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The acceptability of Songs of Love for youth living with chronic pain

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Abstract

Objectives: Music is helpful to young people in healthcare contexts, but less is known about the acceptability of music-based interventions for youth living at home with chronic pain who may be struggling to attend school and participate in social activities. The Songs of Love (SOL) foundation is a national nonprofit organization that creates free, personalized, original songs for youth facing health challenges. The aims of this study were (1) to assess acceptability of SOL from the perspective of youth with chronic pain receiving a song and singer-songwriters who created the songs, and (2) to explore the role of music more generally in the lives of young people living with pain.

Methods: Twenty-three people participated. Fifteen youth (mean age 16.8) were interviewed and received a song, and six singer-songwriters were interviewed about creating the songs. (Two additional people participated in pilot interviews.) Acceptability was assessed by (1) proportion of youth who participated in a second interview about their song and (2) results of reflexive thematic analysis (RTA) to determine acceptability. Themes addressing the role of music in the lives of youth with pain were also explored using RTA.

Results: The program was acceptable as 12 of 15 youth (80 %) participated in second interviews and themes met the

definition of acceptability. Three themes addressing the role of music in the lives of youth living with pain were identified.

Conclusions: This is the first report of the acceptability and experience of SOL and contributes to research on the benefits of music for pain management.

Keywords: pain; music; complementary

Introduction

Chronic pain is common in childhood and adolescence. Between 11 and 38 percent of youth experience pain conditions such as musculoskeletal pain, abdominal pain, and headache [1]. While the majority of youth living with chronic pain do not experience severe pain, the ongoing pain and discomfort they live with are associated with a range of sociodevelopmental challenges, including missed days of school [2], social isolation [3], and increased risk of anxiety and depression [1, 4–6]. Interventions are needed that can help youth living with chronic pain to manage their symptoms and feel more connected, and help to increase quality of life for millions of young people.

The biopsychosocial model is presently the most widely accepted approach to understanding the experience of chronic pain. In this model, pain is viewed as resulting from an interaction between physiological, psychological, and social factors that reciprocally influence one another [7, 8]. Within this approach, creative activities such as music can be used as a way to influence young people's experience of pain.

Systematic reviews indicate that music is helpful to young people in healthcare contexts [9–12]. Music-based interventions in health care can be defined as Music Therapy (MT), where a credentialed music therapist systematically provides tailored experiences within a therapeutic relationship; Music Medicine (MM), where a healthcare professional provides pre-recorded music for listening to promote health; and also other music-based interventions (MBI) that comprise a looser category of music-based approaches, provided by healthcare professionals or musicians, also designed to promote health [9]. Systematic reviews indicate that MT and MM both decrease pain [10] as well as anxiety [10, 11] and stress parameters (heart and respiratory rate) in

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medical procedures [11]. As an example, among children with cancer undergoing lumbar puncture (LP), heart and respiratory rates were significantly reduced among patients who listened to music of their choosing during and after the LP as compared to the group who did not listen to music [13]. For youth living at home with chronic pain but struggling to attend school and participate in social activities, there may be MBIs that can be accessed more informally that have the potential to have a positive impact on their lives.

The Songs of Love (SOL) foundation is a national nonprofit organization that creates free, personalized, original songs for children and teens currently facing a range of health challenges. Founded in 1996, the program has reached over 40,000 children in over 600 hospitals and healthcare facilities in all 50 states and around the world. Given the role of music in pain management, a personalized song has the potential to make a positive impact on the life of a young person living with chronic pain. The aims of this study were (1) to offer the SOL program (i.e., a personalized song) to youth living with chronic pain and assess acceptability of the program for youth with pain, and (2) to further explore the role of music in the lives of young people living with pain. This is the first evaluation of the SOL program in any context.

Materials and methods

Design

As recommended by Sekhon, Cartwright, and Francis [14], we included quantitative and qualitative approaches to measuring acceptability: (1) attendance at a second interview after receiving a personalized song, and (2) semi-structured interviews with youth before and after receiving a personalized song. While our main focus was the experiences of young people living with chronic pain, a small group of singer-songwriters were interviewed once to provide an additional perspective on acceptability of the program specifically for youth living with chronic pain.

