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Heartbeat recordings in music therapy bereavement care following suicide: Action research single case study of amplified cardiopulmonary recordings for continuity of care

Claire M. Ghetti
The Grieg Academy – Department of Music, University of Bergen, Bergen, Norway

Brian Schreck
Behavioral Oncology, Norton Cancer Institute, Louisville, KY, USA

Jeremy Bennett
Cincinnati, Ohio, USA

Abstract

Bereavement services incorporating family-centered practices are emerging within hospital-based care but are often time-limited and lack personalization. This action research single case study explored one father's experience of music therapy using amplified cardiopulmonary recordings (ACPR) during bereavement following his son's death by suicide, to critique current norms and inspire transformative change in systems of care. As co-researchers, a bereaved father, his music therapist, and a music therapy researcher used iterative cycles to qualitatively analyze a series of dialogic reflections upon an 8-year experience of ACPR to construct two overarching themes: 1) continuity experienced as compassion, and 2) process of music therapy with ACPR as tool for resilience and positive growth. Aspects of continuity in the ACPR process, in relation with the music therapist, in journeying through grief, and in the heart and heartbeat were perceived as overwhelming compassion that fostered positive growth in the face of profound loss. We see our study as a first step in promoting culture change by exposing underlying practices, assumptions and policies within the context of hospital-based

Corresponding author:
Claire M. Ghetti, GAMUT – The Grieg Academy Music Therapy Research Centre, The Grieg Academy – Department of Music, University of Bergen, Postbox 7805, Bergen 5020, Norway.
Email: claire.ghetti@uib.no

bereavement care and identifying an exceptional example of possibilities. Our findings add to the literature on action research for transformation by demonstrating that the process of relational knowledge co-creation can be perceived as part of the therapeutic journey.

Keywords
Music therapy, amplified cardiopulmonary recording, bereavement, action research, continuity of care

Introduction

Hospital-based bereavement care

Loss and bereavement are a natural part of human existence, but grief responses may be complicated or prolonged in cases of unexpected death, or when death occurs in the intensive care unit (Boelen & Smid, 2017; Kentish-Barnes et al., 2015; Pearce et al., 2021). Provision of bereavement services within hospital-based care may be limited (Efstathiou et al., 2019), and given in a universal way, irrespective of need (Breen et al., 2014). Though many bereaved individuals find informal supports sufficient, those at greatest risk of complicated grief responses require targeted bereavement services (Pearce et al., 2021). Within pediatric hospital-based bereavement services, bereaved fathers and siblings often receive inadequate support (Donovan et al., 2015).

Bereavement in cases of suicide becomes even more complex. Formal bereavement supports may only be available for a short time and the bereaved may have difficulty engaging informal social supports out of fear of overwhelming them or due to feelings of shame (Maple et al., 2010). Survivors of suicide loss may struggle to find social supports or ways to maintain positive connection with the deceased (Maple et al., 2010).

Music therapy and legacy work

In pre-bereavement, music therapy creates opportunities for those who are dying and their loved ones to share significant moments that sustain the bereaved after the loved one's death (O'Callaghan, 2013). Music therapy helps caregivers identify and process strong emotions, create meaning via reflecting upon memories, and form a secure foundation for healthy bereavement (Potvin et al., 2018). Legacy work within music therapy can include creating songs or albums, music-based life reviews, and recordings of heartbeats or breathing sounds integrated into music (Andrews et al., 2020; Clements-Cortés, 2017; O'Callaghan, 2013; Schreck & Economos, 2018).

Amplified cardiopulmonary recordings

Amplified cardiopulmonary recordings[1] (ACPR), facilitated by a music therapist, involve the recording of a person's breathing and heartbeat rhythms to intentionally co-create an

original musical composition or recreate a culturally and personally-significant song[2] (Clements-Cortés et al., 2021). The personalized rhythmic motif inherent in such recordings expresses the personhood of the dying loved one, even when the person cannot vocalize or verbalize.

The ACPR approach used in therapeutic settings was developed by Brian Schreck in 2013 (Brock et al., 2018; Schreck, n.d., 2015; Schreck & Economos, 2018). A music therapist uses a digital stethoscope or stethoscope microphone to capture and amplify the heartbeat. Loved ones and the dying person themselves contribute to creation of music recordings with their own heartbeats, or by playing instruments, singing, or using their voices (Schreck, 2015). Music therapy incorporating ACPR is used in pre-bereavement and bereavement work by music therapists in over 80 medical centers in the U.S. (Schreck et al., 2022). Though there are examples of ACPR being used as a one-time interaction (Andrews et al., 2020), potential therapeutic benefit is enhanced when ACPR is implemented as a process over time with participation from patient and caregivers (Schreck et al., 2022; Schreck & Economos, 2018).

