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# Creative Arts Therapy Improves Quality of Life for Pediatric Brain Tumor Patients Receiving Outpatient Chemotherapy

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## Abstract

This mixed methods pilot study evaluated the effects of the creative arts therapy (CAT) on the quality of life (QOL) of children receiving chemotherapy. A 2-group, repeated measures randomized design compared CAT with a volunteer's attention ( $n = 16$ ). Statistical analysis of the randomized controlled phase of the study suggested an improvement in the following areas after the CAT: parent report of child's hurt ( $P = .03$ ) and parent report of child's nausea ( $P = .0061$ ). A nonrandomized phase, using a different instrument showed improved mood with statistical significance on the Faces Scale ( $P < .01$ ), and patients were more excited ( $P < .05$ ), happier ( $P < .02$ ), and less nervous ( $P < .02$ ). Provider focus groups revealed positive experiences. Case studies are included to exemplify the therapeutic process. With heightened interest in complementary therapy for children with cancer, future research with a larger sample size is needed to document the impact of incorporating creative arts into the healing process.

## Keywords

creative arts therapy, pediatric cancer, brain tumors, quality of life

The impact of childhood cancer must be examined through the lens of chronic illness (Dragone, 1996). In this light, the long-term psychological influences of the disease increasingly gain importance. Sense of self and quality of life are ways to assess the impact of cancer on the pediatric patient's body and mind (Woodgate & McClement, 1997). Although studies relating the child and adolescent experience with cancer and sense of self remain inconclusive, the initial impact of the disease is undisputed (Hockenberry-Eaton, Dilorio, & Kemp, 1995; Smith, Ostroff, Tan, & Lesko, 1991; Woodgate & McClement, 1997). By using creative expression, a child or adolescent with cancer can express feelings about the course of the disease and tumultuous treatment through dance/movement, music, and art. This outlet allows the patient to creatively and kinesthetically process the assaults of cancer and its treatment, and thus establish a stronger sense of self and improved quality of life.

## Research Problem and Purpose

Little is known about the effect of creative arts therapy (CAT) on the quality of life (QOL) in children receiving chemotherapy in the outpatient venue. Because many children spend 4

to 8 hours in the infusion room, patients, parents, and staff have verbalized the need for additional stimuli such as arts and crafts or music to make the hours spent receiving treatment more tolerable. In addition, there are continuous requests for psychological support from patients and staff. The purpose of this study was to evaluate the effect of CAT on the QOL of brain tumor patients and subsequently all patients receiving infusions in the outpatient hematology/oncology clinic at a tertiary care pediatric hospital.

## Quality of Life

Much attention has been given to QOL in pediatric cancer survivors, but less is known specifically about patients currently receiving therapy. A recent study showed trends

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that quality of life among adolescents with cancer is worse during treatment than for those not currently on therapy (Ward-Smith, Hamlin, Bartholomew, & Stegenga, 2007). Another study has shown that interventions to promote happiness may be a good predictor of QOL in adolescent cancer survivors (Bitsko, Stern, Dillon, Russell, & Laver, 2008). QOL is difficult to assess when the patient's health status is constantly changing on therapy. QOL measurement tools must consider developmental age and stage, as well as characteristics that are important to measure during active therapy (Nathan, Furlong, & Barr, 2004).

Attention must be paid to how QOL is studied in this population. Hinds et al. (2004) documented the importance of including the firsthand reports of patients when studying quality of life of children receiving cancer therapy. Furthermore, recent literature review by Varni, Limbers, and Burwinkle (2007) demonstrate that data show children as young as 5 years of age can self-report their QOL both reliably and validly when an age appropriate instrument is used. This evidence supports using the perspective of the pediatric patient in clinical trials of QOL.

Quality of life in adults with brain tumors has been studied qualitatively. Some of the themes that emerged included the stigma of a mind-body illness, having an invasive disease of the self, dealing with the medical staff, and QOL (Fox & Lantz, 1998). Brain tumors in adults are known to diminish the QOL of the patient during treatment (Lovely, 1998). Considering the quality of life of these patients can help in the assessment of all aspects of the experience of having a brain tumor (Fox, 1998).

Children with brain tumors are at increased risk for permanent damage neurologically because of their growing and developing brains and bodies (Stewart & Cohen, 1998). Current trends in treatment for pediatric brain tumors are to reduce treatment-related side effects and increase QOL in patients with good prognostic features, especially in neurocognitive outcomes (Bull, Spoudeas, Yadegarfar, Kennedy, & CCLG, 2007; Grill, Kieffer, & Kalifa, 2004). Many authors have studied the late effects of the treatment of brain tumors in pediatrics on QOL (Alessi et al., 2007; Jenkin, Danjoux, & Greenberg, 1998; Kosch et al., 1998; Packer et al., 2006).

