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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 paper 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 resilience and quality of life.

Methods—A qualitative descriptive design was used to obtain parents' perspectives. Maximum variation purposive sampling was used to sample 16 parents whose AYA had been randomized to the intervention group. A semi-structured, open-ended interview was conducted between 100 and 160 days following their AYA's transplant.

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Results—Results are 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 acute phase of transplantation.

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 identifies approaches for future study.

Keywords

3-10 Adolescent health services; Behavioral intervention research; Stem cell transplantation; Quality of life; Resilience; Qualitative evaluation; Targeted intervention

Introduction

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) between 11 and 24 years of age, a cancer diagnosis and treatment can heighten stress, place additional demands on coping skills, and increase 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]. Yet 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 paper 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 SMART study, allowed a deeper understanding of critical intervention attributes [14], and thus 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: Stories and Music for Adolescent/Young Adult Resilience during Transplant (SMART) Trial

The SMART trial was a joint National Institute of Nursing Research (R01NR008583) and National Cancer Institute (U10CA098543; U10CA095861) funded cooperative group study (Children's Oncology Group ANUR0631) testing the efficacy of a therapeutic music video (TMV) intervention compared to a low-dose audio books 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, 11-24 years of age.

Specific aims of the larger study were to test whether AYA randomized to the intervention, compared to a low dose audio-books 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 [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 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 the study reported here 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 AYAs' 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 ranged in age from 30-51 years (M=44.5 years); 87.5% mothers. Eighty-one percent were Caucasian, 12.5% African American, and 6.3% 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' experience 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 ranged from 20-60 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 biweekly web conferencing. A consensus process was used to determine the meanings. The full team then worked to cluster the meanings into theme categories and subthemes. This analysis procedure, in addition to the methodological rigor established by close monitoring of the steps of data collection, a team approach to peer review and consensus, formation of an audit trail using MSWord features for data management, and clear description of the study design, sample, and findings, supported the robustness of this study.

Results

Results are grouped into three categories based on the research questions: 1) Helpfulness and meaningfulness of the intervention for AYA adjustment to the transplantation experience; 2) Helpfulness and meaningfulness of the intervention for parents of AYA; and 3) AYA ability to participate in the intervention during acute phase of transplantation. Each category is organized into core themes and subthemes.

1. Helpfulness and meaningfulness of the intervention for AYA adjustment to the transplantation experience

Parents' descriptions of the impact of the TMV intervention on AYA adjustment to transplantation were organized into three core themes (Table 3): (a) Myriad of intervention mechanisms to reduce AYA suffering; (b) Myriad of benefits through TMV process; and (c) Power of intervention to enhance connectedness among AYA, healthcare providers, family, and friends.

The first core theme in this category, Myriad of intervention mechanisms to reduce AYA suffering (Table 2), included perspectives about intervention effectiveness in providing respite from daily suffering and the mechanisms by which it promoted relief and positive health outcomes. Myriad, the Greek term for 10,000, represents the unspecified large number of mechanisms (e.g., engaging in something other than treatment, opening dialogue about the unspoken, use of humor, antidote for uncertainty) identified by parents as relieving suffering and/or strengthening resilience in their AYA. Table 3 displays representative data samples for subthemes within this core theme, such as mitigation of physical symptoms, relief from depressed mood, increased acceptance, and thriving beyond surviving.

The second core theme, *Myriad of benefits through TMV process*, included descriptions of the ways the intervention process provided a range of benefits to AYA. Parents described how work with the interventionist in lyric writing and selection of photos/images was

critical and supported AYA self-expression and reflection, helped AYA connect with others, and led to meaningful conversations. For example, parents identified the lyric writing process as a means for AYA to organize and express their thoughts, communicate and share their experience (even private/painful aspects) with others, and bring about meaningful conversations. The process of creating, selecting, and working with photographs/images was a means for AYA to connect with sources of support, and to express gratitude for those who had been supportive. Parents indicated their AYA found the intervention process to be a manageable, non-stressful, and joyful activity in the midst of an intensive, challenging life event.

