

Adolescent/Young Adult Perspectives of a Therapeutic Music Video Intervention to Improve Resilience During Hematopoietic Stem Cell Transplant for Cancer*

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This empirical phenomenology study reports adolescents/young adults (AYA) experiences of the therapeutic music video (TMV) intervention arm of a randomized controlled clinical trial (Children's Oncology Group; COG-ANUR0631; R01 NR008583) during hospitalization for a hematopoietic stem cell transplant. A purposive subsample of 14 AYA were interviewed using a broad open-ended data-generating question about their TMV intervention experiences. At the end of each interview, we also asked AYA for suggestions on how to improve the TMV. Analysis of the narrative data resulted in four theme categories: (a) An Interwoven Experience of the Transplant and TMV Intervention; (b) TMV as a Guided Opportunity for Reflection, Self-Expression, and Meaning-Making; (c) Telling My Story: The Work of Deriving Meaning; and (d) A Way to Overcome the Bad Side of Cancer. AYA suggestions for improving the TMV are also summarized. Findings provide insight into ways the TMV supports AYA efforts to overcome distress and challenges by providing opportunities to reflect on what is meaningful, connect with others, and explore/identify personal strengths. Findings also inform our understanding about how the TMV may have functioned (i.e., mechanisms of action) to bring about significant change in AYA self-reported outcomes (i.e., positive coping, social support, and family function) for this trial.

Keywords: cancer; psychosocial; music therapy; resilience; quality of life; phenomenology

Hematopoietic stem cell transplant (HSCT) is the curative therapy of choice for many malignancies that require high-dose chemotherapy, but it is an intensive and complex treatment with significant risks. At the start of HSCT (i.e., the conditioning phase), patients are given high doses of chemotherapy and/or radiation therapy to destroy cancer cells that may be resistant to more standard doses of chemotherapy; however, this also destroys normal cells in the patient's bone marrow, including stem cells. After the conditioning phase, healthy stem cells are reintroduced (i.e., transplanted) to reestablish blood cell production in the bone

marrow and in turn, build a healthy immune system (Children's Oncology Group, n.d.).

Adolescents/young adults (AYA) undergoing HSCT experience high symptom distress (e.g., anemia, mucositis, nausea, infection). In addition, with mortality rates as high as 50% (depending on transplant type) they also face uncertainty about their illness and the future (D'Souza, 2017; Keegan et al., 2016). The cancer treatment experience is particularly difficult for AYA because it interrupts and challenges normative developmental events, including efforts to establish independence, form strong peer and sexual relationships, and make plans for the future (Compas, Jaser, Dunn, & Rodriguez, 2012; Docherty, Kayle, Maslow, & Santacroce, 2015; Richter et al., 2015). AYA receiving HSCT are challenged to cope with side effects from treatment, maintain a semblance of independence despite increased dependence on parents and family members, manage their emotions and consider those of others, and seek social support in the midst of social isolation. In addition, they often lack an adequate repertoire of coping-related behaviors and skills needed to manage distress and navigate complex social interactions (Docherty et al., 2015; Lang, Giese-Davis, Patton, & Campbell, 2018; Zebrack & Isaacson, 2012).

Several studies examined AYA-identified psychosocial and supportive care needs during acute cancer treatment (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Keegan et al., 2012; Zebrack & Isaacson, 2012; Zebrack et al., 2014), and identified AYA sources of support including information, family and peers, spiritual beliefs, their own personal resources, and music (Ahmadi, 2009; Bellizzi et al., 2012; Kyngäs et al., 2001; O'Callaghan, Barry, & Thompson, 2012; Zebrack, Mills, & Weitzman, 2007). Despite the tremendous impact of cancer on AYA and evidence regarding their unmet psychosocial needs, there are few interventions developed and evaluated for this population (Phillips & Davis, 2015; Richter et al., 2015; Sansom-Daly, Peate, Wakefield, Bryant, & Cohn, 2012; Seitz, Besier, & Goldbeck, 2009). In their review of AYA intervention studies, Phillips and Davis (2015) identified only five interventions and Richter and colleagues (2015) identified 12; however, both reviewers found that most studies had small samples and few found significant benefit (Phillips & Davis, 2015; Richter et al., 2015). The Stories and Music for AYA Resilience during Transplant (SMART I) intervention study was one of the few evaluated studies

resulting in significant psychosocial benefit for AYA during transplant (R01NR008583; U10CA098543; U10CA180886; U10C095861; UG1CA189955). Efficacy data for the therapeutic music video (TMV) intervention showed improvement for AYA on several resilience in illness model (RIM) outcomes including courageous coping (ES, 0.505; $p = .030$) immediately post-intervention, and social integration (ES, 0.543; $p = .028$) and family environment (ES, 0.663; $p = .008$) 100 days posttransplant (Robb et al., 2014).

In this manuscript, we report findings for the qualitative component of the SMART II trial, which aimed to answer the research question: *What are AYA perceptions of the meaningfulness and helpfulness of the TMV intervention to deal with the experience of undergoing HSCT?* We also report AYA perspectives of TMV limitations and ways to improve the intervention.

Summary Description of the SMART I Trial and TMV Intervention

The SMART I study was a multi-site randomized, controlled trial (Children's Oncology Group; COG-ANUR0631), conducted at eight sites with 113 AYA aged 11–24 years undergoing myeloablative HSCT. The trial examined efficacy of a specific music therapy intervention (i.e., the TMV intervention) to: (a) decrease illness-related distress, (b) improve family environment, (c) increase perceived social support, (d) improve coping, (e) increase hope-derived meaning, and (f) increase resilience and quality of life. Participants were randomized to TMV or a low-dose audio book control group. Two theoretical models informed the study; one guided outcome evaluation, and the other TMV intervention content and processes. The RIM guided the evaluation of mediators (i.e., illness-related distress, defensive and courageous coping, family environment, social integration, spiritual perspective, hope derived meaning) and outcomes (i.e., self-transcendence, resilience resolution, sense of well-being) (Haase, Kintner, Monahan, & Robb, 2014; Haase et al., 2017).