Brain tumor patients are also known to have significant morbidity during treatment as a result of the surgery, radiation, and chemotherapy. Little is published on the day to day effects of treatment on the QOL of pediatric brain tumor patients, but it has been acknowledged that even the act of coming to the clinic weekly for chemotherapy infusions impacts on the patient's life. In addition, Vincristine, a commonly used drug for brain tumors, is also well-known to cause significant morbidity (leg pain, numbness, tingling, and constipation) requiring dose-limiting regimens. Steroids are another common medication with

toxicities affecting QOL. Toxicities of steroids include weakness, sleep and mood disturbance, and pain with dose reduction. The impacts of being treated for a brain tumor are not only observed during therapy but also for years subsequently.

## Complementary and Alternative Medicine

Current trends show increasing popularity in the use of complementary and alternative therapies (CAM), even among children with cancer. Martel et al. (2005) looked at prevalence of use of CAM in children with cancer using a questionnaire in 115 patients. In their survey, almost 50% of the children used at least one type of CAM. The most popular CAM therapies were spiritual/mental and physical strategies of which CAT could be included. The authors suggest that the high prevalence of CAM warrants further studies to improve understanding of the effects of CAM, especially on QOL. Specifically to cancer, in 2009, Post-White, Fitzgerald, Hageness, and Sencer (2009) used a survey of 281 patients within the same geographic area to show that CAM was used in 59% of pediatric cancer patients versus 36% of general pediatric patients. The authors confirmed that children with cancer and other chronic illnesses use more CAM therapies than children seen in primary care clinics.

## Creative Arts Therapy

Creative arts therapy (CAT) is a type of CAM. CAT is a broad term encompassing the modalities of dance/movement, music, art, drama, yoga, and poetry therapies. Bringing creativity into health care is a current trend in oncology nursing and throughout the medical professions (Deane, Carman, & Fitch, 2000; Garland, Carlson, Cook, Lansdell, & Specca, 2007; Lane, 2006; Petterson, 2001; Strickland, 2008). Creative expression has been linked with a child's increased ability to cope with hospitalization. In addition, the processes of creative expression as therapy are known to increase QOL in adult and pediatric cancer patients. A creative arts intervention was tested in the family caregivers of patients with cancer and showed significantly reduced stress, anxiety, and increased positive emotions (Walsh, Martin, & Schmidt, 2004). However, no rigorous studies have been done to date to show the direct improvement of CAT on quality of life.

## Dance/Movement Therapy

In the specific area of movement, adults with breast cancer have reported increased psychological adaptation after dance/movement therapy (Dibbell-Hope, 2000).

Chronically ill pediatric patients have experienced improvement in symptoms and ability to cope with the intervention of movement therapy (Goodill & Morningstar, 1993). More specifically to cancer, Cohen and Walco (1999) state that the inclusion of dance/movement therapy (DMT) as part of the interdisciplinary team for children with cancer can facilitate coping and promotes holistic approaches to cancer care. However, to date, no randomized controlled trials have rigorously studied DMT in the pediatric population (Ritter & Low, 1996).

Madden (1999) completed a pilot study of DMT for adolescents with cancer. The study recruited 7 adolescents from the pediatric oncology clinic at a northeastern university medical center. The intervention of DMT consisted of four 45-minute sessions and was evaluated for its effect on perceived body image. Data were collected using a demographic form and 3 research instruments. Harter's Self-Perception Profile was used to assess self-perception (Harter, 1988). The Youth Self-Report (YSR) measured the adolescents' reports of their own competencies and problems (Achenbach, 1991). The Body Cathexis Scale was used for subjects to rate their degree of satisfaction with different body parts and functions (Secord & Jourard, 1953). The Self-Perception Profile and the Youth Self-Report were used as intake instruments to gather descriptive data. The Body Cathexis Scale was administered prior to therapy and after therapy was completed. The difference in overall perceived body image was not statistically significant, yet the subsets of "physical appearance" and "body build/moving body parts" showed a statistically significant improvement after DMT.

### Music Therapy

The effect of receptive music listening on reducing the emotional trauma, anxiety, and tension has been studied with adult cancer patients (Weber, Nuessler, & Wilmanns, 1997). In the adult population, Standley (1992) randomized adult cancer patients to music therapy during chemotherapy. Groups receiving music therapy reported less nausea than controls. The greatest effects of music were the perceived faster passing of chemotherapy infusion time and a reduction in anxiety and tension (Standley, 1992). O'Callaghan, Sexton, and Wheeler (2007) recently used individual case reports with music therapy to show reduced anxiety for pediatric cancer patients undergoing radiotherapy. Another area of study included effects of music therapy on motivation, well-being, physical comfort, and exercise endurance of bone marrow transplant patients. The patients self-reported an increase in relaxation and comfort levels (Boldt, 1996). Similar to the proposed study, Robb and Ebberts (2003a, 2003b) used music therapy with 6 pediatric bone marrow transplant

patients; 3 of the patients received music therapy and 3 did not. They all received six 1-hour sessions over 3 weeks. Quantitatively, the results showed trends of decreased depression and anxiety. Qualitatively, the authors showed themes of hope, coping, appreciation, mental status, control, time, bewilderment, treatment, and diagnosis. A pilot study looking at the mood in 65 children with cancer before and after music therapy also showed significant improvement, but suggests the need for a randomized controlled trial (Barrera, Rykov, & Doyle, 2002). With a focus on biophysical parameters, other studies have found music therapy to increase IgA levels in the saliva of pediatric cancer patients (Camprubi Duocastella, 1999; Marwick, 1996).

