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A PATH TO COMFORT AND CONNECTION – A PROSPECTIVE RESEARCH DESIGN

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Abstract

Palliative care is dedicated to improving the quality of life (QoL) of patients facing life-limiting illnesses. The growing recognition of holistic care in medicine has led to an increased emphasis on integrative therapies such as music therapy in palliative care settings. Research suggests that music therapy interventions can evoke positive emotions, improve sleep quality, and enhance overall QoL. Despite the promising evidence, structured research evaluating the impact of music therapy in palliative care, particularly within the Indian context, remains limited. The current research is a prospective methodology to evaluate the role of Music Therapy in enhancing emotional & spiritual well-being, and QoL in patients under Palliative Care. The designed intervention consists of structured phases aimed at addressing emotional well-being, relaxation, and overall quality of life. The FACIT-PAL-14 and FACIT - SP-12 which are validated tools designed to measure QoL and emotional and spiritual well-being of patients receiving palliative care, will be incorporated in this research study. As, to the best of our knowledge, there are only limited studies on music therapy in palliative care, particularly in the Indian context, this research offers a structured approach to evaluating its impact. This research design contributes valuable insights for future integration of music therapy into palliative care practices.

Keywords: *Palliative care, Music Therapy, emotional well-being, spiritual well-being, quality of life, sleep quality*

1. Introduction

Background

Palliative care is an approach that centers the patient, and focuses on improving the quality of life of the patient's facing serious, chronic, and life-threatening illnesses. This approach focuses on the physical, psychological, social, and spiritual aspects of an individual [Bradt, J., & Dileo, C. 2014]. Music therapy, an evidence-based intervention, has demonstrated significant benefits in enhancing emotional well-being, reducing distress, and fostering meaningful connections in palliative settings. [Bradt, J., et al 2016]. The growing recognition of holistic care in medicine has led to an increased emphasis on integrative therapies such as music therapy in palliative care settings [Hilliard, R. E. 2003]. Research states that the music therapy techniques such as song reminiscence, music life review, and music-assisted relaxation using Indian classical ragas, can evoke positive emotions, improve quality of sleep, and enhance overall quality of life [Gallagher, L. et al, 2018 and Krishnaswamy, P., Nair, S 2021]. Song reminiscence helps individuals reconnect with their past, facilitating emotional expression and identity continuity [Bunt, L., & Stige, B. 2014]. Particularly, music life review, encourages patients to reflect on life experiences, fostering a sense of meaning and closure [Sung, H. C., et al 2012]. Researches have demonstrated that reminiscence-based music therapy can improve mood, social interaction, and spiritual wellness. This is especially important for patients receiving palliative care because it helps in emotional reconciliation and helps them find peace in their journey [Tamplin, J.,et al 2018 and Garrido, S,et al 2020]. Patients involved in Music Life Review indicate enhanced sense of life satisfaction and a diminished fear of death, facilitating improved end-of-life experiences [Magill, L. 2014]. These music therapy techniques allow patients to reconnect with cherished memories, alleviate anxiety, and foster a sense of peace [Tamplin, J.,et al 2018]. Music therapy can also provide non-verbal means of communication for patients who struggle to articulate their emotions due to illness progression [McConnell, T., & Porter, S. 2017].Palliative care patients frequently experiences sleep disturbances as a result of pain, anxiety, and emotional distress, among other problems [Bradt, J., & Dileo, C. 2014].The therapeutic benefits of Indian classical music, especially ragas, have been investigated which benefits include promoting sleep and promoting relaxation [Krishnaswamy, P., Nair, S 2021]. Raga Darbari Kanada has lowered heart rate variability and improved sleep onset latency in terminally ill patients [Bhattacharya, S., & Chakrabarti, A. 2017]. Moreover, music therapy sessions incorporating ragas have been shown to alleviate pain and emotional distress, which are key contributors to sleep disturbances in palliative care patients [Magill, L., 2014].Despite the promising evidence, to the best of our knowledge, structured research methodologies evaluating the impact of music therapy in palliative care, particularly within the Indian context, remain limited. This study aims to address this gap by assessing emotional well-being, spiritual well-being, QoL, and the effect of music therapy in the sleep quality of palliative care patients.