The Contextual Support Model of Music Therapy guided development and delivery of the intervention by providing AYA in the TMV group with structure, autonomy support, and relationship support in the midst of a difficult life event—the HSCT experience (Robb, 2000; Robb, 2003a, 2003b). The TMV was designed to provide meaning-making opportunities using a structured, yet

individualized approach. The music therapist uses strategies that support AYA autonomy and their ability to communicate what is most important to them. The AYA identifies, explores, and expresses what is important to them through songwriting and creation of a personalized music video over the course of six 1-hr sessions delivered by a board-certified music therapist. Sessions commenced within 3 days of hospitalization, and intervention content was tailored to accommodate changes in the psychosocial and physical status experienced by AYA during the acute phase of HSCT (Robb & Ebberts, 2003). The first three sessions occurred early in the transplant process, when AYA usually experience less fatigue and malaise; thus, these sessions included TMV processes that were more active and cognitively demanding. The last three sessions built on content generated in earlier sessions and had fewer active components, allowing for more flexibility in activity level based on AYA symptom experience (Burns, Robb, & Haase, 2009; Docherty et al., 2013; Robb et al., 2014). See Table 1 for a description of intervention content and experiences for each session.

Methods

The research method for this study was empirical phenomenology, which aims to describe commonalities of lived experiences across individuals (Christensen, 2017). Based on the work of German philosopher Edmund Husserl, empirical phenomenology is characterized by “an attitude of openness for whatever is significant for the proper understanding of the phenomena” (Giorgi, 1970, p.9) and is achieved by the researcher focusing on the phenomenon as initially described by individuals and without consideration of previous knowledge, other perspectives, or prejudice (Tymieniecka, 1962). The analysis involves processes of intuition, reflection, and description and the contents of the phenomena are the data of experience, its meaning for the participant, and the essence (i.e., essential structure) of the phenomenon (Giorgi, 1970). The essential structure is derived from analysis of the open-ended interviews of persons who experienced a phenomenon of interest—in this case, experiences of AYA who received the TMV intervention while undergoing HSCT for cancer. It is important to note that commonalities of experiences do not imply that all participants had the same experience. Rather, commonalities of

TABLE 1

TMV Intervention: Summary of Contextual Support and Intervention Content

Elements of Contextual Support from CSM-MT	Summary of Intervention Content by Session ^a		
	Week	Session	TMV Intervention Content
Structure	1	1	Learn how to use a song-writing script
• Familiar, predictable music			Select music for project (i.e., offered 10 songs from 5 music genres) ^b
• Song scripts			Brainstorm ideas for lyric/video content (i.e., what is important to AYA)
• Storyboards	1	2	Write lyrics to a familiar song using a song-writing script
• Leveled involvement			Discuss lyrics and what is important to AYA
Autonomy support			Sing/practice song with CD accompaniment track
• AYA-directed			Select who will sing on the song recording
• Choices (music, lyrics, visual images, vocalists, involving others)	2	3	Sing/rehearse completed song
• Quality product			Discuss AYA thoughts about/reflections on video project
Relationship support			Digitally record vocal soundtrack for video
• Music to communicate unspoken thoughts, feelings, dreams for future	2	4	Listen to AYA vocals mixed with accompaniment track ^b
• AYA-centered			Begin storyboard process (i.e., select visual images to go with song lyrics)
• Therapist support			Listen to completed song/discuss visual images—memories/importance
• Family, peer, healthcare provider involvement	3	5	Digital camera available during hospitalization
			Gather visual images and/or take pictures
	3	6	Complete storyboard
			Listen to completed song/discuss visual images—memories/importance
			Private viewing of music DVD
			Optional “Video Premiere” (i.e., AYA invites other to view)

Note. AYA = adolescents/young adults; CD = compact disc; DVD = digital video disk; TMV = therapeutic music video. ^aSessions facilitated by board-certified music therapists. ^bCD accompaniment purchased for each music video project. Music selections available upon request. Reprint permission: [Docherty et al. \(2013\)](#). Parental perspectives on a behavioral health music intervention for adolescent/young adult resilience during cancer treatment: Report from the children’s oncology group. *Journal of Adolescent Health, 52*(2), 170–178.

experiences are derived as the researcher considers how the data of each person’s description of their experience contributes to the

evolving understanding of the experience as a whole (i.e., essential structure) (Neubauer, Witkop, & Varpio, 2019).

Participants

A purposive sampling approach was used to select a subsample of AYA who were enrolled in the SMART I trial, received the TMV intervention, had diverse perspectives on their experiences (i.e., both positive and less-than positive) and were from different age groups (i.e., 11–14, 15–18, and 19–26 years) (Tashakkori, 2010). The final sample for this qualitative component of the larger study included 14 AYA (4 female; 11 white, 1 black, 2 more than one race) ages 13–22 years ($M = 17$ years) from six COG sites.

Procedures

Institutional review boards for human subject research at each site approved the study. Prior to enrollment, AYA provided informed consent or assent to participate, which included information about the possibility of an optional interview after they had completed all other study-related activities. Study staff approached AYA for interviews and asked whether they were still willing to participate in the optional interview. Prior to conducting any interviews, study team members at each site received training in qualitative interviewing. Team members conducting the interviews were not involved in the delivery of study conditions or the provision of direct patient care. Interviews took place in a private setting with only the AYA and interviewer present. If the AYA were not scheduled for a return hospital visit, a member of the study team conducted the interview by phone.

The goal of each interview was to obtain a rich and complete description of the AYA's experience. To foster thoughtful reflection, study staff gave AYA the interview guide one week prior to the interview. The initial broad, data-generating question was "Please tell me about your experiences of being involved in the music video study." Interviewers encouraged AYA to discuss any thoughts, feelings, and experiences related to their intervention experience. Probes for deeper reflection focused on what it was like being involved in the music video intervention; whether and how the TMV helped during the transplant experience; what doing the various intervention components was like; and any thoughts on

the potential meaningfulness of the experience. At the end of the interview, AYA were asked about ways the intervention could be improved. Interviews lasted from 4 to 24 min, with a mean length of 15 min.