The third core theme, Power of the intervention to enhance connectedness among AYA, healthcare providers, family, and friends, centered on how the intervention fostered important relationships between AYA and others who could provide support and help. Parents repeatedly reflected on the synergistic benefits experienced by family when the intervention helped their AYA with relationships. Subthemes (Table 3) included: how the intervention enhanced AYA connectedness with health care providers, parents, and family members; how enhanced connectedness allowed AYA to express previously undisclosed thoughts and feelings; and how making the video allowed AYA to strengthen family connections. Parents felt the relationships developed with study staff (both evaluators and interventionists) were critical to positive health outcomes and personal growth for AYA during and beyond the intervention period.

2. Helpfulness and meaningfulness of the intervention for parents of AYA

Although the intervention was targeted at AYA developmental and resilience needs during transplantation, parents derived indirect benefits. Data in this category are organized in three parent adjustment core themes (Table 4): (a) Myriad of intervention mechanisms to alleviate parent suffering; (b) AYA's digital video disk (DVD) as a legacy and source of insight, pride, and joy for parents; and (c) TMV intervention as a valued way for parents to respect and support AYA privacy and independence.

The first core theme in this category, Myriad of intervention mechanisms to alleviate parent suffering, included ways the intervention helped parents throughout the transplantation experience and across 100 days post-transplant. Subthemes included expressions of emotions such as relief, gratitude, awe, and happiness. Parents described benefits they personally experienced, such as insight into their AYA's thoughts and emotions, increased acceptance of the disease, and improved sense of well-being.

The second core theme in the parent benefit category was, AYA's DVD as a legacy and source of insight, pride, and joy for parents, including benefits parents experienced directly from the DVD. Parents found that viewing the DVD helped them gain insights into AYA thoughts, emotions, strengths, and growth (Table 4). Parents also described the DVD as a potential "last record" of their AYA, a lasting legacy that was highly valued and something they would "always keep", and some spoke of the importance of having their child's voice recorded should they not survive their cancer.

The third core theme in the parent benefit category, TMV intervention as a valued way for parents to respect and support AYA privacy and independence, centers on how parents understood and valued their AYA's need for privacy, autonomy, and opportunities to exercise independence and the ways in which the TMV intervention helped them honor and support these fundamental needs. Subthemes included honoring and valuing AYA privacy needs related to DVD creation and respect for AYA decisions regarding who would view the DVD.

3. AYA ability to participate in the intervention during acute phase of transplantation

This final category included parents' perspectives on how symptom distress affected AYA participation and suggestions for improving the intervention. Data were organized into three core themes (Table 5): (a) *Influence of symptoms on TMV participation*; (b) *AYA participation decisions*; and (c) *Suggestions for TMV improvement*.

The first core theme, *Influence of symptoms on TMV participation*, included parents' perspectives on how symptoms influenced AYA participation in the intervention. Parents described how treatment-related side effects created challenges to participation, but said they appreciated the flexibility in scheduling intervention and evaluation sessions. Parents were often amazed at how their AYA continued to participate despite symptom distress. They also noted great value to the AYA in receiving supportive encouragement from the parent and interventionist to participate even when AYA were experiencing increased levels of symptom distress.

The second core theme centered on parents' discussions of *AYA participation decisions*. Some parents described an initial hesitancy from AYA when asked to participate in the study. This was related to disinterest in study activities, efforts to protect parents from painful aspects of the AYA's experience, and anticipation of expected symptom distress. Some parents offered that too many study details given to AYA during informed consent meetings may have overwhelmed the AYA leading to hesitancy to enroll. Acknowledging this "natural" hesitancy was important as they felt that their AYA needed encouragement from parents, study staff, and nursing staff to initially give informed consent or assent to study participation. Parents felt that this encouragement was justified because once study participation was initiated and the first session with the interventions occurred, the AYA became involved and engaged in the study. Parents also emphasized that AYA sense of study commitment was very important to continued participation and completion of the project.

The final core theme was *Suggestions for TMV improvement*. Parents suggested ideas for adjusting the intervention process to avoid periods of high physical distress. They described challenges related to collecting evaluation data; and in particular, three of the sixteen parents reported that completing the measures was long and repetitive for the AYA.

