute; (b) seeing patients at the end of life on an interdisciplinary care team with a music therapist; or (c) doing professional music therapy sessions in a hospital.

The pool of clinicians included nine music therapists and four physicians by profession. However, since music therapy is often added later on in a career due to its existence only as a master's degree in Spain, this same pool of clinicians also included people who were (and still are) psychologists, nurses, and professional musicians. An important note to make is that all clinicians interviewed in this study, despite being involved music therapy and end of life care, hold varied career positions (Table 1). In addition to their professional training (i.e. music therapist versus physician), the duration of time spent working in the field, techniques utilized most frequently in practice, access to patients (small-town or suburban care versus working in the city center), context of care (home care, hospital, etc.), and age group of patients (pediatric, adult, geriatric, etc.) are all factors which certainly affect clinicians' perspectives on their field; their responses to open-ended interview questions were reflections of their professional status, experience, and context.

### Design and Procedures

For this project, semi-structured interviews were utilized to gain participants' perspectives of humanistic approaches to end of life care. Interview questions were pre-de-

terminated and open-ended and elicited both concrete and narrative knowledge of the interviewees (Ayres, 2008). Interviews were all conducted in Spanish, recorded, and transcribed by hand. All interviews were done face-to-face, either in-person or through video chat. A permission form describing the study's intents, purposes, and methodology was read aloud to each interviewee beforehand, and verbal consent to participate was attained from each person. Interviews lasted from 15 to 30 minutes, with 20 minutes being the targeted duration. The interview was formatted in a semi-structured manner, and all included the following questions:

1. Describe your work, as well as your relationship with patients.
2. How do you define wellbeing for your patients?
3. What do you perceive as the most difficult in your work?
4. What are some emotions or thoughts patients often have in this context?
5. How do you see the role of music in your work?
6. How do you perceive the role of spirituality in this context?

## Data Analysis

The process of data interpretation was a narrative analysis approach, which focuses on “experiences and events as the participants understand them” (Schutt, 2011, p. 339). The process of interviewing and interview analysis followed the flow of content clinicians chose to share and attempted to “preserve the integrity of personal biographies,” in this case biographies regarding physicians’ and music therapists’ professional lives (Schutt, 2011, p. 339). The process of generating themes from interviewees was inductive, utilizing grounded theory. The primary interview material was the basis for constructing categories and generating theory (Denzin & Lincoln, 2008). This study utilizes a constructivist approach to value individual clinicians’ subjective experiences and perceptions on approaches to care (O’Callaghan, 2009). While I had an idea of how to organize the responses to my questions pre-interview, the categorical themes included in analysis emerged from the lens of informal conversation with clinicians, relying also on my own subjective perception of what they expressed as important to end of life care, such as their tone of voice and emotional reactions to my questions.

## Results – derived themes

Analysis consisted of three main stages. First, upon listening to the complete interview recordings and reading the transcriptions once, seven categories of overarching themes were noted among all the interviews: (a) illness and relational identity, (b) definitions of suffering and wellbeing, (c) spiritual themes, (d) emotional and psychosocial themes, (e) co-constructing routes of healing between patient and provider, (f) reflexivity, and (g) distinctions between care and cure (the latter two were later combined into one category due to their overlap). On the next pass through the interview transcripts, each of the seven themes were color-coded. Lastly, all of the color-highlighted text from each interview was compiled into a single document and interview quotes were systematically removed until three to four representative or significant quotes remained in each category.

Note: as therapist quotations are more numerous, quotes from interviews are from music therapists unless marked as physician quotes.

## Illness and relational identity

Patients’ relational networks came from other people or daily activities that defined them as a person. Firstly, the clinicians interviewed frequently reported that music therapy assisted in some way with the experience of pain, highlighting the interconnectedness of patients’ physiological outcomes with their sense of personhood. Likewise, the role of the music therapist in seeing an individual’s “capacities” beyond illness and disability addressed challenges to one’s daily life routine and therefore chal-

allenges to one's sense of self. Wellbeing in this case can be defined as something that may not be seen at the moment of the clinical encounter but became evident looking at the patient in the context of their relational network, as the music is passed from therapist to patient to family. In the following quotes, participants discussed how patients' sense of self and relational networks impacted their clinical practice.

