Experiencing Music Therapy Cancer Support

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Abstract

I portray health-related research outcomes in an arts-informed representation that disrupts the traditional discursive-scholarly format of journal writing to privilege better the participants' accounts and communicate these experientially. The representation uncovers meaning through alternative ways of communicating and conveys the ineffable quality of music in a manner that may be understood through and beyond words. This expands the convention of health-related research outcomes, including ways of knowing, what can be known and how this can be represented. I elaborate my intentions for this experiential report, discuss theoretical underpinnings of this methodology and describe a music therapy support group model.

Keywords

- arts-informed research
- cancer support group
- music therapy

(VIVIAN wakes in horrible pain. She is tense, agitated, fearful. Slowly she calms down and addresses the audience.)

VIVIAN: (*Trying extremely hard*) I want to tell you how it feels. I want to explain it, to use *my* words ... (Edson, 1993/1999, p. 70, emphasis in original)

The experience

The experience of first starting another support group got me a bit unsettled—what's that going to be like? Why am I here? What am I hoping to gain from this experience?



Figure 1. View of the Music Therapy Centre street front.

I've always liked music. When I sing along with records in the privacy of my home, I sing just like them. [group laughter] And if anybody was to hear me, they'd just tell me to be quiet, which is what they did when I was a kid. So, I am very self-conscious about it.

I realized just how scared I was to sing with people. Am I ever going to get over this? I just feel immediately that I'm going to go on and crack, take the wrong key, and everything and anything that is unattractive.

I was excited when I saw the notice about the music therapy group. I called and wanted to come, and came. And in a way I wasn't really sure what was going to happen. But I found that I was really looking forward to coming every time. That regardless of outside things or the illness, regardless, I always felt better when I was here and felt better when I left and really hated it that time I couldn't come.

It's just a great feeling to walk through these doors each week. From one o'clock to three o'clock I'll be free to focus on this and drop everything else in my busy life and just come in here and create.

We're there for the purpose of experimenting about music and we're all doing it and we're all doing a really good job. And, as you know I expressed the first time, I wasn't going to sing. And then I found by the second time I sang and I didn't care if I was going off key and so I didn't go off key and I was pretty impressed.



Figure 2. Inside the front door of the Music Therapy Centre.

It's very healing to not judge ourselves, to be compassionate and just to be part of a group, to feel part of a community. I felt like it was a community and that's very healing.

While the group was going I never felt separate from everyone. Thank you so much because that happens a lot.

I find those few hours a week that I participate in the group very soothing and healing—creating a sense of well-being. I really mean creating vs feeling a sense of well-being. It, creativity, becomes the focus, the energies of exploring beyond our regular experiences. Very little in our life becomes a creative energy. Most of the things I do have become routine.

Something really magical happens with the group energy. And any inhibitions that you might have about being able to play music or make music, that you lose yourself within the group, and almost become, like one. We forget ourselves and we stop thinking.

There's an energy in the group that, to me, acts as its own catalyst. So it just keeps rolling along.



Figure 3. Large clinic room before group.

I don't find it to be much different—the cancer journey for everyone is the same in so many ways and different in everyone's way. And so it doesn't matter what our definitions are of what cancers we have or what age we are or what gender or what our name is even, just the fact that we were together and it was one song. That was just the most important part.

Because of the group I actually started listening to music more. Not actually getting CDs out and listening to them but just when I hear a song playing on the radio as I was walking by a restaurant I take note. Or during group I would notice we're actually singing and humming with each other. And I thought this is a great environment. Like, I started actually responding to that more and I started remembering it. And I wrote down in my journal songs, songs that started popping up into my head. Those things were there and I used to do that before, take note of music more. But then when I got sick it seemed to be something I put on the shelf. So that really started to feel good.

Today at the music therapy group when we sang, I felt that my heart was singing. I felt that my voice was reverberating this sweet sound of joy, of happiness to my body parts that have been sad and depressed for so long.

I thought I didn't like to drum but I converted. It just kind of took off. [giggle] We were playing off each other. There was something that was happening to the whole group. And I don't know what happened, but it happened. I was thrilled. I felt elated, uplifted. It felt good. And it stayed with me.