Discussion

Adolescent/Young Adult Benefit

The Resilience in Illness Model specifies both risk and protective factors that contribute to positive outcomes of resilience and quality of life. The risk factor, illness-related distress, includes experiences of symptom distress and uncertainty [19]. Parents indicated that the TMV was effective in alleviating symptoms, provided respite and distraction from daily suffering, and provided an antidote for the uncertainty that is pervasive during transplantation [20]. Parents acknowledged the challenge of encouraging AYA involvement during periods of intense symptom distress, but viewed AYA involvement as beneficial, stating that with encouragement AYA were able to participate in the TMV and rise above transplantation-associated distress. As AYA symptom distress and uncertainty diminished, parents also perceived improved quality of life for their AYA. These findings highlight the importance of targeted interventions to manage symptom distress and uncertainty to improve quality of life during the acute phase of high risk cancer treatments, and are consistent with previous research demonstrating benefits of active and receptive music therapy interventions to decrease distress and improve mood in patients during transplantation [21, 22].

Parents also provided insights regarding benefits of the TMV to promote positive coping through the use of confrontive coping strategies. For example, the intervention provided a way for AYA to “organize and express their thoughts” and begin to “communicate and share their experience with others.” Particularly important are parent statements that the intervention helped AYA face their illness and in some cases their mortality. Parents clearly valued the unique opportunity for self-reflection afforded by the TMV. Many reported positive changes in AYA ability to communicate “previously unspoken thoughts” and renewed interest in social connections. These positive behavioral outcomes are consistent with the Resilience in Illness Model and other research indicating that positive coping strategies are associated with better adaptation to chronic illness [19,15,23].

Improved communication and enhanced connectedness with family, friends, and study personnel were additional parent reported benefits. These are consistent with the model protective factors - family environment and social integration. Parents indicated that the process of writing lyrics and selecting photos/images gave AYA a platform to engage in meaningful conversations with parents, extended family, and friends. Previous research has described the difficulties that very ill children and adolescents experience when trying to communicate painful experiences with their parents [3]. During cancer treatment, AYA distress-coupled with efforts to avoid distressing parents – often stifle AYA-parent communication about cancer-related concerns [3,15,21,22]. In addition, many parents may avoid important cancer-related conversations with their child in an effort to diminish their own and their AYA’s suffering. Perhaps one of the most meaningful outcomes of the TMV is the opportunity for AYA to organize and reflect on their thoughts and experiences, and then communicate these through a non-threatening and preferred medium – music.

Parent Benefit

Although not directly targeted, parents reported deriving benefit from their AYA’s receipt of the TMV intervention, including the opportunity to share positive emotional experiences with their AYA in the midst of a life-threatening treatment. For many families, the processes of witnessing and/or helping AYA create their video and viewing the completed video afforded opportunities for meaningful conversations and a way to gain insight into their AYA’s cancer experience, what they value, and their desires for the future. These insights helped parents and other family members gain acceptance and experience an improved sense of well-being.

Given the strong relationship between parent and AYA distress, it is not surprising that parents derived indirect benefit from this intervention [24-27]. As parents witnessed improvements in their AYA’s symptom distress and emotional well-being, they too experienced relief. The music video project provided a non-threatening way for AYA and parents to initiate conversations about the cancer experience.

Mechanisms of Action: Importance of Structure, Autonomy Support, and Relationship Support

While great improvements have been made to the physical environments in which AYA undergo transplantation, the necessity for protective isolation during periods of immunosuppression and the intensity of treatment still restrict AYA autonomy, opportunities to interact with significant others, and to have control over their lives. Restrictions to these developing competencies can lead to anxiety, depression, and defensive coping [28]. Previous studies have documented that AYA with cancer often view themselves as being more dependent on their parents than their same-age peers [3,28].

Parents described how the TMV intervention gave their AYA a structured project to work on that was private and personally meaningful. The intervention was designed to create a supportive, structured environment that would give AYA opportunities to experience autonomy and independent decision making regarding the music, topics for the video, whether to involve family, friends, or care providers in the production process, and once completed, who would view it. Parents appreciated the flexibility of the intervention to accommodate changes in AYA distress, support AYA's need for privacy and independence, and support or renew important relationships for their AYA. These findings indicate that parents perceive structure, autonomy support, and relationship support as important elements of the intervention. The Contextual Support Model specifies these as essential for creating environments that support and encourage active engagement in music-based interventions [16,29]. Previous studies also demonstrate that music-based interventions can effectively provide patients opportunities to make choices and independent decisions, which are diminished in isolated environments [16,30,31,32].