Rationale for the study

In cases of complicated grief, typical hospital-based bereavement care may not be sufficiently extensive or personalized (Aoun et al., 2017; Breen et al., 2014). Music therapy using ACPR can provide a personalized form of continuity of care responsive to changing needs over time, thereby transcending current limitations in care. We used dialogic reflection among a recipient of ACPR music therapy, his music therapist, and a music therapy researcher to explore an exceptional example of what the ACPR process can afford a bereaved parent across time and contexts, to inspire change in care systems.

Methods

We used an action research single case study (Blichfeldt & Andersen, 2006) to explore an in-depth personal experience of music therapy with ACPR in order to critique current norms in hospital-based bereavement care and inspire transformative change. Through dialogue, we enabled cycles of inquiry, action, and reflection (Blichfeldt & Andersen, 2006; Stige & McFerran, 2016). The participant researcher engaged in decision making in all study phases, and the process unfolded in accordance with such decisions (Hughes, 2008). Grounded in a constructionist epistemology, we view the knowledge generated in this study as socially and collaboratively constructed (Alvesson & Sköldberg, 2009), and future forming (Gergen, 2014).

Ethical considerations

This study was registered and approved by the University of Bergen – System for Risk and Compliance in Research Projects (Project number: R412) on April 7, 2020; and considered exempt from further review as health research. We followed ethical guidelines for participatory action research (McNiff, 2013; University of Sheffield, N.D.). The

participant signed a written informed consent form, including a description of opportunities for co-researching, prior to engaging in the study.

Our participant researcher wished to be transparent with his identity. Considering ethical challenges related to this choice (Giordano et al., 2007; McNiff, 2013), we obtained written permission for non-anonymity from the participant researcher, listing possible negative and positive ramifications. We also obtained written permission from the participant researcher's adult son, who could potentially be indirectly identifiable through the non-anonymity of the participant researcher. Both father and surviving son had a chance to review and amend the manuscript prior to its submission for publication.

Recruitment, participants and setting

We used purposive sampling to identify a parent who had rich experience of using ACPR in their grieving process. The music therapist extended an invitation to partake, described the aims of the research study, and obtained signed informed consent from the participant researcher (Jeremy).

Jeremy is the father to four sons, one of whom was in the pediatric intensive care unit (PICU) after life-threatening trauma from a self-inflicted gunshot wound to the head. In the PICU, Jeremy and his family were offered pastoral care, child life and integrative care (including music therapy); and thereafter hospital-organized bereavement services consisting of an annual memorial ceremony and cards of remembrance. The hospital was located in a large city in the Midwest of the United States.

The music therapist researcher (Brian) who provided the ACPR music therapy was employed in the children's hospital's inpatient intensive care units and home-based outpatient palliative care and hospice agency at the time. The third researcher (Claire) is a music therapy clinician, researcher, and educator. All co-researchers contributed to: 1) deciding which data would be collected, 2) determining logistics of the dialogues, 3) determining how to analyze data, 4) choosing which forms of action would form feasible next steps, 5) writing up the manuscript, and 6) deciding how to disseminate findings.

Reflexivity and trustworthiness

We used the domains of the EPICURE evaluation agenda for qualitative research to help guide our reflexive process (Stige et al., 2009) and engaged in critical self-reflection (McNiff, 2013) by periodically dialoging about our process and reflecting upon our situatedness:

> Claire: I am a music therapist and researcher who has used song with families at end-of-life, but I have no first-hand experience of ACPR.
>
> Brian: I am a music therapist with humanistic orientation. I developed this process-based ACPR intervention and have used it with families and investigated it since 2013.
>
> Jeremy: I come to this research as a father and musician who was introduced to music therapy by Brian when I lost my son tragically in 2014. We utilized music therapy with ACPR to help my grieving process.

This was the first time any of us had co-researched with/as a participant researcher.

Description of the ACPR music therapy received

In the PICU, the music therapist (Brian) first met with Jeremy's younger son, who described his brother's music preferences and encouraged his father to try music therapy. Brian met with Jeremy to provide a brief music therapy assessment, with live music at bedside, and to describe ACPR. Jeremy accepted the offer of ACPR and provided consent for recording of his son's heartbeat, which Brian completed. The next day, Jeremy's older son was compassionately extubated. Brian integrated the amplified heartbeat when creating instrumental recordings of music that ZZ chose due to personal salience. Two days after the death, Brian called Jeremy and provided him with the first parts of the ACPR composition, which Jeremy listened to at the funeral home. Approximately two months later, Brian provided follow-up contact and asked if Jeremy wanted to participate in a hospital-initiated video about ACPR. Thereafter, Brian and Jeremy maintained a monthly check-in with each other via phone or email. They continued adding new music to the collaborative ACPR album for approximately a year and maintained periodic contact thereafter for a period of eight years.