Drumming was something I have never done before. Beating my hands on the drum was like a resonant sound that wanted to come from within the very core of my being. To see and hear all of us enraptured in that creative moment, to let go to the music, to our heartbeats, to the calling of our souls to play together. Drumming was shouting our anxieties away. Drumming was telling our bodies not to give up. The crescendo in the drumbeats, and all of us moving to that crescendo without any orders ever being spoken or directions being given.

I enjoyed the drumming very much. I felt it as a mystical experience, primal and simple, which connected me with something very deep inside myself. It was as if this deep component had awakened, come out and joined the rest of the people.

Creating our own music and conducting it was very touching for each person. Each one of us felt like real creators, and allowing other people to express their creativity and just being with them and feeling them joining in that creative process was very rewarding. I felt like I accomplished something that came as close to being creative as I will ever be. I really felt that as long as I live, I will probably not be given another opportunity like that again.



Figure 4. Instruments.

It sounded like raindrops.

It sounded like chimes.

It sounded as if everybody had written the music specifically in that way as opposed to people just doing something on their own. And, as well, I definitely was in the moment, which is not usual for me, which is nice.

Music goes to your viscera. It's in your sternum or in your stomach. It's not just in your head or in your ears.

It is an incredible way to pass the time in a healthy way. It's not a bad thing to be playing music and losing yourself in something that's creative. And realizing later that you've made that, that it wasn't somebody else just showing you a movie. No, you were making something and you lost yourself in it and you didn't feel pain anymore.

I had an interesting sort of emotional experience this week. I realized that I am going to be in treatment for the rest of my life. I'm going to have to live with the side effects of that. And so I might as well get used to it and not let it dominate. And, of course, the point is not how long you live but whether you're living while you're doing it. So that gave me a lot of energy, despite the aches and pains. I think that I have been waiting for something to be over and then I'd be sort of normal again. And this is normal now.

Ran an unexplained fever, felt pretty horrible. Had to cancel dinner plans with friends. Is it a side effect? A recurrence? Food poisoning? Every little thing that comes along—is this it?! Once your body betrays you, it's hard to trust it again.

RYKOV: EXPERIENCING MUSIC THERAPY CANCER SUPPORT

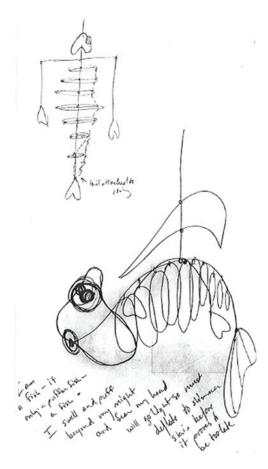


Figure 5. Scanned journal entry (fish).

I feel isolated with cancer. Because it's happening to me, I feel isolated. Most people don't actually know what it feels like. I feel like I'm on the top of a very high mountain and the tip is very sharp and I could lose my balance at any minute. That's isolation.

I see isolation outside this group. We understand each other. But outside the group it is more difficult. Talking about cancer they have another perception than us. I don't talk about it because I know my friends won't understand.

Cancer. Marital problems. Sexual problems. Money problems. And I'm supposed to be cheerful?

It's a humbling experience to be confronted with your mortality.

You feel like a leper 'cause people are really avoiding the conversation and think that they are being helpful by not mentioning it. You feel like you're a bad person because you got cancer and now you're putting friends through this uncomfortableness. Now they can't talk to you the way they normally do.

I realized, as I was looking at my family, that we are all individually and collectively struggling towards a new normal, a new definition of what this family is and represents and what new values will emerge—family values and personal values, as well.

Well, I had a week of rejecting my normal. I'm sick and tired of being bored. That's what fatigue does to you. I started cutting things out of my life because I just wasn't capable of doing them. And I realized I'm not doing anything.

Since the beginning of my illness I am trying not to think about it all the time and read about it all the time. I want to work because I can forget that I have cancer. I want to work because I don't want to think.

The chemo just destroyed me, physically. I had aches and pains throughout my whole body. I am still not recovered. And after that I had radiation and I'm still not recovered from the burns. On top of that I had depression and I didn't understand it. That made it even worse. I'm working with a therapist now. I'm more positive than I was a year ago.



Figure 6. Scanned journal entry (needle).

Cancer certainly presents a barrier with some people. I really don't like it when people ooze compassion. There's a kind of sickening sympathy, which kind of depersonalizes you. Even if they're trying to be cheerful, it's distancing. My friends were talking about my courage. And I thought, 'What's courage got to do with it?' It doesn't feel like courage to me—it feels like a struggle. It was distancing, the fact that they were seeing what I was saying as courageous.

