
“Sometimes There Just Aren’t Any Words”: Using Expressive Therapy With Adolescents Living With Cancer

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ABSTRACT

The intense physical, emotional, and spiritual challenges that adolescents who live with cancer face on a daily basis require a therapeutic approach that moves beyond traditional talk therapy. This article features the art and poetry of two patients, and details the process of bringing creative, expressive arts into counselling with adolescents living with acute or chronic illness. Through exploration of their art work, the teens find valuable hints to healing, and gain wisdom and insight that begins to soothe their souls. An innovative technique of publicly showcasing expressive works as part of the therapeutic process is also described.

RÉSUMÉ

Les défis intenses de nature physique, émotive et spirituelle que doivent relever les adolescents atteints de cancer dans leur vie quotidienne exigent une approche thérapeutique qui va au-delà de la thérapie traditionnelle consistant à discuter des problèmes. Cet article présente les œuvres artistiques et les poèmes de deux patients et explique en détail comment incorporer des activités créatives et expressives aux services de counseling offerts aux adolescents souffrant d’une maladie aiguë ou chronique. En explorant leurs œuvres artistiques, ceux-ci y retrouvent des messages utiles à leur guérison et en retirent une sagesse et une connaissance approfondie de soi qui calment l’esprit. L’auteure décrit également une technique innovatrice qui consiste à présenter leurs œuvres artistiques dans le cadre d’expositions publiques en tant qu’élément du processus thérapeutique.

The intense physical, emotional, psychological, and spiritual challenges that adolescents who live with cancer face on a daily basis require a therapeutic approach that moves beyond talk therapy. For the past nine years, I have honed my skills in the psychological methods conventionally used with teens that live with illness. These techniques include encouraging adolescents to talk about their feelings, helping them learn problem-solving skills and providing environments in which they can practice cognitive behavioural techniques to help them cope with procedures such as bone marrow aspirations and difficult intravenous starts. Inevitably though, in my experience, traditional supportive psychotherapy reaches an endpoint with adolescents. Therapy gets stuck. There just isn’t any more to say about being sick or having cancer.

When you are 15 and have breast cancer it’s hard to find words to explain how it feels to have a mastectomy the same week that your school friends are out shopping for new bikinis. When you are 16 and have been getting chemotherapy treatments every two weeks for 10 years, it seems pointless to try and put into

words why it's hard to view your friend's breakup with her boyfriend as a "life and death" tragedy.

Nicole was that 15-year old . . . Nicole was diagnosed with a rare type of breast cancer in December 1997. She began therapy with me that same month, one week before her mastectomy. During our first session, I invited Nicole to put some of what was happening "inside her" onto paper. Within 20 minutes Nicole had created several drawings filled with emotion and insight. Over the next 18 months, as Nicole faced surgery, breast reconstruction and recovery, we journeyed together, using Nicole's creative spirit as our guide. Through a series of drawings, Nicole journalled her experiences, and learned how to access thoughts and feelings beyond those she could express with words.

Jessica was that 16-year old . . . Jessica was diagnosed with Langerhans Cell Histiocytosis in February 1987. At the age of six, she began chemotherapy treatments that would continue for over a decade. Jessica endured nausea, vomiting, hair loss, weight gain from steroids, fatigue from radiation, and literally countless pokes for intravenous lines. In addition to these physical effects of treatment, Jessica experienced numerous emotional challenges as well. Jessica and I began working together in January 1996, and every so often she would share a poem with me that she had written in her journal. We soon realized that her poetry contained valuable hints to healing.

The purpose of this paper is to present some of my clinical experience with a process that brings creative, expressive art into counselling with adolescents living with acute or chronic illness, and to focus specifically on an innovative technique which involves teens publicly showcasing their creations.

