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Art Intervention With Family Caregivers and Patients With Cancer

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Purpose/Objectives: To describe the implementation and preliminary evaluation of an art intervention at the bedsides of patients with cancer and their family caregivers.

Data Sources: Field notes from ongoing encounters with family caregivers and patients with cancer, research literature, and descriptions of other programs.

Data Synthesis: An "Art Infusion" intervention was developed and offered to family caregivers and patients with cancer during treatment at a comprehensive cancer center. Training of interventionists, timing and delivery of the intervention, and the availability of art activity choices were key factors in the intervention's success.

Conclusions: Family caregivers and patients with cancer are interested in and responsive to art interventions. Additional research is needed to quantify the effects.

Implications for Nursing: Art interventions enhanced and extended the scope of care for family caregivers and patients with cancer. Nurses are in key positions to establish, supervise, and promote such interventions.

Key Points . . .

- ▶ An "Art Infusion" intervention was designed to provide stress relief and promote positive feelings in family caregivers and patients with cancer while patients were receiving treatment at a regional comprehensive cancer center.
- ▶ Prior to implementation of the intervention, volunteers participated in a training program that included study and discussion of Hogan's End-of-Life Model, role playing, and learning how to implement program activities.
- ▶ Since 2001, more than 450 family caregivers and patients with cancer have participated in the intervention and continue to express appreciation for these creative activities.

The positive effects of creative arts activities in a variety of vulnerable patient populations have been reported (Carlisle, 1990; Heiney & Darr-Hope, 1999; Walsh, 1993; Walsh & Hardin, 1994; Walsh & Webb-Corbett, 1995; Young-Mason, 2000). Arts-in-medicine programs have been established in hospitals to implement creative arts activities for both family caregivers and patients (F. Falk & P. Jacobsen, personal communication, November 5, 2001; Lane & Graham-Pole, 1994). Lane (1994) has provided a model for creative approaches with patient populations. Lane and Graham-Pole and Samuels and Lane (2000) have documented case studies that describe family caregivers and patients who reported transforming, illuminating experiences during and after their participation in creative arts activities. The benefits of participation in arts activities have been reported in patient populations including children with cancer (Heiney & Darr-Hope), hospitalized pediatric patients with cancer (Lane & Graham-Pole), palliative care patients (Shaw & Wilkinson, 1996), women with breast cancer (Predeger, 1996), adolescents who are suicidal (Walsh, 1993), adolescents who have survived natural disasters (Walsh & Hardin), and patients recently discharged from psychiatric units (Walsh & Minor-Schork, 1997). For example, in a qualitative study of patients with breast cancer, participants

used a variety of aesthetic methods to tap inner creativity, use form to make meaning, and promote feelings of empowerment (Predeger). In their work with children, Heiney and Darr-Hope included family members as they assisted children and family members in coping with difficult feelings during and after hospitalization.

The health and welfare of family caregivers, particularly those caring for patients who are terminally ill, are compromised seriously (Carter & Chang, 2000; Chan & Chang, 1999). Researchers report that 20%–30% of family caregivers suffer from psychological and mood disturbances (Blanchard, Albrecht, & Ruckdeschel, 1997). Usual roles and responsibilities often are shifted, adding distress and decreasing caregivers' quality of life (Steeves, 1996; Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999; Weitzner, McMillan, & Jacobsen, 1999). Investigators

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have identified problems in family caregivers related to stress, depression, physical health, and social support (Robinson & Austin, 1998), psychosocial resources (Goode, Haley, Roth, & Ford, 1998), anxiety (Higginson & Priest, 1996), and quality of life (King et al., 1997; McMillan, 1996; McMillan & Mahon, 1994; Weitzner McMillan, et al., 1999).

Family caregivers are difficult to reach because they are reluctant to focus on themselves even when they acknowledge their need for help (Walsh, Estrada, & Hogan, in press; Walsh & Schmidt, 2003). Family caregivers' ongoing and consuming focus on patients prevents them from taking part in interventions that may provide stress relief (Weitzner & McMillan, 1999; Weitzner, McMillan, et al., 1999). Researchers have suggested that new, innovative approaches are needed to reach vulnerable caregiver populations (Boyle et al., 2000; Ferrell, 1996; Kozachik et al., 2001; Meisel, Snyder, & Quill, 2000). No studies have been reported that focus on using creative art approaches solely with family caregivers.