Being present in the moment is hard to do right now because I am at that point in treatment recovery where I can be almost obsessed by prevention. How can I redefine myself? And it's not letting me just be myself.

The positive-thinking prison, I call it. It's just this prison that people put you in. If you don't think positively, your cancer is going to come back, you know. You have to be positive. You can't let this get you down. You have to be strong.



Figure 7. Scanned journal entry (body).

There's another whole thing that I'm not dealing with and that's the fear. And I'm not dealing with it because I don't know how. But I know what the fear is about. The fear is about dying. Not being dead, but dying—the process of dying. Are the kidneys going to pack in, is my back going to start disintegrating? You know, that sort of thing. But it doesn't sound good.

I felt sadness (a recurrent theme for me) during the singing. Its roots are very old. As kids I (we) was in a house with a lot of depression. There was no 'high energy fun'. I eventually concluded that I'm not supposed to enjoy myself. The high I experienced drumming was great but I felt embarrassed by my energy level.



Figure 8. Artwork following group guided Imagery & Music.

I've been very depressed for about a week. I've been there before. It's very difficult. I realize I spend a lot of time in my head. Emotional energy, not sure if it's going in or out. I was very emotional during the imagery. Sad. No body sensation or location for the sadness. I don't know what to do with that energy, that sadness. I go through it quite regularly. I'm also aware how reluctant I am to talk about it in the group. I don't want to tell my friends about it. I'm sure I'll get through it. [sigh]

When others talk about their cancer, it can be some kind of a mirror of what is going on inside me. For me, sometimes when I don't want to talk about cancer, that's what I really need to do. There are times when I'm talking about it all the time and I really need not to. I don't think I walk away from here feeling depressed because I talked about cancer. I wasn't depressed when I came in, so why should I be?

Our stories can be taken away from us in their telling, but no one can take away and re-tell the emotional and creative experiences we created, shared, reciprocated, appreciated and valued. The music experience is a process that is spontaneously in the moment. It's not written, it's not recorded. It's just felt, expressed, explored and loved by us all. It unites us, in that moment, and it makes me feel special as a creative human being to be honoured by all of us being together, and feeling that power of creativity.



It taps into a whole realm of perception and communication that is often neglected. It kind of expands you.

Figure 9. Artwork following group guided Imagery & Music.

Music is a universal voice that allows us to say things that we haven't been able to put words to yet. And the fact is that everyone else there has experienced similar things to you, so they understand.

As I was playing I realized that I was carrying a lot of anxiety and stress that I felt I needed to control. But during the playing I felt a great need to allow the drums to soothe the range of emotions that I was feeling. Anger at being ill came to mind, but I realized that I was angry not so much at being ill, but that I also wanted to remove my fears from upcoming doctors' appointments to tell me what my next course of treatment is. I drummed so hard, hoping that the beat would heal me, and make me whole again. It felt good. In discussion it became very apparent that we are all touched by the experiences we share. Each one of us leaves this space and time feeling better.

Communion is what it felt like for me. And just by making music. I tried very hard not to be competitive and that way I wouldn't worry about it. I just felt like I was part of it. I found it so thrilling and all I was doing was shaking those little shakers. But I still felt part of it. And I had fun even if I wasn't doing anything particularly.

In music, we are all together and this is very important because doing music together helps us to become more aware of our internal connectedness, that we are all the same. And this is beautiful. And I think that this is the feeling that we get from this group working together, because it helps us to develop this feeling we are connected, we are the same. Yeah, there was like a kind of harmony in all of us together.

You allow your creativity to come out and others do the same. Many cancer patients have problems repressing feelings and there is a lot of fear because of the diagnosis so I think that any therapy that allows you to free those fears and blockages will help. And if you can get connected to yourself and connected to others, it's the healing process.

I feel this acute sense of self—a heightened awareness of everything that is me that I wasn't aware of before having cancer. It pulls you into yourself. A few of my friends have actually commented on that.



Figure 10. Artwork following group guided Imagery & Music.

When others tell their stories, it sometimes brings up things you haven't really dealt with yet. This can be painful. But it's not harmful because, in a way, that's really helpful.

I think it's easier to talk about your fears once you've bonded through the music.

Sometimes I have been tired when I came here but afterwards I feel very calm and relaxed. For me, being part of the group is rejuvenating.