Data collection

Dialogical interviews served as a primary means of inquiry. An initial dialogue (54 min.) between Jeremy and Brian was carried out via video conferencing software[3] in August of 2020, probing Jeremy's experiences with ACPR from initial meeting to follow-up contact. Jeremy had a chance amend topics in advance (see Supplementary Appendix), and contribute questions of his own. We then decided that Claire would complete a preliminary analysis of the transcript, which would serve as the basis for the second dialogue.

The second dialogue (58 min.) occurred virtually with all three co-researchers in March of 2021. We dialogued around themes from the first analysis to deepen our reflection and promote trustworthiness of themes. This stage of reflection gave way to new inquiry, as we considered how to put our understandings into action (McKay & Marshall, 2001). Both dialogues were transcribed verbatim by Brian for subsequent analysis, and shorter rounds of dialogue followed during revision of the manuscript.

Data analysis

We used iterative cycles within our qualitative analysis, moving between inductive generation of coding patterns to deductive verification of such (Mills et al., 2010). Our steps consisted of Claire reading the first dialogue transcript several times, demarcating portions of text pertaining to the research question, using in vivo coding to retain participants' single words or phrases to represent these portions (Ivankova, 2015), re-reading transcripts and adjusting/expanding codes, constructing sub-themes and themes to represent groups of codes, and sharing the coded transcript draft (with themes and sub-themes) with Jeremy and Brian for cycles of reflection and inquiry.

We integrated themes and sub-themes from both dialogues into a table with quotations, organized by two overarching themes constructed by Jeremy to represent the most salient features of his experience. As a final stage of this dialogic process, we reflected over relational workings between the human and non-human actors involved in this case and integrated such perspectives into the narrative account of findings.

Data sharing statement. A complete data set is not publicly available to maintain the participant researcher's privacy.

Findings

During the process of dialoguing and analysis, Jeremy identified two themes that reflect the most dominant and salient aspects of his experience of ACPR, which we therefore consider overarching themes: 1) continuity experienced as compassion, and 2) process of music therapy with ACPR as tool for resilience and positive growth[4]. Aspects of continuity in the ACPR process; in relation with the music therapist, in journeying through grief, and in the heart and heartbeat; were perceived as overwhelming compassion. The ongoing process of ACPR enabled multiple forms of interpersonal and intrapersonal connection, and as such was perceived as an awe-inspiring, flexible and constructive tool for promoting resilience and positive growth in the face of loss.

Continuity experienced as compassion

Through dialoging about his experiences and reflecting upon the dialogues, the one word that Jeremy identified as reflecting the core of his emotions was that of receiving ongoing "compassion." Continuity present in his evolving process with ACPR, his relationship with Brian, his movement through his grief journey, and all that has transpired since he began sharing his story has been experienced as a living and evolving form of compassion. When reflecting on his experience, Jeremy draws parallels between the continuous nature of grief, continuous process of personal growth, and nature of music itself.

Grief is continuous and variable – must decide how to relate to it. Jeremy experiences grieving as a continuous and variable process. It has no specific ending point where feelings cease and "everyday life just hops back into where it was." Instead, grief changes over time through "winds and turns" and is not always the same. Each time the sense of loss arises, he has to figure out how to relate to it:

> …now how do I relate to it this time? Do I just be pissed off? Or do I find some way to like, *hold* it and get the anger out separately, and then go forward? (Jeremy)

Certain times of the year, like anniversaries, tend to be difficult. Other times it is a remembrance of an opportunity lost that catches him. This triggering process is very much

integrated in his everyday life, and it is something he has learned to go through. Difficult feelings do not cease over time, but he learns how to relate to them in constructive ways:

> I grieve every bit as much as I did [eight] years ago. I grieve today. I may do it differently. I may use my tools differently. I may use my story differently. (Jeremy)

Some family members think he should not let the grief be such a controlling factor in his life, but he sees this differently. Through active and constructive grieving, he maintains connection: with his son, with his history, and with his emotional experience of life.