Participants

Twenty-three youth were interviewed as part of the current study. Fifteen of the participants were young people recruited to receive a personalized song and to be interviewed about their experience. Inclusion criteria were: (a) be 13–21 years of age, (b) have a self-reported, physician-based diagnosis of chronic pain, and (c) be fluent in English. Six singer-songwriters were also recruited to be interviewed. To be included, the singer-songwriter had to have created a song for one of the 15 young people enrolled in the study (One additional youth and one additional singer-songwriter were recruited to participate in pilot interviews). Purposeful sampling [15] was used to recruit a sample of youth diverse in age and pain type, to learn a range of perspectives on the research questions. The study was approved by the Institutional Review Board at Simmons University.

Procedure

Recruitment materials were distributed through the website, newsletter, and social media accounts associated with the nonprofit Creative Healing for Youth in Pain (CHYP) (www.mychyp.org), which provides free, education, self-help tools, social support, and creative arts experiences for youth with chronic pain and their families. The Founder (Author LKZ) and President of CHYP also emailed the clinical advisory board for CHYP and sent recruitment fliers to families of past and present patients treated at LKZ's private pediatric pain clinic and to other pediatricians in her network.

The Project Coordinator (PC) sent screening questions and consent forms to caregivers (or young adults) who expressed interest in the study, and then scheduled 60 min phone or Zoom calls with participants.

The interviews were conducted by four female interviewers, none of whom had prior relationships with the participants. One youth identified as having selective mutism and submitted typed responses. After the first interview, the PC emailed to SOL the information needed for the personalized song. Within 30 days, SOL sent an original, personalized song as an mp3, as well as on a USB drive, to the PC, who then sent the song directly to the participant, or caregiver of a participant under 18 years of age. The PC then requested to schedule a second interview, noting that if the youth participant did not want to take part in the second interview, they could still keep the song they had received.

The SOL foundation sent emails of invitation to singer-songwriters who had created a song for one of the 15 participants in the study; the PC sent a consent form to those who expressed interest and then scheduled a 60 min Zoom video conferencing or telephone interview with the participant. The singer-songwriter interviews lasted 60 min. None of the participants received any monetary compensation. Interviews were recorded and later transcribed.

Development of interview guides

Two frameworks informed the interview guide questions. To understand acceptability of the program, we drew on Sekhon, Cartwright, and Francis's theoretical framework [14] of acceptability that consists of seven component constructs: affective attitude, burden, perceived effectiveness, ethicality, intervention coherence, opportunity costs, and self-efficacy. To assess how people use music to regulate their emotions, we drew on Saarikallio's theoretical model of music-related mood regulation in adolescence [16] as operationalized in the Music in Mood Regulation Scale [17]. In addition, the first interview guide included questions that the SOL foundation uses to collect information for the personalized songs, and the second interview guide included questions about how music could be incorporated into future programming designed to offer creative opportunities to youth living with pain. The goal of the singer-songwriter interviews was to understand singer-songwriters' perspectives on the SOL program and whether they consider it to be a good fit for youth living with chronic pain. This interview guide was designed to mirror the interview guides used for youth living with chronic pain as much as possible. Author ED created the first draft of the interview guides and integrated feedback from the research team. Please see Table 2 for sample interview guide questions.

Pilot interviews

Methods: As recommended [18], pilot interviews were conducted prior to beginning the interview process. One 15-year-old female with chronic

pain and one female singer-songwriter – recruited in the same way as previously described – were interviewed independently for 60 min (over Zoom). Each participant was informed that the goal of the interview was to understand their impression of the questions in the interview guide, specifically: (1) adequacy of the instructions; (2) whether any questions were confusing, (3) flow of the questions. The four interviewers (who later conducted the interviews) each asked a set of the interview guide questions during piloting. The participants were each asked to comment out loud on the interview-guide instructions as well as the content and flow of the questions (e.g., whether anything was confusing or redundant). The research team agreed on edits that Author ED made to the interview guides.

