

Creativity at the End of Life

By Hannah Fiske, *Social Work Today Magazine*, March 10, 2003

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Social workers in all settings are learning to help dying patients and their loved ones in new and creative ways. Expressive arts therapists are opening doors to a more holistic end-of-life experience.

Introduction

In recent years, as medical technologies have advanced, extending the human life beyond the expected range of even our grandparents, a new focus has arisen on end-of-life care. Across the country, hospices—poorly funded as they often are—struggle to provide services that can enhance quality of life for the dying patient as well as his or her family.

While efforts are often, and justifiably, directed toward palliative care, a new breed of therapists, social workers, and other personnel involved in end-of-life care is also incorporating elements of mind and spirit in work with patients who have been diagnosed with terminal illnesses. This new direction toward creativity, as well as the newly rediscovered respect for the role art plays in communication and emotional release, is extended to the families of patients during the bereavement process as well.

An Emerging Trend

The trend toward incorporating creativity and creative expression in end-of-life care is continuing to evolve and grow according to Elizabeth Clark, PhD, ACSW, executive director of the National Association of Social Workers, Washington, DC. “We are moving toward this as a society” she continues. “There are some initiatives, such as Project on Death in America, that fund many of these programs.”

While many social workers receive little formal training in end-of-life care, Clark believes an aging population, combined with medical advances resulting in patients who live longer with chronic or terminal illness, will serve to underline the importance of including end-of-life care in social work education programs. “We need social workers to pay more attention to this issue and to think about ways they can become more skilled in end-of-life care,” she says. “There is much that social workers can do to help people adapt to all of the changes and struggles involved in this period of their lives.”

Types of Creative Expression

Among the types of creative expression social workers and others find most helpful in working with patients who are terminally ill — and their families — are painting, quilting, poetry, music, and the dramatic arts, Clark explains. “Years ago, I was working at a hospice — in conjunction with a social worker and a creative arts therapist — with a group of children whose parents had died,” she recalls. “One of the activities was to have the children draw a mural.” Among the children’s concerns, she says, was a fear of ghosts. “So, one of the children drew a ghostbuster on the mural. This seemed to help all of the

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children deal more effectively with their own ghost anxieties.”

While painting and poetry are more familiar forms of art therapy, quilting has become a popular form of expression and remembrance — as evidenced by the huge [AIDS](#) quilt that travels around the country on display. Living Art also incorporates mask-making into its program, while another Montana-based organization, Chalice of Repose, offers music at the bedside of dying patients. “They use harps and actually match the music to the beating of the patient’s heart,” she describes. “It is overwhelming and amazingly effective.”

Social Workers Helping Terminally Ill Patients

When working with patients who are terminally ill, one of the first things a social worker or therapist learns is that they are worried about the physical pain that will be associated with their deaths, according to Kathy Persson, LCSW (VA), LCSWC (MD), director of grief and loss services at the Hospices of the National Capital Region, Fairfax, VA. “Yet, what you find in working with dying patients is that the real pain at the end of life is emotional and spiritual,” she continues. “Addressing those two pieces of the problem takes a little more creativity because we have medicine to alleviate the physical pain, but not the emotional.”

Emotional pain, Persson adds, is directly connected to physical pain, since tense people tend to hold their bodies stiffly which worsens bodily discomfort. “What we have to do, as therapists, is find out what is going on with the patient and his or her family” she says.

“Often, the patient is in a good place, but the family is not. That can cause a lot of emotional pain for the patient. Persson and her colleagues incorporate shadow boxes, music, and life review in their work with hospice patients to help them return to better places in their lives, she says. “It is important for them to see their lives as a continuum, instead of what it is right at this moment. It helps people to know that their lives were good, that they had meaning, and that they affected others in a positive way.”

In creating shadow boxes, letters, journals, and other works of art, she continues, patients are also able to leave behind something they find meaningful and beautiful for their families. Persson explains that art therapy is useful for both children and adults—sometimes especially adults, who seem to have more trouble finding ways of releasing and releasing their emotions.

Helping patients and families explore difficult emotions is one of the most basic and valuable benefits of creative arts therapy in end-of-life care. “We are not only our minds, nor are we simply our bodies. Art helps people deal with life holistically and express themselves with their hearts and souls, as well as their minds,” Persson says. “It is a deeper form of expression.”

Many times, she continues, art therapy also helps people cry, allowing them to travel through layers of repression to a deeper emotional level. “It is amazing how a therapist can help a patient with a creative activity and suddenly the tears flow,” she says. Artful expressions, Persson adds, allow people to be touched emotionally when they have been holding their feelings in check by intellectualizing their experiences.

Creating a New Understanding of Death

Art, poetry, music, dramatic arts, and other forms of creative therapy can also provide patients and their loved ones with a new and more creative understanding of, or approach to, death and dying. “It is important to define *creative*,” she cautions. “There are many different ways of being creative, and sometimes what is creative is the way in which a patient approaches his or her family, the interpersonal work they do before death.”

Those of us who are well, Persson adds, have accepted the notion that death is the most horrible thing that could happen to us. What she finds most incredible, however, is that most deaths are peaceful, with the patient achieving a state of acceptance that diffuses anger and bitterness.

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