Though Jeremy recognizes that there may be no end to the grief, he also knows there is no end to the therapy, since he has the evolving process of ACPR to help:

> I know I'm going to struggle with this for the rest of my life. I also know that I have [ACPR] to help me the rest of my life, you know. So maybe there's no end to the grief. But there's also no end to the therapy. (Jeremy)

Likewise, the relationship Jeremy has with his son who has died will not end, an aspect that can feel daunting at times, but ultimately can be a positive thing: "…if you try to make that into a positive thing, it can be very positive if you let it." Continuity in relationship to his deceased son emerges as vital, just as continuity in relationship to the music therapist and music therapy process also emerge as important factors in his grieving journey.

Relationship is Primary in MT/ACPR and consists of sensitive connections over time. As a music therapist, Brian perceives relationship as primary and aims to establish a sense of "I'm here for you" from the start. Brian starts by developing a relationship and partners with those engaging in music therapy to figure out together what would benefit them. Brian reports that many music therapists who use ACPR focus predominantly on product instead of process, and thus cut the relationship short. For Jeremy, the ongoing and evolving process with Brian and ACPR is what makes this approach unique and effective for him and his family.

Jeremy and Brian both experience that for families in crisis, forming the initial connection between family and care personnel can be challenging, and requires sensitivity. Jeremy's family suddenly found themselves in the PICU with one child on life support and their lives turned upside-down:

> You feel so raw in that time when you're going through a period of loss and pain, and it's hard to let your guard down and let somebody else in….it is a little scary, it's a little hard to do….but you do need to do that. (Jeremy)

When Brian first approached them in the PICU, Jeremy's mind was "not in a good place" and he was not particularly receptive. Instead, it was Jeremy's younger son who served as a crucial "gatekeeper" who encouraged his father to consider the offer and made it possible for Jeremy to give the experience a chance. Jeremy had never heard of music

therapy before and was not sure what it could offer him and his family. As Brian talked with Jeremy about ACPR, conversations opened up around shared music preferences between Jeremy and his son who was on life support. By describing the ACPR process, the focus redirected to the healthy parts of Jeremy's son, namely his heart. Brian describes his experience of this early process of communication and connection,

> To me this was the first "light bulb" that turned on in the dark, that strengthened their connection with one another using the heart sound and its symbol of love which never dies and continues to move. (Brian)

Jeremy selected two songs, "Lego House" by Ed Sheeran (2011) and "Demons" by Imagine Dragons (2012), that were favorites of his son. The process of introducing and planning the ACPR opened communication between Jeremy and Brian. This early stage of ACPR marks the point at which connections between Jeremy, his son's heart, salient pieces of personally-significant music, and the music therapist began to form and interact.

Ongoing MT/ACPR process experienced as compassion – "going to keep moving together". As a music therapist, Brian does not aim to make things immediately better and cheer up family members, but instead tries to communicate that he is diving in with the family and is there to "ride the waves" together. Early on, Brian conveyed to Jeremy that they were going to "keep moving" using the process of ACPR:

> [The heartbeat] is something that's alive, and it's continuing to move. So in my mind, my way of trying to put it to you in those early days was, "We're going to keep moving…somehow." (Brian)

This simple mantra became a very powerful concept for Jeremy. At that point in his life, movement was the last thing Jeremy could imagine:

> That spoke to me very much that we're going to keep moving. That was very powerful. Because you know, at that time in my life, I was not thinking of things keeping moving. In my mind at that time, everything stopped. (Jeremy)

For Jeremy it was "huge" that someone committed to jumping into the emotional crisis with him and committed to being with him through its "ups and downs." This connection was vital, as otherwise he felt isolated and alone, like the only person in the world going through that experience.

In the PICU that served Jeremy's family, follow-up bereavement support was limited. Brian recognized a gap in bereavement care for families once they left the hospital, especially in cases of acute trauma. In addition to his duties on the PICU, Brian held a position offering hospice and bereavement care through a different part of the hospital. Taking initiative to provide continuity of bereavement care, Brian extended an offer to keep checking in with Jeremy and his family to continue their process of ACPR, which they accepted.

After Jeremy's family left the hospital, Brian continued to check in and they added pieces of music matching where Jeremy was in his grief process over time. Brian wanted to support Jeremy in "going where he needed to go" with the music, and to go there with him. Jeremy experienced Brian's reaching out as "hugely important" as it gave him something positive to look forward to at a time when he really needed it. Continuity of relationship was important:

> That was huge for me, because I'd never heard of that even happening before. What doctor calls their patients after their services are quote "done" and checks to see how things are going? (Jeremy)

Since his grieving did not go away after a certain period of time, Jeremy experienced that it was more important to have this long-term relationship and support over time than to have it during the acute crisis.