The purpose of this article is to describe the implementation and preliminary evaluation of a unique intervention to infuse art into nursing care of family caregivers and patients. In an effort to provide interventions during times of caregiver accessibility, the "Art Infusion" intervention was offered to family caregivers and patients while patients were receiving treatment at inpatient and outpatient sites in a regional comprehensive cancer center in the southeastern United States. The timing and delivery site of the intervention was a key factor so that hard-to-reach family caregivers would be receptive and available (Walsh et al., in press; Walsh & Schmidt, 2003).

Conceptual Framework

The End-of-Life Model (ELM) guided the timing of the art intervention and promoted the interventionists' understanding of the family caregivers' struggles following the diagnosis of a life-threatening disease. The ELM defines the processes experienced by family caregivers from the time of diagnosis of a life-threatening disease to patients' death (Hogan, Morse, & Tason, 1996) (see Figure 1). Findings from a subsequent study with family caregivers of patients with cancer support the processes described in the ELM (Walsh et al., in press). Participants in the study described family struggles as they attempted to cope with stressors after patients' cancer diagnoses. Therefore, additional caregiver and patient stress was anticipated during patients'

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1. Getting the news—Getting the diagnosis
 - A. Shock
 - B. Calculating the odds
 2. Dedicating resources
 - A. Family being there for the patient
 - B. Accommodating care
 3. Negotiating treatment
 - A. Fighting for life
 - B. Enduring stress
 - C. Shutting it out
 - D. Maintaining hope
 4. Losing the battle
 - A. Seeing the obvious
 - B. Ending the suffering
 5. Death occurs
-

Figure 1. End-of-Life Model

Note. Based on information from Hogan, Morse, & Tason, 1996.

treatment with the corresponding fears of treatment failure and patients' death despite medical efforts. Thus, during hospitalization, family caregivers would be experiencing the "dedicating resources," "negotiating treatment," "losing the battle," or "death occurs" categories of the ELM. The Art Infusion intervention was developed to help reduce stress and anxiety as families moved through these ELM processes.

During the interventionists' preparation for implementation of Art Infusion, they studied these five ongoing processes, described initially in Hogan's theoretical grief-to-personal growth framework, which Hogan later relabeled as the ELM (Hogan & DeSantis, 1994, 1996; Hogan, Greenfield, & Schmidt, 2002; N.S. Hogan, personal communication, May 30, 2002), and subsequently in the family caregiver study (Walsh et al., in press). Thus, knowledge of Hogan's work helped interventionists to identify and understand the vulnerabilities of patients and family caregivers following a cancer diagnosis. Although the Art Infusion intervention was not a direct outcome from this framework, communication with patients and family members during the Art Infusion implementation was based on the interventionists' awareness and sensitivity to ELM family processes during patients' hospitalization and treatment.

Art Infusion was modeled after the arts-in-medicine programs at H. Lee Moffit Cancer Center and Research Institute at the University of South Florida in Tampa (F. Falk & P. Jacobsen, personal communication, November 5, 2001) and Shands Hospital College of Medicine at the University of Florida in Gainesville.

Training Program

Before the implementation of Art Infusion, the authors conducted a three-hour workshop at the comprehensive cancer center to train volunteers who had expressed interest in the project. These volunteers were a mix of professional artists, art students, and undergraduate and graduate nursing students. To prepare for the program, one of its leaders attended a "train the trainer" workshop sponsored by a nonprofit organization that promotes art activities with vulnerable populations in healthcare settings, Very Special Arts (VSA) of Florida, to learn specific training techniques for individuals working with patients who are terminally ill and their families. Workshop leaders decided that screening prospective participants to obtain information from volunteers was essential. The screenings addressed participants' reasons for wanting to work with patients who are terminally ill and their families, previous volunteer experiences with vulnerable groups, and volunteers' current state of physical and mental health. The coordinator of volunteer services, who assisted with recruiting and coordinating volunteers for the project, also participated in the workshop and eventually helped implement the Arts at the Bedside program.

At the beginning of the three-hour workshop, introductions were made and workshop leaders encouraged participants to share their reasons for involvement in the project. The leaders presented didactic information and situations (including the ELM) that the volunteers would encounter when working with family caregivers and patients with cancer. Trainees then participated in a number of role-playing situations where scenarios were presented that highlighted various difficulties that they could encounter at the bedsides of patients who are terminally ill. After role playing and discussion, the five Art Infusion intervention activities were shown using a computer

presentation that included graphics and directions for each activity. All activities were easy to implement and required no previous art experience. Workshop trainees then practiced constructing each of the objects that would be offered to family caregivers and patients.