### Art Therapy

Art therapy with pediatric cancer patients addresses the emotional and developmental needs of the children undergoing treatment (Councill, 1993). It has been reported in case studies as a powerful tool to facilitate the emotional expression of children with cancer (Sourkes, 1991). Massimo and Zarri (2006) evaluated spontaneous drawings of 50 Italian children with cancer in the outpatient clinic. The pictures denoted the children's perception of the disease, their fears and hopes. The authors suggest that art therapy must be included in the total care of a severely ill child in the hospital. In 2005, Rollins used quantitative and qualitative methods within a grounded theory approach to look at drawing in 22 children receiving treatment for cancer. Findings showed that drawing enhanced communication for these patients. Favara-Scacco, Smirne, Schiliro, and Di Cataldo (2001) used art therapy as an intervention during painful procedures and suggest it may prevent permanent trauma. In addition, art therapy has been used for this population to improve coping and facilitate normal development (O'Neill, 1989; Pinchover, 1998; Walker, 1989).

Although participants in many of these studies self-report benefits such as an increased self-esteem and active participation in their own healing, more rigorous studies with measurable results need to be conducted to fully understand the effects of these therapies.

### Research Questions and Hypotheses

Research questions for the study included the following:

- Does CAT improve reported QOL for pediatric brain tumor patients receiving chemotherapy?
- Does CAT in a group setting improve the mood of children receiving outpatient infusions?
- How is CAT received by providers in a busy outpatient clinic/infusion center?

The primary hypothesis was tested by comparing parent-report and child-report scores on the Pediatric Oncology Quality of Life Inventory (PedsQL) using a randomized trial with a pilot-sized sample of 16 patients who were currently receiving chemotherapy (Varni et al., 1998). A secondary hypothesis was tested by comparing prepatient and postpatient report emotional/faces scales when receiving 1 hour of CAT in a group during infusions in the clinic. Finally, a third variable was evaluated by eliciting qualitative feedback of the CAT using nurse focus groups. It was anticipated that this study would offer nonthreatening, experiential activities that would aid children with brain tumors in coping with the physical, mental, and emotional aspects of their illness both during treatment and afterward.

## Methods

### Design

This pilot study used a mixed-methods design. Primarily descriptive, the study with repeated measures was conducted in 3 phases. First, there was a small randomized pilot with the brain tumor patients only. Next, the descriptive study observed all eligible hematology/oncology patients who received CAT. Finally, qualitative interviews were conducted with medical and nursing providers.

### Sample and Setting

After institutional review board approval was obtained, the study was conducted in the outpatient oncology clinic at a 250-bed tertiary care, university affiliated, pediatric hospital. At the time of the study, the clinic had approximately 2552 scheduled patient visits to the infusion center each year. The patients receive chemotherapy/medication infusions or blood product transfusions in the infusion room of the clinic. Very little chemotherapy for brain tumor patients at this institution is given inpatient.

Inclusion and exclusion criteria were divided between the 3 arms of the study. For randomized subjects, the following criteria were followed: patients were between 2 and 18 years of age, diagnosis of a brain tumor and currently active treatment, treatment continuing for at least 3 continuous months, and at least 6 consecutive expected infusions in the clinic (no less than 1 week apart and no greater than 2 weeks skipped). Exclusion criteria included children younger than 2 years or older than 18 years, as well as children not diagnosed with brain tumors.

For nonrandomized subjects, inclusion criteria were as follows: patients receiving at least 1 hour transfusions/infusions in the infusion room, any type of diagnosis, and older than 6 months of age.

Subjects currently receiving the intervention on the randomized portion of the pilot study were excluded from

the nonrandomized arm; although they could participate in the nonrandomized arm after the 6 sessions of the randomized arm were completed.

For the provider's phase of the study, inclusion in the group interview of the nurses required the nurse to have been present in the clinic during any session of CAT (randomized or nonrandomized). Nurses included were also the primary nurse for any patient who has received CAT. Nurses were excluded who were not been present in the clinic during CAT. One physician participated in the focus group.

### Instruments

During the randomized pilot phase of the study, the patient (aged 5 years and older only) and parents completed the PedsQL and the demographic form. The demographic form addressed confounding factors such as age, gender, time since diagnosis, type and location of brain tumor, neurological injuries or symptoms, and previous exposure to art, music, and movement.

The PedsQL 4.0 Cancer Module is evolved from the PedsQL 4.0 Generic Core Scale (Varni et al., 1998). The PedsQL 4.0 Generic Core Scale was designed to measure the dimensions of physical, mental, and social health as defined by the World Health Organization, as well as role (school) functioning in this population (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002; Varni, Seid, Knight, Uzark, & Szer, 2002). The system employs a Parent-Proxy Report for ages 2 to 18 years and a companion Child Self-Report for children aged 5 years and older. The normative group was recruited from families receiving care in a variety of pediatric health care settings. Validity and reliability testing for both the Core Scale and Cancer Module has been extensive.

