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Exploring the ability of a drawing by proxy intervention to improve quality of life for hospitalized children

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Objective: The primary objective of this study was to explore the ability of a one-time drawing by proxy intervention to improve perception of quality of life for hospitalized children. *Methods:* The quantitative/qualitative study used a one-group pre-test/post-test design with 50 hospitalized children (ages 6–19 years), who participated in a 45–60 minute intervention based on *The Moon Balloon* book. The PedsQL™ Present Functioning VAS, a Parent Survey, and participatory observation were used to measure results. *Results:* Findings revealed a statistically significant improvement in perceptions of the child's momentary quality of life. Most parents reported learning something about their child that they had not known before. Children used imagery to express feelings about when images speak the unspoken, of beauty, of stress, and of transformation. *Conclusions:* Drawing by proxy improved children's perceptions of their present quality of life, and provided an effective method for expressing their thoughts and feelings. Studies are needed to determine the intervention's effectiveness in other settings and the characteristics individuals require for facilitating effective drawing by proxy interventions.

Keywords: children; hospitalization; drawings; quality of life; arts in healthcare

Hospitalization is a landmark event in a child's life (Vessey, 2003). Children are required to submit their small bodies to adult control and restriction upon admission. People ask them to "hold still" for painful procedures that perhaps they do not understand; they are left feeling powerless and confused. When placed in passive roles with limited opportunities to make meaningful choices, it is no wonder that children's emotions are often intense and confusing (Rollins, 2005a).

Although there are many similarities in hospital experiences among children, each child's experience is unique. Also, other stressors in a child's life do not disappear during hospitalization. Like children everywhere, hospitalized children may experience stress from parents who are fighting, divorcing, or re-marrying; girl- or boyfriend problems; school problems, bullies, and so on. Some children, even those with life-threatening disease, report these types of issues as more stressful than dealing with their illness (Rollins, 1990). Further, it is a rare person who has only one stressor in his or her life at a time. Brenner (1984) argues that when several stresses are combined, the effects are more likely to increase geometrically than to be simply additive.

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Often the feelings children have about these experiences are too scary or difficult to put into words. Further, children, particularly young ones, may not have the vocabulary to describe what they are feeling.

Considering the stressors, it should not be surprising that children who are ill and hospitalized typically have a lower quality of life (QoL) than healthy children. In a study comparing QoL of hospitalized children, ill children in outpatient settings, and healthy children ages 6–14 years of age ($N = 201$), Michopoulou et al. (2005) reported that QoL was higher for healthy children, and somatic and school domains were affected more negatively for hospitalized children. Other research reveals that the hospitalized child's emotional state has an impact on his or her QoL. For example, Gonzalez-Gil, Rio, Gomez-Vela and Robaina (2007) studied 105 hospitalized children aged 6–15 years and found a significant association of lower QoL with worry, anxiety, fear and sadness.

Borysenko (2005) tells us that people who experience illness or trauma, when they can give voice to their emotions, have an enhanced QoL, better immune function, less distress and a greater chance of cure. Unreleased feelings are given the ability to fester and grow (Pennebaker, 1997). Over time, the work of inhibition gradually undermines the body's defenses. Excessive holding back of thoughts, feelings and behaviors can place individuals at risk for both major and minor diseases. Further, suppressing emotions also can reduce rapport and inhibit the formation of relationships between individuals (Butler et al., 2003).

Expressing feelings can help children cope by providing an opportunity for them to work through, reflect, and find meaning in their experiences. Dealt with openly and honestly, difficult feelings lose some of their strength. For example, programs intended to promote expression of feelings have achieved positive results on psychosocial measures in grieving children (Heiney, Dunaway & Webster, 1995), children whose parent or grandparent has cancer (Heiney & Lesesne, 1996), child witnesses to violence (Rollins, 1997), children with leukemia undergoing painful procedures (Favara-Scacco, Smirne, Schilirò & DiCataldo, 2001), and school-aged children of alcoholics (Emshoff & Anyan, 1991).

Ryan-Wenger (1992) identifies emotional expression as one of 15 important strategies children use to cope with stress. Expressing fears or concerns can sometimes relieve tension or anxiety. A variety of techniques have been used to elicit children's experiences, which include drawing, storytelling, acting, writing in a diary, explaining a film or DVD, participating in a focus group, and talking through a doll or toy telephone (Curtin, 2001). LaMontagne (2000) used interviews to ask direct questions to determine the coping strategies of children having surgery. Lindeke, Nakai and Johnson (2006) used a similar method to determine children's description of hospitalization and their recommendations for change, and Pelander, Leino-Kilpi and Katajisto (2007) for examining children's opinions of the quality of nursing care received.

However, less directive techniques (e.g. drawing) may be particularly useful in eliciting a child's feelings because these methods are non-threatening and allow the child to express perceptions that they may not be "consciously aware of or able to express verbally" (Bellack & Fleming, 1996, p. 10). In a study of four methods to elicit children's views of hospitalization, Carney et al. (2003) obtained the most concrete information from a structured questionnaire; however, the visual structured questionnaire (five drawings of hospital events) was most effective in eliciting *feelings* about the hospital experience.

Choosing images or symbols to represent emotions may feel less threatening than using words. Stocker (2002) proposes that symbols are more effective than words because they are more quickly interpreted and can overcome language barriers. The use of symbols to express emotions is not new. We are reminded of the Victorian practice of sending a certain type of flower to express love or other emotions, and today's practice of using emoticons in emails.