When the music-making started, I felt very tired and exhausted and stressed, heaviness in my shoulders and neck. As we continued, I felt release of tension coming off my shoulders. I felt the tiredness leave my body, and a great sense of well-being generating in my body. A calmness and peace entered my body. I felt more centred and energized. I felt at peace when I left the session.

I was really tired that day and all I know is that it felt—you know, I think I just completely lost myself in the music. I just felt like I wasn't here and no one else was here but it was just the sound. It was like a pulse running through my blood giving me oxygen for the soul. It felt like it was feeding me.

It was so much more powerful than any of us.

It was a very sacred space that was created, I think.

I'd rather make music than describe what I feel about this group. It's really joyous. There wasn't a day I didn't step out of the door with a bounce in my step because of the energy that everyone contributed.

I let go of stress that I was feeling. I was allowed to be creative and explore different musical instruments that would connect me to the rest of the group. I was happy I came. I felt elated, and connected again. Very healing.

It was like a whole orchestra with no rehearsal.

It felt like, to me, a whole lot of kids playing. Just playing and having a good time.

Was it really about the music? No, more than anything, the experience was about all of us, being in that space and sharing and learning. Music was a tool that we used to explore and 'explain' our feelings. Music was a way of gently easing our pains, and talking of our hopes and dreams.



Figure 11. View from large clinic room to front door.

I felt total unconditional love from you all. When we all came in we were nervous, we didn't know what to expect. But it seems every week that went by we opened more to each other. That, to me, has been the healing part. Just being in a group and feeling like you can be yourself—that you are totally accepted and cherished for who you are. So it has helped me to accept myself more because of the validation you [the group] have given me.

This has surpassed any idea I could ever have. Making music with people is just magic. And making music with people you have gotten to know on such an amazing level in such a short period of time because of our common suffering, if you will, has been an extraordinary experience. And I really think it helped. As I monitor my own reaction to life as it comes at me over these last couple of weeks, things changed.

You know that the pauses between, and the dynamics of, the music showed me that there was so much more of unspoken language with music that we don't talk about with words, that we can only talk about with music. And there is something so incredibly beautiful about that, just to be able to be free with sound in a group, with a group of people who've come there to create this space to communicate.

Any illusion of control I thought I had in my life was destroyed when I received my cancer diagnosis. Here in music therapy the music is neither directed nor controlled, but created—like a life. This was very empowering.

Experiencing the experience

MY INTENTIONS for this arts-informed phenomenological report are three-fold. First, my intention is to honour directly the experience of the researched—the participants—in a manner that strives to emulate their creativity and risk-taking. I incorporate non-verbal, visual means to enable the participants to 'show' what cancer is like. And I let them 'talk' about music therapy using their own words without further elaboration or analysis from me. In addition, opportunities to hear the participants making music can be accessed on-line (http://hdl.handle.net/1807/4797).

Second, my intention for this research representation is to honour the lived experience of music. True to the flow of music itself, the music therapy experiences reported previously are uninterrupted by section headings. There are no disruptions to announce, for example, that we are 'leaving the key of D major now and bridging the modulation to B^b minor'. Also similar to music, the intention is to be immediate and engaging but there are no one-to-one truth correspondences. Meanings are open-ended, indeterminate and ambiguous.

Third, my intention is to perpetuate 'new paradigm inquiry' (Finley, 2003) methods and representation that expand the conventions of research form and challenge the myth of the primacy and transparency of language. Corrine Glesne (1997) likens experimental form to a clearing in the woods:

Experimental form is an opening, a clearing in the woods of research regularities. The clearing away of accustomed practices releases a rare feeling of reflective play ... In this opening, light shines on interconnections among researcher and participants. Readers are invited to join in, not only with critique, but also with their feelings and personal reflections. The clearing ruptures traditional patterns of scientific knowing and notions of research purposes. No longer content to just 'understand,' the writer of experimental form seeks ... transformative powers ... to open, in some way, all participants: researcher, researched, and readers. (Conclusion section, para. 1)

I further acknowledge that using the arts in and as research constitutes a political stance. I report these research findings in an equitable manner intended for a wide readership beyond professional and academic audiences. I challenge the hierarchical notion of what constitutes 'knowledge', 'truth' and 'fact' in research process and research representation.