Process of MT/ACPR as tool for resilience and positive growth

With recognition that the processes of grieving and growing are both continuous, Jeremy views his experience with ACPR as a central and "multi-edged tool" that can contribute to resilience and positive growth.

Recordings as multi-edged tool for connection – beauty in the process. The heart of Jeremy's son is present and alive in the music recordings made through ACPR. Brian first experienced such presence and impact while creating music recordings from the son's preferred music. Listening to the heartbeat while creating the recordings enabled the music therapist to connect with the son through his music preferences and his heartbeat, "While I record I'm not only connecting with the patient and their music, but also celebrating their life" (Brian). For Jeremy, having his son's heartbeat as a constant presence in his life and coping process is profound. The significance of his son's heartbeat struck him the first time he heard it, a moment he will never forget. Brian had worked quickly to create instrumental versions of their first song, and Jeremy received it while waiting for his family at the funeral home.

> As soon as I heard that song it was like, "Wow!" – it went straight to my soul – "It is incredible that we can do this kind of thing." And immediately that song made a huge impact on me and everyone else that heard it. (Jeremy)

The family played the song at the funeral and Jeremy integrated it into his grieving ritual at the cemetery. He experiences the presence of the heartbeat as a powerful way to connect with his son, whenever and wherever he wants.

Jeremy experiences that music taps into deep emotions, which can be challenging but also a significant resource. For him it is important to understand that it is "okay to go there" and cry, because one can still come back:

> You can't stay in the shadows in the darkness, you can't do that to yourself. But you can journey there to get the emotions out. If you don't, they bottle up and come out in another negative way, which can be negative for other people. (Jeremy)

Thus, Jeremy experiences this process of connecting to deep emotions as a necessary and helpful process in dealing with grief.

As a musician, Jeremy had always experienced singing as coming from a "happy place in [his] soul and heart." After his son died, he was not sure that place existed anymore. Though it was difficult, on the first marking of his son's birthday following his death, Jeremy sang the song "In Loving Memory" by Alter Bridge (2004) for a heartbeat recording: "That song spoke to me so much, I really felt I needed, I wanted to and I needed to record that song." On this challenging occasion, the song acted as motivation for Jeremy to connect with his own musical resources. It meant a lot to Jeremy that he managed to express himself musically at such an emotional time and could constructively use music in his grieving process.

Jeremy perceives a deep beauty and unique function in how the ACPR process works. The presence of his son's heartbeat paired with salient music that he himself has played, gives him a way to connect with his son, with his emotions, and with others in a way that promotes his healing and positive growth. This versatility strikes Jeremy, "I don't know of any other medium that can do that, you know, besides music." His son who has died makes a vital contribution on two levels: his donated heart continues to beat and gives life to a young woman, while his heartbeat is woven into the music that helps his father cope with his loss. These circles of connection and continuity of life are profound, painful and beautiful to Jeremy.

> So that heart that made all of that music is still pumping, still beating, still pumping life and that's a huge thing for me to help put things into perspective. (Jeremy)

The recordings serve as a means of introduction to share the significance of the story with others. Jeremy perceives that it is difficult and awkward to talk to people about what happened with his son and share his own related emotions, but the songs serve as a "jumping off platform" to do so. The recordings express the gravity of the situation and help people relate without requiring Jeremy to go into detailed descriptions. Jeremy "quickly goes to [his] phone" to share the recordings with new people he meets and finds that people can "grab onto" the music and be impacted by it, without needing to have the full story each time. Jeremy is able to share and convey deep emotions without overwhelming himself or the other person, and thus he can more genuinely forge a connection with others.

Whole Process as Therapeutic (from Recordings, to Sharing, to Co-researching). Jeremy perceives the whole process from making the ACPR recordings to sharing his story with others, including the press, to co-researching as therapeutic.

> This whole thing has been therapeutic for me…I really can't imagine going through this situation and not having this. So it just really makes me smile, giving more people the opportunity to have that situation. (Jeremy)

He expresses pride in recognizing that sharing his story with larger audiences via the press has helped bring more awareness to this type of music therapy.

Engaging in the ACPR process over time became a positive anchor for Jeremy's mental state. Eight years after the first recording was made, Jeremy still uses it most days. When he is feeling down, missing his son, or when the situation is weighing heavily on his heart, listening to the recordings helps, even if he only listens for a minute or two. There are also positive memories tied to the process of choosing, playing and recording the songs; thus, the process of making them in itself was helpful for Jeremy.