Although children can use any opportunity to draw as a means of communicating, certain drawing techniques have shown promise in promoting expression of feelings. Illuminative artwork (Spouse, 2000) offers a simple method. In this method, the child is asked to render a drawing based on a certain topic or theme. The work is not analyzed; the facilitator instead encourages the child to use the artwork as a communication tool. With Sourkes' Scariest Image Drawing, for example, children are asked to think of the scariest experience, thought, feeling, or dream they have had since they became ill, and to draw it. Children are invited to bring out the extreme fear, often the very image that they are most afraid to express (Sourkes, 1995, 1999).

Councill (1993) points out that children can use drawing to maintain communication with the treatment team at times when relationships are strained by anger, withdrawal, fatigue, and feelings that are too emotionally charged to be expressed with words. Drawing also has the power to bring out mixed, poorly understood feelings, in an attempt to bring them to order and clarity (Bentley, 1989; Dalley, Case & Schaverien, 1987).

Drawing for the child, or drawing by proxy, is another way to help children communicate their feelings (Rollins & Mahan, 2010). Using this method, children are asked to imagine images or symbols to represent their thoughts and feelings, and someone else actually renders the drawing itself. The child is continuously asked for feedback and verification to insure the image is exactly as the child envisions it. The creative process is a series of decision-making, and the child is making the critical decisions along the way. Thus, the drawing is truly the child's invention, and the person who renders the drawing is a tool acting on the child's behalf.

The Moon Balloon: A Journey of Hope and Discovery for Children and Families, written and illustrated by Joan Drescher (1996, revised 2005), was created to give children the opportunity to explore their emotions through a journey, represented by various hot air balloons. The interactive picture book invites children to talk about, write, and draw their own feelings and images. Well-presented stories about anger, fear, joy, sadness, and other emotions can validate children's feelings (Marion, 1995), and talking about emotions helps children understand their feelings (Brown & Dunn, 1996).

If the act of drawing is helpful for children, can someone drawing *for* the child achieve similar results? The primary objective of this study was to explore the ability of a one-time drawing by proxy intervention, using *The Moon Balloon* book, to improve present functioning QoL for hospitalized children. Study aims were (1) to determine the effectiveness of drawing by proxy in helping hospitalized children express their feelings, and (2) to describe the feelings a sampling of children who are hospitalized experience.

Methods

This quantitative/qualitative exploratory study used a one-group pre-test/post-test design. Triangulation was used to enhance credibility.

Sample and Setting

Following institutional review board approval, the study was conducted over a one-year period in the general pediatric medical/surgical inpatient units at a 907-bed tertiary care university-affiliated hospital in the New England region of the United States. The second author (Drescher) approached children and their parents in the child's hospital room and presented the letter of introduction to the study, reviewed consent/assent forms, and discussed the study using a special colorful recruitment document that explained the study in

simple terms. Some children and parents readily agreed to participate without further consideration. For those who wanted more time to think about it, Drescher left the materials and returned later to answer any further questions. In other instances, Drescher facilitated expressive activities to establish rapport with reluctant children; some children later agreed to participate.

Among approximately 100 potential participants Drescher approached, a convenience sample of 50 English-speaking children, aged 5–19 years, and a parent for each child, were recruited. Reasons cited for inability to participate included fatigue, not feeling well, or a time issue, such as a pending surgery, test, or procedure.

Instruments

Three instruments were used: the PedsQL™ Present Functioning Visual Analogue Scales, a Parent Survey, and participatory observation.

PedsQL Present Functioning Visual Analogue Scales (PedsQL™ VAS). Sherman, Eisen, Burwinkle, and Varni (2006) developed the PedsQL™ Present Functioning Visual Analogue Scales (PedsQL™ VAS) to measure anxiety, sadness, anger, worry, fatigue, and pain as experienced at-the-moment. A similar version was also developed to measure parents' perceptions. Sherman and colleagues administered the six-item instrument to 70 pediatric patients aged 5–17 years and their parents upon admittance to the hospital environment and again two hours later. The results demonstrate preliminary test–retest and internal consistency reliability and construct validity of the PedsQL™ Present Functioning VAS instrument for both pediatric patient self-report and parent proxy-report.

The instrument uses 100mm lines anchored at one end with a happy face and at the other end with a sad face. The instructions ask children to “Please put a mark on each line that best shows how you feel now. If you have no problem and feel fine, put a mark at the end of the line by the happy face. If you have some problems and do not feel that well, put a mark near the middle of the line. If you feel very bad or have lots of problems, put a mark by the sad face.” Parents were asked to “Please put a mark on each line that best shows how your child feels now.” Children and parents/guardians completed the instrument pre- and post-intervention.

Parent Survey Parents completed the investigator-developed survey post-intervention. It consisted of one Likert scale question and three open-ended questions:

1. How effective was the Moon Balloon session in helping your child express feelings about hospitalization, fears, or frustrations?
2. Did having the Moon Balloon session give you an opportunity to discuss any of these feelings with your child afterwards?
3. Is there anything you learned from your child from the Moon Balloon session?
4. How did the Moon Balloon session affect you?