Data Analysis

We used Haase's adapted version of Colaizzi's (1978) method of analysis of open-ended interviews to derive the essential structure of AYA experiences of the TMV intervention (Haase, 1987). Prior to analysis, transcribed audio-recordings for each interview were de-identified and checked for accuracy. Team members worked in pairs to complete the first four analysis steps for their assigned interviews, including: (a) gaining understanding of the AYA's experience as a whole by reading transcripts in their entirety; (b) identifying significant statements; (c) restating them in the general language of science; and (d) formulating meanings. (See Table 2 for exemplars.)

Then, the whole team worked together via web-based conferencing to: (e) reach consensus on the formulated meanings for each participant, (f) organize the meanings into the main theme categories that consist of related theme clusters, and (g) develop the essential structure of the AYA experience derived from the analysis and agreed upon by the team members. Trustworthiness and credibility of findings were enhanced by use of an audit trail and involvement of a team during all steps of analysis. There was encouragement for and expectation to reach consensus as a team at each step of analysis (i.e., agreement on significant statements, formulated meanings, themes, theme clusters, aggregated theme categories, and the essential structure of the experience).

Results

Four theme categories emerged from the data. See Table 3 for an outline of these theme categories and their related theme clusters. Here, we provide a narrative summary of the four theme categories with illustrative exemplars (i.e., participant statements), followed by the essential structure statement. We then provide a narrative summary of AYA's responses about intervention limitations and ways to improve. Because empirical phenomenology aims to describe the lived experience (as expressed in the now), we report results using present verb tense (Christensen, 2017).

TABLE 2
Empirical Phenomenology: Exemplars for Analysis Steps 2 through 4 for a Single Participant

Question	Significant Statements (Step 2)	Restatements (Step 3)	Formulated Meanings (Step 4)
I: We really are interested in hearing how this whole experience was for you in general, but then also how the experience was for you by session, and so forth like that. I appreciate you taking time to talk to me about it.	AYA9, SS9.1 It was, it kept me preoccupied with everything.	AYA9, RS9.1 Kept the AYA preoccupied.	AYA9, FM9.1 AYA perceived TMV as helpful because it helped keep the mind off the cancer.
I: Did it?	AYA9, SS9.2 Yeah	AYA9, RS9.2 Yes	
I: In what way did it do that? What were the things about it that did?	AYA9, SS9.3 It kept my mind off everything we were going through.	AYA9, RS9.3 Participating in the intervention helped keep AYAs' mind off the transplant experience.	AYA9, FM9.3 Kept mind off disturbing thoughts related to cancer experience.
I: Good.	AYA9, SS9.4 And plus I am really into music.	AYA9, RS9.4 Plus the AYA is really into music.	AYA9, FM9.4 An additional benefit of the TMV was that it involved an activity the AYA really enjoyed (music)
I: Oh, OK. So it was a good fit for you then?	AYA9, SS9.5 Yes, and the intervener was really, really, really, really nice.	AYA9, RS9.5 Another plus of the intervention was that the intervener was really nice.	AYA9, FM9.5 A benefit of the TMV was working with someone, with whom the AYA could really connect.

TABLE 3

AYA Experiences of the TMV Intervention: Theme Categories and Theme Clusters

Theme Categories	Theme Clusters
Interwoven experiences of the transplant and TMV intervention	A Crappy experience that results in loss of personhood Putting the cancer experience in perspective Making the transplant a “We” experience
The TMV intervention as a guided opportunity for reflection, self-expression, and meaning-making	The guided TMV development process Song selection: deeply personal, about me Lyric writing: exploring what is important Video production: multidimensional-like me Video premiere: a way to share Valued guidance from the music therapist Family, friend, HCP involvement in the intervention process An overall meaningful experience
Telling my story: the work of deriving meaning	Telling my story as a way to remember, existentially reflect on, work through, and derive meaning A clear message to convey Sharing my authentic experience The meaningful people in my story: touchstones to my past and essential support during my cancer journey
A way to overcome the bad side of cancer	Getting through treatments Myriad of activities worthy of my time and effort Making meaningful connections A way to express gratitude and help others

Theme Category 1: Interwoven Experiences of the Transplant and TMV Intervention

AYA’s experiences of having an HSCT and making their TMV were intricately connected. As such, these experiences influenced and impacted each other. Theme Category 1 includes the following three theme clusters.

A crappy experience that results in loss of personhood. Having a HSCT takes a physical and emotional toll on AYA that negatively affects AYA sense of self. Transplant medications, side effects including pain and fatigue, and the isolation required to protect from life-threatening infection all influence the AYA’s sense of personhood: “You lose a lot of your things that make you a person, I think, when you’re in the hospital” (Part. 1, Site 1).

Putting the Cancer Experience in Perspective. Despite distress associated with HSCT treatments, participants develop strategies

to mitigate their distress and find perspective. Strategies expressed during interviews included: comparing their experiences to those of other patients, “compared to other people, I went through it really well” (Part. 2, Site 2); expressing gratitude for what they can do and what they have, “I’ve always been able to exercise, and stay physically active, extremely physically active like running almost every day” (Part. 3, Site 1); and marking important milestones, often in terms of a specific day, “[it’s been] 110 days since transplant” (Part. 2, Site 2).

Making the Transplant a “We” Experience. The TMV process helps AYA connect with others in several ways. Describing their experiences helps AYA gain a sense of having others understand what they are going through. “... I told them [what] I did [to] overcome everything ... and they understood” (Part. 4, Site 1). Completing the TMV amidst a life-threatening illness also fosters a shared sense of pride and accomplishment: “My mom and dad know I’m ... shy about it and they [were] kind of was surprised that I did it... I thought it all worked out well and so did they” (Part. 4, Site 1). Making the TMV is also an opportunity for AYA to reflect on important people in their lives, and their shared the experience of the transplant journey: “It kept my mind off everything we were going through” (Part. 5, Site 3). In addition to sharing their HSCT experiences through their video, AYA appreciate the “we” opportunities of having family, friends, and HCPs involved in the shared, and sometimes amusing, process of video production: “We had to do it [sing song] like three times. The first time we didn’t get the beat right..., then the third time we got it right” (Part. 6, Site 4). Creating the TMV fosters reciprocal relationships: “...then after I did that [video premiere], they [HCP] all would bring pictures of their children and what they did, and how their holidays and their Halloween and their Christmas were...” (Part. 4, Site 1).

