



A qualitative study of blood and marrow transplant patient experiences participating in art making and music listening[☆]



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ABSTRACT

Purpose: To explore patient experiences of engaging in art making or music listening while receiving treatment in a blood and marrow transplant clinic.

Method: Researchers recruited 25 individuals receiving blood and marrow transplant (BMT) treatment, 12 men and 13 women aged 22 to 74, from a Midwestern outpatient BMT clinic. Participants engaged in a painting activity or listened to music on an iPad using an internet music application for one hour. Researchers interviewed participants after the one-hour activity to gain insight into participants' perceptions of the art making or music listening experience. Interviews were recorded, transcribed verbatim, and independently coded by members of the research team. Researchers met on several occasions to analyse codes and agree on emerging themes.

Results: Nine themes emerged from the data including, *Engaging in Activity, Art and Music in Daily Life, Expression, Engaging with Equipment, Novelty, BMT Process, Activity Process, Social Support, and Living Situation*. Participants enjoyed art making and music listening and found the activities beneficial during treatment.

Conclusions: Participants benefited from art making and music listening because these activities increased the variety of options available during treatment, allowed for self-expression, and could be done alone or with caregivers.

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According to the World Health Organization, nearly one million people received a blood-related cancer diagnosis in 2012, often requiring a blood and marrow transplant (BMT) (Pasquini and Wang, 2012). Blood and marrow transplant (BMT) treatment is possible due to the advancements in use of stem cell research for blood and marrow cancers or blood disorders (Frodin et al., 2011; Mohty and Apperley, 2010). Prior to receiving a transplant of healthy blood cells, a person goes through a preconditioning phase consisting of high-dose chemotherapy and/or radiation to destroy the diseased cells (University of Kansas Cancer Center, 2013). After transplantation, blood and platelet infusions are needed while the immune system and bone marrow return to normal functioning requiring frequent hospital visits and lengthy recovery.

Although BMT treatment has had positive effects on blood and marrow cancers, it can result in adverse side effects creating the need for alternative and creative therapies (Carlson and Bultz, 2008; Gabriel et al., 2001; Nainis et al., 2006). Side effects of the preconditioning phase include diarrhea, fever, loss of appetite, mouth sores, nausea, vomiting, skin changes, sterility, temporary hair loss, pain, and fatigue (KUCC, 2013; AOTA, 2011). Individuals receiving a blood or marrow transplant might also experience complications related to the transplant, such as graft versus host disease. This occurs when the healthy transplanted cells attack the patient's body and can result in infection, rash, or damage to vital organs. These health problems can become chronic and last a lifetime (Chen, 2014).

In addition to physical side effects, a person may experience depression, anxiety and a decline in cognitive function related to BMT treatment (AOTA, 2011). Due to a compromised immune system and physical side effects related to treatment, many individuals may stop working or follow strict precautions limiting contact with others. These drastic changes in daily life may cause negative psychological side effects (Henry et al., 2008). Patients

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may also need to travel long distances or relocate to access specialized treatment, temporarily removing them from their home and community (Henry et al., 2008; Payne et al., 2000). This could have an impact on preferred activities and social interaction, making it even more important to identify safe alternatives that promote coping, health, and quality of life.

In recent years, cancer patients increasingly seek out complementary approaches to cope with negative side effects associated with standard oncology treatment (Mische Lawson et al., 2012a; Verhoef et al., 2005). Complementary treatment approaches are used in addition to standard medical treatment (National Cancer Institute, N. D). Many people report a decrease in negative treatment-related side effects, such as anxiety after engaging in complementary approaches (Eckhouse et al., 2014; McCaffery, 2008; Mische Lawson et al., 2012a; Smith et al., 2014). Specifically, research indicates engaging in creative activities and music listening promotes relaxation, control, self-esteem, a sense of purpose, and feelings of increased social support (Nightingale et al., 2013; Perruzza and Kinsella, 2010). This demonstrates the potential benefits of engaging in complementary treatment to promote health and well-being while undergoing cancer treatment.