Participatory Observation. The second author (Drescher), who conducted the intervention, recorded her observations in field notes after each session. Items recorded included but were not limited to the child's physical status, mood, interest, and response; others present; whether or not Drescher had worked with the child in the past; the length of the session; and an overview of what took place.

Procedure

After obtaining informed consent from the parent/guardian and teenagers 14–17 years, and assent from children under age 14, Drescher asked the child to complete the PedsQL™

Present Functioning VAS and the parent to complete the parent version. Then Drescher did the following.

1. Gave an overview of *The Moon Balloon* book and offered the child drawing materials should he/she want to draw as well.
2. Invited the child to choose a balloon, and to tell her what to put in it.
3. Drew the balloon, including the child's requested images, continually asking the child questions to describe details to generate richness and enhance interaction (e.g. "What color is your dog?"), and asking for verification.
4. Asked the child to select a second balloon, and repeated the activities in #3.
5. With the child's permission, exhibited the drawings in the child's room.
6. Thanked the child for participating, and provided him/her with Moon Balloon book for future use.

Sessions lasted approximately 45–60 minutes. After the session, Drescher provided the parent/guardian with Parent Survey, the second PedsQL™ Present Functioning VAS for parents, and the child with the second PedsQL™ Present Functioning VAS for children, with instructions to complete, enclose, and seal them in the provided envelope. Drescher wrote her observations immediately after each session, and returned afterwards to collect the envelopes from the children's rooms.

Data Analysis

The PedsQL™ Present Functioning VAS was scored using the instructions accompanying the instrument. Pre- and post-scores were calculated and compared for the six individual items as well as for overall scores means for children and parents. Paired *t*-tests were conducted to compare scores. Regarding the Parent Survey, Question 1 was analyzed for mean. Investigators reviewed responses to open-ended questions on the Parent Survey as well as Drescher's field notes for content, coded and categorized content by topic areas and developed themes.

Results

Demographics

A total of 50 children aged 5–19 years participated in the study. Average age was 10.94 and median age was 10.5 years. There were 14 boys and 36 girls. See Table 1 for a breakdown of age and gender. Because of the terms of the study, the investigators did not have access to patients' records; thus ethnicity data or patient characteristics regarding

Table 1. Participants' Age and Gender.

Age	Boys	Girls	Total
5–7 years	7	7	14
8–10 years	3	8	11
11–13 years	3	9	12
14–16 years	0	7	7
17–19 years	1	5	6
Total	14	36	50

medical condition (unless the patient or family revealed this information) was not obtained.

PedsQL™ Present Functioning VAS

Children and their parents perceived an improved present functioning QoL in all six areas (see Tables 2 and 3). When taken as a whole, results for the children were very statistically significant ($p = .001$), and for the parents, extremely statistically significant ($p = .0001$). Regarding individual items, in only one instance, for the children for Item 1: “I feel afraid or scared”, was the result not statistically significant by conventional criteria. For the remaining children’s items, results were either very or extremely significant.

For parent scores, item 5: “My child feels tired” was statistically significant ($p = .0201$). Results for the remaining items were either very or extremely significant. There were no significant differences between child and parent perceptions on any of the items, pre- or post-intervention.

Parent Survey

Mothers were the respondents on nearly all Parent Surveys (85%). A father, two grandmothers, one grandfather, and one aunt completed the remainder. The majority of respondents (98%) believed that *The Moon Balloon* was very or somewhat effective in helping their child express feelings about hospitalization, fears, or frustrations. A full 93% said they had learned something about their child that they had not known before. Regarding discussing *The Moon Balloon* with their child, 84% indicated that they had, and the remaining 16% said that they planned to do so.

Several parents who stayed in the room for the Moon Balloon intervention commented that they enjoyed it and found it a stress reliever for them as well as for their children. They were surprised and pleased that their children took the opportunity to express themselves. Some expressed amazement at the “power of images.”

Participatory Observations

Children used the sessions to express their feelings. A review of Drescher’s field notes revealed that the Wish Balloon was chosen more often than any other balloons, followed closely by the Love Balloon (see Table 4). Children expressed and explored their feelings. Four themes emerged.

When Images Speak the Unspoken. Through images, children expressed previously unspoken feelings about illness, feelings, stress, and love.

Table 2. Children’s Pre- and Post-test PedsQL Present Functioning

	<i>n</i>	Pre <i>M(SD)</i>	Post <i>M(SD)</i>	<i>t</i>	<i>p</i>
1. I feel afraid or scared.	49	2.02(2.90)	1.38(2.19)	1.60	.1143
2. I feel sad or blue.	48	3.16(3.42)	1.50(2.27)	3.91	.0003
3. I feel angry.	48	2.56(3.18)	1.21(1.71)	3.25	.0021
4. I worry about what will happen to me.	48	4.11(3.27)	2.39(3.10)	3.61	.0007
5. I feel tired.	48	3.55(3.21)	2.26(2.74)	2.71	.0093
6. I feel pain or hurt.	48	3.16(3.32)	2.36(3.13)	3.60	.0008
Total	–	3.13(.755)	1.85(.542)	6.79	.0011

Table 3. Parents' Pre- and Post-test PedsQL Present Functioning.