The Research Design

This research study will follow an observational cross-sectional design employing a convenient sampling method and will be conducted over a period of six months in selected palliative care units and hospice settings in the southern part of India.

The sample size was calculated considering the mean Quality of Life after the music therapy intervention was provided as 15 ± 1.0 in previous literature [Dong, J., & Qu, Y. 2024]. By assuming $\alpha = 0.05$ precision = 0.5, the minimum sample size was calculated to be 16.

$n = [[((z \sigma)/d)]]^2$

$Z = 1.96$ $\sigma = 1$ $d = 0.5$ [2.5% mean]

Participants

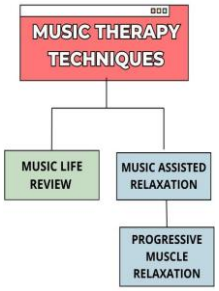
Patients under palliative care with terminal illnesses who are over the age of 18 years will be included as participants for this research study. It is necessary that the participants stay in a hospice / palliative care setting and to provide informed consent to be part of the study population. Those who are unable to comprehend or communicate effectively will not be considered as participants as understanding the music therapy protocols is necessary. Additionally, patients under active life

support such as ventilators will not be included as participants.

Music Therapy techniques:

A method in music therapy refers to the overall type of music experience used between the therapist and the client. A technique is a specific way of using a method. It includes the detailed steps or actions a therapist takes within a method to meet a client's needs[Bruscia 1998]. The Music Therapy techniques used in this study will be given in fig: 1

Figure: 1 - Music Therapy Techniques



Music Life Review - Music Life Review is a structured music therapy technique that involves guided reflection based on significant life experiences using personally meaningful songs. It is rooted in the concept of reminiscence therapy, Which uses music as a catalyst to evoke memories, encourage emotional expression, and help people feel a sense of identity, legacy, and closure (Tamplin et al., 2018). This technique helps patients review their life journey, reconnect with positive emotions, and deal with unresolved feelings. This makes it especially valuable in palliative care settings (Magill, 2014; and Garrido et al., 2020). Music Life Review can enhance spiritual peace and improve emotional well-being by letting them express themselves and share meaningful stories with loved ones (Magill, 2014; and Garrido et al., 2020).

Music assisted relaxation - Music-Assisted Relaxation is a receptive music therapy technique where patients listen carefully chosen music designed to encourage relaxation. The therapist may use either live or recorded music with slow tempo and steady rhythmic music to create a relaxing atmosphere. To promote relaxation, this method frequently uses verbal cues, directed imagery or guided breathing[Warth et al. 2019].

Progressive Muscle Relaxation - Progressive Muscle Relaxation (PMR) is a relaxation induction technique that entails tensing and then gradually releasing various muscle groups in the body. It eases muscle tension, which is frequently linked to stress and anxiety and helps people become more conscious of their physical sensations. PMR is a effective technique for reducing emotional distress and encouraging profound relaxation when paired with soothing music. Because it can improve sleep and this technique is especially helpful for patients receiving palliative care. [Mollayeva et al. 2016].

Assessment tools:

To assess the variable the following scales are used (table-1)

Table -1 : Study variables and scales used

Study Variables	Scales used
Emotional well being and quality of life	Functional Assessment of Chronic Illness Therapy – Palliative Care 14 (FACIT-PAL-14)
Spiritual well being	Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being 12 (FACIT-SP-12)
Sleep Quality	Pittsburgh Sleep Quality Index (PSQI)

Assessing a patient's emotional, spiritual and overall well-being in addition to their physical symptoms is crucial to understand the role of music therapy in palliative care. Three validated and