OVERVIEW OF EXISTING LITERATURE

For centuries, "art has been used to express inner feelings and to portray humankind's story" (Heiney & Darr-Hope, 1999, p. 183). Established in North America as a profession for over 70 years (Schikler & Turner-Schikler, 1992; Ziesler, 1993), art therapy is now widely used in health care settings. Specifically, "art therapy has begun to be recognized in the field of Psycho-Oncology" (Luzatto & Gabriel, 2000, p. 265). Through arts (visual, literary, and performing), patients are encouraged to explore their cancer journeys, to express unspoken thoughts and feelings, and to respond creatively to the effects of their cancer diagnosis and treatment (Deane, Carman, & Fitch, 2000; Smith, 1995; Walker, Nail, & Croyle, 1999; Zammit, 2001). Koppman (2001), a member of the National Association for Poetry Therapy and a workshop facilitator at Memorial Sloan-Kettering Cancer Center, writes that "when we make use of the art of poem writing in the healing process, we are aiming to elicit a response from the patient that will help him or her become involved in his or her own healing" (p. 3).

Art therapist Cathy Malchiodi best describes the use of art therapy with cancer patients as *medical art*, which is "designed with the overall medical treatment

of the patient in mind, and with a knowledge of the particular illness, medications or procedures involved in each individual case" (Malchiodi, 1993, p. 3). Medical art therapy is available to adult cancer patients through individual sessions with art therapists, artist-in-residence programs (Rockwood & Graham-Pole, 1994), and group art therapy sessions such as the art therapy/museum education program at Toronto-Sunnybrook Regional Cancer Centre (Deane, Carman, & Fitch, 2000) and the Revlon Arts in Medicine program at Edmonton's Cross Cancer Institute (M. Hundleby, personal communication, November 26, 2001). Professionals who facilitate sessions, as well as participants who attend, attest to the powerful healing value of medical art therapy, as it moves beyond physical healing, to encompass psychological and spiritual healing as well (Luzzatto & Gabriel, 2000; Zammit, 2001).

Although not a focus of this article, the use of medical art therapy with children, specifically children living with cancer, is also well established in the literature. For example, art therapy techniques are used prior to painful procedures (Favara-Scacco, Smirne, Schiliro, & Di Cataldo, 2001), to enhance adjustment and coping (Councill, 1993; Sourkes, 1991) and in research as a method of gaining knowledge about children's perceptions of health and illness (Bradding & Horstman, 1999).

The benefits of expressive art therapy for both adults (over 18 years of age) and children (under 13 years of age) are well documented and appear to be researched on an ongoing basis. Surprisingly though, there is little information published about expressive therapy as it relates to adolescents. Despite an extensive literature search, conducted by a research hospital librarian, using key words such as adolescent, art, art therapy, poetry, illness, expressive art, creativity, cancer, medical art etc., only one research article was identified that referred to the use of expressive therapy with adolescents. Schikler and Turner-Schikler (1992) describe the use of art therapy in a gynecology clinic to help alleviate pre-examination anxiety in adolescents.

When I use expressive therapies with adolescents, it is always within the context of a therapeutic counselling session. As I read the art therapy literature, it was interesting to note that art therapy literature and psychological literature are not well integrated (Camic, 1999). Indeed, "a serious gap exists between the psychotherapy world and the art therapy world" (Luzzatto & Gabriel, 2000, p. 265).

INVITATION TO CREATE

One of my favorite counselling phrases is, "Sometimes there just aren't any words. . . ." That comment is often followed by a long pause, a time for the client to reflect on the work they have been doing during the session, or to think about the gravity of an issue we may be exploring. When working with adolescents in particular (who can be clients of few words to begin with), that phrase is my "in," my springboard to inviting teens to express themselves beyond the spoken word, to explore other languages for feelings and thoughts and wonderings. Although

adolescents may stop talking, they most certainly do not stop thinking or feeling. The thoughts and feelings just get stuck inside.

As anyone who has worked with adolescents who are ill knows, they are just that . . . adolescents first, and ill second. The presence of illness does not typically alter the adolescent attitude — the “I am fine, I need to be in control, I don’t really think I need your help, I’m petrified about what’s happening to me, but I’m not going to show it, I have no reason at all to trust anyone new, much less a therapist!” and the “I don’t need or want to talk.” Usually, when I encounter teens that don’t seem to have much to say, I just agree with them.