Results: Regarding the youth interview guide, a question was clarified; a question was removed because it was redundant; genres of music available for the participant to request for their song were added (after confirmation from the SOL foundation); clarifying details were added to the last section of the second interview pertaining to future programming ideas. For the singer-songwriter interview guide, questions about benefits to singer-songwriters were incorporated.

Measures

Our acceptability criteria were: (1) 70 % of participants will participate in a second interview about their song based on criteria from another creativity-based, feasibility study for youth with chronic pain [19], and (2) the members of the research team will determine that the themes from the youth and singer-songwriter interviews, associated with receiving or creating personalized songs, indicate that SOL is acceptable for youth living with chronic pain, according to Sekhon, Cartwright, and Francis's [14] definition of acceptability: "a multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention."

Data analysis

Data were analyzed with reflexive thematic analysis [20] using a deductive approach where coding and theme development were informed by Sekhon, Cartwright, and Francis's [14] acceptability framework and a theoretical model of music-related mood regulation in adolescence [16, 17].

Three members of the research team independently reviewed each transcript and discussed their impressions as a group, making references to the wider literature on music in healthcare contexts (e.g., [9–11]). Author ED created the initial coding structure for the youth data. To address the first goal of understanding acceptability of the program with youth living with chronic pain, Author ED created codes based on Sekhon, Cartwright, and Francis [14] acceptability framework. To address the second goal of understanding the role of music in helping young people to manage emotions and cope with pain, she created codes based on Saarikallio's theoretical model of music-related mood regulation in adolescence [16] as operationalized in the Music in Mood Regulation Scale [17]. Three members of the research team first applied the codes to part of a transcript during a team meeting, then independently, and the coding structure was modified to address any ambiguity in how

to apply the codes. Two analysts then independently applied the codes to each transcript and resolved any discrepancies through weekly discussion. In addition, during weekly meetings, the analysts met with the lead researcher who was available to help resolve any remaining discrepancies.

To identify themes, the three main analysts independently reviewed data associated with each code, rereading the text, and noting patterns within codes, as well as patterns seen across codes. The analysts then met as a group to discuss emerging themes. Once initial themes were identified, two researchers/clinicians with relevant expertise (A clinical psychologist and a board-certified music therapist) were invited to independently review portions of the data, then give impressions and discuss alternative ways of interpreting data during team meetings. Author ED incorporated the additional feedback into the analysis and the team agreed on a small set of overall themes. Each of the five analysts were asked to report whether the themes met Sekhon, Cartwright, and Francis's [14] definition of acceptability. The team followed standard guidelines [21] for reporting qualitative data.

Results

Participant characteristics

Six singer-songwriters (three female; three male) and 15 youth (age range 13–21 years; mean age 16.8 years old), participated in the study (Table 1). One additional female singer-songwriter and one additional 15-year-old female participated in pilot interviews.

Descriptions of pain provided by the youth participants who received the songs included complex regional pain syndrome, headaches, widespread chronic pain,

Table 1: Participant characteristics of youth with chronic pain who received a song.

	Frequency	Percent
Total	15	100
Gender		
Female	11	73.33
Male	2	13.33
Non-binary	1	6.66
Other	1	6.66
Race		
Black	1	6.66
Other	1	6.66
White	13	86.66
Ethnicity		
Hispanic	2	13.33
Non hispanic	6	40
Did not answer	7	46.66
Age		
Range: 13–21		
Mean: 16.8 (SD: 2.65)		

sickle cell anemia, fibromyalgia, irritable bowel syndrome, erythromelalgia, arthritis, and functional abdominal pain syndrome.

Acceptability

The program was considered appropriate for youth living with pain as 12 of 15 participants (80 %) participated in a second interview.

In addition, all five analysts reported that the themes (below) met our [14] definition of acceptability.

Main themes

The two main themes that emerged from the youth interviews were: (1) Musical portraits mirror young people's strengths, and (2) Personalized songs foster feelings of connection. The singer-songwriter interviews provided an

additional perspective with the following themes: (1) Gratitude for an opportunity to share their gift, and the belief that (2) Music has an important role in health, regardless of health condition. Please see Table 2 for more information about organizing frameworks, sample interview guide questions, codes, and themes associated with participant interviews.