As the workshop progressed, trainees became acquainted and noted each other's talents. During discussions, artist trainees expressed hesitation about approaching the bedside, but they were very comfortable with the art activities and handling art supplies. Conversely, nurse trainees felt confident about approaching patients and family members but were somewhat insecure about implementing art activities. Therefore, to take advantage of the unique skills that would complement one another, the group decided that a nurse and artist team would offer the intervention.

Implementation

Art Infusion was presented first to family caregivers and patients as a service available to interested parties. Coordination and cooperation between the interventionist team and staff were essential from the beginning of the project. A unit manager was recruited to refer the interventionist team to interested patients or family members and, more importantly, alert the team to situations where patients may be physically isolated because of low white blood cell counts or placed on precautions that would prohibit the team from working with them.

Art Infusion activities were not considered a form of art therapy but rather a package of creative art activities designed to promote a creative experience, distract caregivers and patients, promote focus on something positive, and increase communication between family caregivers and patients. Art Infusion supplies were introduced to participants by the intervention team via the "ArtKart," which was stocked with supplies and pushed into the patient area (see Figure 2). Examples of each activity were displayed on the side of the ArtKart. A detail of one completed activity (a silk wall hanging) is illustrated in Figure 3. A written "menu" of activities was provided to patients and family caregivers as they considered art activity choices (see Figure 4). The menu's five creative arts activi-

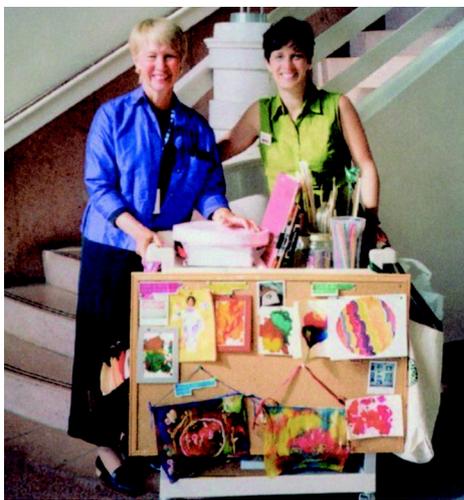


Figure 2. ArtKart and Interventionist Team



Figure 3. Detail of a Completed Silk Wall Hanging Activity

ties were tested during multiple intervention studies (Walsh, 1993, 2000; Walsh & Estrada, 2000; Walsh & Hardin, 1994; Walsh & Minor-Schorck, 1997; Walsh & Webb-Corbett, 1995). After the family caregivers or patients decided to try one or more of the activities, the intervention team helped the participants with instructions and supplies.

The team often noted uncertainty from family caregivers and patients when they first approached them about participation in the project. However, when they recognized that their participation was voluntary and Art Infusion was offered as a free service with a variety of activities, they became more receptive. Participants began to ask questions about the length of time each activity would take or how much skill was required. Additionally, when uncertainty about the future was an ever-present reality, some choices and control over their situation during participation may have been appealing to the caregivers and patients.

You decide what you want to do. The nurse and artist team will start you on the activities, and, if you want to continue after 15 minutes, will leave additional supplies with you. You can seek their help at any time.

1. **A "healthy" image poster of self or others.** Make a fun poster of yourself or a family member using a picture placed on top of an image that you choose from an image workbook. Time: about 15 minutes per image
2. **Monoprint art activity.** Choose your favorite colors to make abstract designs using watercolors. This is very quick and easy. Try it. You will want to make several. Time: about one to two minutes per print
3. **A mandala (circle) creation.** All family members can be involved in this circle creation containing a drawing or painting of anything such as your favorite foods, favorite sayings, or an abstract of colors. Time: can take as long as 45 minutes
4. **A silk wall hanging.** Painting on silk is easy and fun. One person or a group of people can paint on a small piece of silk. This can be completed in 30–45 minutes, and the team will help you prepare the wall hanging when you finish.
5. **Greeting cards to keep or send to others.** Draw your own design or even use one of your monoprints. Can be made in one to two minutes, or you can take a long time and use many of the supplies from the ArtKart. It depends on you.