	<i>n</i>	Pre <i>M(SD)</i>	Post <i>M(SD)</i>	<i>t</i>	<i>p</i>
1. My child feels afraid or scared.	46	2.80(2.71)	1.21(1.84)	4.00	.0002
2. My child feels sad or blue.	46	3.04(3.05)	1.53(2.04)	3.47	.0011
3. My child feels angry.	45	2.55(3.22)	1.26(2.01)	2.75	.0085
4. My child worries about what will happen to him/her.	44	4.13(3.15)	1.92(1.89)	5.00	.0001
5. My child feels tired.	45	4.20(3.38)	2.81(2.77)	2.41	.0201
6. My child feels pain or hurt.	45	3.31(2.83)	1.94(2.60)	4.49	.0001
Total	–	3.30(.595)	1.77(.516)	11.28	.0001

Participant 16 – Girl, 10 years old: H. was hospitalized for seizures. She was hooked up to machines and electrodes. She seemed worried and sad, but was eager to do art. I told her how I used art as a child when having a difficult time. She first chose the Love Balloon, and drew along with me in her journal. For her second choice, she selected the Tear Balloon. She said that she was scared of falling, but had never mentioned it to anyone. She told me how to draw “falling.” Once she started, lots of other things came out that she said she could not speak about, such as shots, blood draws. When her mother came back to the room and saw the drawing, she said that she was amazed that her daughter said she was sad about falling because she had never spoken of it before. With H.’s permission, I posted the drawing on the wall to share with the medical team.

Participant 18 – Girl, 15 years old: D. didn’t want to do it at first because she thought she was too old. When she found out I was a writer, she changed her mind. She likes to write stories and poetry. Her room was dark because the light hurt her eyes. She first chose the Stress Balloon. She had internal malformations, one hand larger than the other, and port wine stain birthmarks, which she directed me exactly on how to draw, red stains on face, hands, and feet. She told me exactly where to put the chalk. She asked me to draw her holding her head with part of her brain coming out. She had me draw her mom, who takes care of her, in her police uniform, and to cover half of the sun because sun hurt her face. She spoke of noise, frustration, and depression because there was no cure for her condition. Her second choice was the Love Balloon (see Figure 1). She asked me to draw her face as the basket, and, once again, to include the port wine stains. She asked me to draw her mother as the balloon part, because “My mother keeps me afloat. I couldn’t have done anything without my mom.” She put herself with her mother, to “show the love we have for each other.” When I was leaving, she said the session helped her to feel better than when working with any of the therapists.

When Images Speak of Beauty. Through images, children expressed their feelings about the beauty of family, vision, and peace.

Table 4. Children’s Balloon Choices.

Balloon	1st Choice	2nd Choice	Total
Wish (Star/Butterfly)	21	4	25
Love	7	13	20
Sun	7	7	14
Stress	6	8	14
Peace	3	5	8
Giggle	1	7	8
Angry	4	4	8
Tear	1	2	3



Figure 1. A 15-year-old Girl Used the Love Balloon to Represent the Love and Appreciation She Feels for Her Mother. Courtesy of Joan Drescher.

Participant 41 – Girl, 13 years old: N. is a chronically ill child, a frequent flyer. I've known her since age 6, and she always seems to have a positive attitude. For her first selection she chose the Sun Balloon, which we filled with images of swimming, a dog running on the beach, cookouts, watermelon. She next chose the Wish Balloon. N. has a vision of saving the earth. The balloon's images refer to polar bears, rain forests, energy. She spoke of another wish, to become a nurse. As soon as she turns 14, she plans on volunteering at a local hospital to read to the children. I'm wondering if having a vision is what helps some children survive and thrive under difficult circumstances.

Participant 42 – Girl, 13 years old: T. was a little unsure at first. I left the book and came back later. T.'s mother was there and seemed quite stressed out. T. recently had left the hospital, only to have to return two days later. Her mother mentioned how difficult it was to get to the hospital with all the traffic. T. told her mom to sit down, that she (the mother) needed the Stress Balloon. Her mother suggested images of cars and traffic; T. mentioned noise, people coming in and out of her room, the uncertainty of when she would be going home, homework undone, painful shots. For the second selection, T. chose the Peace Balloon (see Figure 2). She said that she loved to sit in a favorite green chair with her favorite blanket around her and read vampire stories, listening to the rain. She described peacefulness of sitting with her golden retriever puppy and stuffed animals watching the sunset. She also enjoyed shopping with her mother and riding on the duck boat, and not having to be in the hospital. T. told me she planned to visit the Peace Balloon whenever she felt stressed.

When Images Speak of Stress. Through images, children spoke of stress about sadness and isolation, anger, noise and interruption, and uncertainty and pain.

Participant 10 – Girl, 10 years old: When I arrived, B. seemed sad and depressed. Her father was there, but seemed restless, and soon left the room. B. chose the Wish Balloon, and had me put her in it. She wouldn't look at me, kept her head down. She has cancer, and said she wanted to go to Disney World, to catch stars, see fish jumping out at Sea World. She was very hesitant about making color choices. She next chose the Tear Balloon. It was then that she opened up about what she was sad about, being in the hospital, meds, in bed, couldn't be in the



Figure 2. A 13-year-old Girl Finds Comfort Doing Things that Bring Her Peace in the Peace Balloon. Courtesy of Joan Drescher.

playroom, isolation, in the process of losing her beautiful red hair. Lots of tears in the balloon, but her favorite stuffed animal, a bunny, was also there to provide comfort. Her father walked in and asked, "Why did you choose the Tear Balloon? I told you I'd take you to Disney World?" Then he left again. I left the book with her and told her it was her friend. When I returned to see her the following week, her mother was there. She said, "You have no idea how important that book was to her. We have used the book ever since."