Art making and music listening are considered complementary and diversional therapies, meaning no skilled therapist or treatment plan are required (McCaffery, 2008). This may make it a preferred treatment option in settings without access to licensed music or art therapists. Patients may find these activities enjoyable and staff may find diversional therapies easy to implement (Eckhouse et al., 2014; Vianna et al., 2013). Art making and music listening can also appeal to many people due to the wide variety of options available.

While there is evidence regarding prevalence and types of complementary treatment used among cancer patients, little is known about the patient experience when engaging in specific complementary approaches (Verhoef et al., 2005). Based on the current literature, Perruzza and Kinsella (2010) suggests researchers study the reasons some individuals seek complementary treatment while others do not. Qualitative research can help answer this question as well as provide insight to patients' experience while participating in complementary treatment. Therefore, the objective of this study was to explore patient experiences of engaging in art making or music listening while receiving treatment in a blood and marrow transplant clinic.

1. Methodological approach

This qualitative research was conducted as part of a larger, randomized control trial investigating the effects of art making and music listening on therapy related symptoms of BMT patients (Mische Lawson et al. in press). The study took place in the outpatient BMT clinic of a cancer center in the Midwestern United States with the approval of the Institutional Review Board. Researchers individually invited patients receiving treatment to participate in an art making program called "Tiles of Hope." Interested individuals were invited to participate in the randomized control trial investigating the effects of art making, music listening, or treatment as usual. Participants of the art making and music listening groups were interviewed immediately following participation in the interventions to provide data for this qualitative study. Researchers used qualitative methodology to investigate patient perceptions of engaging in art making and music listening during treatment (Portney and Watkins, 2009).

1.1. Participants

Patients were included in the study if they were receiving care at

the Midwestern outpatient BMT clinic, at least 18 years or older, capable of participating in one hour of art making or listening to music, and expressed interest in participating. A patient was excluded if nurses indicated the patient was unsafe to participate. Twenty-five patients, ranging in age from 22 to 74 years, participated in this study. If the participant met inclusion criteria, researchers obtained consent and participants completed a demographic form prior to participating in the interventions. Full details of participants are provided in Table 1.

Fourteen participants engaged in art making, which involved painting a 4 × 4 inch ceramic tile for one hour. Eleven participants engaged in the music listening which involved listening to music for one hour using an ad-free version of Spotify, an internet radio program (<https://www.spotify.com>) on an electronic tablet. Patients who engaged in music listening were given instructions on how to operate the tablet, and researchers took security measures to ensure participants only had access to Spotify on the tablet. Researchers brought all materials to the participants' private treatment rooms and followed infection control precautions to protect participants with compromised immune systems. The interventions were supervised by a certified recreational therapist

Table 1
Demographic information.

Sample characteristics	N	%
Age (Years)		
22–30	4	16
31–40	3	12
41–50	3	12
51–60	6	24
61–70	8	32
71–74	1	4
Gender		
Male	12	48
Female	13	52
Cultural Background		
White	19	76
Black/African American	4	16
Latino/Hispanic	1	4
Other	1	4
Marital Status		
Married	15	60
Single	5	20
Divorced	3	4
Separated	1	12
Not reported	1	4
Education		
Grade school	1	4
High School Grad/GED	5	20
Some College/Technical Degree/AA	11	44
College Degree (BA/BS)	2	8
Advanced Degree (MA, PhD., MD)	6	24
Diagnosis		
Acute Lymphoblastic Leukemia (ALL)	5	20
Acute Myelogenous Leukemia (AML)	10	40
Lymphoma- Hodgkin's or other	2	8
Aplastic anemia	2	8
Chronic lymphocytic leukemia (CLL)	2	8
Myelodysplastic Syndromes (MDS)	2	8
Acute Promyelocytic Leukemia (APL)/AML	2	8
Multiple Myeloma	2	8
Treatment		
Pre-Transplant	8	32
Post-Transplant	14	56
No Transplant*	3	12
Type of Transplant		
Autologous	2	8
Allogeneic	17	68
No Transplant	6	24

*Patients' conditions may have improved enough to not necessitate transplant at the time or patient was receiving maintenance treatment.

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