Study Limitations and Summary

These findings are based on a small predominantly maternal (87.5%) sample of parents, and thus subgroup comparisons, such as differences in parental role, cannot be made. The size of the sample allowed us to conduct an in-depth examination of parents' perspectives on the helpfulness and meaningfulness of the TMV intervention, and reach data saturation (or the point at which no new information is added to the codebook). While the generalization of our findings is limited by the size of the sample they are strengthened by the use of 6 intervention sites from which the sample was obtained.

As caregivers, parents witnessed their AYA's experience with the TMV trial and were able to realize personal benefits from this theory-based, AYA-targeted, behavioral music therapy intervention. These data confirm the importance of targeted outcomes identified in the Resilience in Illness Model and mechanisms of action proposed through the Contextual Support Model. Because parents gained insight into their AYA's experience and communication was opened as a result of the intervention, future study is needed to identify ways to support parental efforts to sustain communication with their AYA and support AYA positive coping.

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Implications and Contributions Summary Statement

Multiple sources can inform understanding of mechanisms of action for targeted behavioral interventions. Parents are eye-witnesses 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.

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Table 1
Therapeutic Music Video Intervention: Summary of Contextual Support and Intervention Activities

| Elements of Contextual Support from CSM-MT* | | Summary of Intervention Activities by Session** | |
|---------------------------------------------|---------|-------------------------------------------------|-------------------------------------------------------------------------------------------------------------|
| Week | Session | TMV Intervention Activities | |
| 1 | 1 | - | Learn how to use a songwriting script |
| | | - | Select music for video project (i.e., offered 10 songs from 5 music genres) |
| | | - | Brainstorm ideas for lyric/video content (i.e., what is important to AYA) |
| 1 | 2 | - | Write lyrics to a familiar song using a songwriting script |
| | | - | Discuss lyrics and what is important to AYA |
| | | - | Sing/practice completed song with CD accompaniment track |
| 2 | 3 | - | Select who will sing on the song recording |
| | | - | Sing/rehearse completed song |
| | | - | Discuss any AYA thoughts about/reflections on video project |
| 2 | 4 | - | Digitally record vocal soundtrack for video |
| | | - | Listen to completed, mixed soundtrack (i.e., AYA-directed vocal track mixed with CD accompaniment track)*** |
| | | - | Begin storyboard process (i.e., select visual images to go with song lyrics) |
| 3 | 5 | - | Listen to completed song/discuss visual images – memories/importance |
| | | - | Digital camera available to AYA during hospitalization |
| | | - | Gather visual images and/or take pictures |
| 3 | 6 | - | Complete storyboard |
| | | - | Listen to completed song/discuss visual images – memories/importance |
| | | - | Private presentation/viewing of completed music DVD |
| | | - | Optional “Video Premiere” (i.e., AYA invites other to view video) |

* Grounded in motivational and developmental coping theory, the CSM-MT describes how music can be used to provide structure, autonomy support, and relationship support to diminish distress and promote positive health outcomes during cancer treatment hospitalization.

** All session activities were facilitated by a board-certified music therapist.

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*** A CD accompaniment soundtrack was purchased for each AYA music video project.

Table 2

Parent Interview Questions

| Interview Question |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. We are interviewing parents of participants in the music therapy study to try and understand how your adolescent felt about the therapy. We want to learn more about what worked well with this therapy and what did not work as well. To start, please tell me about your experience of having your adolescent in this study and in particular making the music video. |
| 2. Please tell me your thoughts and feelings about the completed video. |
| 3. Please tell me your thoughts about the meaningfulness of the music video intervention for your adolescent. |
| 4. Please tell me your thoughts about the usefulness of the music video intervention for your adolescent. |
| 5. Please tell me your thoughts about the meaningfulness of the music video intervention for you. |
| 6. Please tell me your thoughts about the usefulness of the music video intervention for you. |

Table 3

Helpfulness and Meaningfulness of the TMV Intervention for AYA Adjustment to the Transplant Experience.