Participant 9 – Girl, 16 years old: When I arrived, E. was having trouble with her IV and seemed to be in pain. She told me she has Crohn's disease. Her mother was with her. E. started with the Stress Balloon (see Figure 3), and spoke of homework, school stress, then stress in the hospital. We put the pain in her stomach going up one side of the balloon in red. Asking her questions – "Where in the stomach?" "What color is it?" – we were able to define the pain, with colors and the location on the drawing. She wanted pills in all colors and amounts

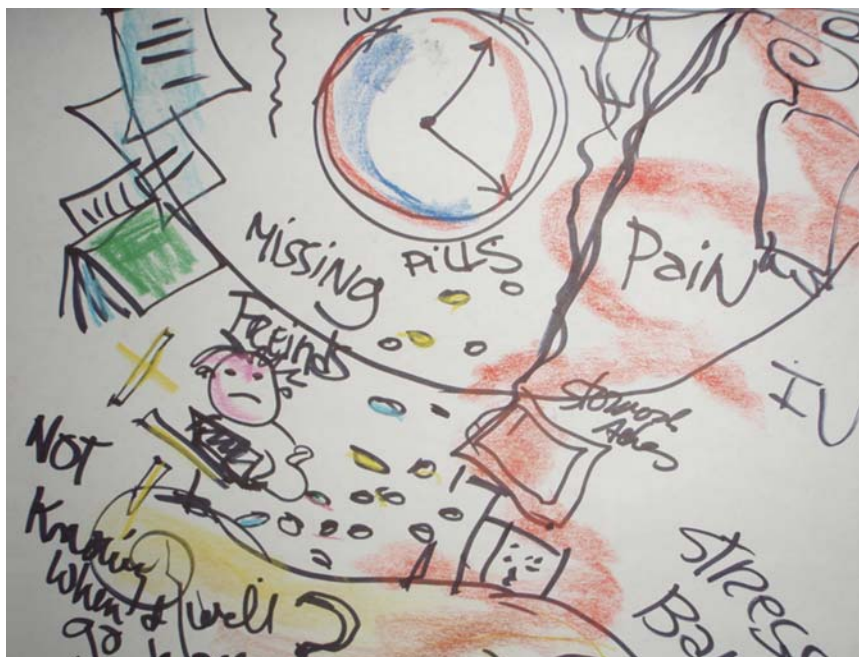


Figure 3. A 16-year-old Girl Depicts Illness and Hospital Stressors Along with Stressors She Faces Outside the Hospital. Courtesy of Joan Drescher.

covering the inside of the balloon. The large question mark represents the uncertainty of when she could go home; she said not knowing was very stressful. She next chose the Love Balloon and put her whole family in it, including the family pets. She described all of the family members to me so I could draw them accurately, and added some funny stories. It was a good way to get to know E. and her family. Her mother said she thought it was helpful to not think about serious medical issues for a while, but to put these issues into a fun conversation, to put things in perspective through drawing and humor.

When Images Transform. Through images, children transformed where they were, cultural barriers and visions of themselves.

Participant 45 – Boy, 11 years old: G. is a child with cystic fibrosis that I worked with before a few years ago. His mother was there. He was making paper airplanes with an intern and seemed to be a bit tired but said he was anxious to do the Moon Balloon. He chose the Love Balloon, and wanted to put his mom in first, followed by his black lab, his best friend. He had me add riding his bike in the mud, playing with cars, being outside, his older brother, and parakeets. His next choice was the Wish Balloon. He was Superman, with a cape, flying in the sky. We talked about where he would go, what the weather would be like, trying to get him to imagine with all the senses. We added a pet monkey, a rainbow he once saw, and magic cars that went very fast and didn't use real gas. He seemed to transform himself to a better place. His mother said that the Moon Balloon reminded her of all the things that make her and her son happy, and that she could use it for herself when things got unsteady for her.

Participant 44 – Girl, 18 years old: O. was from El Salvador. Her grandfather, who did not speak English, was with her. She chose the Wish Balloon. She missed her parents and five sisters and brother who were all in El Salvador. We drew them with a heart. She asked me to draw trees, bunnies, and butterflies. Her major wish was to go to Cambridge College. She next chose the Stress Balloon (see Figure 4). While we were working, child life invited O. to play bingo for prizes, but she said she wanted to stay and finish the balloon. She wanted me to draw her nasogastric (NG) tube in her nose. She was stressed about not having a green card.