Reliability, assessed by internal consistency, yielded coefficient  $\alpha$ s ranging from .80 to .90 across total and individual scales and are, thus, appropriate for the group comparisons planned in this study. The Cancer Module is a 27-item instrument that assesses 8 subscales (pain and hurt, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, and communication). It is easily completed by parents in less than 10 minutes and reverse-scored and linearly transformed in 5 minutes or less.

Validity for both the Cancer Module was established by expert panel review; similarly, construct validity was performed by comparing the responses of children with cancer across both measures to a group of healthy matched controls. In all cases, the PedsQL 4.0 Cancer Module was able to distinguish the responses of children with cancer from those of healthy children at a statistically significant level. Strengths of the PedsQL Cancer Module include its ease of administration and scoring, an easy-to-follow



instructional manual, standardization using an adequately sized sample, and sound validity and reliability evidence. As with all parent/self-report instruments, parent subjectivity may influence recorded responses (Varni, Burwinkle, et al., 2002; Varni, Seid, et al., 2002). The instruments have been successfully employed in several small studies of children with cancer (Bhat et al., 2005; Meeske, Katz, Palmer, Burwinkle, & Varni, 2004). In addition, a 10-minute interview involving 3 open-ended questions was administered to the patient and parents after the sixth and final infusion.

After several months of the pilot study, it was observed that children in the infusion center receiving group CAT separate from the protocol were experiencing improved QOL and mood. It was therefore decided to gather data (after approval from the IRB) using the simplest, 1-page questionnaire possible (because of time constraints in a busy clinic). The nonrandomized phase of the study included a brief demographic form (age, gender, diagnosis, current treatment) at the top of each scale. The Faces Scale (subjects <7 years old) and the Emotional Reactions Checklist (subjects  $\geq$ 7 years old) were used to collect predata and postdata on the subjects receiving group CAT during their transfusions/infusions in the infusion room. Parental report was used for subjects younger than 3 years old; otherwise, subject report was used. The Emotional Reactions Checklist is a 1-page form that asks the subject to rate how happy, sad, excited, angry, calm/relaxed, scared/afraid, and nervous/worried they felt on a 4-point rating scale. Validity data by Reid, Gilbert, and McGrath (1998) include correlations between the emotional distress measure and measures of general emotional adjustment (Revised Child Manifest Anxiety Scale, State Trait Anxiety Inventory, and Center for Epidemiological Studies Depression Scale). The scales have demonstrated adequate estimates of reliability and validity (Reid et al., 1998).

The Faces Scale has been used for evaluating emotional responses to pain in children 3 to 17 years old. It is a 1-page form with 9 faces in order of happy to upset. Numerical values are given to each face as determined by children's perspectives for an affective value by asking 200 children to directly scale the feelings depicted by the faces. Consistent rating was measured by children older than 5 years regardless of age, gender, or health status (McGrath, 1990). The scale is a facial affective scale and has been integrated as a routine measure for management of acute, recurrent, and chronic pain (McGrath, 1990; McGrath et al., 1996). For children younger than 3 years old, parents were asked to complete the Faces Scale. Although this scale has been used for emotional response to pain, it is felt to be an appropriate measure for the emotional response to the discomfort and anxiety in the infusion room.

## Intervention

For the randomized pilot phase, after written informed consent was obtained from the parent or legal guardian, appropriate brain tumor patients were randomized to 2 groups. Each group was tested before, during, and after the intervention. The experimental group received CAT whereas the control group received a volunteer's attention (Table 1). The interventionist was a master's prepared, licensed dance/movement therapist who was experienced in music and art therapies as well. The intervention consisted of 6 sessions, 2 sessions of each modality of CAT. The specific activity was replicated for every patient in the same order. The sequence of activities replicated developmental expression from body movement, to sound, to graphic representation. Each session lasted for 1 hour and occurred weekly with no greater than 2 weeks skipped. The experimental control consisted of a trained volunteer sitting at the patients' bedside in the infusion room and paying attention to them through reading, talking, or watching TV. No art activities were allowed for the control group during the volunteer's attention. Nonrandomized patients in the infusion room were included in the descriptive phase of the study. The CAT therapist provided 1-hour group sessions for any patient (hematology, oncology, bone marrow transplant) in the infusion room each week. The patients were grouped according to age or developmental stage and were tested before and after the group intervention (Table 1).

To obtain data regarding providers' perspectives of the program, a focus group of the staff nurses involved in the patients' care took place after 1 year. Nurses and one physician were led through a group discussion with open-ended questions. The discussion was tape-recorded and notes were taken. Lunch was provided during the group discussion. In addition, before the study began, staff in-services were provided to orient the staff to the process of CAT. The in-services were provided by the master's prepared, licensed, dance/movement therapist.