Young people living with pain

Theme 1: Musical portraits mirror young people's strengths. Some young people described how the songs they received served as a reminder of what they valued in life and a source of strength and comfort during challenging times.

A reminder of what is important. For some young people, songs written for them by the SOL songwriters helped the teens to focus on the positive aspects of their lives, and to be reminded of rewarding experiences that make life feel worthwhile even when pain made life difficult. One

Table 2: Organizing frameworks, and sample interview guide questions, codes, and themes associated with participant interviews.

Organizing framework	Sample interview guide questions	Sample codes	Sample themes
Sekhon, Cartwright, and Francis's (2017) acceptability framework [14]	Tell me about receiving the song. How did you feel when you heard the song? What did you expect? How did it compare to your expectations? (Youth) Tell me about the process of creating the song that you recently created for a young person with pain. What is your process? What is your goal when you create the song? How easy or difficult is it? How is it different (if at all) from creating a song for a young person who is hospitalized? (Singer-songwriters)	Experiences and beliefs related to the personalized song (after receiving song) Benefits to singer/songwriter being involved with SOL	Musical portraits mirror young people's strengths Gratitude for an opportunity to connect by sharing a gift
Items to be included in song	What inspires or motivates you the most? I am going to list some styles of music. Please let me know at least three of your favorites. (Youth)	Content for personalized song	
Model of music-related mood regulation in adolescence [16, 17]	When do you play music when you are experiencing pain? Why do you play music when you are experiencing pain? Some people find that music helps them to recognize different feelings or get through hard experiences. Is that true for you? o Can you give me an example of when that has happened? (youth) Can you tell me about whether this program is a good fit for young people living with chronic pain? How do you think it is helpful? Do you ever get feedback from families? (singer-songwriters)	References to music helping with mood regulation when in pain: Solace: emotional validation and support when down Beliefs about benefits to youth to being involved with SOL	Teens find solace and comfort when their feelings are validated through music Music makes people feel better regardless of health condition
Ideas for future programming	When you think about the role is music in young people's lives, is there anything that you think should be offered to youth living with pain? (youth)	References to ideas for music programming	Personalized songs foster feelings of connection

participant described how the SOL song serves a function that is unique from other music to which they typically listen to cope with pain and other difficult experiences.

“Music kind of helps me detach from life and detach from my pain and detach from everything that’s going on in the world. But then coming back with a song like that, that is about my life and is about everything that’s important to me, I kind of feel like it’s a – almost like the circle of events it – it helps me come back to the real world after I’m done listening to the music that helps me detach. So I think that it’s a thing that a lot of people should be able to experience.” – 004(02)

Empowers and comforts. As well as providing a direct and immediate reminder of the positive aspects of the participants’ lives, such as family and friends, participants also described feelings of comfort or strength evoked by listening to the songs, for example:

“It felt very empowering and it’s kind of something that I was listening to if you know I’m having a bad day or something because I really enjoyed that. It basically said that like nothing can push me down.” – 008(02)

Theme 2: Personalized songs foster feelings of connection. For the youth in the study, music provided a sense of connection, across a wide spectrum. For some, the act of listening to their song was therapeutic. For others the song was a tool for connecting with others around them, or it sparked ideas for how they might be able to connect with other youth living with pain.

Youth feel less isolated after listening to music. For some, listening to the song provided a general sense of solace, as one participant described:

“It helps me refocus a little bit, but it also reminds me that I’m not alone in this, you know? So, it’s, I find comfort in knowing that like it’s not just me that experiences it. That experiences chronic pain. And it makes me feel like I have somebody going through it with me.” – 008(02)

For others, the song helped them to feel close to the people they loved:

“The song had information about my family and it named my parents and my dog so it was kind of cool to, you know, have that experience where you use music to make yourself happy when you’re having a tough pain day, but this music keeps you connected to life while you’re trying to disconnect from the pain. It’s cool.” – 004(02)

Some participants described feeling moved and connected when they felt understood by the songwriter, for example:

“I mean music is such an important aspect to me and just knowing that someone cares and having a song of comfort.” – 014(02)

The song provided a way to reach out to others. For other participants, the song provided a way to connect to the people around them. One participant described sharing the song with a family member.