"When you enter [the room] to work with someone in a vulnerable situation, I believe that you first see more suffering and pain. In this first contact, the illness can affect you, seeing all that the person can't do, their physical state, their emotional state. But later you see the person as such, more the essence of the person – and if you see the essence of the person, the physical suffering loses a bit of its force. Then you achieve much more than a sick body, and that is when you can really begin to work with and develop the person's abilities."

"One's self-perception is that every time they can do less...to feel capable is to do something more, and give more power to the person with the little they can do, to give them greater license to decide, so that the person begins to think of themselves in the same way."

"When she found out she was dying, she had gone three or four years with the cancer, and hadn't returned to painting for years...but she felt she could not return to painting like this because for her it was really frustrating – to want to, and not be able to. Music was not her language...but we used it to play an image...and later, she improvised about one of her own paintings. It was something which helped her relate to her painting, but was not painting directly...it was not forgotten for her, it was something she had to touch, and did so through the music."

"I did a few sessions with her, a few months before her death, and my perception during these sessions was that there was a lot of distance, that she had her resistances to music therapy, that she did not open herself to all of it. But later what we did in the music therapy sessions she shared with her family, telling her family of these experiences. It had that value and for me it was a surprise, because she was a person who you see as tense, whom you really don't know is connecting with you or not, or maybe it's not her place in that moment – you question if that person is able to feel well. Well, maybe not in the session, but it had this value for her because she brought it to her family."

## Definitions of suffering and wellbeing

A common theme for conceptualizing what it means to suffer as well as what it means to be well was deferring to the knowledge and perceptions of the patient. From the perspective of the participants, a patient defined what wellbeing and suffering meant for themselves, with one physician noting that health was "What the person considers to be well." Additionally, some saw another's wellbeing as a reflection of themselves, and vice versa, highlighting the reciprocal nature of defining suffering and wellbeing. The following quotes describe patient and provider's subjective experiences in deciding what it means to be well and guiding care accordingly.

"First, we have a minimum level of objectives, of comfort, and later also we ask about the person's history. Because someone feels better when they can express themselves." [physician]

"I believe that you see me, you know me...if you feel well, it's easy for the other person to be well. Like a mirror – we are mirrors of others, and we accompany one another. But there are physical things – if someone is breathing, if their arms are open, if they have trust, a body posture that's not closed – if they are quiet, or animated, on the level of gestures, in the face, or a smile – and you know that person is well."

"well, in my case, asking many times because most people have speech – it's certain that there are people who don't – there was a woman with a reclined seat, and she doesn't speak but her facial expression changes – she opens her eyes or becomes emotional. How she tears up when she listens to songs that were important in her life. Then, I believe wellbeing can be seen there, because it is a cry of emotion."

"I believe it is a feeling. I believe that it gives you a connection so human that in the end, when you feel this naturality and quiet, it's because they are feeling well too. From their



facial expression and bodily expression, a smile or relaxing facial features, or they can say phrases such as, 'how good.' But I believe that above all, I know because I feel it too."

## Spiritual themes

All clinicians interviewed noted that a patient's spirituality were important, even essential, to their wellbeing and in relevance to their therapeutic or medical relationship with the patient. Additionally, clinicians interviewed noted distinctions between spirituality and religiosity by the absence of formal beliefs and emphasis on subjective feeling, such as of peace. For the music therapists, rather than just coping or facilitating a means to an end, music at the end of life became a process of growing, rising, and generating spiritual meaning. Physicians especially noted that they did not feel that their medical training prepared them to address spiritual needs. The quotes to follow detail participants' perceptions of spiritual aspects of their practice.