## Results

The sample demographics are presented in Tables 2 and 3. The randomized arm of the study accrued 18 patients, but 1 patient withdrew from the study after signing consent. A second patient did not receive chemotherapy because of tumor changes after the consent was signed. Therefore, 16 subjects completed the study, of which 14 were males, and 4 were females. The subjects were primarily diagnosed with low-grade astrocytoma (69%), followed by primitive neuroectodermal tumor (19%), and high-grade glioma (12%). Similarly, 69% of the subjects were receiving low-dose chemotherapy and 31% were receiving high-dose chemotherapy. A total of 56% of the subjects stated they had prior experience

**Table 1.** Protocol Assessment Table

Phase of Study	Time 1	Intervention	Time 2	Intervention	Time 3
Randomized phase	Demographic Form, PedsQL	Three 1-hour weekly sessions of creative arts therapy (CAT; 2 movement, 1 music)	PedsQL	Three 1-hour weekly sessions of CAT (1 music, 2 art)	PedsQL
Nonrandomized phase	Demographic Form, Faces Scale or Emotional Reactions Checklist	One 1-hour group session of CAT (movement, music, art)	Faces Scale or Emotional Reactions Checklist		

**Table 2.** Randomized Arm Patient Characteristics

Variable	n
Eligible patients	18
Patients who completed study <sup>a</sup>	16
Males	14
Females	4
Median age in years (range)	5.3 (2-13)
Lansky Performance Status	
100	5
90	2
80	6
70	1
60	1
20	1
Diagnosis	
High-grade glioma	2 (12%)
Primitive neuroectodermal tumor (PNET)	3 (19%)
Low-grade astrocytoma	11 (69%)
Tumor location	
Thalamus	3
Hypothalamus	1
Suprasellar	2
Temporal lobe	2
Posterior fossa	3
Brainstem	3
Spine	1
Leptomeningeal	1
Therapy	
High-dose chemotherapy	5 (31%)
Low-dose chemotherapy	11 (69%)
Prior arts experience	9
Neurologic injury	10

<sup>a</sup>One patient withdrew after signed consent. Second patient did not receive chemotherapy because of tumor changes after signed consent.

with arts, and 62% of the subjects acknowledged a neurologic injury.

The nonrandomized arm consisted of 32 subjects with 18 males and 14 females. The median age was 8.3 years with a range from 3 to 21 years of age. The diagnoses

**Table 3.** Demographics of Nonrandomized Arm

Variable	n
Eligible patients	32
Males	18
Females	14
Median age in years (range)	8.3 (3-21)
Diagnosis	
Brain/spinal cord/nerve sheath tumor	14
Leukemia	7
Lymphoma	1
Neuroblastoma	1
Neurofibromatosis	1
Sarcoma	2
Wilms' tumor	1
Hematologic disorder	4
Renal failure	1
Therapy <sup>a</sup>	
High-dose chemotherapy	2
Moderate-dose chemotherapy	12
Low-dose chemotherapy	9
Transfusion	5
Exam only	1
Total body irradiation for bone marrow transplant	1
Nonchemotherapy infusion	2

<sup>a</sup>High-dose chemotherapy = preparative regimen for transplant; moderate-dose chemotherapy = carboplatin, cisplatin, cyclophosphamide, cytarabine, etoposide; low-dose chemotherapy = low-dose weekly carboplatin.

were varied and the therapies received included chemotherapy, transfusions, and nonchemotherapy infusions.

Mixed effects models were used to examine the trend effects of CAT on the outcome measures. Our goal was to assess if the CAT group had consistent improvement in the outcome measures compared to controls during the study course. Each subject on the randomized phase of the study completed 3 assessments (baseline, mid-study, and end-of-study). Statistical analysis of this phase of the study suggested an improvement in certain

**Table 4.** Randomized Arm Results

Variable (Parental Report) <sup>a</sup>	Estimated CAT effect (slope)	Standard Error	PValue
<b>Pain and hurt</b>			
Aches in joints and/or muscles	-0.39	0.25	.13
Having a lot of pain	-0.40	0.17	.03
<b>Nausea</b>			
Becoming nauseated during medical treatments	-0.21	0.37	.57
Food not tasting very good to him/her	-0.95	0.32	.006
Becoming nauseated while thinking about medical treatments	0.10	0.30	.73
Feeling too nauseous to eat	-0.24	0.31	.44
Some foods and smells making him/her nauseous	-0.26	0.33	.44

<sup>a</sup>Child report yielded too few subjects in each age group to produce reliable results.

areas after the CAT versus the control (volunteer's attention). Areas that showed statistically significant improvement were parent-report of child's hurt (problems with having a lot of pain),  $P = .03$ , and parent-report of child's nausea (becoming nauseated while thinking about medical treatment),  $P = .0061$  (Table 4). The negative coefficient indicated a decrease in the measured scores over time for the patients in CAT group. Unfortunately, the child self-report variables all had too few subjects within each age group for an adequate analysis. If the total number in a group (either CAT or control) was 4 subjects or less, we did not analyze that group. We did not want biased results because of the fact that a small number within the group may not have represented the whole study population. Therefore, all of the child self-report variables were eliminated.