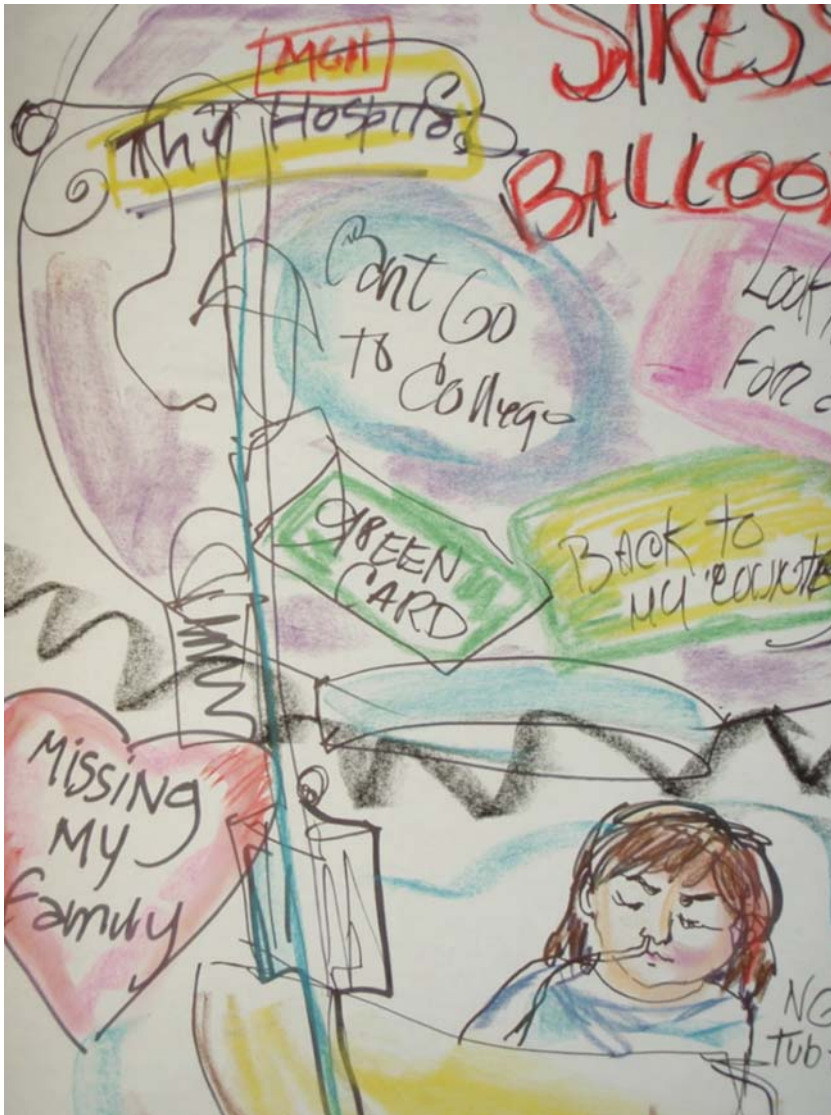


Figure 4. Stress Balloon Images Helped Transform Cultural Understanding by Transcending the Language Barrier for this 18-year-old Girl from El Salvador. Courtesy of Joan Drescher.

She really wanted to go to college. She said that she wanted to leave the hospital, that being sick was really depressing her. When we finished, she remarked that it was really helpful to identify all her stressors, and that she recognized what she wanted in her future and what she needed to work on. Later, one of her physicians told me that none of the pediatric care team had been able to connect with O., and that the images depicting the sadness and wishes O. was experiencing transcended the cultural barrier and helped all of them understand and take better care of her.

Discussion

Drawing by proxy was effective in improving both children's and their parents' perceptions of the child's present functioning quality of life. In all but one item (Children's item #1), results were statistically significant. Parents' perceptions were not significantly

different from their children's. This was not unexpected, as parents are traditionally viewed as experts on their children's emotional state. However, in this study, some parents expressed surprise at what their children were feeling.

Miller (2000) explains that the extent to which parents are able to appropriately represent their child's experiences may be limited. A growing number of researchers believe that the best method for understanding children's experiences is to ask them (e.g. Coyne, 2006; Darbyshire, Schiller & MacDougall, 2005; Forsner, Jansson & Sorlie, 2005; Pelander & Leino-Kilpi, 2010; Rollins, 2005b). Bastin (2000) points out that the traumatic impact of hospitalization on children may be twofold: the impact of the sick body on how children perceive their own body and live with it, and disruption of familiar and environmental benchmarks. Listening to children's experiences and discovering how *they* feel about them provides information for developing care plans designed to meet their individual needs, and a starting point for helping them cope with these experiences. In fact, through the United Nations Conventions on the Rights of the Child, listening to children and taking their feelings and opinions seriously are now enshrined in the laws of most nations, making it imperative that the options of children are considered when decisions concerning them are made (Taylor, 2000).

Drawing by proxy, through the Moon Balloon intervention, provided not only a non-threatening and safe environment for children to express their feelings, but also an opportunity for the child to become "artist" and create a visual means for sharing and taking ownership of them. Although artists only began exploring the logical limits of artist by proxy during the conceptual revolution of the 1960s, evidence of its practice goes back to the Old Masters (Galenson, 2006). Rubens, crippled by gout, sometimes found it difficult to work on the small scale that was necessary in preparatory drawings for his prints:

This physical limitation led him to experiment with a novel procedure. He dictated his ideas to Erasmus Quellinus who then recorded them in a drawing. . . . Even though he had not lifted a pencil in the manual execution of a work, Rubens was thus recognized as the inventor of a visual image – a revolutionary idea in the 17th century. (Filipczak, 1987, p. 82)

The idea or concept is the most important aspect of the work in conceptual art. All of the planning and decisions are made beforehand and the execution is a perfunctory affair; the idea becomes a machine that makes the art. In the case of the Moon Balloon intervention, one immediate consequence of this kind of art is that it is usually free from the dependence on the skill of the artist (in this case, the child) as craftsman (LeWitt in Zevi, 1994). Once the idea was established in the child's mind and the final form was decided, Drescher, a highly skilled artist, carried out the process.