"If [the patient] has a history of connecting with a spiritual life, during this time it will also appear. In music, they are experiences that can manifest more easily. Because music in general, not just at the end of life, is something that helps us encounter ways to transcend...if we are at the end of life, in a sensitive situation, we have prepared ourselves to accept that this is a way to connect in a greater way to love, to energy."

"Generally, the spiritual needs are for example a life review, to express love, to feel loved, to feel recognized, to be in peace, then, I believe that to be loved for example with a person who already cannot speak, even with the little they can express, I believe it has to do with the spiritual and doesn't have anything to do with expressing beliefs or speaking of the beyond...and for the people who are very agitated, people who cannot encounter wellbeing at the end of life, well, the power to do a spiritual work, to facilitate that they may be in peace, it is a spiritual process."

"To me [spirituality] is not a role – the sick person is ill with everything, their spirituality, and with their personality – to not address it, is to not treat the case completely. Most likely, we aren't [professionally] prepared." [physician]

"It's fundamental. Above all, the first few years I worked, I felt ill-prepared for it. Well, the first thing to do is to listen. But you have to prepare yourself...whatever the person believes, when one is conscious and is very aware they are going to die, because at the end, sometimes it took a lot for me to say they were going to die...the important thing is that what happens happens in the best way possible. But few people allowed you that type of relationship...but you would note that the human being is transcendent, that they don't know where they are going or what is going to happen, it's a really big emptiness." [physician]

"With regard to the end of life, I believe that spirituality is really that which can be growing until we die, our physical, mental, and functional capacities are shutting down, then, above all the spiritual can have a greater development. Above all, it's a way of giving an answer to all of the needs of the person. The person at the end of life really already experiences that spiritual part – they know that their existence has a limit, and have been planting things beyond, of the situation, of what you and I do – then to put oneself in that situation, the spiritual flowers. Then, if a therapist is capable of pulling from this spiritual flowering, well they can facilitate spiritual development so that the person can keep growing until the end of life." [physician]

## Emotional and psychosocial themes

Clinicians interviewed tended to declare emotional and psychosocial issues, such as emotional release and self-acceptance, as inextricable from medical issues. A key component of involving emotional and psychosocial issues in care was to both allow a person to express emotions such as fear, and pick up on non-verbal cues of emotion such as presence and family cohesion. Additionally, many of the music therapists noted that feelings at the end of life were not purely negative but included joy and release in tandem with difficulty and suffering. In the following quotes, participants describe instances in which they found navigating emotional and psychosocial aspects of care es-

sential, such as protecting family cohesion, giving acceptance to someone experiencing self-blame, and fear and frustration giving way to peace.

“I had a very difficult situation with a young woman who was at the point of death...and her husband was with her and was waiting to say goodbye to her son. And in that moment I felt that it was a space to care for the both of them, giving her a hand I was saying that she could go...and in that moment, it was caring for the environment – a space of farewell for her husband too, not only for her. As the end is to create an aura between the two, and you are in some way maintaining this little bubble that you are protecting in that moment.”

“I believe that [the most difficult part] is when a person is constantly fighting with themselves. Because they feel guilty, they judge a lot, they don’t permit themselves to do nor feel nor be...for you to reflect that permanence is to give permission, it’s unconditional acceptance when the other person doesn’t have it.”

“it can pass – at the end everything arrives at love, empathy, humility, affection and to let oneself love...more than the fear of death, it’s the fear of leaving behind – and those fears, are expressed in different ways too. But at the end, frustration or rage from fear that one feels...the discharge is marvelous – there are other moments that can pass that give a lot of peace, tranquility, and that helps the family achieve that contact and communicate that non-verbal affection that they feel for the patient.”

### Co-constructing routes of healing between patient and provider

Another recurring theme among clinician interviews was the immense value placed on patients’ desires, understandings, and skills in building their clinical encounter. The clinicians interviewed frequently mentioned themes of co-constructing psychosocial, spiritual, and physical healing alongside patients. Rather than serving exclusively as bearers of knowledge, they tended to describe their clinical roles as ones of accompaniment, which prioritize and empower the voice of the patient. In the following quotes, clinicians describe their mindset of deferring to the patient’s voice while delivering care.