To assess the parents' satisfaction with the randomized phase, a short questionnaire with open-ended questions was administered. Their responses were positive. In fact, even the parents of children who received the volunteer's attention enjoyed the experience (Table 5).

For the nonrandomized phase, the Emotional Reactions Checklist and Faces Scale were analyzed. For the Emotional Reactions Checklist, a total score for emotional distress was yielded by summing the positive ratings on a 4-point scale (0 = *not at all* to 3 = *really*) for happy, excited, calm/relaxed and reverse coding the responses for sad, angry, scared/afraid, and nervous/worried. Each face on the Faces Scale was given a numerical value, which represents the magnitude of emotional distress depicted by the face from children's own perspective. The scale ranges from 1 to 9, where 1 equals *saddest feeling possible* and 9 equals *happiest feeling possible*. Paired  $t$  tests were used to assess if the prechanges and postchanges in the outcome measures were significantly different from zero. The nonrandomized phase showed improved mood with statistical significance on the Faces Scale ( $P < .01$ ), and patients

were more excited ( $P < .05$ ), happier ( $P < .02$ ), and less nervous ( $P < .02$ ) on the Emotional Responses Checklist (Table 6).

The focus group of nurses was tape-recorded, the tapes were transcribed, and the transcripts verbatim were reviewed informally for insightful comments. Future analysis of the transcripts is planned employing formal qualitative methods. Table 7 provides examples of specific quotations from providers.

Anecdotally, the response to CAT was overwhelmingly positive from patients, families, and providers, and prompted several large monetary donations to continue the project. Although the study is now closed, the program continues with part-time salary support for the creative arts therapist through grant funding. Patients, parents and staff daily request the therapist and are disappointed that she is not available full time.

## Case Studies Presented by the Creative Arts Therapist

### Case Study 1: Anxiety Relief Through Dance/Movement Therapy

A 13-year-old boy presented for the CAT intervention on his first day of chemotherapy. The day before, he underwent surgical placement of a subcutaneous infusion port. He was pale, spoke in a shaky voice, and claimed to be nauseous. He moved in a rigid, guarded manner and isolated his port side as if he were paralyzed. The patient was tearful as he explained that he would be unable to play baseball this year. The therapist empathized with his fear of the future. After briefly introducing the concept of mind-body interaction, the therapist began tossing balls to him. The patient was encouraged to use both hands to catch balls of various size, color, and texture. He slowly relaxed and continued the "game" for about 10 minutes. When his attention



**Table 5.** Parental Reports on Open-Ended Questions

Questions	Experimental Group Parental Responses (Creative Arts Therapy)	Control Group Parental Responses (Volunteer's Attention)
What was it like being part of this study?	<p>"Pretty cool . . . got her mind off different things." "She always wanted to be with the therapist and loved playing."</p> <p>"Kept [patient] really comfortable . . . was nervous [to fill out] questionnaires."</p> <p>"We were happy to participate in this study and feel that it was a benefit to [him] . . . [he] looked forward to it."</p> <p>"It was fun and interesting. It was something different."</p> <p>"Helpful for [patient], liked idea of study."</p> <p>"Looked forward to it."</p>	<p>"Good, liked the attention."</p> <p>"Good thing . . . missed [volunteer] when completed study."</p> <p>"It made things a lot easier for myself to have someone preoccupy him."</p> <p>"Really liked having the volunteer."</p> <p>"Gave [patient] something to look forward to—[her] 'own friend.'"</p> <p>"Nice that it wasn't forced on [patient]."</p>
How did it feel being part of this study?	<p>"Our child enjoyed these visits, so we felt that it is a worthwhile program."</p> <p>"It felt good, he got into it after a while and liked it."</p>	<p>"No different."</p> <p>"Good to have the volunteer with the sibling, too."</p> <p>"First week stressful with so many people."</p>
Based on your child's temperament, how did this go for your child?	<p>"Really good, would like to do more."</p> <p>"She still asks for [the therapist], she was nicer, she changed, she really liked it . . . then when [the therapist] left, she got mad."</p> <p>"He was able to express his feelings and creativity."</p> <p>"Really good. It kept his mind off of things."</p> <p>"He likes art, but is resistant to 'creative play.' He looked forward to music and art and was excited."</p> <p>"Helped being here, helped us relax, helped us get more comfortable."</p>	<p>"Helped the whole family loosen up . . . better than sitting by ourselves."</p> <p>"Had fun playing."</p> <p>"I think it made this better for him to have somebody put all of their attention on him."</p> <p>"Great to have extra attention in the busy infusion room."</p> <p>"Something to talk about."</p> <p>"Good because no forced activity."</p>