Education, access and choice are needed for others to benefit. Like many families in the PICU, Jeremy's family had not heard of music therapy or ACPR when Brian first approached them. This lack of familiarity contributed to uncertainty in the initial phase. If his younger son had not encouraged him to give the approach a chance, Jeremy thinks he likely would not have accepted the offer. Given the lasting impact his journey of music therapy has made, Jeremy marvels at the chance encounter that made it possible.

At that time, Brian had mostly used ACPR for children with complex medical histories and long-term hospitalization. Jeremy's son was one of the first teenagers involved in the process, which marks the first time Brian used the approach during an acute trauma. Jeremy perceived his coming together with Brian as a meaningful play of forces. Being "picked" to receive an offer of music therapy with ACPR felt very good to Jeremy, and made his children feel that they "had a say in something," which he believes was helpful.

Jeremy believes that the therapeutic potential of music therapy could be more apparent if it were more universally available. In his view, through experiencing it, more people would understand that music therapy with ACPR is therapeutic. He identifies it as important for healthcare professionals at hospitals to be educated on this approach and what it offers, and to increase access to services. A first step is to "jumpstart the conversation" among health professionals, "Bring it to the front door of places, you know, knock on their door loudly, I just think is going to eventually be a very positive thing" (Jeremy).

Jeremy acknowledges that this therapeutic approach is not for everyone. In particular, aspects of music therapy with ACPR can be emotionally challenging to go through and one needs to be willing to open up and deal with a range of emotions:

> Music takes you on a journey. So yes, prepare yourself for going on a journey. The journey is up and down, but I don't think that's a negative. I just think that's something you have to be aware of that there are going to be challenges. (Jeremy)

Brian wonders if some families might experience follow-up music therapy services as an intrusion, reminding them of the hospital and when they were in a different mindset. Jeremy sees a fine balance between reaching out and intruding. For Jeremy, the early

phase of ACPR follow-up started forcing "overlaps" in areas of his life and emotional experience that were challenging:

> So yeah, sometimes that is overwhelming…your things are overlapping into other parts of your life that maybe you're not quite ready for yet. But that also helps prepare you for the process.

Though this overlapping was challenging, Jeremy believes that learning to cope with such overlap helped his process of grieving, though he did not realize it at the time.

Jeremy shares that he still grieves every bit as much as he did eight years ago, and that he and his family still go through a process that is "every bit as important" as it was earlier. In his view, the biggest fear of families is that their loved one will be forgotten, and he views heartbeat recordings as a powerful tool for presence and remembrance. The heartbeat is there, and thus his son is there, as a permanent presence. Jeremy takes comfort in knowing that this collaboration is still evolving, and that there may never be a finished, final product. For Jeremy and Brian, the heartbeat music collaboration is a living, evolving relationship that is mutually giving.

Discussion

We used dialogic reflection among a recipient of ACPR music therapy, his music therapist, and a music therapy researcher to explore what the ACPR process affords a bereaved parent across time and contexts. Our aim was to use this extraordinary case of compassionate continuity of care to critique current norms in bereavement care and inspire transformative change in health care systems. Continuity present in the ACPR process; in relation with the music therapist, in journeying through grief, and in the heart and heartbeat, were experienced as a living and evolving form of compassion. The ongoing process of ACPR acted as an anchor, enabling multiple forms of interpersonal and intrapersonal connection, and as such served as a constructive tool for promoting resilience and positive growth in the face of loss.

Action researchers have highlighted the necessity of building upon possibilities and strengths when trying to promote culture change in healthcare contexts (McKeown et al., 2016). Appreciative forms of inquiry shed light on good solutions to organizational problems that already exist as a way to promote transformative change (Duncan & Ridley-Duff, 2014). Through an extraordinary case example, we show how an extended course of ACPR music therapy can be experienced as continuity of care in a way that flexibly and responsively meets the bereaved one's needs over time. Our study responds to action researchers' calls to lift patient and caregiver voices in healthcare research by integrating them in dialogical processes that challenge hierarchy (Abma, 2019). It also provides an example of the importance of embracing and probing relational space within the process of transformative change (Bradbury, 2022). Our relational process of dialoguing gave us a space to pause and sensitively reflect before we began co-creating our understandings. We hope that this single, salient example of what works can serve as an inspiring form of knowledge that stakeholders can put into action (Bradbury, 2022).