This documentation is intended to be vicariously evocative so that the reader experiences, to some extent, cancer, music therapy and music therapy cancer support. I employ an experiential methodology in the interpretivist paradigm rooted in a lineage of social science theory stemming from Dilthey (1831–1911) that includes Husserl (1859–1938), Merleau-Ponty (1908–1961), Gadamer (1900–2002) and Habermas (1968/1971).

Dilthey's legacy to the history of ideas is monumental. Of note is his contention that methods used in studies of the physical world (*Naturwissenschaften*) to quantify and to explain causes are not appropriate for use in the human studies (*Geistwissenschaften*) to describe fully and understand experiences. Other contributions of his methodology to the methodology employed in the study reported here are his inclusion of literary works as valid sources of knowledge, and his belief that all study should begin with examination of complex experience in the human world. (Dilthey, 1976).

Merleau-Ponty's (1945/1958) phenomenology was derived from Husserl's (1970) ontology (beliefs about being in the world) and epistemology (beliefs about what we can know)—that all we can know is being/existence (*Dasein*) in the intersubjective lifeworld (*Lebenswelt*). Merleau-Ponty points to the primacy of direct, embodied experience, that 'the world is not what I think, but what I live through' (1945/1958, p. xviii). These worldviews provide the foundation for Gadamer (1989), a student of Heidegger, who further developed his teacher's hermeneutic phenomenology, claiming that we cannot understand experience outside of the context of our own subjectivities.

Habermas (1968/1971), a student of the Frankfurt School, articulates a questioning of science (among other things) that echoes a postmodern challenge found in the science studies literature (for example, Haraway, 1991; Harding, 1991; Latour, 1999). The interpretivist paradigm may be seen as a Kuhnian (1996), constructivist, poststructuralist answer to this challenge that arose to provide different lenses and methods for inquiry of issues and questions that cannot be adequately described, explored or understood by objective, atomistic, positivist means. Interpretivist inquiry—where truth is multiple, partial, situated and constructed—enables multiple ways of knowing (Berger & Luckmann, 1966) where the arts convey truths equal to and different from science.

Forinash and Grocke (2005) detail the various ways that phenomenological inquiry has been employed in music therapy research. This music therapy phenomenological inquiry, predicated on human science theory and interpretivist methodology, is articulated here in an arts-informed (Cole & Knowles, forthcoming) representation.

Two elements inherent in constructing knowledge when using arts-informed research (Cole & Knowles, forthcoming) are:

- it is grounded in a particular orientation of the qualitative research paradigm, which in this case is phenomenology. At the point of that grounding the researcher is inspired through, by and/or in the arts and the intuitive, structured and procedural elements of that form; and
- there are possibilities of reporting the research in ways that hearken to the arts modality and form, and that these ways and means need not rely on textual representation alone. Indeed, the

arts may also be incorporated at the inception of a project when formulating the research question (Austin & Forinash, 2005).

Similar to the interpretive research paradigm in which arts-informed research is grounded, there are no prescribed methods for using the arts in research, nor is there one correct method. Rather, the researcher finds what makes inherent good sense for what she or he is trying to do. There are no scripts or formulas to be followed. The researcher must risk charting a new path that facilitates the goals, skills and intentions of the project. This is distinct from other phenomenological methods that specify prescribed procedures (e.g. Giorgi, 1985).

Furthermore, the whole story can never be told and no inquiry can ever be complete or definitive. As van Manen (1990/1997) points out, rather than telling the whole story, phenomenology 'addresses any phenomenon as a possible human experience. It is in this sense that phenomenological descriptions have a universal (intersubjective) character' (1990/1997, p. 58).

The music therapy group as cancer support

The music therapy experiences reported here pertain to eight weekly groups that met for two hours as part of a phenomenological inquiry during May and June of 2004. Most of the research participants were selfrecruited by means of an invitation flyer posted in hospital cancer departments, community settings and newsletters. One was referred by a family physician and another by a psychologist.

Ten individuals (nine women, one man) participated in the study. They ranged in age from 24 to 72 years and had diverse cancer diagnoses at different stages of the disease trajectory. Many participants (six out of 10) had advanced (i.e. metastatic, recurrent or multiple) disease. Three were receiving treatment for their cancer during the group and two more began treatment shortly after the group ended. Two have since died.

The participants had various musical backgrounds and preferences. Two of the participants had some previous music skill but were not professional musicians. All others were non-musicians. One participant derived great joy from playing a digital keyboard synthesizer but otherwise had no musical instrument skills.