How empowering it must feel to a child to see visible proof that someone heard, understood, and was able to transform their feelings into something concrete. As the creator, the child has a sense of ownership in the art. A sense of ownership has been associated with a perception of control over one's environment (Killeen, Evans & Danko, 2003), something often sorely needed by the child in the hospital. We argue that this conceptual art is more than a communication of feelings and experiences that are helpful for the medical team, but also a visible and external record of the self in good times and in bad (e.g. birthmarks, vivid descriptions of pain, transported through imagination, peaceful, comforted, loved, vibrant, visionary). Such art can serve as a form of what Malchiodi (1999) refers to as "visual legacy," a quality that can be particularly important during life-threatening circumstances such as HIV/AIDS, cancer, or other serious illness. In the event of death, such art survives as permanent proof of the child's existence.

The Moon Balloon theme of a journey in hot air balloons offered a framework for children to express emotions related to hospitalization, illness, and to some stressors with no relationship to either. They described common issues that cause stress for hospitalized children such as painful injections, uncertainty, and boredom. However, of particular interest was the number of children who mentioned noise. Despite efforts in recent years to reduce noise in hospitals (e.g. eliminating overhead paging), an increase in cell phone usage has supplanted and perhaps even exceeded the impact of previous sources.

There are several limitations, foremost the lack of a control group and randomization. However, a short interval between pre- and post-testing (within 15–30 min post-session) was selected in an effort to minimize the probability of the occurrence of intervening factors that could have affected scores. That said, although statistical significance with a randomized controlled design is the “gold standard” of research, clinical significance is also extremely important (Madden, Mowry, Gao, Cullen & Foreman, 2010). We believe the qualitative results of this study spoke to this issue, although more data would have been generated with audiotapes/videotapes of the sessions. Having a more equal girl/boy ratio as well as awareness of all of the children’s diagnoses would have provided the opportunity for additional analysis. We could possibly then predict which children could benefit most from the intervention.

Drescher brings a wealth of experience as an artist and writer, and in working with children who are dealing with difficult feelings and experiences. She has begun training other individuals in the drawing by proxy method. It would be interesting to see if these individuals can achieve similar results.

The Moon Balloon intervention was effective in improving the perception of momentary quality of life for hospitalized children, and provided an effective method for children to express their feelings about the hospital, illness and unrelated issues. Studies are needed in other settings where the Moon Balloon is used, such as in hospice and bereavement groups, and in other cultures. Research also is needed to address the characteristics that individuals require to effectively facilitate drawing by proxy interventions.

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References

- Bastin, T. (2000). Children and illness: Psychological aspects of hospitalization. *Archives of Pediatrics & Adolescent Medicine*, 7(4), 405–409.
- Bellack, J., & Fleming, J. (1996). The use of projective techniques in pediatric nursing research from 1984 to 1993. *Journal of Pediatric Nursing*, 11, 10–28.
- Bentley, T. (1989). Talking pictures. *Nursing Times*, 85(31), 58–59.
- Borysenko, J. (2005). Foreword. In J. Drescher, *The moon balloon*. Waltham, MA: Arvest Press.
- Brenner, A. (1984). *Helping children cope with stress*. San Francisco, CA: Jossey-Bass.
- Brown, J.R., & Dunn, J. (1996). Continuities in emotion understanding from three to six years. *Child Development*, 67(3), 789–802.
- Butler, E.A., Egloff, B., Wilhelm, F.H., Smith, N.C., Erikson, E.A., & Gross, J.J. (2003). The social consequences of expressive suppression. *Emotions*, 3(1), 48–67.
- Carney, T., Murphy, S., McClure, J., Bishop, E., Kerr, C., Parker, J., & Wilson, L. (2003). Children’s views of hospitalization: An exploratory study of data collection. *Journal of Child Health Care*, 7, 27–40.