| Core Theme 1. Myriad of intervention mechanisms to reduce AYA suffering | | |
|-------------------------------------------------------------------------|---------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Theme | Subtheme | Data Sample |
| Positive impact on symptoms | physical symptoms | "...an escape route to get his mind off the pain and the down time he had and for the times he felt bad. It put him in a different world so to speak, an escape and getaway." (Mom of 14 yr old male) |
| | depressive mood | "I know that she's taking medicine for depression but I feel that the study definitely helped her to come out of that." (Mom of 16 yr old female) |
| Mechanism to alleviate suffering and improve outcomes. A means to: | engage in something other than treatment | "...it was important because she had something to do. She had an assignment. She had a project and she was a very dedicated person and a very active person so when you take away all that activity she had nothing to do. So having something to work on was very helpful to her...that did a lot for her mind." (Mom of 16 year old female) |
| | open a dialogue about the unspoken use of humor connect with others | "... it kind of got her to be able to focus on that (family), and not just lay there and think about that, but to actually think about them and to almost like, she was there with them." (Dad of 20 year old female) |
| Resilience outcomes | provide hope confront challenges of transplant growth | "...he's always been mature and very adult about things and I had seen him sit and face staph infection or fungal infections and brain surgery and lung surgery with just this very matter of fact attitude. Well, okay, what are we going to do? We got to do it, you know." (Mom of 15 year old male) |
| Anecdote for uncertainty | acceptance thriving beyond surviving confidence and mastery | "...she needed something to take her mind off of what she was going through and she needed something to lift her up. I know when people tend to just sink into their situation, instead of rise up above it." (Dad of 20 year old female) |
| Core Theme 2. Myriad of benefits through TMV process | | |
| Theme | Subtheme | Data Sample |
| Opportunity to give unique reflection of self | | "...the way they changed the words to really fit because he's a, I mean being from Louisiana he's a fisherman and a hunter. The whole thing was about things that he enjoyed doing so that was really nice." (Mom of 21 year old male) |
| | Manageable, non- stressful, joyful activity | "...I know that he enjoyed it a lot, he had a good time doing it, and um, and I can honestly say that because he was putting stuff together and we would talk about it, it was a terrific way for him and I to interact." (Grandmother of 16 year old male) |
| Process of lyric writing. A | organize and express thoughts | "I think it was meaningful for him b/c it made him take a look at what was going on with himself a little more b/c he had to write the |

Core Theme 1. Myriad of intervention mechanisms to reduce AYA suffering

| Theme | Subtheme | Data Sample |
|------------------------------------------------|-----------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| means to: | | words.” (Mom of 18 year old male) |
| | communicate/share experience with others | “Maybe it was this and the leukemia and the battle and everything he’s been through, but I think that this exercise has been a good way for him to realize that you need to get it out and you need to express it whether it’s on paper or whether it’s in a video or whether it’s saying it.” (Mom of 16 year old male) |
| | precipitate meaningful conversation invest in getting the words right | |
| Process of selecting photo images. A means to: | connect and reconnect with others | “one of my sisters came and spent the night with her and she said, “wow she didn’t talk before”. She was talking all night...so the pictures have helped b/c she is showing us times in her life that have some significance to her that we were not aware of.” (Mom of 16 year old female) |
| | precipitate meaningful conversation | |
| | express gratitude | “Then she was very concerned about having everybody in the video, the people from over there and the people that helped her here for the two months that she was here. So she was always trying to figure out where they fit best in the video.” (Mom of 16 year old female) |

Core Theme 3. Power of intervention to enhance connectedness among AYA, healthcare providers, family, and friends

| Theme | Subtheme | Data Sample |
|------------------------------------------------------|--------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Enhancement of connectedness with parents and family | strengthened and renewed parent-AYA connectedness | |
| | allowed AYA to talk about undisclosed thoughts/feelings | “Before she didn’t share her emotions but now she’s just letting it out all the time. So we’re not used to that. She is talking more... She is sharing things that she had never shared before that we didn’t know about her past.” (Mom of 16 year old female) |
| | making video means to reconnect with family | |
| Enhancement of connectedness with others | connectedness with study personnel | “...if I would have left it up to him I don’t think he would have finished it except he liked the study staff.... So whether he felt good or not he was going to finish the study because he liked the people that he was working with.” (Mom of 21 year old male) |
| | provided a way to have meaningful relationship with study personnel who were non-family/nonstaff | |