“...what you do has the same value as what the other person does. It’s not I who applies a treatment, I don’t go with my musical medicine and apply it to you and you feel well – no. I listen to you, I get to know you, I accompany you, then, all that may be in music therapy, not only in palliative care, centers on the person – what the person brings, what they express, then, in palliative care above all – when the person is very vulnerable, when they are in a very fragile situation – it has this value that they can take part to decide, even the people who seem as if they no longer have the capacity to decide – always a gesture, a form of doing things, to know what the family tells you of that person, it is a way for this person who is very limited to participate and be the protagonist of the entire process.”

“you can’t see the sick person from above, where I tell you what happens.”

“Before I wanted to help people so they would get better; this vocation continues, but right now from a perspective more from you-to-you, from person-to-person...and for us professionals not to have so much protagonism.”

“But in the end it could be that you do something completely different, you must be prepared for anything, to discard what you have prepared and embrace what the patient has to say to you in that moment.”

### Reflexivity and distinctions between cure and care

This final section on reflexivity refers to a prominent tendency of the clinicians interviewed to reflect on their own individual perceptions, feelings, and shortcomings in the first-person. The clinicians frequently noted methods of medical treatment or healthcare intervention, both their own or systemic, which they did not find adequate to care for patients at the end of life. In doing so, they brought up perceived distinctions between methods meant to cure or fix an ailment and ones that center on caring for the patient as a holistic being, which they favored, with one music therapist even describing their work as when “medicine arrives at this point when it can’t do any



more.” In the following quotes, clinicians detail their perspectives on how to be aware of their own limitations in practice.

“We are educated for it – my education was more knowledge for the purpose of knowledge, but later you see, knowledge only without more, I am very poor.” [physician]

“But yes I feel, when there are difficult situations, it is an enormous fortune to encounter them with a tool like music. Because in many situations it can do that at which you can’t reach.”

“Above all, I recognize that the first year it gave me fear, and I sought refuge in the medical. It was a chapter that took a lot out of me – I did not have training – but it has an enormous importance, because it is an area that together with the emotions, arrives until the end. The spiritual, the emotional, the affective, you can work with until the end, until the last moment, right?” [physician]

“I always say that when everyone has finished with their work, when the doctor can do no more, nor the nurse, the music always arrives. It’s a wellbeing that is the capacity of a person to be themselves.”

“the truth is that at the beginning, I had in mind the idea of getting data to convince the doctors, you know? And put them in numbers, the numbers that interested them, the effects of the music...in the end, all depends on what the patient tells me, you know? Well, if they didn’t want it, I didn’t do it. Then, we would say that the work is to help the person so that they feel a little better, in the moment we initiate the therapy one had to aid the wellbeing of the person...how to help the person feel well with themselves.”

A commonality spanning all seven derived themes was the lack of focus on medical illness itself, whether the interviewee was a physician or not. While medical literature frequently centers on distress, trauma, and pain, patients’ lived experiences contained a mixture of these themes along with positive elements less commonly associated with death, such as joy, love, and clarity (Brennan, 2017). When clinicians in this study brought up patient cases, they briefly mentioned disease states of patients – if at all – and tended toward describing patients’ psychosocial circumstances. One physician provided an anecdote regarding the value of basic human contact, such as conversation, and stated that it should not be underestimated in its healing power. They remarked, “I met a patient who told me, the person most important to me is the cleaning lady. Because every morning she chatted with him, and then achieved much more than I did...people want to go where the human can reach.”

## Discussion

This project provides a window into the experiences of clinicians involved with music therapy in end of life care and how artistic engagement in end of life contexts sets up a model for avenues of spiritual, psychosocial, and medical care. Even outside of an end of life context, clinicians may broadly adopt the “palliative soul” and incorporate the needs of patients and their relational networks into clinical practice. This model of the “palliative soul” aims to heal not just by applying a treatment with an anticipated effect but constructing what it means for a person to be well with that person and their loved ones, moment by moment.