Our findings demonstrate how human and nonhuman actors interact within complex processes of human grieving and thriving. The deceased son's heart has a profound presence in these interworkings: it literally provides life for a young woman who has received it, its manifestation as heartbeat acts as motivation for the father to connect with his own musical resources and forge connections with people in ways that support his well-being, and it provides a way for the music therapist to connect with who the son was and to support the father in his evolving grieving and growing processes. The heart's capacity for agency (Sayes, 2014) is reflected in the father's words: the "heart that made all of that music" is still pumping life and creating possibilities in the lives of many.

Our findings offer a vivid example of the importance of continuity of relationship during provision of bereavement support. Existing research affirms that continuity of relationship, not just continuity of service, contributes to the likelihood that bereavement support will be perceived as helpful (Aoun et al., 2017). Such continuity assures that the carer is familiar with the bereaved families' needs, and contributes to development of rapport and trust that are crucial to helpfulness (Aoun et al., 2017). Our study illustrates that the grief process evolves over time, and bereavement support must do the same. Music therapy with ACPR focused on the specific needs of the bereaved, created a link between pre- and post-death experiences, and provided a constructive outlet for working through challenging emotions; all factors associated with better perceived bereavement support (Aoun et al., 2017; Butler et al., 2015).

Though the length of time the therapist kept in contact with the father would be assumed to be helpful regardless of specific therapeutic approach, we feel our findings illustrate that features of ACPR were particularly facilitative in fostering communication and connection that were helpful in processing loss. Early within the ACPR process, talking about song preferences of Jeremy's son opened conversations about the son's life and personhood, and redirected Jeremy's focus to the still-functioning part of his son, namely his heart. The connection to the heart became an avenue for motivation, hope and possibility for Jeremy, Brian and Claire.

The degree of continuity and follow-up described in this case study is exceptional. The music therapist provided continuous follow-up to this family, though such extended follow-up was not a formal part of his duties. In many parts of the world, hospital-based bereavement services are provided in an undifferentiated way, lacking tailoring to specific needs and timing, despite evidence-based guidelines recommending the opposite (Breen et al., 2014). We argue that health providers cannot allow lack of staff time and funding to prevent the provision of effective bereavement support. Acknowledging that resources are finite, we agree with Breen et al. (2014), that those at risk for complicated bereavement should be prioritized, along with those who lack ability to connect to informal supports in the community.

Bereaved parents of children who die by suicide often lack social settings in which they can process their experience and lack means for maintaining a positive ongoing relationship with their deceased child (Maple et al., 2010; Schaefer et al., 2020). Our findings illustrate how ACPR addresses these aspects by: providing a positive and constructive way to talk about the child, and serving as a creative means for working through challenging emotions. Our findings address gaps in the literature regarding bereavement

services for bereaved fathers and following unexpected death (Breen et al., 2014; Donovan et al., 2015).

Ethical considerations

Given that listening to a loved one's heartbeat recordings can be a highly emotional and intimate experience, as our findings support, we question Andrews et al.'s (2020) suggestion that such recordings can be provided as a single session offer. The profundity of our participant researcher's experience of ACPR and its helpfulness in his grieving and growth process was directly related to the aspects of continuity and adaptation he experienced. As the bereaved father worked through various emotions and struggles, the music therapist provided continuity of relationship and supported active use of ACPR in the coping journey.

Our findings suggest that ACPR is not appropriate for all bereaved. It can be intensely painful to hear the heartbeat of a loved one who is no longer physically present in the world. Though this process was ultimately helpful to this bereaved father's grieving and growth process, he recognizes that not everyone will be able to deal constructively with such strong emotions. Such salient recordings, and/or the music therapist checking in over time, might be perceived by some as forcing undesired recollections or emotions. It is conceivable that the ACPR process might cause distress or even trigger re-traumatization for those who experienced the traumatic death of a loved one (Omerov et al., 2014). It is also possible that in some cases, an ongoing process of ACPR over several years might reinforce perseveration on the loss and prompt dependence on the therapist. Our participant researcher found that recollections tied to the process of ACPR offered him a chance to learn how to constructively grieve, but others might not be as well-equipped to cope.

The use of heartbeat recordings is tied to considerations of consent. Before the heartbeat is recorded, signed consents for recording are obtained from the patient themselves or from legal guardians. Our participant researcher gave consent as a legal guardian for his son, who could not provide consent himself. Such cases raise the question of whether the person whose heartbeat is recorded and embedded into musical recordings, would have consented to such use. This dilemma is particularly challenging in the case of suicide, where we wonder if the needs of the surviving family members should receive precedence over the need to protect a non-living person's privacy and autonomy (inability to give consent). Interestingly, ethical dilemmas related to consent are rarely discussed in the literature about legacy work. We recommend that ACPR be offered to families as early in the course of a life-threatening illness as possible, so that the person with a life-threatening health situation can partake actively and provide consent.