standardized tools (fig.2) will be used in the current study design to understand further about the patient's experience and quality of life both before and after the music therapy intervention.Functional Assessment of Chronic Illness Therapy – Palliative Care 14 (FACIT-PAL-14): FACIT-PAL-14, a questionnaire designed specifically for patients undergoing palliative care. It helps assessing various aspects of patient's life, including their emotional sate, daily functioning and perceived level of support . It is a 14-item questionnaire derived from the comprehensive FACIT measurement system -39, especially for palliative patients. The tool assesses physical, emotional, social, and functional well-being of people with terminal illnesses. Responses are recorded on a Likert scale, with higher scores denotes a better quality of life and emotional well-being. This provides a more comprehensive view of the individual's emotional well-being and quality of life. Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being 12 (FACIT-SP-12): This tool will be used in order to comprehend the spiritual aspect of wellbeing. This tool investigates the ways in which patients find peace, meaning, and faith during their illness. It measures the spiritual well-being of critically ill patients which consists of 12 items. Intended to capture faith, meaning, and peace, which are essential dimensions of spiritual health. Uses a Likert scale (e.g., 0 = not at all, 4 = very much) to assess responses. In palliative care, these aspects are especially important as people often reflect on their life and seek inner calm and connection. Music, being a potent medium for spiritual and emotional expression, and this scale aids in monitoring those developments. The necessary license and permission to administer and utilize these instruments were obtained by the primary investigator from the FACIT Measurement System prior to the commencement of the study. This guarantees that ethical guidelines are followed and that approved instruments are only used in palliative care research. Pittsburgh Sleep Quality Index (PSQI) : This tool aids in determining how well patients are sleeping, how frequently they wake during the night, and how rested they feel. It consists of 19 self-rated questions and 5 additional questions rated by a bed partner or caregiver (if available). The PSQI assesses seven components. Each component score ranges from 0 to 3, with the overall score ranging from 0 to 21. Higher scores indicates poorer sleep quality. The PSQI has been validated in palliative care settings to evaluate insomnia, pain related sleep disturbances, and the impact of interventions such as music therapy on sleep patterns. Since guided relaxation using soothing ragas, is a technique in music therapy intervention, this tool helps in determining whether such sessions are improving the patient's sleep quality. Together, these tools provide a comprehensive picture of how music therapy may be enhancing the lives of patients receiving palliative care—not only physically, but also emotionally, spiritually, and in terms of daily comfort and rest.

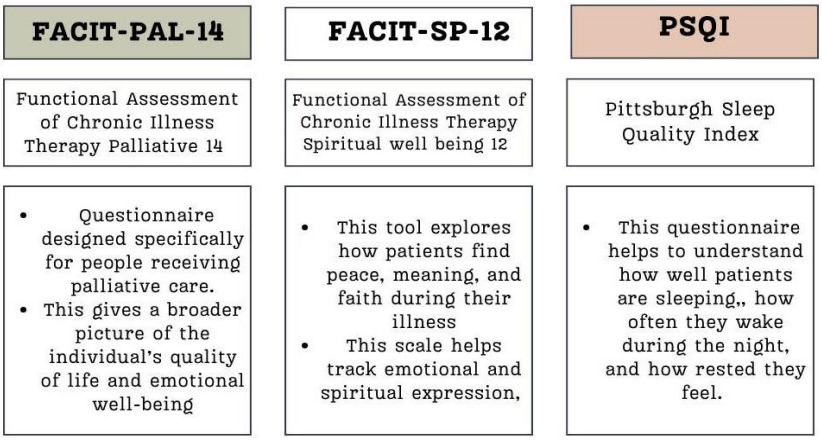
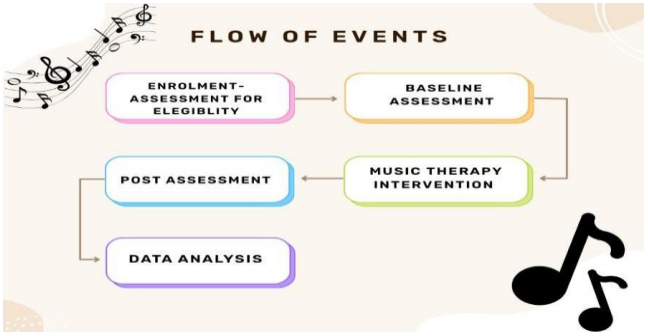