The artistic engagement reported from the music therapists in the interviews tend to prioritize the patient’s identity first as a human being and second as a patient (Brennan, 2017). They acknowledge that the person dying is more than just a product of their medical diagnoses and therefore often elicit words and experiences from the person that are non-medical in nature. As medical sociologist Allan Kellehear noted in *The Study of Dying*, “dying people reinforce their importance to themselves and their networks by affirming their relevance right up to the very end of life” (Kellehear, 2011, p. 4). “Theories of agency” at the end of life emphasize playing an active role in maintaining activities, relationships, and responsibilities important to them even before the onset of illness (Kellehear, 2011, p. 4). In this sense, affirming a patient’s personhood at the end of life is contingent on what the patient expresses to the clinician as signifi-

cant concerns to them. In *On Death and Dying*, psychiatrist Elisabeth Kübler-Ross noted that dying patients are “often treated like a person with no right to an opinion,” and possess wishes and desires at the end of life which are too often unheard or ignored by both medical staff and their loved ones (Kübler-Ross, 2009, p. 8). In deferring to what the patient perceives as important at the end of life, clinicians share power to speak, make decisions, and generate routes of healing with their patients.

Additionally, clinicians strongly believe spiritual wellbeing and distress to hold significance at the end of life. Likewise, music therapy’s role in spiritual care has been well-documented in clinical literature. In a study by Włodarczyk (2007) on the effects of music therapy on spirituality, the author found that terminal patients were significantly more likely to discuss spiritual themes and issues during music visits than non-music visits. McClean, Bunt, and Daykin (2012) noted in a study, on the subjective reports of palliative care patients on spiritual healing functions of music therapy, that spirituality is used as a blanket term to discuss personal challenges more broadly and may or may not be related to religion. Despite institutional leanings toward Catholicism in Spain, it is important to distinguish religiosity from spirituality, the latter of which can be defined as one’s subjective experience of meaning-making which may or may not be influenced by religious traditions (Daaleman & VandeCreek, 2000).

While music therapy in end of life care directly engages adverse psychosocial circumstances and embraces experiences of death and dying, human culture as a whole tends to shy away from pain and death. Cultural norms draw us to sequester experiences of dying at the margins of society, and it may be difficult to sort through such norms and expectations of what constitutes a beautiful life to reach and care for the human (Brennan, 2017). Ultimately, the themes in clinical practice outlined in this project highlight some of the significant ways in which elements of the “palliative soul” challenge cultural assumptions of beauty and humanity at the end of life, as well as the social norms that compel us to turn away from complex, multidimensional suffering.

## Conclusions

The interviews in this project give perspectives on how health professionals may humanize patients facing near impossible circumstances such as the end of life and do justice in caring for their patients: leaning in to experiences of suffering with intention and an open ear, approaching patients in anticipation of their potential spiritual, emotional, and psychosocial needs, defining suffering, wellbeing, and effective clinical intervention through the patient’s voice, thinking actively about their own biases and shortcomings in care, and overall seeing the beauty and humanity in people both within and despite their arrival at end-stage disease. This article encourages any professional caring for people in states of medical and psychosocial vulnerability to contemplate elements of the “palliative soul,” and how they may take root and flourish in their own clinical practices.

## About the author

Zoe Tao is a medical student at the University of Texas Southwestern Medical School in Dallas, Texas. She received her Bachelors of Arts from Rice University in Houston, Texas in Psychology and Religion. She hopes to continuously engage with multidisciplinary scholarship and practice throughout her medical training, especially as they pertain to music in psychiatric and palliative care settings.

## Acknowledgements

Supported by: The Rice University Wagoner Fellowship.