Theme Category 2: The TMV Intervention as a Guided Opportunity for Reflection, Self-Expression, and Meaning-Making

AYA describe their experience of the TMV intervention on two levels: at the process level (i.e., AYA describe their experience of the intervention components such as songwriting, sound recording, storyboarding) and as a gestalt (i.e., AYA’s overall experience). Below, the first theme cluster captures AYA experiences at

the “process level,” followed by three additional theme clusters about their experiences with the therapist, involvement of others, and their overall experience.

A Guided TMV Development Process. AYA commented on their experiences of all four components of the TMV intervention: song selection, lyric writing, video production, and video premiere.

Song Selection: Deeply Personal, about Me. During the consent process and first session, each AYA chose one song from a list to use as the musical structure for their project. AYA describe song selection as something they have some control over, and as deeply personal and reflective of their individuality. Familiarity of musical genres (e.g., country, rap) and even particular songs make song selection and lyric writing easier: “If they wouldn’t have...[offered] a song that I already ... listened to quite a bit, then I don’t know if I would have even signed up ...if it was a song I didn’t know ... then it wouldn’t have been as fun” (Part. 7, Site 4). The variety of genres in the song list, which includes both slower and more upbeat musical styles, also help AYA to begin exploring which messages are important to convey in their videos.

Lyric Writing: Exploring and Expressing What Is Important. Writing song lyrics gives AYA the opportunity to explore, reflect on, and express what is important to them. Because, some AYA experience lyric writing as the most difficult part, song lyrics from the original recording can serve as a springboard for AYA to write about their unique experiences: “...making sure you’re expressing what you’re really feeling...” (Part. 1, Site 1). AYA are sometimes surprised at their ability to express feelings and emotions through the lyrics: “I thought it was going to be hard to share my feelings and emotions, but it was actually quite easy once I started writing” (Part. 1, Site 1). AYA find brainstorming the lyrics with the music therapist helpful to clarify ideas, “... she [music therapist]helped me pick out words that I’d tell her [about] what I thought, and she would help me put it into words and fit it into the song” (Part. 4, Site 1).

The story within the lyrics creates a snapshot of what AYA are going through and what is important to them. The song writing process gives AYA opportunities to reflect on their HSCT experiences, “How did I get it all in [*my video*]? I was... able to go through the whole process from diagnosis to the current transplant, so I covered two years” (Part. 1, Site 1), and also reflect on meaningful

people or events, “I got all of the elements that I wanted: family and friends, and faith” (Part. 1, Site 1).

Video Production: Multidimensional, Like Me. AYA describe the video production process, including soundtrack recording and storyboarding, as multidimensional—like themselves. Recording the soundtrack for the video provides multiple opportunities for self-expression of both the process of making the TMV and the HSCT experience itself, “I had a good time; it was fun. The only problem, for me was doing the singing. I had mucositis at the same time so it really, really hurts when you do it...” (Part. 8, Site 5). AYA who do not see themselves as singers appreciate support from the music therapist and others willing to sing along during sound track recording, “I like songs to where you can have more than one person..., I thought... more than one person singing it sounded better than just me by myself, ...I’m kind of tone deaf” (Part. 4, Site 1). AYA also enjoy and find humor in the shared process of recording the video soundtrack with healthcare providers (HCPs), “It was kind of funny listening to them sing” (Part. 6, Site 4). Recorded song lyrics also create a mental image that guides picture selection and flow of the project, “After I had the lyrics, I just had a mental picture of what I wanted the pictures to be and how I wanted it to flow” (Part. 6, Site 4).

It was important for AYA to capture just the right photo, and having a digital camera enabled AYA to collect pictures throughout the day, “... if a nurse came in...I would have a camera there already so we would just take pictures. I had the camera with me everywhere I went” (Part. 5, Site 3). Carefully selected images augment experiences conveyed through lyrics, “If I was talking about somebody having a difficult time or being depressed,[in the song] ...I’d use a general picture of somebody having a hard time” (Part. 3, Site 1). AYA also used pictures to express gratitude for friends, family, and HCPs.

Although AYA expressed the importance of having images in their video, they also describe the experience as tedious. The tedium is mitigated by reflecting on the images and enlisting help from family and friends, which also fosters connectedness between AYA and others during treatment, “Doing the pictures and the slide show, I would be able to look at my young childhood ... all my friends and the people who gave me photo albums ... and think about family back home....it brought me through it [the HSCT] a

lot faster than it probably would have if I'd just been sitting there" (Part. 4, Site 1).

Video Premiere: A Way to Share. When AYA describe the video premiere, they consider the role and purpose of their audience. For AYA who elect to share their video, sharing is a way to tell family and friends about their experiences. Showing the video fosters meaningful conversations about the treatment experience and AYA's ability to overcome difficulties, "...but then I told them [what] I did [to] overcome everything and I felt like doing it, and it helped pass time and they understood" (Part. 4, Site 1). Sharing the video also helps AYA connect with HCP on a more personal level, "...the nurses I showed [*the video*], I was close to...they kind of got to see a side of me that they might not have known...." (Part. 4, Site 1). AYA are thoughtful about if and with whom they want to share their video. They often share with family, friends, and HCPs; however, some choose to keep the TMV to themselves: "... I just always felt like it was something private, that I did personally" (Part. 1, Site 1).

Prior to the premiere, AYA have a range of emotions and reactions to sharing their video, many akin to opening-night jitters and concern about being judged, "Then I had to watch [view] it. I was just hoping it was good" (Part. 5, Site 3). These emotions are often juxtaposed with joy and satisfaction from the supportive reactions of those present for the viewing, "My mom and dad know I'm kind of shy about it ... they kind of [were] surprised that I did it" (Part. 4, Site 1). AYA also experience nervousness in sharing the video because of the amount of effort put into its creation; the also they value the extra attention and genuine interest of those attending the premiere, "...it was just nice to have someone else besides [friends, family], like the normal people [healthcare providers] that are around that came by and knew who I was...." (Part. 8, Site 5).