Core Theme 1. Myriad of intervention mechanisms to reduce YA suffering

| Theme | Subtheme | Data Sample |
|-----------------------------------------|--------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Enhancement of connectedness with peers | relationship with interventionist source of therapeutic connection | "...with the intervener having the knowledge, I think they made a connection. Before when she started getting sicker, then she started saying, "I don't want to play anymore". But now it kept her mind off of what was getting ready to happen to her. The not knowing, I think it kept her mind busy, she knew at a certain time she (intervener) would be there and they would be able to work on stuff" (Mom of 14 year old female) |
| | means of staying connected to peers | "She became totally isolated from her friends b/c of the illness. So when she had to put these pictures in she had to go in Facebook and then she would see what her friends were writing to her. So she was able to share with her friends through these pictures and began that contact with them again and just break that isolation process." (Mom of 16 year old female) |
| | means of discussing illness with peers | |

Table 4

Helpfulness and Meaningfulness of the Intervention for Parents of AYA.

| Core Theme 1. Myriad of intervention mechanisms to alleviate parent suffering | | |
|----------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Theme | Subtheme | Data Sample Illustrative of Themes and/or Subthemes |
| Parent emotional experience – relief, gratitude, awe, happiness | positive emotional experience b/c of increased openness of AYA | “I feel so much better b/c I feel that was part of her depression. Just being able to talk about it is a great thing that she has been able to face her illness. That has helped her quite a bit.” (Mom of 15 year old female) |
| Parents gain insights | relief/happiness as AYA has positive experience with study to buffer distress | “I said I’m so happy. That gave me a little more of ‘yes he’s doing this and this is better. He’s doing good now.’” (Mom of 14 year old male) |
| Parent/family gain acceptance leading to improved well-being | therapeutic connection with emotions while viewing video | “...it helped her to bring out her emotions but it helped me to understand her emotions and it also helped me to see the value that she had placed in different people.” (Mom of 15 year old female) |
| Parent trust in study personnel relieved anxiety | about AYA thoughts and emotions about self | “I knew that at least he was going to have company when the study people were there to talk with. That gave me ease, especially in SCT b/c you know who that person is who was going to walk in the door.” (Mom of 21 year old male) |
| Core Theme 2. AYA’s DVD as a legacy and source of insight, pride, and joy for parents | | |
| Theme | Subtheme | Data Sample |
| Viewing DVD helped parents gain insight into: | AYA thoughts, emotions, strengths, growth Self | “I smiled the whole time and probably cried a little bit, you know, just because it, like I said because it was him.” (Mom of 15 year old male) |
| DVD lasting documentation of SCT experience | lasting legacy | “...this could be the last record we have of him. In that regard, it was a big deal. It’s definitely something we’ll always keep.” (Mom of 22 yr. old male) |
| DVD source of joy and pride for parent and AYA | | “It showed how much she cared about me and about how much she cared about everything and how she hated being in the hospital. It showed everything she was going through at that period of time.” (Mom of 14 year old female) |
| Showing/sharing DVD facilitated | Family | “When she brought the DVD and played it she was just be-bopping and singing with it. We had some of the nurses come in and a couple of the other parents that we had met on the floor. It was just so exciting. Then we took the video and sent it home with the teacher. She took it back and played it for the girls.” (Mom of 15 year old female) |
| | | “I think the whole DVD was just to explain the most important things in |

Core Theme 1. Myriad of intervention mechanisms to alleviate parent suffering

| Theme | Subtheme | Data Sample Illustrative of Themes and/or Subthemes |
|-------------------------------|----------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| connection b/t AYA and others | health care providers friends | her life were her family and her friends.” (Dad of 21 year old female) “I’ve watched it a couple of times. If a friend of mine comes over we’ll watch it. My boyfriend, he’s watched it because he never came up to the hospital and visited, he couldn’t handle it. So I brought it home for him to see her while she was in the hospital.” (Mom of 14 year old female) |