**Table 6.** Results of Nonrandomized Arm

Variable	n	Mean (SD)		Post – Pre Mean	P Value
		Preintervention	Postintervention		
Faces	15	6.93 (1.83)	8.53 (0.64)	1.60 (1.92)	.0061
Angry	17	1.35 (1.00)	1.06 (0.24)	-0.29 (0.85)	.17
Calm/relaxed	17	2.65 (0.86)	2.82 (1.01)	0.18 (0.88)	.42
Excited	17	1.88 (0.99)	2.53 (1.18)	0.65 (1.17)	.04
Happy	19	2.84 (0.76)	3.26 (0.81)	0.42 (0.69)	.016
Nervous/worried	17	1.71 (0.99)	1.18 (0.39)	-0.53 (0.87)	.024
Sad	17	1.47 (0.94)	1.18 (0.39)	-0.29 (0.92)	.21
Scared/afraid	17	1.24 (0.75)	1.06 (0.24)	-0.18 (0.81)	.38

was directed back to his physical symptoms, he was surprised and relieved to say that he was no longer having pain or nausea. The patient then expressed hope by saying

that he might be able to play hardball sooner than he thought. He was learning that he could focus free floating anxiety through meaningful action.

**Table 7.** Focus Group Questions and Answers

Questions	Quotations
What changes have you noticed in patients receiving creative arts therapy (CAT)?	“More responsive and positive. It encourages the kids that aren’t physically active to move around. They are happier to be here.” “They love it, they are totally interactive. I think the kids really look forward to it; it really keeps them occupied . . . unless they are feeling really bad, it is such a nice distraction.”
What are certain types of patients (e.g., temperament, age, personality, diagnosis, treatment) that seem to respond better or worse to the CAT?	“It’s hard . . . to get teenagers to engage . . . there are some that [are more] withdrawn who will interact when I would not think they would . . . they will do [CAT] when they will not do something else.”
How does the CAT program change your care of patients in the clinic?	“On days we are not busy, it is great, but on a busy day it is chaotic if there are drums” “I love it on the days [of CAT] because it is such a nice distraction.”
What are some examples of specific patient behaviors that you have noticed during or after CAT?	“I have observed laughter, and have seen children engaging in conversation that don’t necessarily talk . . . Patients coming out of their shell!” “It allows parents to have their own private time without being involved in it.” “Laughing, they seem happier.”
How could CAT best be used in the clinic?	“If we had a play room in the clinic, ideally that would be best, that the nurses could still do chemo in.”
Would you like to see CAT continued in the clinic? How?	“Yes, oh yes”

### *Case Study 2: Increasing a Positive Outlook Toward Treatment Through Therapeutic Music*

A 10-year-old boy was particularly comfortable with symbolic expression. On his second music session, a variety of musical instruments was spread on his bed when he began improvising on bongo drums, tambourines, bells, and percussive shakers. When asked what he wanted to start with he answered, “Stop yawning!” He began to play with increased energy as he talked about how he was frustrated with the sedating aspects of his medication. He explained that despite the side effects of the diphenhydramine, it helped him with his nausea during chemotherapy.

He paused in his improvisation and then began to play again. This time he played 2 contrasting rhythms. The first was slow, quiet, and irregular. The second was loud, even, and driving. The patient described the 2 rhythms as two sides of himself arguing. One side said, “No, I don’t want to take the meds and treatment.” The other yelled, “Stop arguing! Just do it.” He and the therapist discussed how difficult it was to go forward with treatment that was unpleasant.

The patient then began to speak about his frustration with losing arm and hand control because of his brain tumor. The therapist asked him to play that frustration on the drum and he meticulously tapped a careful rhythm. The therapist then stated that his rhythm was surprising because if she were losing control of her body, she would be much angrier. He smiled and began pounding the drum with rhythms that supported verbal phrases such as “Do what you’re supposed to do, arm,” and “I can fight it.” This improvisation lasted for quite awhile.

When he was through, the patient said he’d like to return to the hospital when his cancer was gone so that he could help other kids get through the experience. He looked forward to every CAT session as it helped him express otherwise unspoken feelings.

### *Case Study 3: Increasing a Sense of Happiness Through Meaningful Expression Through Art*

This 5-year-old girl came from a somewhat chaotic family where her illness was not directly discussed. By her fifth CAT session, which was her first art session, she was happily anticipating the CAT time. When told the session would include art materials, she responded, “Goodie, I want to paint.” As watercolors were set up by the therapist, it became obvious that she had never before used a new paint set. She spent a great deal of time carefully putting water into the paint. She then painted spots of each individual color. At one point two colors ran together and she became focused on their blending. She blended more and more colors until the paint box and the paper were both a muddy brown. She paused and looked puzzled. She was asked if she liked all the colors mixed or if she would like to paint with the individual colors again. She said she would like to clean the colors. The therapist mirrored her actions and words stating “you’d like to get things cleared up.”

After cleaning out the paint box, the patient began painting on a new piece of paper. She and the therapist had been talking when she said “Shhh . . . there are lots of sick people here.” The therapist whispered, “Are you sick?” She answered, “No. The medicine is making me

better." This patient's graphic clarity was accompanied by her verbal or cognitive clarity. As with most people, she was happier when she was clearer with her life situation.

## Discussion

Improving QOL for pediatric cancer patients is a current trend. This study adds to the body of knowledge of CAM, with an emphasis on the population of pediatric cancer patients. Our results indicate that children undergoing chemotherapy may benefit therapeutically from CAT during infusions.