“I started with my mom because she also suffers from chronic illness which she was diagnosed with it in her like adult years and I showed my mom this song and we both kinda giggled because it was really cute.” – 008(02)

When asked about whether music or personalized songs could be used to build community among young people living with pain, many participants responded with ideas, for example:

“I know how important music is to other chronic pain patients and I feel like with these songs and- just with the personalized factor of it, it would really help and it would really help them connect with life more.” – 004(02)

Singer-songwriters

Theme 1: Gratitude for an opportunity to connect by sharing a gift. Like the young people in the study, singer-songwriters all expressed deep gratitude for the opportunity to connect with others through music by sharing their gift in a meaningful way, and most reported feeling validated that their talent was helping someone.

“If you have a skill or a gift it’s not much of a gift if you’re not giving it, so it’s my pleasure to be able to do this.” – 101

Theme 2: Music has an important role in health, regardless of health condition. Consistent with the biopsychosocial approach to health, the singer-songwriters all reported that music has a role in health. In addition to suggestions that music might refocus attention away from pain and provide comfort, most singer-songwriters emphasized their belief that – regardless of health condition – it is important to be reminded of one’s own unique strengths during challenging times.

“I’m not a doctor. I can’t heal the thing that they have in any sort of medical way, but I know how powerful music is – 100% – and I when I write this music, I think about how it’s going to affect that child and that family” – 103

One singer-songwriter described how they try to offer comfort to the song recipient:

“I try to make a song that reassures them that they are loved and that they are unique and that they are celebrated in their uniqueness and that’s more what the focus of the song is about.” – 102

Exploratory goal: how, if at all, is music helpful to youth living with chronic pain?

The second goal was to explore, more generally, how music is helpful to youth living with chronic pain. The two themes that emerged to address this question were (1) Music reduces the perception of pain, and (2) Teens find solace and comfort when their feelings are validated through music.

Main themes (Youth living with chronic pain)

Theme 1: Music reduces the perception of pain

Almost all of the participants described that over time they had learned that music reduced their pain, and that they could turn to it as a way to manage their pain. Some people explained that music redirected their focus away from their pain.

Music is actively used by youth living with pain as a tool to reduce pain. Significantly, most participants described that they chose to listen to music to reduce their sensation of pain. Many participants alluded to the pain-stress cycle in their reports of how music helped them manage their health, for example:

“Pain is something I’ve been managing for most of my life, due to frequent injuries and other health conditions, and expanding my tool kit is also always a good thing. Music has been a stable part of how I manage my pain and stress.” – 016(01)

A few participants described finding relief through fully immersing themselves in music, for example:

Sometimes on those really bad days where I’m in pain I’ll take out like my microphone and just kind of pretend that I’m on stage a little bit in my living room and just let go and it takes a weight, it takes my mind away from the pain. So, sometimes I’ll leave after singing or while I’m singing, I’ll be like “hey I’m not in pain, it doesn’t hurt right now.” – 008(01)

Energy is redirected to creative activities. Most participants perceived that their pain was reduced as a result of redirecting their energy from the pain to something creative such as music, as one participant explained:

“It doesn’t solve my issues, but it gives me a good distraction and allows me to focus and put my energy into something productive.” – 005(01)

Theme 2: Teens find solace and comfort when their feelings are validated through music

As many teens had described in the context of listening to their personalized song, some participants described feeling

comforted and less alone when they listened to music, as one person described:

“When I’m just scared, I just like listen to the music. And don’t worry about like, being scared. And I just fall asleep with the music with when I’m scared.” – 007(01)

Another participant described feeling validated:

“I think that when I am upset, it sort of calms me down and makes me realize that it is fine to show emotion and it is not something that you should be ashamed of.” – 002(01)

One participant described feeling connected through music:

“You may not find someone who has had the exact same experience, but you’ll find someone that’s gone through something and you know they have somehow, been able to attain, they’ve been able to kind of overcome what they’ve been facing and they shared that through their music.” – 015(02)