AYA gain awareness of the impact their video has on others because of strong emotional reactions they observe when others watch the video, "Yes, my mom and grandma cried" (Part. 5, Site 3). Some AYA interpret these emotional reactions as pride for accomplishment or finishing the video in the midst of treatment. AYA also have a palpable sense of pride and pleasure that friends/family are impressed with their video, "Yeah, they enjoyed it and thought it all was put together well" (Part. 4, Site 1). AYA experience a general

sense of pleasure regarding their video, even when their overall experience is characterized as uneventful, “I guess [I had] a little bit of pride” (Part. 9, Site 1).

Valued Guidance from the Music Therapist. AYA recognize the music therapist as central to the process and view their relationship as easy, supportive, and meaningful. AYA feelings of being valued by their music therapist enhance the establishment of trust and open communication, “...she [music therapist] would bring in her guitar and play a song and we would sing together; and that helped. And then we would play...and sing my song” (Part. 1, Site 1). Having time, and making music, with the therapist is an opportunity for shared experiences and unconditional acceptance, “I know sometimes I was kind of... rude...because, I mean I just didn’t feel good—and they understood” (Part. 4, Site 1). Consistent music therapist support and guidance throughout the process is appreciated, “she really helped out as far as helping things fit together in the end” (Part. 3, Site 1). Finally, AYA appreciate ways the MT ensures a quality end product for which the AYA can be proud, “She [the MT] sung (sic) on it as well. It sounded really good, the end product” (Part. 10, Site 1).

Family, Friend, HCP Involvement in the Intervention Process. AYA appreciate being supported to make their own decisions about the involvement of others in the process of developing their music video. Family, friend, and/or HCPs are often involved in various phases of the intervention and AYA appreciate that the TMV offers a new way to interact and connect through lyric writing, picture selection, and/or song recording, “The only thing we kind of like, I mean we play games and stuff together and do crosswords but never anything like that [the TMV]” (Part. 6, Site 4). “My dad has a great voice, so I liked it. I like hearing him sing and I thought it sounded pretty good” (Part. 10, Site 1). Friends are recruited to assist in aspects of TMV development, such as choosing pictures that accurately reflect the AYAs’ uniqueness, “... I used a lot of... pictures because... they [the pictures] kind of show what I was about and about ...what I did at home” (Part. 4, Site 1). Healthcare providers are often involved in the song recording. AYA describe how flexibility of the recording session fosters creativity, shared humor, and spontaneous collaboration with HCPs. While most AYA choose to involve others, as previously noted, some AYA choose to work only with the therapist and keeps their video private.

An Overall Meaningful Experience. AYA describe their overall experience of making the TMV video as a meaningful experience,

“If I could make another one I would... It was something to look forward to each week. We would write it on the calendar” (Part. 6, Site 4). They also describe the experience as flexible, enjoyable, and helpful for breaking the monotony that comes with transplant and protective isolation. “It gave you something to do...because, when you’re sitting in your room for a month, it gets a little stagnant” (Part. 8, Site 5). The process is experienced as straightforward, and working with the music therapist is valued, because the therapist tailors each session based on the “in-the-moment” needs of the AYA. The structure inherent in sessions support AYA engagement, “I liked the structure... it was very flexible...[I could] do some work on my own, and then use that in the next session...” (Part. 3, Site 1). Flexibility around sessions accommodates changing needs of AYA, “They ... learned when I would be sick [and adjusted timing]” (Part. 4, Site 1). AYA have a sense of ownership and pride in their final music video, often seeing it as a reflection of self that they want to share with friends, family, and HCPs, “I think it shows my point of view on what I’ve been through” (Part. 3, Site 1).

Theme 3: Telling My Story: The Work of Deriving Meaning

All AYA have a unique story to reflect on and share with others. Throughout the TMV process AYA: (a) tell their story as a way to remember, existentially reflect on, work through, and derive meaning; (b) develop a clear vision of the messages they want to convey; and (c) want to share their authentic experience to help others fully understand what is important to them.

Telling My Story: A Way to Remember, Existentially Reflect on, Work through, and Derive Meaning. The TMV process offers AYA opportunities to reflect on their experience of cancer, and what is important to them: “...it was a way to express what I was dealing with either at the time, or from the past, with cancer” (Part. 1, Site 1). It also provides opportunities to reflect on who and/or what is important and meaningful: “Seeing all the pictures with the family ... made me think back ...helped me to use the song... to put everything together” (Part. 4, Site 1). For AYA who choose to create a video focused on their cancer or transplant experience, making the TMV helps to reflect on and make meaning from a very difficult time in their lives: “...I wanted to express the way I was feeling and the way I was handling treatment for cancer” (Part. 1, Site 1). For some AYA, making meaning includes their

spirituality, “There was some religious connotations because faith was very really important to me to get through this” (Part. 1, Site 1). For AYA who choose to create a video about a different life experience, the TMV provides the opportunity to recall enjoyable, positive life experiences and recreate precious memories, “I used some childhood pictures of...fishing and when we have a family barbeque and stuff like that” (Part. 4, Site 1). The TMV is also a meaningful way for AYA to create new connections, enhance current relationships, and reconnect with significant people in their lives, “It was meaningful in that it was another way to share ... my story” (Part. 3, Site 1).

A Clear Message to Convey. AYA want to express what is important to them in their music videos in ways that gives others a clear, full understanding of their experience. Their messages focus around four overarching themes: (a) Who I am—the cancer does not define me, “...the nurses...they kind of got to see a side of me that they might not have known because they didn’t know me from back home” (Part. 4, Site 1); (b) expressing gratitude, “My mom helped me through a lot with everything” (Part. 5, Site 3); (c) the realities of having cancer, “I wanted mine [music video] to focus on my cancer and my diagnosis of it” (Part. 1, Site 1); and (d) the hardships of transplant, “Trying to convey the real hardships that I went through” (Part. 2, Site 2).