Figure 4. "Menu" of Art Activities for Patients and Family Members

Results

When the project began, the purpose was to determine the interest and feasibility of offering family caregivers and patients the opportunity to participate in creative art activities in cancer center settings. From the onset, brief field notes were made regarding numbers of contacts and types of activities chosen. In 215 encounters with patients and family members, no one activity was preferred over others. A monoprint that could be created quickly and required little concentration and effort seemed most user friendly. After participants created one monoprint, they usually wanted to continue and often made several versions to use as small pieces of art or created monoprint designs on blank note cards or postcards.

Art Infusion was well received, useful, and feasible. However, continued operation of the project is dependent on the availability of artists and other volunteers. Future funding will be needed for research efforts, art supplies, and staff salaries. Positive responses and anticipated significant results of the ongoing quantitative study are hoped to provide an impetus for funding a full-time Art Infusion interventionist to promote and supervise the program.

Family caregiver and patient participation and staff recognition of the positive effects of the program in inpatient and outpatient situations led to a research proposal being funded by the University of Miami's General Research Support Award to measure outcomes with family caregivers (Walsh, Martin, & Schmidt, in review).

Family caregivers and patients continue to report that they not only enjoyed creating their works of art, but also felt less anxious as they participated in Art Infusion. Direct quotations included, "I almost forgot how stressed I was," "This is fun and helps me to relax," and "I immediately felt better when I started choosing the colors for the poster image." Participants often continued with activities for several hours and, in some cases, throughout their hospital stays. One patient scheduled for discharge called her son and said, "Don't pick me up until late this afternoon. I need to complete several art projects before I leave." Several participants indicated that they had a renewed interest in art and planned to purchase additional sup-

plies when they returned home. Table 1 lists additional examples of responses to Art Infusion.

The current study's authors developed several assumptions about how and why Art Infusion is effective. These assumptions originated from this project and parallel discussions by Young-Mason (2000) on the healing power of art.

- Family members and patients were provided with an opportunity to create something new and different at a time when they were highly stressed. The structured activities gave them a new focus and something to do. Although many family members would not leave patients' sides, they said they were not interested in reading nor could they concentrate on any task. Yet when family members and patients were approached, family members said that they could not resist trying a new and intriguing activity if they could remain with the patients. Therefore, family members' energy was diverted, and they appeared to enjoy and benefit from creative activities.
- This intervention returns participants to childhood and puts the right side of the brain to work. One patient noted that he had not colored since grade school and laughingly said he may consider art as a new activity for the future.
- Family members and patients have reported in previous investigations that they felt vulnerable with little or no control over the healthcare system (Councill, 1993). Thus, a choice of five different activities provided participants with some control, including the ability to stop activities at any time. By choosing from a menu of activities, they were able to make decisions about the types of activities that interested them at times when they felt that they had few choices about other matters in the healthcare system (Walsh et al., in press).
- Art Infusion provides patients and caregivers with something different to talk about with others. Involvement in the art activities appeared to enhance positive communication between family caregivers and patients, between patients and nurses, and between family caregivers and nurses. Participants laughed, discussed activities, and offered advice regarding how to proceed with activities.

Table 1. Art Infusion Participants' Responses

| Participants and Situation | Reaction to Art Infusion |
|---|---|
| Five family members were gathered around a dying patient (who died the next day). They all created image posters of themselves and placed the posters on the wall of the room for the patient to view. | The patient was alert and smiled when he viewed the posters. Family members began to talk among themselves and also smiled occasionally. |
| A fragile, older woman requested the ArtKart but then said, "I do not have the strength." However, she was able to press postcards onto a small piece of plexiglass to make abstract monoprints that contained her favorite colors. | Her son, although initially not interested, began to help his mother create the monoprint postcards. The patient said she finally found something she could send to her grandchildren, "even though I'm so sick." |
| A daughter-in-law had spent long hours at the bedside and immediately wanted to try each activity. She kept many supplies and worked diligently on various activities for many hours. | The patient and his wife watched their daughter-in-law with interest as she created various objects. They then requested that her art be displayed in the room. |
| A businessman receiving chemotherapy said he always had wanted to be a basketball player, so he made a basketball player self-portrait. | He laughed and said it was a good joke. He put the poster on a bulletin board in his room. |
| A dying woman and her family created a silk wall hanging together. This woman loved beautiful clothes and bright colors. | The family had good memories about creating the silk piece together and, after the patient died, they placed it in her casket. |

- Participants, after completing one or more activities, had something tangible to share with others. These creations often became gifts that family members gave to one another. This ability to create and give things to others at times when they felt useless and insignificant has been valuable, particularly to some patients who are very ill.