Early in the life of the group I actively provided structure (Lieberman & Golant, 2002; Toseland & Rivas, 2005) but as the participants gained familiarity with the music materials and each other, the content and direction of the sessions was increasingly determined by them. Music therapy experiences included singing, vocal improvisation, instrumental improvisation, music listening, adaptations of the Bonny Method of guided imagery and music (Bruscia & Grocke, 2002) and art processing of the music-evoked imagery, collective imagery and music and optional journal writing. Had the life of the group been longer, song-writing might also have been incorporated (Baker & Wigram, 2005). There was an emphasis on self-expression through improvised music making that facilitates group cohesion (Burns, Harbuz, Hucklebridge, & Bunt, 2001; Waldon, 2001). A playful, aesthetic context fostered an atmosphere conducive to building trust, empathy and intimacy.

All individual meetings (initial and follow-up) and the music therapy group sessions were audiorecorded. The research data included text (transcribed individual and group meetings, journal entries, session evaluation forms), music (pre-recorded, vocal and instrumental improvisation, song), images (photographs of settings and instruments, participant artwork and journal entries) and numbers (descriptive statistics). In addition to the main research questionthe meaning of the music therapy support group for the participants-the research data were analysed (i.e. viewed, read and heard) intuitively and repeatedly using a set of steering questions until no new information was forthcoming. These questions pertained to the meaning of music and the music therapy group for the participants, how this music-oriented group differs from verbal support groups, what participants say about their cancer experience and what they say before and after music making. Interpretation of this empirical data was guided by reflection on van Manen's (1990/1997) lifeworld existentials (i.e. lived time, lived body, lived space and lived relationship) and by reading related research, poetry and fiction.

A music therapy support group model

The group model described here is informed by feminist theory (Burstow, 1992, 2003; Hadley, 2006; Maracek, 2002), empowerment practice (Parsons & Gutier Cox, 1998) and support group self-help philosophies (Daste & Rose, 2005). Common to all these approaches is a striving for empowerment as a process and a goal. The model is framed by relational-cultural theory in therapy (Jordan & Hartling, 2002; Worell & Remer, 1996/2003) and it is influenced by the radical pedagogy movement whereby therapy clients are perceived to be learners and therapy is re-conceived as 'education-about-theself' (Rykov, 2006, p. 194).

While all music has the potential to be 'therapeutic', music therapy is defined as 'the creative and professionally informed use of music in a therapeutic relationship with people identified as needing physical, psychosocial, or spiritual help, or with people aspiring to experience further self-awareness, enabling increased life satisfaction and quality' (O'Callaghan, in press). The purpose of the brief, time-limited, closed music therapy support group is to provide psycho-spiritual, existential support for cancer patients and survivors through active participation in various music and related creativeexpressive experiences (Rykov, 2002). The music therapy interventions vary according to the unique characteristics and needs of each support group.

My music therapy practice is informed by 28 years of clinical work with individuals, singly and in groups, of all ages and with diverse presenting issues. The music therapy group experience chronicled here addressed the needs of cancer patients and survivors. This music therapy support group model may be applied to individuals facing other health challenges.

Concluding summary

I report the meanings of a music therapy support group for 10 adult cancer patients and survivors and describe a music therapy support group model. The report is an arts-informed research representation of phenomenological music therapy inquiry rooted in human science theory and the interpretive research paradigm. I use alternative ways of representation to communicate more directly and convey the ineffable quality of music and other non-verbal therapeutic experiences. I expand the notion of reporting health-related research outcomes, including ways of knowing, what can be known and how this can be represented.

The experiential music-centred focus of the music therapy support group diminished differences of age, gender, cancers and disease stage. The participants talked about feeling lonely and isolated as cancer patients. They experienced the music therapy support group as profound, non-verbal connection to themselves, to each other and as connection to something larger—the music—beyond themselves.

The experience of improvised music making in the music therapy support group was particularly empowering. This provided opportunities for experiencing feelings of control during a time of loss-ofcontrol inflicted by the disease and ensuing experiences of illness. Furthermore, participants explored and expressed their own inherent creativity that some were not aware they were capable of. The positive effects of the music therapy support group were reported to be long-lasting.

Having read my intentions for, and explanations about, this research process and representation I invite you to re-visit the images and insights of the participants.

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