Results of earlier studies show specifically that pain and emotional distress are appropriate targets for treatment interventions to enhance QOL for children with cancer (Varni, Burwinkle, & Katz, 2004). Similarly, our study showed trends of improvement in reported pain as a result of the CAT intervention. In addition, the emotional improvements with CAT were documented with the Faces Scale and Emotional Reactions Checklist. The areas of reported pain and emotional distress present pertinent topics to focus further research on specific realms within QOL.

Hockenberry and Hooke (2007) recently discussed the multiple symptoms experienced by pediatric cancer patients, including fatigue, sleep disturbances, and pain. These symptoms are distressing and prevalent. The authors recommend that nurses be aware of such symptom distress to decrease the interference with a child's ongoing development as well as to manage the symptoms. The present study reflects that these symptoms could be alleviated with CAT. The symptoms of nausea and pain during therapy showed trends toward improvement with the intervention of CAT in our study.

The literature reports increasing evidence of strategies to improve QOL in this population. In addition to CAM therapies, home chemotherapy infusions are an example of a service provided to improve the day-to-day QOL for these patients (Lashlee & O'Hanlon Curry, 2007). We strived to establish evidence-based documentation in this study for the use of CAT as a hands-on strategy for improved QOL. CAT is not only a distraction but also a focused intervention specific to the patient's psychological needs. It is a personal process of psychotherapy in comparison to a product focused art project.

Although statistical significance is often the "gold standard" of research, clinical significance is also extremely important. Through anecdotes and case studies reported here, CAT was shown to have clinical significance for children participating in this pilot study. Further evidence is needed to specifically demonstrate quantitative improvement in reported pain or other cancer symptoms in the pediatric patient.

## Limitations

The small sample size of this study limits the generalization of the findings. Although a broad age range was

needed to accrue an adequate sample size, it also limits the study in terms of application to specific developmental stages. Because the PedsQL Cancer Module is divided by age groups, the small sample size created too few subjects per group to be properly analyzed. A further limitation within the small sample size of 18 was patient attrition. When dealing with subjects in this population, one must remember the difficulty of retaining subjects during the early diagnostic and therapeutic phases of treatment. This study should be replicated with a larger sample size to increase the power to detect differences in the groups.

Quality of life is an important outcome measure in the pediatric cancer population (Woodgate & McClement, 1997). The PedsQL Cancer Module was an appropriate tool for this population; however, the small intragroup sample size limited the ability to achieve statistical significance. Any subset with fewer than 5 subjects was not used in the results because of the small number easily skewing the results. A possible limitation of the PedsQL Cancer Module was that it measures the subject's QOL over the prior 4 weeks. Perhaps CAT is best measured immediately after the intervention, or perhaps more than 6 sessions are needed to accurately assess a difference in QOL related to CAT. Also, QOL changes for brain tumor patients as they proceed through the trajectory of diagnosis, recovering from neurosurgery, and starting treatment. The QOL may improve just from time passing and not related to the CAT intervention. Conversely, as the treatment toxicities accumulate, (procedural anxiety and anticipatory nausea may increase), the QOL may decrease over time not related to the intervention.

In addition, as the study evolved, it became clear that all children in the infusion room should be offered the benefits of CAT. The study was originally designed as a randomized controlled trial, but it became obvious that we did not want to be exclusive in the infusion room. To gather data on the changes seen in the patients in the infusion room, we changed instruments that would more quickly assess a subject's QOL (based on mood or emotional response). A limitation of this study is the use of disparate instruments between the randomized and nonrandomized phases.

Future studies would benefit from gathering data on a concrete biophysical parameter such as IgA levels in saliva or perhaps vital signs (Camprubi Duocastella, 1999; Marwick, 1996). Potentially a more defined measure such as patient report of nausea or pain would provide more significant results. The Faces Scale and the Emotional Reactions Checklist used for the non-randomized arm provided a more succinct answer to the research question, especially related to the immediate changes seen in the patients in the infusion room receiving CAT. It would be interesting to use one of these measures in a randomized study of CAT in this population.

Finally, there is a conceptual limitation in using science to study artistic expression. It is difficult to quantify the

changes seen in the children before and after CAT. Perhaps statistical significance is not the appropriate measure when studying CAT. Clinical significance may better represent the outcomes seen in children moving their bodies, creating music, or expressing visual art all the while undergoing chemotherapy. Future qualitative investigation may help to further define and describe such outcomes.

## Conclusions

This study suggests that CAT may improve QOL in the pediatric cancer patient undergoing therapy. All participating patients and parents reported satisfaction with the CAT intervention and stated that they would like to see the program continue. Currently, patients and parents continue to ask for more hours of CAT in the infusion room. Future research investigating biophysical measurements or specific symptoms (pain, nausea) is warranted to provide concrete evidence to the medical community of the benefit of CAT. In addition, in this era of holistic nursing, CAT is the perfect example of how a nurse can involve the whole patient using the creative arts to aid in healing from the traumatic treatment of cancer in a child.

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## Bios

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