Reflections on the co-researching process

Our study used a co-researching process to assure that the contributions of our participant researcher were transparent and centered. By serving as a co-researcher and electing to waive the right to anonymity, our parent co-researcher assumed agency within the

research process (Giordano et al., 2007). What we did not expect but were pleased to find was that the participant co-researcher perceived co-researching as part of his therapeutic journey and helpful for his grieving process. The music therapy researcher found the participant co-researcher's understandings as informative for her own grief processes. Dialoguing among the three of us, paired with reflection upon our findings helped us more clearly identify and recognize the relational dynamics between the human and nonhuman actors in this exceptional case of ACPR. Co-researching has thus helped us each become more aware of the layers of influence that the heartbeat, ACPR music and related interpersonal relationships have in contexts such as complex grief.

The process of co-researching is not free from ethical and methodological conflicts. Challenges arise regarding how to balance various voices and agendas, and negotiate different competencies and forms of experience. We took steps to reduce the chance of harm related to non-anonymity by naming potential negative and positive ramifications when we obtained written permission from the participant researcher and his adult son (Giordano et al., 2007; McNiff, 2013). In addition, both father and son had a chance to review and amend the manuscript prior to its submission for publication.

Part of the "action" we take in this action research case study is to contribute to "future-forming inquiry" as Gergen (2014) describes, presenting a case of "what could be" if continuity in bereavement care were prioritized. We countered the tendency to find only what we expected to find by dialoging about when ACPR was uncomfortable, felt unsafe or was unhelpful. Since we purposefully recruited a participant who had an exceptional experience of continuity of care, we critically considered how this experience might be uncommon and how it might be problematic. Cycles of participant validation were embedded in all stages of the research process.

Conclusions

This extraordinary example of music therapy with ACPR serves as a "case of" meaningful continuity of care that critiques the status quo of bereavement care and aims to prompt change processes in institutionalized practices of health care. We see our study as a first step in promoting culture change by exposing underlying practices, assumptions and policies within the context of hospital-based bereavement care and identifying an exceptional example of possibilities. Thus, we view the sharing of this single case study as a critical incremental step in the process of transformative change. The music therapist took initiative to offer an on-going process that developed over time with the bereaved father's needs and evolved into a relationship that crossed boundaries and contexts. We acknowledge that the experiences described in this study raise questions about professional boundaries, potential for professional burnout or compassion fatigue and re-activating of the bereaved. We believe that it is important to critically engage with these dilemmas, so that they are not used as impediments to providing optimal bereavement care. We hope that by illustrating what is possible when one transcends system limitations, we provide clear evidence of what is missing in current health systems. We hope to inspire those who hold power in such systems to share power in making transformative change. Our findings add to the literature on action research for transformation by demonstrating that the

process of relational knowledge co-creation occurring through co-researching can be perceived as part of the therapeutic journey.

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ORCID iD

Claire M. Ghetti https://orcid.org/0000-0002-3892-4706

Supplemental Material

Supplemental material for this article is available online.

Notes

1. Alternatively referred to as "music therapy cardiography" (Clements-Cortés, 2017) and "heartbeat recordings" (Schreck & Economos, 2018).
2. Loewy (2015) uses "song of kin" to denote culturally and personally-significant songs used for therapeutic purposes.
3. Face-to-face dialogue might have been preferable but was deemed to be ethically irresponsible due to the COVID pandemic
4. Where possible, we incorporate Jeremy's wording within themes and sub-themes to bring his voice forward, using quotation marks to denote illustrative shorter phrases he or Brian used.

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Author biographies

Claire M. Ghetti is a professor of music therapy at University of Bergen, Norway, who seeks to center user involvement in research within healthcare contexts. Her research focuses on how music and the relationships that are enabled through musicking serve as resources that create positive growth in intensive medical contexts.

Brian Schreck is a board-certified music therapist who has been serving the chronically ill since 2004. Brian has a bachelor's of arts in music therapy from Berklee College of Music and a master's of arts in music therapy from New York University. Brian has presented locally, nationally, and internationally on his innovative work in medical music therapy. Schreck pioneered the use of heartbeat recordings as a way to rhythmically connect with patients and their families through ongoing recording projects. This rhythmic stem cell is something that can be worked on, changed, and transformed into music forever.

Jeremy Bennett has been an HVAC tech for more than 28 years. Jeremy began this process of action research 6 years after the death of his son and was excited to join the effort since music therapy has meant so much to his healing process.