Figure: 2 - Parameters used in the study

Flow of Events

Consent procedure: All eligible participants will undergo a detailed informed consent process prior to the start of the music therapy intervention. They or their primary caregivers, will receive a thorough explanation of the study's nature



and goals including the potential benefits, procedures involved, and their freedom to withdraw from the study at any point without compromising their medical care. A written informed consent form in the participant's preferred language will be required of those who voluntarily consent to participate in the study. Baseline evaluation: Following the consent process, each participant will undergo a baseline evaluation to determine their initial state of physical, emotional, spiritual, and sleep-related health status. The following standardized tools will be used for this assessment:FACIT-PAL-14 (Functional Assessment of Chronic Illness Therapy – Palliative Care 14): the purpose of this tool is to evaluate the quality of life and emotional well-being of patients undergoing palliative care. It encompasses domains such as physical comfort, emotional state, and ability to engage in meaningful activities.FACIT-SP-12 (Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being 12): Spiritual well-being is measured by using this scale which includes questions related to inner peace, faith, and life meaning, which are especially significant in end-of-life care. PSQI (Pittsburgh Sleep Quality Index): This tool evaluates various components of sleep quality over the previous month, such as sleep duration, disturbances, latency, and overall restfulness. The effectiveness of the music therapy interventions in improving emotional and spiritual well-being will be assessed by comparing the results of these baseline assessments with post intervention scores.

Figure : 3- flow of events

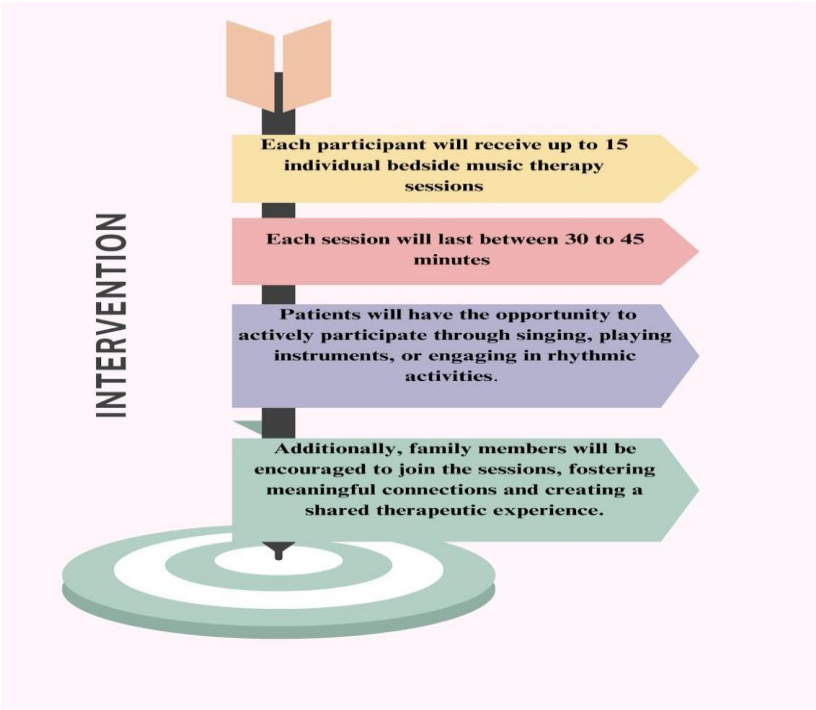


Figure : 4 - Intervention details

Over the course of 15 days, each participant will receive 15 separate bedside music therapy sessions, one session per day. Participants should have attended a minimum of ten sessions in order for the data to be used for analysis. Each music therapy session will last for 45 minutes using personalized song selections to encourage engagement and emotional connection. In order to foster a supportive and

collaborative therapeutic environment and to enhance emotional connections, family members will be also invited to attend sessions whenever it is possible.

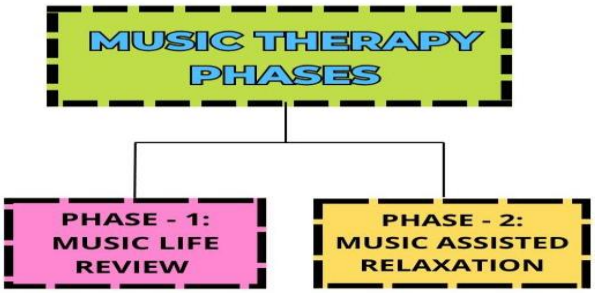


Figure : 5 - Music therapy phases

Each music therapy session will include 2 main phases that are intended to address the goals and objectives

Phase 1: Music Life Review, the therapist will facilitate discussions focused around the patient's personal life experiences. The participants will be encouraged to reflect on important life events, relationships, and personal identity through the use of songs / musical pieces that they personally associate with. This process helps patients express emotions, explore their legacy, and find closure for unresolved feelings or thoughts.