Outcomes

During the first year of the project, with teams available six to eight hours per week, the groups worked with 215 patients and caregivers. To the intervention team, the most evident and gratifying outcome often was displayed on the smiling faces of those who were able to create something beautiful, humorous, or inspirational during such difficult times. The husband of a patient who was diagnosed with mouth cancer told the intervention team that he and his wife had been extremely anxious and depressed since the diagnosis. While his wife was receiving chemotherapy, he created a silk wall hanging with "I love you" written on the silk. When the husband gave his wife this gift, her eyes filled with tears, and she began to smile. She held the silk piece on her lap and continually looked at it. Both said that their participation in Art Infusion provided a positive experience for them during very difficult times.

The study's research portion was completed after 40 subjects had enrolled. Results were highly significant ($p < 0.01$) on three self-report measures that showed lowered stress, reduced anxiety, and increased positive emotion in family caregivers after participation in arts activities (Walsh et al., in review). A growing body of literature demonstrates that stressors are associated with decreased immune function (Ader, Cohen, & Felten, 1995; Baron, Cutrona, Hicklin, Russell, & Lubaroff, 1990; Cacioppo, Poehlmann, Kiecolt-Glaser, Malarkey, & Burlinson, 1998; Herbert & Cohen, 1993; Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995). Therefore, in future studies, researchers plan to take salivary cortisol measures before and after the intervention to enhance self-report findings. The use of cortisol to measure stress has been discussed by Bartlett, Kaufman, & Smeltekop (1993) and Antoni et al. (2001).

Currently, three intervention teams are in place, and more than 450 family caregivers and patients with cancer have participated in Art Infusion since its implementation in 2001. The initial idea of creating nurse and artist teams to capitalize on the unique talents of both nurses and artists has been validated. The team approach also provided team members the opportunity to debrief one another after what were often very poignant events. Thus, team members were able to share their responses and reactions with others.

Nursing Implications

Nurses are in key positions to determine whether patients and family caregivers are likely to benefit from a creative art approach (Carlisle, 1990; Councill, 1993; Heiney & Darr-Hope, 1999; Walsh & Hogan, 2003; Young-Mason, 2000). Little time

is required to make a referral, participate, or simply encourage patients or caregivers to complete the activities. As a result of involvement in arts activities, family caregivers and patients may require less time and attention. The authors also anticipate that positive communication will continue during and after these activities as family members share thoughts about their art activities with one another and nursing staff. In the programs that already are established, nurses are collaborating with others to provide different and creative interventions with patients and families (F. Falk & P. Jacobsen, personal communication, November 5, 2001; Lane & Graham-Pole, 1994). Thus, nurses who are interested and willing to learn new approaches may become involved more significantly in promoting similar creative arts activities and programs with a variety of patients and family members.

The outcomes of Art Infusion are evaluated continually, and quantitative outcomes will be reported at the completion of the research project. Future qualitative work, including in-depth interviews with participants, also may provide new information about how the intervention works. If quantitative results from the current investigation determine that Art Infusion is effective, future plans may include expansion of the project to other healthcare facilities.

Summary

Family caregivers and patients with cancer noticeably changed their demeanors and attitudes as soon as they engaged in creative art activities. They became animated, debated about colors and designs, and laughed and joked about one another's efforts. Art Infusion is a novel approach that merits further investigation both quantitatively and qualitatively with family caregivers because researchers continue to suggest that new, innovative approaches are needed for the hard-to-reach family caregiver population (Aranda & Hayman-White, 2001; Ferrell, 1996; Kozachik et al., 2001).

Nurses and artists were able to learn during a three-hour workshop how to facilitate and implement the intervention. During this implementation and preliminary evaluation, Art Infusion provided distraction, promoted communication, and appeared to be a comforting and stress-reducing intervention. Family members and patients validated that participation helped them to have illuminating, joyful memories even during very difficult times. The use of creative art activities was an innovative and useful approach to infuse art into the nursing care of family caregivers and patients with cancer.

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For more information . . .

- ▶ Clinical Trial: Mindfulness-Based Art Therapy for Cancer Patients
www.clinicaltrials.gov/show/NCT00034970
- ▶ Thomas Jefferson University Hospital Art Therapy
www.jeffersonhospital.org/livebetter

Links can be found using ONS Online at www.ons.org.