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Original article

Parental Perspectives on a Behavioral Health Music Intervention for Adolescent/Young Adult Resilience During Cancer Treatment: Report From the Children's Oncology Group

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ABSTRACT

Purpose: This article describes parental perspectives on the helpfulness and meaningfulness of a behavioral health music therapy intervention targeted to adolescents/young adults (AYA) with cancer undergoing stem cell transplantation. We demonstrate how qualitative methods may be used to understand critical aspects of an intervention and mechanisms by which the intervention impacts the target AYA outcomes of resilience and quality of life.

Methods: A qualitative descriptive design was used to obtain parents' perspectives. A maximum-variation purposive sampling technique was used to sample 16 parents whose AYA had been randomized to the intervention group. A semistructured open-ended interview was conducted between 100 and 160 days after the AYA's transplant.

Results: Results were grouped into three categories: (1) helpfulness and meaningfulness of the intervention to AYA adjustment to the transplantation experience; (2) helpfulness and meaningfulness of the intervention for parents; and (3) AYA ability to participate in the intervention during the acute phase of transplant.

Conclusions: Parents observed and interacted with their AYA who participated in a targeted behavioral intervention. Thus, parents were able to describe mechanisms through which the intervention was helpful and meaningful for the AYA and indirect personal benefits for themselves. The results suggest the importance of the targeted outcomes identified in the Resilience in Illness Model and mechanisms of action in the Contextual Support Model of Music Therapy, and identify approaches for future study.

IMPLICATIONS AND CONTRIBUTION

Multiple sources can inform understanding of mechanisms of action for targeted behavioral interventions. Parents are eyewitnesses to their AYA's experience with an intervention and can report mechanisms by which the intervention was effective and the ability of the AYA to participate in the intervention during the acute phase of transplantation.

Normative events experienced during adolescence/young adulthood, such as puberty, increased responsibilities, and school changes, are often associated with a significant amount of stress. For adolescents and young adults (AYA) aged between 11 and 24 years, a cancer diagnosis and treatment can heighten stress, place additional demands on coping skills, and increase

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the risk for adaptation problems [1,2]. Cancer treatment with stem cell transplantation is a particularly stressful experience for AYA and may result in significant short- and long-term decrements in quality of life [3–5]. However, few behavioral health interventions have been targeted to this unique and vulnerable population.

Interventions targeted to a specific group are designed to address critical attributes with the potential to affect outcomes [6]. Critical attributes to consider when designing interventions to support AYA adaptation to cancer treatment include aspects of AYA development, such as a developing sense of personal identity, stress management, coping skills, and an increasing need for autonomy and capacity for meaningful relationships. These developmental competencies, which are essential to a healthy transition into full adulthood, are also known to impact adaptation to cancer treatment [7].

Despite their own high distress throughout the transplant trajectory [8], parents are a primary source of support to AYA undergoing cancer treatment [9]. Parents also have a unique vantage point as key informants for evaluating behavioral interventions. Parental perspectives on music therapy interventions for children/adolescents with cancer offer a perspective on the benefit of such interventions, while also providing insight into the value of an intervention for themselves [10–13]. This article presents a study of parental perspectives on the helpfulness and meaningfulness of a behavioral music therapy intervention targeted to AYA undergoing transplantation. It is aimed at demonstrating how qualitative methods used with a sample of parents of AYAs who had participated in the Stories and Music for Adolescent/Young Adult Resilience during Transplant (SMART) study, allowed a deeper understanding of critical intervention attributes [14], and thus an insight into the mechanisms by which it may have affected the targeted outcomes of resilience and quality of life.

Background on the Larger Intervention Study: SMART Trial

The SMART trial was a joint cooperative group study funded by the National Institute of Nursing Research (R01NR008583) and the National Cancer Institute (U10CA098543; U10CA095861) (Children's Oncology Group ANUR0631) aimed at testing the efficacy of a therapeutic music video (TMV) intervention compared with a low-dose audiobook control condition for AYA undergoing stem cell transplant for cancer. Participants in this randomized clinical trial were recruited from 6 pediatric and 3 adult hospitals across the United States; the sample included 113 AYA aged 11–24 years.

Specific aims of the larger study were to test whether AYA randomized to the intervention, compared with a low-dose audiobook control group, experienced: (1) reduced illness-related distress, (2) improved family environment, (3) increased perceived social support, (4) improved coping, (5) increased derived meaning, and (6) increased resilience and quality of life.

Two theoretical models informed the larger study and intervention design. The Resilience in Illness Model [15] guided conceptualization of the study problem; the Contextual Support Model of Music Therapy (CSM-MT) [16] informed design of the TMV intervention by providing AYA with structure, autonomy support, and relationship support in the midst of a difficult life event. The TMV intervention was designed to help AYA explore, identify, and express what is important to them through creation of a personalized music video. The TMV was delivered over the course of six 1-hour sessions by a board-certified music therapist. Sessions were initiated within 3 days of hospitalization and were designed to accommodate the physical and emotional demands of the AYA during the acute phase of transplantation. The TMV protocol focused many of the cognitive and active intervention components during the first 3 sessions, when AYA experience less fatigue and malaise. The last 3 sessions had fewer active components, allowing for more flexibility in activity level. Table 1 provides a brief description of activities completed during each session.

The aim of this study was to explore parents' perspectives on the helpfulness and meaningfulness of the TMV intervention.

Methods

A qualitative descriptive design, using unstructured qualitative interviews, was used to obtain parents' perspectives of the helpfulness and meaningfulness of the TMV intervention.

Participants

A maximum-variation purposive sampling technique [17] was used to construct a parent sample that represented diverse perspectives on their AYA's experiences with the TMV intervention. TMV interventionists were asked to identify cases that represented positive and less-than-positive AYA responses to the intervention. The final sample, obtained from 6 sites, included 16 parents of AYA who had completed the TMV arm of the trial. Parents' ages ranged from 30 to 51 years (M = 44.5 years); of the 16 parents included, 87.5% were mothers. Eighty-one percent were Caucasian, 12.5% were African American, and 6.3% were Hispanic.

Procedures

Approval for this study was received from each institution's review board for human subject research. Informed consent for interviews was obtained from parents after their AYA had completed all intervention sessions. Study team members trained in qualitative techniques conducted audio-recorded interviews between 100 and 160 days post-transplant in a setting comfortable and convenient for the parents. The interview guide included open-ended topics assessing parents' experiences with their AYA's participation in the TMV intervention and their perceptions of the helpfulness and meaningfulness of the intervention for the AYA and themselves (Table 2). Interviewers encouraged parents to discuss any thoughts, feelings, and experiences related to the study. Interviews lasted from 20 to 60 minutes.

Data analysis

Digital recordings of interviews were transcribed, checked for accuracy, and analyzed by a team of nine investigators trained in the adaptation of Colaizzi's phenomenological method of analysis [18] first described by Haase [15]. Team members focused on exploring the meaning behind parents' perceptions and understandings of the experience of their AYA. Each interview was assigned to two investigators who first read through the interview for an understanding of the parent's overall experience with the study. Next, the pairs worked together to identify significant statements and discuss possible meanings. Pairs then presented these meanings to the entire investigator team via