Phase 2: Music-Assisted Relaxation will involve listening to the Indian classical raga Darbari Kanada, which is renowned for its calming and introspective qualities [Bhattacharya, S., & Chakrabarti, A. 2017]. Deep breathing and progressive muscle relaxation techniques are combined in this phase to help reduce anxiety, enhance emotional regulation, and promote restful sleep.

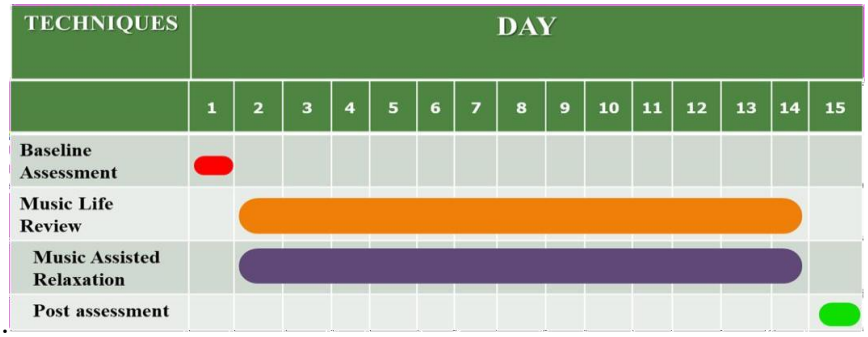


Figure : 6 - outline of the sessions

Post-intervention evaluation:

A post-intervention assessment will be conducted to evaluate the changes in the participants' well-being after the completion of the music therapy intervention. This assessment will be carried out using the same standardized tools that were used during the baseline evaluation to ensure consistency and accuracy in measuring outcomes. [FACIT-PAL-14 , FACIT-SP-12, PSQI] .By comparing the pre- and post-intervention scores, the study will aim to determine the effectiveness of the music therapy intervention in enhancing emotional, spiritual, and physical aspects of well-being. These assessments will also provide valuable insight into the potential of music therapy as a supportive and non-pharmacological approach in palliative care settings.

Expected outcomes

This research may show improvement in emotional well-being with reduced anxiety, sadness, and emotional distress after music therapy sessions. The music therapy intervention can enhance spiritual well-being, with patients expressing increased peace, hope, and connection to life's meaning or personal faith. This research can noticeably improve quality of life (QoL) through positive patient feedback, increased social interaction, and better coping with illness. The study can Improve sleep

quality, as indicated by PSQI scores, with fewer disturbances, longer sleep duration, and better restfulness. Development of a culturally relevant, non-pharmacological intervention model suitable for Indian palliative care settings. This study can be an evidence supporting the integration of music therapy into palliative care through interdisciplinary collaboration between medical professionals and music therapists. Significance of this study: The study focuses on improving terminally ill patient's the quality of life which is an critical but often under-researched component of palliative care. Through life reflection and meaningful musical experiences, the study may help patients find emotional closure and spiritual peace, which is crucial in end-of-life care. The findings can guide clinical procedures and pave the way for integrating music therapy to be incorporated with regular palliative care practices in hospitals and hospices. The study supports the role of music therapists within healthcare teams, promoting collaborative and holistic approaches to care. There is limited structured research on music therapy in Indian palliative care. This study contributes valuable data and insights to fill that gap.

Conclusion:

This study seeks to investigates the therapeutic efficacy of music therapy as a meaningful, culturally relevant, and holistic intervention in palliative care. By addressing not only the physical but also the emotional, spiritual, and psychological dimensions of well-being, music therapy offers a compassionate approach that supports terminally ill patients. Improvements in emotional well-being, spiritual connection, quality of life, and sleep quality are expected to reinforce the value of integrating music therapy into routine palliative care services. Additionally, the study also emphasizes the significance of interdisciplinary collaboration and the necessity for culturally appropriate non-pharmacological alternatives in Indian healthcare settings.

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