- Councill, T. (1993). Art therapy with pediatric cancer patients: Helping normal children cope with abnormal circumstances. *Art Therapy, Journal of the American Art Therapy Association*, 10(2), 78–87.
- Coyne, I. (2006). Consultation with children in hospital: Children, parents' and nurses' perspectives. *Journal of Clinical Nursing*, 15, 61–71.
- Curtin, C. (2001). Eliciting children's voices in qualitative research. *The American Journal of Occupational Therapy*, 55, 295–302.
- Dalley, T., Case, C., & Schaverien, J. (1987). *Images of art therapy*. London: Tavistock.
- Darbyshire, P., Schiller, W., & MacDougall, C. (2005). Extending new paradigm childhood research: Meeting the challenges of including younger children. *Early Child Development and Care*, 175, 467–472.
- Drescher, J. (2005). *The moon balloon*. Waltham, MA: Arvest Press.
- Emshoff, J.G., & Anyan, L.L. (1991). From prevention to treatment. Issues for school-aged children of alcoholics. *Recent Developments in Alcoholism*, 9, 327–346.
- Favara-Scacco, C., Smirne, G., Schilirò, G., & DiCataldo, A. (2001). Art therapy as support for children with leukemia during painful procedures. *Medical and Pediatric Oncology*, 36(4), 474–480.
- Filipczak, Z.Z. (1987). *Picturing art in Antwerp, 1550–1700*. Princeton, NJ: Princeton University Press.
- Forsner, M., Jansson, L., & Sorlie, V. (2005). The experience of being ill as narrated by hospitalized children aged 7–10 years with short-term illness. *Journal of Child Health Care*, 9, 153–165.
- Galenson, D. (2006). *Painting by proxy: The conceptual artist as manufacturer*. Cambridge, MA: National Bureau of Economic Research.
- Gonzalez-Gil, F., Rio, C., Gomez-Vela, M., & Robaina, N. (2007, June). *Perceived quality of life and health of hospitalized children*. Paper presented at ISCI Inaugural Conference, Chicago, IL.
- Heiney, S.P., & Lesesne, C.A. (1996). Quest. An intervention program for children whose parent or grandparent has cancer. *Cancer Practice*, 4(6), 324–329.
- Heiney, S.P., Dunaway, N.C., & Webster, J. (1995). Good grieving – An intervention program for grieving children. *Oncology Nursing Forum*, 22(4), 649–655.
- Killeen, J., Evans, G., & Danko, S. (2003). The role of permanent student artwork in students' sense of ownership in an elementary school. *Environment and Behavior*, 35(2), 250–263.
- LaMontagne, L. (2000). Children's coping with surgery: A process-oriented perspective. *Journal of Pediatric Nursing*, 15, 307–312.
- Lindeke, L., Nakai, M., & Johnson, L. (2006). Capturing children's voices for quality improvement. *Maternal Child Nursing*, 31, 290–295.
- Madden, J., Mowry, P., Gao, D., Cullen, P., & Foreman, N. (2010). Creative arts therapy improves quality of life for pediatric brain tumor patients receiving outpatient chemotherapy. *Journal of Pediatric Oncology Nursing*, 27(3), 133–145.
- Malchiodi, C. (Ed.). (1999). *Medical art therapy with children*. London: Jessica Kingsley Publishers.
- Marion, M. (1995). *Guidance of young children*. Columbus, OH: Merrill.
- Michopoulou, A., Nikolaou, A., Goula, V., Iliadou, A., Voikli, K., Giannios, D., & Papatheodorou, S-M. (2005, November). *Pediatric patients and their quality of life*. Poster presented at The 2nd International Congress on Brain and Behaviour, Thessaloniki, Greece.
- Miller, S. (2000). Researching children: Issues arising from a phenomenological study with children who have diabetes mellitus. *Journal of Advanced Nursing*, 62, 622–641.
- Pelander, T., & Leino-Kilpi, H. (2010). Children's best and worst experiences during hospitalization. *Scandinavian Journal of Caring Sciences*, 24(4), 726–733.
- Pelander, T., Leino-Kilpi, H., & Katajisto, J. (2007). Quality of pediatric nursing care in Finland: Children's perspective. *Journal of Nursing Care Quality*, 22, 185–194.
- Pennebaker, J. (1997). *Opening up: The healing power of expressing emotions*. New York, NY: Guilford Press.
- Rollins, J. (1990). Childhood cancer: Siblings draw and tell. *Pediatric Nursing*, 16(1), 21–27.
- Rollins, J. (1997). Minimizing the impact of community violence on child witnesses. *Critical Care Nursing Clinics of North America*, 9(2), 211–219.
- Rollins, J. (2005a). The arts in children's health-care settings. In J. Rollins, R. Bolig, & C. Mahan (Eds.), *Meeting children's psychosocial needs across the health-care continuum* (pp. 119–174). Austin, TX: ProEd.

- Rollins, J. (2005b). Tell me about it: Drawing as a communication tool for children with cancer. *Journal of Pediatric Oncology Nursing*, 22(4), 203–221.
- Rollins, J., & Mahan, C. (2010). *From artist to artist-in-resident: Preparing artists to work in pediatric healthcare settings* (2nd ed.). Washington, DC: Rollins & Associates.
- Ryan-Wenger, N. (1992). A taxonomy of children's coping strategies: A step toward theory development. *American Journal of Orthopsychiatry*, 62(2), 256–263.
- Sherman, S., Eisen, S., Burwinkle, T., & Varni, J. (2006). The PedsQL Present Functioning Visual Analogue Scales: Preliminary reliability and validity. *Health and Quality of Life Outcomes*, 4, 75. Retrieved from <http://www.hqlo.com/content/4/1/75>.
- Sourkes, B. (1995). *Armfuls of time: The psychological experience of the child with a life-threatening illness*. Pittsburgh, PA: University of Pittsburgh Press.
- Sourkes, B. (1999). Art techniques with pediatric oncology patients. In S. Bertman (Ed.), *Grief and the healing arts: Creativity as therapy* (pp. 119–125). Amityville, NY: Baywood.
- Spouse, J. (2000). An impossible dream? Images of nursing held by pre-registration students and their effect on sustaining motivation to become nurses. *Journal of Advanced Nursing*, 32, 730–739.
- Stocker, G. (2002). Use of symbols instead of words. *Quality Progress*, 35(11), 68–72.
- Taylor, A.S. (2000). The UN Convention on the Rights of the Child: Giving children a voice. In A. Lewis & G. Lindsay (Eds.), *Researching children's perspectives* (pp. 21–33). Buckingham: Open University Press.
- Vessey, J. (2003). Children's psychological responses to hospitalization. *Annual Review of Nursing Research*, 21, 173–201.
- Zevi, A. (1994). *Sol LeWitt critical texts*. Rome: Editrice Inonia.