You’re right, you probably don’t need to talk, but your parents thought it would be a good idea for us to spend some time together, so if nothing else, you’ll be helping them feel better. You know, lots of the teens that I work with don’t feel much like talking either. So, why don’t we try this . . . I’m going to give you this piece of white paper, and your job will be to put something, and I don’t care what it is, about what is happening inside you, outside onto this paper. You can draw, write, scribble, doesn’t matter, just put something down. It doesn’t have to make sense to anyone else. Sometimes it won’t even make sense to you, but see what you can come up with. You can use pen, pencil, pencil crayon, felts, paint — whatever seems right for you. Now, I know that this might seem a little weird, but it could be interesting, so let’s just see how it goes. Would you like me to turn on some soft music?

Often, during a first session I will leave teens alone for about twenty minutes, so they have some private time to get used to the idea of expressing themselves on paper. If a teen seems really at a loss for what to express, I will ask if they’d like an assignment. If they do, I will suggest that they put something down about what it was like the very first time they heard that they had cancer, or something about what makes them who they are, or something about change for example. The

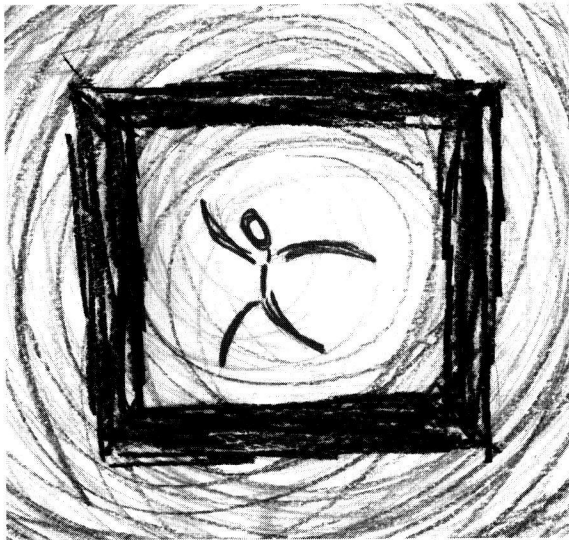


Figure 1. Dancing (December 1997)

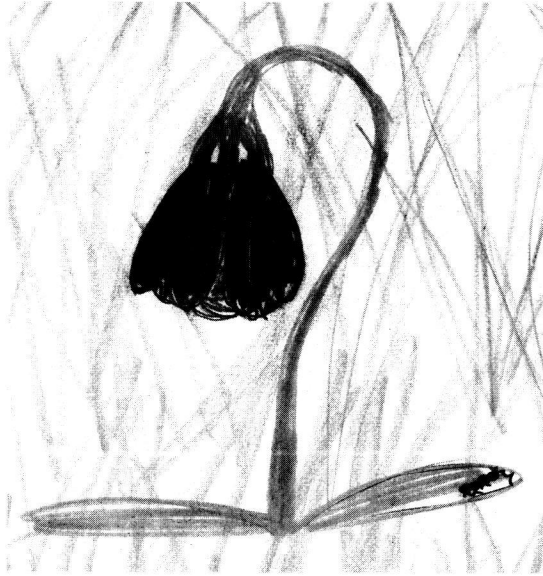


Figure 2. In a Big Field (November 1998)

assignments are purposely vague, but do seem to provide hesitant teens with some added and comforting structure.

Initially, Nicole was one of those hesitant teens, but by about the fourth session, she would arrive asking what she would be drawing about that day. Nicole almost always requested assignments, yet her creative side often took her well beyond anything I suggested. Jessica, whose expressive medium was poetry, always wrote at home, and merely needed the invitation to explore and share her work. At the beginning of our work together, Jessica would often talk about her poems, carry them with her in her school bag, and even ask me, at the end of a session, if I'd like to see them. My response to Jessica was to invite her to bring a poem or two to the beginning of a session, but only if she was prepared to work with it. She arrived the next week with her whole poetry journal, and continued to add to her collection over the years.

THE EXPRESSIONS

During our first session, Nicole drew a picture of a stormy sea scene filled with waves and ominous clouds, with a small orange raft bobbing in the waves. She titled it "Staying Afloat" and described it in the following way: "I am the raft, and there is a big storm at sea — the sun is covered by the clouds, lots of waves, confusing, I was tossed around . . . but I am inflatable, so I stay floating. Eventually the clouds will go away and the sun will come out again — it's taking a while." Later in the same session, Nicole completed a second drawing (see Figure 1), saying "I felt like dancing, but I couldn't, because the cancer was too serious.