Discussion

The purpose of this study was to assess whether receiving a personalized song is acceptable to young people living with chronic pain and to learn more about the role of music more generally in the lives of young people living with pain. The results suggest that the Songs of Love program is a good fit for youth living with chronic pain, based on interview themes describing how the program is experienced not only by the recipients of the songs but also by the individuals who create the songs. The findings also contribute to the large body of literature on the benefits of music for health (e.g., [9–12]), as many young people in the study also reported actively using music in their own lives as a strategy to reduce the sensation of pain and finding solace through listening to music.

Most of the youth in the study wanted to discuss their song and perceived the songs to be a mirror of their strengths. Given the increased rates of depression and anxiety among youth living with pain [1, 4–6], it is an important finding that, for some of the youth in this study, their song could elicit happiness, comfort, or a sense of empowerment. Pediatric pain interventions that target modifiable risk factors such as pain beliefs, catastrophizing, and coping typically use cognitive-behavioral approaches to reduce fear of pain and increase participation in normal activities [22, 23]. Knowing more about how tailored songs such as these may be able to elicit positive emotions in times of distress could be useful information for pediatric pain clinicians and interventionists.

The youth in the study also reported that the songs they received helped them to feel connected to others. At first

glance, this finding is extraordinary, given that there was no interaction between the youth participants and the singer-songwriters; however, neurobiological research supports the finding that even if a listener is alone when they listen to a song, music can provide a sense of connection (e.g., to a performer, songwriter) with emotions to which they can relate [24]. Not only did some of the youth in this study report feeling a sense of solace from listening to the personalized songs, but many interviewees reported that they were interested in creating, sharing, or listening to music as a way to connect with other youth with pain. Music has been characterized as a powerful facilitator of social bonding and the development of social identities [25] and has been used to structure social support groups in other populations [26]. A support group centered around music may also be a promising approach for youth with pain given that they often experience isolation [3] and can benefit from connecting with other peers with pain [27, 28].

Many youth also described turning to music as a strategy to reduce their sensation of pain, a finding supported by a large body of research on the role of music in pain management [12]. Research from our study adds to this literature with accounts of how youth living at home use personally selected music to manage their pain. Between 11 and 38 percent of youth experience pain conditions such as musculoskeletal pain, abdominal pain, and headache [1], and yet, music-based interventions are an underused strategy in chronic pain management [29]. Educating families about the potential benefits of music for youth with chronic pain and encouraging them to support youth in efforts to organize informal music-based groups to connect with other youth living with pain, may be helpful information to provide to families looking for ways to support a young family member managing pain.

Finally, regarding acceptability of SOL program for youth living with chronic pain specifically, the singer-songwriters interviewed found the experience of creating songs deeply rewarding, primarily because they too felt a sense of connection as a result of using their skills to provide a positive experience for others, and perceived that the personalized songs they create could benefit people with any health condition, including those with chronic pain. These findings suggest that singer-songwriters are motivated to continue to create songs for this group.

We incorporated several methods to address limitations associated with qualitative research [30]. To reduce bias resulting from using a single perspective [30, 31], we discussed interpretations of the data within the context of the wider literature (e.g., [9–12]), incorporated a range of perspectives, and as analysis progressed, solicited feedback from two researchers who had not been involved in the

main analysis. We used purposeful sampling to recruit a sample of youth with as much diversity as possible in terms of age and pain type to provide a range of perspectives on the SOL program. Still, we acknowledge that this non-probability type of sampling does not allow for generalizing to young people with chronic pain in general, a group which encompasses millions of people with a wide range of health conditions and experiences. Finally, while it can be challenging to convey all the nuances involved in qualitative research, we have explicitly noted the theoretical approaches used to inform data collection and analysis [14, 16, 17], as well as the specific steps that the team followed to guide the process of data analysis [20].

Future studies may extend current findings by examining the acceptability of SOL to a wider range of young people, but the present study is the first report of the acceptability and experience of SOL for youth with chronic pain and contributes to a growing body of research on the benefits of music for pain management.

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