Sharing My Authentic Experience. Regardless of the focus, the meaningful connections and reconnections made during the music video development are as many and varied as the people with whom the AYA are connected. Within the trusting space created while working with the music therapist, AYA can connect with their HCPs in ways that are not usually possible during routine patient care. “They kind of learned how I was” (Part. 4, Site 1). As examples, AYA invite their HCP to sing, “I wanted [the video] in three parts...one with the nurse singing, one with the CAs [*clinical assistants/nurse aids*] singing, and one where the child life specialist was singing” (Part. 6, Site 4); pose creatively for pictures included in the video (e.g., staff in Santa hats); and help HCPs learn more about them as individuals through the TMV premiere, “the nurses I was close to...they got to see a side of me that they might not have known...” (Part. 4, site 1). The completed TMV also provides a way for AYA to express appreciation, “I showed it to...my nurses...they all enjoyed

it as much as I did” (Part. 4, Site 1). At times, AYA feel successful in conveying their authentic experience, but they also wonder whether people can ever truly understand, “..it looks good and everything, but just to me it looks fine. But when I show it to other people I just think it doesn’t look right to them” (Part. 6, Site 4).

The Meaningful People in My Story: Touchstones to My Past and Essential Support during My Cancer Journey. Making the TMV is a way to recall important memories, while creating new memories and meaningful connections in a novel way among family, friends, and HCPs with whom AYA feel connected. These connections occur even at a distance, “Well, when it all started ... a couple of my buddies got a bunch of pictures from New Year’s parties, ...hunting pictures, and stuff that they...put [in] a photo album together” (Part. 4, Site 1). After completing the project, AYA reflections on the process of developing and premiering the video fostered continued dialogue and memories about the AYA’s experience during the HSCT.

Theme 4: A Way to Overcome the Bad Side of Cancer

The benefits AYA experience from the TMV intervention serve, to some extent, as a counterbalance for their distress related to the cancer and the HSCT experience. These benefits include: (a) a means of getting through the transplant treatment; (b) activities worthy of the time and effort; (c) a way to meaningfully connect with others; and (d) a way to express gratitude.

Getting through Treatments. In general, the TMV intervention juxtaposes AYA’s experience of a potentially life-threatening experience with experiences of distraction, raised spirits, joy, and optimism. Developing the music video is a way for AYA to pass the time and keep their minds off the difficulties of the transplant, including symptom distress. “It passed a lot of time, and not just passing time, it made me not think about everything else” (Part. 4, Site 1). Even when AYA have treatment-related distress, they often make intentional decisions to push on with the project to gain a more positive perspective, “I felt, well I’ll try ...and when I was feeling bad, I did it anyway because it made me feel better” (Part. 4, Site 1), “...I think that with my video and the lyrics that I used, it kind of helped me realize that this is just a temporary thing and that I’m not going to be stuck in the hospital all the time or forever” (Part. 3, Site 1).

A Myriad of Reasons the TMV Activities Are Worthy of My Time and Effort. Participants identified many reasons why their

experiences were worthwhile. Working on their video provides an opportunity for creativity, new positive life experiences, and personal growth, “It was good to expand my horizons, but it was fun. If I could make another one, I would” (Part. 6, Site 4). The TMV project provides a source of pride and sense of accomplishment during a difficult time, “I usually don’t finish things... That was the first one... I really, really finished” (Part. 5, Site 3). Work on the video also provides opportunity to reflect on and cope with the cancer, “The study provided a mechanism to express the way I was feeling and the way I was handling treatment for cancer through myself” (Part. 1, Site 1). Additionally, the TMV is a way to document and remember, “[I] listen to it every now and then” (Part. 2, Site 2).

Making Meaningful Connections. AYA view their TMV project as a way to connect with others who are important to them, including their family, friends, and their larger community, “My dad helped me... and it was kind of fun... I like hearing him sing and I thought it sounded pretty good” (Part. 10, Site 1). The TMV is a way to involve others in meaningful conversations, “some of my friends ... laughed about [making the video], and then I told them [what] I did [to] overcome everything and [that]I felt like doing the [TMV] and ... they understood” (Part. 4, Site 1). The video also fostered increased and meaningful connectedness with HCPs, “They... learned how I was and what I did back home and they learned more about me” (Part. 4, Site 1). AYA used the video as an opportunity to reach out to their providers by inviting their participation in the video and attending their video premiere. “Hearing [nurses] laugh whenever they saw their own picture, that was the best” (Part. 6, Site 4).

A Way to Express Gratitude and Help Others. AYA use their video to express gratitude to family, friends, HCPs, and God. The video is also used altruistically to help others experiencing cancer, “I don’t think that God did this to me ..., but I think that he can use this [TMV] to help people through, no matter what” (Part. 3, Site 1) and “Just being kind of part of a survey is pretty cool, helping out with other kids in the future” (Part. 2, Site 2).

Essential Structure of the Experience of AYA Participating in the TMV Intervention

AYA experience HSCT as isolating and distressful. The TMV provides an opportunity to mitigate the difficulties of having cancer

and receiving a HSCT by helping AYA reflect on and communicate their experiences. The TMV intervention supports AYA through the cancer and HSCT in both specific and existential ways. In addition to providing diversion, the TMV provides: (a) a meaningful way to connect with others, including connections with HCPs, family, friends, and even their home communities; and (b) opportunities for AYA to reflect on and creatively express what is difficult, what is helpful or distressful, and what is meaningful and important. As AYA reflect on and express what is important, they appreciate the individualized and flexible support of their music therapist to: (a) develop a music video envisioned by the AYA—one that is personal, expresses what is important, and accurately reflects multiple dimensions of the AYA; (b) complete the project successfully in the midst of the HSCT experience; and (c) for many, to share their music video with others through a premiere or in other ways. AYA want their TMV to be an authentic reflection of their thoughts, emotions, and experiences—both positive and difficult—so others can more fully understand and meaningfully connect with the AYA. They work closely with the music therapist to develop a music video that creatively conveys past and/or current significant life experiences, special memories, and/or hopes for the future. AYA also use their music videos to express gratitude for the significant others in their lives including those known before the cancer and those who accompany them throughout the cancer journey.

