Playlist of the Grief Journey: Humanizing Bereavement Through Music

NCT # Unassigned

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Background

The death of a loved one is a universal experience and one of life's greatest stressors. Although most bereaved individuals navigate through a period of intense acute grief that lessens with time, approximately 10% will develop a prolonged grief condition (PGD). For these individuals, experiences of unrelenting bereavement responses result in functional impairment beyond cultural norms, and is characterized by elevated and persistent mental distress including maladaptive thoughts (e.g., blame), avoidance behaviors, an inability to manage painful emotions, differences in health and social status, and lack of social support that interferes with adaptation to loss. In addition, in light of the ongoing COVID-19 pandemic, there has been a potential increase in PGD cases. Altogether, wherever individuals are on the grief spectrum, from low grief to PGD, these emotional states put individuals at different degrees of risk for other medical issues including intense distress, poor physical health, shortened life expectancy, suicide, and other psychological comorbidities like anxiety disorder, PTSD, and depression. Considering that PGD has only been recently added as a mental illness in the DSM-5 in 2022 and how proper guidelines about effective and comprehensive bereavement strategies are lacking, research in this field to develop effective therapeutic protocols is of tremendous interest.

Notably, the use of music-based interventions has been well-established to enhance the recovery process in individuals in all walks of life. For example, in the cancer setting Rossetti et al. showed that curated music therapy services significantly lowered patient anxiety and distress during radiation therapy. Another population that has benefited greatly from music intervention is individuals with dementia-related disorders. Active music therapy with these individuals can help in treating cognitive and/or behavioral symptoms of the disease by engaging existing auditory-reward functional connections in the brain. These individuals simultaneously engage in social interaction when utilizing active music therapy which itself provides acute benefits. However, even without a trained music therapist present, studies have shown that passive music listening (e.g., musical playlists) can also ease psychosocial symptoms associated with dementia.

Only recently have studies begun to explore the role of the expressive arts in the setting of bereavement. When examining the impact of a 12-week closed group art and narrative therapy program in Ontario for individuals experiencing a grief or bereavement process, Nelson et al. showed that the program enabled participants to make strong connections with other participants and the community, to learn new skills and coping mechanisms through the integrated offerings of art and narrative therapies, and to learn new self-care tools and management strategies. However, the implementation of music-based interventions in bereavement has been lacking and poorly studied. Given the many known modalities through which music engagement has healed individuals, especially in chronic settings, it is necessary to elucidate music's role as a potential mechanism to facilitate and honor the grief journey of grieving individuals.

Objectives

The goals of this project are three-fold:

1. Creating personalized music playlists with survivors after conversing with them about their grief journey to not only humanistically explore and reflect on their experience but also to create a long-lasting tool they can keep and be effectively utilized to help process their grief.

- 2. This playlist will also be shared amongst participating individuals so that their story can be shared in this novel and creative way. Participants can also learn about other's stories and reflections through this shared medium.
- 3. Integrating this project into the Warren Alpert Medical School curriculum as part of the new Medical Humanities Initiative, and having first through third year medical students pairing up with grieving individuals, having a conversation with them, and co-creating a personalized music playlist.

Design and Methods

HopeHealth offers a variety of free support groups that are open to anyone in the Rhode Island and Massachusetts community who has endured a loss within the last two years. They also welcome anyone who has had a loved one on HopeHealth's service, regardless of where they live. Most groups meet virtually via Zoom and several in-person groups are also available, and capped at 15 participants — groups meet on weekly, biweekly, or monthly cadences.

This study will focus on the adult population from HopeHealth's Loss of Spouse/Life Partner Support Group. This group is comprised of men and women ages who have lost a spouse or partner in the last 18 months. Sixty percent of this support group had a loved one cared for by HopeHealth in hospice care while the other forty percent of support group individuals are referred from the broader Rhode Island and Massachusetts community. Individuals in the group are a mix of those who experienced both anticipated loss of their loved one as well as unexpected loss. There are four Loss of Spouse/Life Partner support groups that meet virtually every week Tuesdays through Thursdays in addition to an in-person meeting on Wednesday afternoons, with 10-15 individuals per group.

The study design and methods are as follows:

- 1. With the help of Spouse/Life Partner Support Group facilitators, the study investigator will present an overview of the study to support group participants during their weekly support group meetings so they're able familiarize themselves with the investigator's presence and ask any initial questions. At the conclusion of the meeting, the study investigator will send out a recruitment flyer to support group participants that describes the project goals and eligibility criteria. Support group facilitators may also reach out to participants they believe would be candidates for this project and direct them to the study investigator via email.
- 2. Interested individuals will reach out to the study investigator directly via email and the investigator will send time availability to meet with the individual for 75 minutes over Zoom.
- 3. The morning of the meeting, the study investigator will send an email to the participant reminding them about the meeting and will attach the bulleted written informed consent form to the email.
- 4. At the meeting, the study investigator will talk over the informed consent form, acquire verbal consent from the participant and then send the pre-experience survey link via the Zoom chat for them to fill out.
- 5. Once the pre-experience survey link is complete participants will engage in a 30 minute conversation about their grief journey and hearing stories of their loved ones using questions the study investigator has preemptively determined with the help of

HopeHealth staff. From what is learned in these conversations the study investigator and participant will discuss different keywords or themes that describe aspects of their grief journey and can be applied to a musical playlist. Using the study investigator's professional musical background as a violinist, the investigator will help guide participants in how to create a more extensive playlist, offering them to not only consider lyrics, but how rhythm, tempo, dynamics, and timbres of different pieces can bring about different emotions about their experiences. Ultimately, their music choices are their own. The session will end by the investigator giving instructions on finishing their musical playlists over the course of the next week and listening to the playlist.

6. After a week, the study investigator will email participants to fill out the post-experience survey which includes reflections on their playlist themes and if the process helped participants process and/or perceive their grief in a new perspective. This survey also gives participants the opportunity to share their playlist links as well as elaborations on particular songs that meant the most to them. With the individual's consent, the finished playlist (and/or select pieces) along with their reflections will be stripped of identifiable information and added to a shared internal resource at HopeHealth. The goal of this shared resource is to allow survivors to hear others' stories and to find meaning in themselves through others' musical choices and reflections.

There are no statistical analyses to run on this data, including adjustments made for testing multiple variables. Differences in data between the pre-assessment and post-assessment survey questions will be compiled across participants and reported in a chart. Data from the participant reflection questions are qualitative in nature and will be listed out in a table.