Figure 3. My Badges

I wanted to pretend it all wasn't happening — to forget it all, but I couldn't — the little purple box kept me in."

Nearly a year later, Nicole reflected on all that was going on in her life (see Figure 2). "I'm the flower . . . in a big field . . . all alone. No one else has gone through cancer and their parents splitting up in one year. The little caterpillar is eating my leaves. I don't know what that caterpillar is, what it stands for, but I don't like it."

Close to the end of her therapy, Nicole explored how proud she was of herself for surviving her cancer journey (see Figure 3).

Today in math class I told a friend what happened, about my cancer . . . I want people to know what I've been through so they can be proud of me . . . but I don't want it to be quite as showy as this medal . . . oh I know, I've got it . . . they know that I did *something*, but they don't know *what* — I didn't put anything on the medal to say what it's for . . . but I know . . . It's a hard earned medal. I didn't believe I had breast cancer because I was only 15. I'm proud of me for coming through this all so well. It made me feel good about myself. I can tell people — why should people be scared? It's in the past. It's not contagious.

Being a fourteen-year veteran of "chemotherapy every two weeks," Jessica's demeanor, her behaviour, and especially her words over the years have typically said "Despite everything that's going on, I'm doing ok." Her poetry tells a different story. As you will read, Jessica's poetry is reflective, personal, and at times hauntingly honest.

Alone

Alone,
Is the only word which can even begin to describe how I am feeling
Deep inside of me I feel an empty hole, that with each dark moment
burns deeper and darker
This big hollow space can be filled with nothing

I feel as though I don't belong, as though I am somehow
 incredibly different than others, as though I have nothing to offer
 Alone,
 Is where I seem to come from, I feel as if I don't belong
 Sometimes because I know too much, sometimes because I know too little
 Maybe it's because I've experienced too much
 Maybe it's because I've not experienced enough
 I guess I'll never really know why I don't quite fit in
 But I do know that deep within myself
 I will always be alone (December 1994)

RESPONDING TO THE EXPRESSIONS

As Nicole and Jessica's work was created within the context of their psychotherapy, it was essential that their creativity informed their therapeutic process. While I commented generally on their work, the intent of my comments was to encourage Nicole and Jessica to respond to their own work, to find their own meaning and insights. I often used phrases such as, "wow, that is impressive, talk about it," or, "hearing you read that poem gave me shivers, what does it say to you?" Often, we would arrange groups of drawings or poems on the floor, looking for themes, or changes in the work over time.

At times I also questioned Jessica and Nicole, asking how a particular drawing or poem might have been different six months ago, or how it might change if they were to do it again in a year. Questions about how Nicole might choose to frame a particular picture or with whom Jessica might share one of her poems were designed to encourage deeper exploration. Because Jessica was also reacquainting herself with work that she had written years earlier, I stressed the importance of Jessica reading her poetry out loud to me, rather than me simply reading it from her journal.

If It Wasn't For You (excerpt)

For if I would not have encountered you so many years ago
 I would not be who I am today
 If it had not been for you I wouldn't have my best friend
 Or the life lessons that I have learned
 People say that I am very brave for putting up with you
 But I don't remember my life another way
 Besides I don't have much choice, now do I?
 But I don't blame you for that because if it wasn't for you
 I wouldn't be me! (April 1996)

Becoming comfortable with her work, and with the wisdom she gained from the poems, was an important step for Jessica.

SHOWCASING THE CREATIVE WORK

During the past decade, as my office walls, bulletin boards and filing cabinets filled to overflowing with the work teens had created, I realized that the teens and

I had not tapped the full therapeutic potential of the expressive art process. While the teens had learned much about themselves, and their cancer journeys, their wisdom and insight remained largely hidden inside my office. Jessica and Nicole, for example, worked so hard to uncover thoughts and feelings which had often been outside of their conscious awareness prior to their creative explorations. While they had succeeded at making the private visible, both to themselves and to me as therapist, I wondered about taking the process a step further. Might there be value in encouraging Jessica and Nicole to take the products of their therapy beyond the walls of the counselling room into a public forum? Although art therapy group literature describes the sharing of expressive work with other group members (Deane, Fitch, & Carman, 2000; Heiney & Darr-Hope, 1999; Ziesler, 1993), there do not appear to be any references to the purposeful display or sharing of work beyond a therapeutic environment.