Intervention Limitations and Ways to Improve

At the end of the interviews, we asked AYA about their overall perceptions of the TMV intervention and ways it might be improved. While few AYA suggested improvement, two participants shared reasons why they had a less-than-positive experience with the TMV and ways we could improve the intervention for AYA like themselves. One participant suggested expanding the TMV intervention by providing: (a) more opportunities to connect socially with peers, “I preferred [another project], ... because it was working with friends instead of just working on my own” and (b) greater intervention independence and complexity, “... maybe try and create your own song, I guess on a computer, mixing up different beats and make your own actual song and your own lyrics, instead of just copying someone else and changing a couple of words,...

or maybe making an actual video instead of just pictures” (Part. 9, Site 1). Although this participant did not characterize his experience as bad, it was clear that the participant would have benefited from a more complex (less structured) intervention, and one that promoted more social connectedness. When the structure of the intervention leaves AYA uninspired, they invest less effort and time, “I guess I could have been more involved instead of just changing the lyrics and putting a couple pictures up” and limit potential of the TMV to provide meaningful distraction, “I felt like the World Cup helped... more, because that was going on all the time” (Part. 9, Site 1).

The second participant found the TMV to be tedious and taxing, comparing it to school work or doing the dishes, “...just like dishes – I know I have to do it. It’s not a problem to do it and I know it helps in some way but just at the time it doesn’t make me feel good – just like dishes – why am I doing this?” (Part. 11, Site 2). When asked what he would suggest, he shared “If I were to do anything musical wise, it probably have to be something (sic) [just listening to. Because you really can’t make a project that everybody is going to be able to do, [something] that would take their mind completely away from something” (Part. 11, Site 2). This suggestion for a different intervention, that offered distraction over meaning making, was consistent with the participant’s self-described way of coping during HSCT, “I’m really patient. I can sit there and do nothing and as long as I have something to think about, I can get by a lot of stuff. But when I have to do something I kind of don’t want to do, it kind of puts pressure on me – not stressful pressure but pressure as in, ‘I have to do this because I’m supposed to do it’...” (Part. 11, Site 2). For this participant, listening to music would have been more consistent with his coping style, and may have provided him with a more meaningful and less stressful form of distraction: “Basically, it’s really just trying to help someone find something that they can do that wouldn’t stress them out from the work that they have to do – the input that they have to do-and something they like” (Part. 11, Site 2).

Finally, one participant reported experiencing pain due to mucositis during the sound recording phase of the project, and suggested altering the time frame, “I think it might be better to shoot it...later in the transplant when the mucositis isn’t as bad. It wouldn’t be as painful” (Part. 8, Site 5).

Discussion

Findings from this study are consistent with prior studies documenting AYA identified challenges and needs associated with HSCT (Dyson et al., 2012; Keegan et al., 2012; Zebrack & Isaacson, 2012; Zebrack et al., 2014). AYA comments affirm the complexity of the HSCT experience, and emphasizes challenges associated with the emotional and physical side effects of treatment and social isolation, as well as how these factors contribute to a loss of personhood. In addition, AYA described how TMV intervention processes: helped them overcome these challenges through meaningful opportunities to access and strengthen their connections with family, friends, and HCPs; identify their own personal strengths; and share their story with others. These three areas of support are consistent with previous qualitative research investigating the forms of support AYA find most helpful (Bellizzi et al., 2012; Kyngäs et al., 2001; Zebrack et al., 2007). Finally, AYA statements support our quantitative findings that the intervention helps AYA in the areas of family support, social integration, and positive coping (Robb et al., 2014).

Another important finding is that the TMV intervention functioned as intended, with AYA statements validating the theoretical concepts that informed its design (Robb, 2000; Robb, 2003a, 2003b; Robb et al., 2014). AYA described specific experiences of three forms of contextual support (structure, autonomy support, and relationship support) that contributed to their motivation and ability to remain engaged in (and derive benefit from) the TMV. By design, the music therapist tailors the music experience by leveling these three forms of contextual support throughout the intervention, helping AYA remain actively engaged in the therapeutic process despite changes in physical and emotional distress that occur over the course of HSCT. For example, AYA noted that the use of familiar music, songwriting scripts, and storyboarding offered **structure** by providing a scaffold for lyric writing, reasons to interact with others, and a catalyst for meaningful conversations. Regarding **autonomy support**, AYA experienced song selection, lyric writing, and video production as being under their control, and a process that reflected their individuality. Decisions about family, peer, and HCP involvement and whether the final video would remain private were driven by the AYA, and the result was an intervention where AYA felt their independence and privacy were

honored. Finally, **relationship support** was experienced through AYA interactions with the music therapist, identifying and reflecting on people important to them, and opportunities to invite others to work with them on their project.

AYA identified the music therapist as central to their experiences with the TMV and viewed their relationship with the therapist as an important factor that contributed to their ongoing engagement and success with the intervention. AYA indicated they felt valued by the music therapist, which helped to establish trust and open communication. The AYA also noted therapists' flexibility in meeting their changing needs and described their relationship as collaborative. These findings are consistent with psychology literature examining attributes of the therapeutic relationship that AYA identify as important to their experience (i.e., trust, collaboration, and therapist flexibility), all of which are predictive of engagement and subsequent benefit from therapy (Chu & Kendall, 2009; McPherson, Kerr, Casey, & Marshall, 2017; Munson, Scott, Smalling, Kim, & Floersch, 2011; Oetzel & Scherer, 2003). Unique to the TMV, and central to music therapy, is the use of shared music experiences to develop collaborative relationships, and support engagement in therapy. Given music is a medium that many AYA find meaningful, it is an important and powerful point of connection (McFerran, 2010, 2014; Miranda, 2013).

Our findings also suggest that it was not the scripted delivery of TMV experiences that resulted in benefit; rather, it was how music therapists tailored intervention delivery using theoretical principles specified in the intervention design. Based on AYA descriptions, the structure and content, along with skilled delivery from a board-certified music therapist, creates a flexibility that can accommodate the individual needs of AYA, and does not propose a "one-size-fits-all" approach. Throughout the intervention, the music therapist works with the AYA to determine their self-directed needs and desires for the intervention. This approach is consistent with empowerment in mental health literature, where therapists and clients are viewed as partners (Buckingham, Brandt, Becker, Gordon, & Cammack, 2016; Chu & Kendall, 2009; Iachini, Hock, Thomas, & Clone, 2015; Kim, 2012; Oetzel & Scherer, 2003; Thompson, Bender, Lantry, & Flynn, 2007). In addition, from a developmental perspective, this approach is consistent with what AYA are seeking and value—respect for their emerging independence

and individuality (Compas et al., 2012; Docherty et al., 2015; Kim, 2012; Oetzel & Scherer, 2003).