## References

- Ayres, L. (2008). *The SAGE encyclopedia of qualitative research methods: Semi-structured interview*. London: Sage Publications, Inc. <http://dx.doi.org/10.4135/9781412963909>.
- Brennan, M. (2017). *Life at the end of life: Finding words beyond words*. Bristol, UK: Intellect.
- Benito, E., Barbero, J., & Dones, M. (2014). *Espiritualidad en clínica, una propuesta de evaluación y acompañamiento espiritual en cuidados paliativos* [Spirituality in the clinic, a proposal for spiritual evaluation and accompaniment in palliative care]. Madrid: Síosí Punto Gráfico.
- Clements-Cortes, A. (2016). Development and efficacy of music therapy techniques within palliative care. *Complementary Therapies in Clinical Practice*, 23, 125-129, <https://doi.org/10.1016/j.ctcp.2015.04.004>.
- Daaleman, T. P., & VandeCreek, L. (2000). Placing religion and spirituality in end-of-life care. *Journal of the American Medical Association*, 284, 2514-2517, <https://doi.org/10.1001/jama.284.19.2514>.
- Denzin, N. K., & Lincoln, Y. S. (2008). *Strategies of qualitative inquiry*. Thousand Oaks, CA: Sage Publications, Inc. pp. 203-206.
- Hartzband, P., & Groopman, J. (2009). Keeping the patient in the equation—humanism and health care reform. *New England Journal of Medicine*, 361(6), 554-555.
- Janaudis, M. A., Fleming, M., & Blasco, P. G. (2013). The sound of music: Transforming medical students into reflective practitioners. *Creative Education*, 4(6A), 49-52, <https://doi.org/10.4236/ce.2013.46A009>.
- Kellehear, A. (2011). *The study of dying: From autonomy to transformation*. Cambridge: Cambridge University Press.
- Kübler-Ross, E. (2009). *On death and dying: What the dying have to teach doctors, nurses, clergy and their own families*. New York, NY: Taylor & Francis.
- Lee, J. H. (2016). A qualitative inquiry of the lived experiences of music therapists who have survived cancer who are working with medical and hospice patients. *Frontiers in Psychology*, 7, 1840, <https://doi.org/10.3389/fpsyg.2016.01840>.
- McClellan, S., Bunt, L., & Daykin, N. (2012). The healing and spiritual properties of music therapy at a cancer care center. *The Journal of Alternative and Complementary Medicine*, 18(4), 402-407, <https://doi.org/10.1089/acm.2010.0715>.
- Newell, G. C., & Hanes, D. J. (2003). Listening to music: the case for its use in teaching medical humanism. *Academic Medicine*, 78(7), 714-719.
- O'Callaghan, C. (2009). Objectivist and constructivist music therapy research in oncology and palliative care: An overview and reflection. *Music and Medicine*, 1(1), 41-60.
- O'Kelly, J., & Koffman, J. (2007). Multidisciplinary perspectives of music therapy in adult palliative care. *Palliative medicine*, 21(3), 235-241.
- Olarte, J. M. N., & Guillén, D. G. (2001). Cultural issues and ethical dilemmas in palliative and end-of-life care in Spain. *Cancer Control*, 8(1), 46-54, <https://doi.org/10.1177/107327480100800107>.
- Patrick, J. H., Pruchno, R. A., & Rose, M. S. (1998). Recruiting research participants: A comparison of the costs and effectiveness of five recruitment strategies. *The Gerontologist*, 38(3), 295-302.
- Schutt, R. K. (2011). *Investigating the social world: The process and practice of research*. Thousand Oaks, CA: Pine Forge Press. <https://doi.org/10.1177/1943862109337135>.
- Van Roessel, P., & Shafer, A. (2006). Music, medicine, and the art of listening. *Journal for Learning through the Arts*, 2(1), 1-14.
- Wlodarczyk, N. (2007). The effect of music therapy on the spirituality of persons in an inpatient hospice unit as measured by self-report. *Journal of Music Therapy*, 44, 113-122, <https://doi.org/10.1093/jmt/44.2.113>.
- World Health Organization. (2018). *WHO Definition of Palliative Care*. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>.