Core Theme 3. TMV intervention as a valued way for parents to respect AYA privacy and independence

| Theme | Subtheme | Data Sample |
|-------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Parents understood, valued, supported AYA’s need for privacy | privacy to develop DVD privacy and respect for decisions related to sharing DVD | “I was in and out. I wasn’t really there the whole time. I let them just do whatever they needed to do. I gave them their time alone basically.” (Mom of 17 year old male) |
| Parents understood, valued, supported AYA’s need for independence | honoring need for independence and ownership of project assumed a supportive role that was driven by AYA | “...I really didn’t participate in it at all. I kind of stepped back and let her do her own thing, her own project, her own searching.” (Mom of 16 year old female) |
| Honoring independence and privacy meant parents unaware of some TMV activities TMV means to meet AYA needs when parents not able | | “He kept it pretty, pretty hush. He didn’t, he didn’t tell me too much. He wanted me to be surprised.” (Mom of 15 year old male) |

Table 5

AYA Ability to participate in the intervention during acute phase of SCT.

| Core Theme 1. Influence of symptoms on TMV participation | | |
|-------------------------------------------------------------------|------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Theme | Subtheme | Data Sample |
| Treatment side effects created challenges to participation | Participation dependent upon feeling well enough | “...to me, if he would have been feeling better he probably, it would have been even better, b/c I know there were some days where the intervener had to really help him out a lot b/c he just wasn't feeling good.” (Mom of 13 year old male) |
| | Continued participation despite symptom distress | “everyone was real generous, real helpful. If she didn't feel up to doing something, they would come back, especially when we were doing the surveys and different things. They helped her out when she was not up to par and that really...I felt pretty good about that.” (Dad of 20 year old female) |
| | Value in encouraging AYA participation despite symptoms | |
| Core Theme 2. AYA participation decisions | | |
| Theme | Subtheme | Data Sample |
| Many sources of initial participation hesitancy | efforts to protect parent | “She didn't want to talk about her suffering with me. It was not a subject we could talk about which is why she resisted making the video a little bit. So that's why I stepped away, b/c I wanted her to be able to get it out whether it was with me or with somebody else. I wanted her to be able to talk about it.” (Mom of 16 year old female) |
| | anticipation of physical symptoms | “I think it was just him and because of his sickness. I think he was feeling down and probably was tired and all and just thought and just didn't want to be bothered. I think that's what it was.” (Mom of 14 year old male) |
| | initial disinterest in study activities | “I know that he felt it was kind of a dorky thing to do, but I can honestly say that b/c he was putting stuff together and we would talk about it, it was a terrific way for him and I to interact. It was definitely something to do that he otherwise would never have done, had never done and probably won't ever do again.... But how fun is that?” (Grandmother of 16 year old male) |
| AYA sense of commitment important to participation and completion | too many details of study procedures given in info session | |
| | encouragement from parent was critical | |
| | initial hesitancy lifted after | “But once he started, ... and seen some results of what he had to do he |

| Core Theme 1. Influence of symptoms on TMV participation | | |
|---------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Theme | Subtheme | Data Sample |
| Parent awareness of study purpose and benefits led to encouragement | first intervention session | became very involved in it.” (Mother of 14 year old male) |
| | initial hesitancy lifted after first intervention session changes in AYA priorities influenced level of engagement | “...well I thought it would be a good thing for him when it was first presented to us, as far as what the study was supposed to show. So it did sound like it was pretty interesting. So that’s why I kind of talked him into moving forward with it.” (Mother of 21 year old male) |
| Core Theme 3. Suggestions for TMV improvement | | |
| Theme | Subtheme | Data Sample |
| Intervention | adjustment of timeliness to avoid periods of high distress | “Sometimes, for instance, I would say, “the intervener is coming today”, and she would say, “not today; I can’t do it”. So they wouldn’t get as much done. But I felt that she could have maybe pushed her a little more or let’s say encouraged her a little more b/c they’re going to feel tired. Maybe they can draw a little more out of them.” (Mother of 16 year old female) |
| | wish AYA was pushed harder | |
| Data collection process and measurement completion | suggested generalizing intervention to other patient populations | |
| | no trouble completing measures completing measures was long and repetitive | “...so that was the good part of the activity that they had her do. That it was flexible. For me, that was one of the most important parts of it that they didn’t have to do it every other day, or it wasn’t set in stone what you could do.” (Father of 20 year old female) |
| Technology difficulties | flexibility in completing measures was helpful and appreciated | |
| | parent encouragement and AYA commitment important | “...a lot of times when she (MT) came in and did the video or whatever and got things done, it was not prepared. It was too much screwing around, trying to plug in and stuff, trying to do this, trying to do that.” (Mother of 14 year old female) |