Across the phases of their project, AYA had multiple opportunities to involve, or not involve, others in their projects—and the need for either enhanced connection or private reflection were honored by the music therapist. It is important to recognize that the messages contained in the AYA's videos were deeply personal and a product of therapy. As such, decisions about sharing (i.e., whether to share, with whom, and when) must remain under the control of the AYA with support from the music therapist to ensure an informed decision that will be honored (Baker, 2015). Given the high levels of psychosocial and existential distress experienced by AYA during HSCT (Clark, Eiser, & Skinner, 2008), and the therapeutic skills required, we recommend TMV delivery by a credentialed music therapist. The emergence of songwriting programs in pediatric hospitals and other healthcare agencies that are delivered by volunteers (without supervision from a credentialed therapist or other qualified health professional) should be carefully monitored (Baker, 2015; McFerran, 2014).

AYA experiences with the TMV also align with factors identified in the RIM, providing additional insight into the potential mechanisms of action underlying the intervention. Specifically, the RIM can provide insights into ways the TMV may foster the significant changes in AYA self-reported measures of social integration (i.e., social support from peers and HCPs), family environment (i.e., support from family), and positive coping observed in this trial (Haase et al., 2014, 2017; Robb et al., 2014). In the RIM, hope-derived meaning is influenced by spiritual perspective, social integration, and family environment. The TMV intervention provides an iterative, cyclical process that begins when the music therapist initially helps AYA decide on their TMV theme by encouraging them to think about “whatever is important to you.” This wording was deliberate and aimed to help AYA reflect on and communicate what is meaningful through the TMV. Meaning-making provides a way for individuals to mentally connect their experiences of things, events, and relationships (Park, 2010). Themes within AYA video content and interviews reflected all three, but focused primarily on events (e.g., family gatherings, sports, transplant day) and on relationships with family friends, HCPs, and God. This may account for the significant changes

we found on AYA self-report measures of social integration and family environment (Robb et al., 2014).

In the RIM, spiritual perspective, social integration, and family environment are also drivers of courageous coping (i.e., the use of positive coping strategies: optimistic, supportant, and confrontive coping). Themes that emerged from our analysis indicate that AYA valued the opportunity to tell their unique stories. In their interviews, AYA indicated that the TMV helped to counterbalance negative aspects of their cancer experience by focusing on positive aspects of themselves, their lives, their resources, and their families. Based on the RIM, these findings suggest that through self-reflection, AYA may have developed greater awareness about their own personal resources (i.e., support from family, friends, HCPs, and spirituality), which is related to the formation and use of positive coping strategies. This is consistent with our quantitative finding that AYA who experienced the TMV reported greater social integration and family environment (i.e., support from family, friends, and HSCPs), and greater use of positive coping strategies than AYA who was assigned to the control condition (Robb et al., 2014).

As anticipated, the TMV will not be the best intervention for all AYA undergoing HSCT for cancer. As we continue this program of research, one of our goals is to identify for whom the intervention is most beneficial, and under what circumstances. Although only AYA shared a less-than-positive experience with the TMV, they provided important information that informs therapist decision-making on when to use interventions like the TMV. Participant 9 wanted a more complex and less structured intervention that included writing original music. This was not possible during the controlled trial (i.e., therapists followed a standardized songwriting protocol that used scripts), but writing original music is something that is frequently done in music therapy clinical practice. A common theme that emerged from this analysis was that the songwriting scripts offered the right amount of structure and autonomy support, but for some (as with Part. 9) the structure was too confining. This speaks to the importance of tailoring the intervention to the needs of the individual. Our interview with Part. 11 indicates that the TMV intervention was not consistent with his way of coping, and that he would have likely found more benefit from a music listening intervention designed to promote distraction and relaxation. Again, this speaks to the importance

of clinical assessment (which is a standard of practice for credentialed music therapists) to determine AYA needs and inform selection of music interventions to meet the needs and preferences of the individual. With regard to Participant 8's suggestion, TMV intervention activities were planned to avoid the common timeframes for symptoms like mucositis. However, if the participant did not begin sessions as specified in the protocol, they had an increased chance of experiencing symptoms like mucositis during the sound recording session. When this occurred, music therapists were able to provide alternative choices when AYA were not able to complete tasks due to treatment complications (e.g., having MT, family/friend, or HCP sing).

Limitations

Phenomenological studies describe commonalities of experiences across individuals who have had the experience of interest. While we anticipated identifying commonalities among participants with both positive and less-than-positive experiences, only two of the participants we interviewed had any less-than-positive experiences. The less-than-positive aspects of these two participant experiences were not common among other participants interviewed, and therefore were not reflected in the results. To account for these important differences, we included information unique to these participants in our findings labeled, "Intervention Limitations and Ways to Improve." Implications of these findings are included here in the discussion section of the manuscript.

It is important to acknowledge that interview findings may be positively skewed because AYA who agreed to enroll in the study may have been more likely to expect that making a music video (or listening to audio-recorded books, our control condition) would be interesting and potentially helpful. Whereas, AYA who declined participation may not have viewed the study conditions as interesting or potentially helpful. In addition, participants who withdrew from the study or declined an interview ($n = 4$) may have had a less-than positive experience. A second potential limitation was our decision to omit the last step of Colaizzi's method of analysis (i.e., confirmation of the essential structure by individuals who had the same experience). The rationale for this decision was grounded in Haase's prior phenomenological studies wherein the

extra interviews did not result in changes to study findings and we did not want to place undue burden on study participants.

Conclusion

In summary, this qualitative analysis has broadened our understanding of how AYA study participants experienced the TMV during transplant, and how the TMV may have functioned to bring about positive outcomes as reported in our quantitative article (Robb et al., 2014). In particular, this analysis provides increased understanding of the social and relational experiences that resulted from participation in the TMV and their importance in helping AYA cope with HSCT and a greater understanding about specific music therapy processes and therapist skills that were essential to sustained engagement and benefit from the TMV. The key finding from the qualitative analysis is that the TMV provided a way for AYA to: remember, existentially reflect on, work through and derive meaning from their experiences during HSCT; to sustain and build supportive social connections; and for many it provided an opportunity to gain understanding from others as they shared their story.

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