For Jessica and Nicole, the public sharing of their work began on a small scale, and gradually grew. I asked Jessica if she would be interested in having one of her poems published in the quarterly newsletter published by our Kids with Cancer parent group. I requested permission from Nicole to use some of her drawings at an international presentation to other professionals. Jessica agreed to let me share some of her poems with other adolescents who were in therapy with me. She liked the possibility that her thoughts and feelings might help others struggling with similar issues.

The Show (excerpt)

Is this supposed to be a punishment, for something I once did?
 Whether yes or no, I'm fading fast
 I feel I'm no longer in the spirit of a kid
 My freedoms seem to have been taken from me by my "guardian angel"
 Who's locked and bolted the doors and thrown away the key
 To my future and what may be left of me (July 1996)

Initially, I assured Jessica and Nicole that their work could be presented anonymously, but was quickly put in my place when they were both astonished at the suggestion; "No, please use my name, it's okay, it's MY story." That was my first clue to how really important it was for Jessica and Nicole to take ownership of their creative work, and the insights they had gained through the expressive process.

Once Nicole and Jessica were comfortable having their work presented, I offered them the opportunity to display their work as part of a healing arts gallery that featured the expressive work of adult cancer patients. Jessica and Nicole took time off from school to represent their work in person at the gallery. They also took part in an artists' evening where they spoke about the impact of the expressive art process in their personal journeys to recovery while their work was projected on a large screen behind them. Both teens have also reproduced pieces of their work on hand-painted eight-inch ceramic tiles which are part of a permanent tile display that depicts what it is like to live with cancer. The tile display covers a waiting room wall in the newly built pediatric outpatient cancer clinic.

Nicole, who had been reluctant and even fearful to share her cancer diagnosis with her friends when I first met her, volunteered to tell her story on the six o'clock provincial evening news. She spoke openly about her diagnosis, treatment, and physical and emotional healing as she recalled her expressive art process, and the insights she gained. Following taping of the segment, Nicole drew a picture of a large door just beginning to open, which she titled "The Open Door." "I've told my story to the whole province. The door is open now. There's a little bit of light shining through. People know what I've been through, but they still don't know what it's been like inside . . . how it feels" (April 1999).

As exciting as showcasing or exhibiting work can be, it is essential to remember that for the adolescents, this public display is part of their therapeutic journey. Prior to the times that Nicole and Jessica shared and talked publicly about their work, we spent time anticipating potential questions and comments that witnesses of their work might have. In addition, we tried to prepare for any emotions that might surface for Jessica and Nicole as they displayed their work and talked of what the expressive art process had been like for them. While the teens had their work on display, they and their families were aware that they could contact me anytime during the day for emotional support.

BECOMING EXPERTS

In creating their expressive work, Nicole and Jessica journeyed through the roles of patient, victim, and sufferer, to that of survivor. By showcasing their work, they moved even further; they proudly took ownership of their journeys, and established themselves as experts in creative healing. As they shared their insights and personal wisdom, their journeys were acknowledged, validated, valued and celebrated by others.

Nicole's use of art in therapy allowed her to heal her heart and soothe her soul. "Art has really helped me through my cancer experience. When Susan gets me to do all the drawings, I'm able to focus — it's all muddled in my head, and when I draw it becomes clear. I can clearly see what's happened." Nicole graduated from high school in June 2000, and is currently working while she contemplates what post-secondary education she wants to pursue. She recently completed a course in watercolor painting.

Untitled Work (written by Jessica during a brief time of remission)

Now that I am free from you, now that we have come apart
 I sometimes wish you were still a part of me,
 From deep down in the darkness of my heart
 I feel like I can't handle what life is handing to me now
 I am completely lost without you, I don't know who or what or how
 I have wished for so long to be free and healthy again
 But I still feel I'm losing the battle, no matter what I can't ever seem to win (1999).

Jessica celebrated her first "off chemo" year in 1999, but her disease recurred and her treatments continue. She is completing her third year in a culinary arts program, and continues to write poetry.

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