

Listen to the Children and Honor Their Pain

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The title of this article comes from the philosophy that children need to be heard during the traumatic experience of illness or death of a family member. In this article, I will present a continuity of care model that supports children and their families from the point of diagnosis through to three years postdeath, should remission not occur. This model integrates the arts and has evolved through a process of listening to what children say they need to cope and adapt to the multiple transitions that a serious illness or death imposes on their lives. Grief is defined as any change or loss that causes sadness or anxiety. We use this definition throughout the spectrum of illness so that a child can be prepared for loss and death within a framework of hope while maximizing a healthy adaptation response. Dealing with grief is considered a necessary life skill.

All of the programs at Arthur G. James Cancer Hospital have evolved through feedback obtained from children and their families. We use the arts for healing because children do not have the cognitive development to express their fears and emotions with words. Art therapists, artists, mimes, quilters, storytellers, dancers, musicians, and photographers help children express themselves. A group of children of any age cannot sit in a circle and tell you how they feel about illness or death. However, if children are given the means to express themselves through art, the richness of the expression of pain and its subsequent healing can be quite remarkable.

Using the arts permits and encourages a child to express his or her feelings and open up to therapeutic intervention. The arts also help adults to express themselves more openly, and they give the entire family an opportunity to share emotions that they do not know how to talk about.

Literature Review

In their book, *How to Help Children Through a Parent's Serious Illness*, McCue and Bonn (1994) wrote, "With all our advanced techniques for treating serious disease, for saving or prolonging life, we in medicine have forgotten one very important affected group: the children of our patients" (p. 1). Yet, according to the National Cancer Institute and U.S. Census Bureau, approximately 129,089 children had a parent diagnosed with cancer in 1998 (Birenbaum, Yancey, Phillips, Chand, & Huster, 1999). The grief literature indicates that children who lose a parent at an early age may suffer from an inability to develop intimacy, depression, drug abuse, and failure in general life skills. Rait and Lederberg (1989) focused specifically on children of patients with cancer. They identified these children as a hidden high-risk group whose problems were minimized by overwhelmed parents and were invisible to healthcare staff. This study noted increased incidences of psychological symptoms such as changes in cognitive development and self-esteem and acting-out behavior.

Call (1990) concluded that children do not receive adequate support either during a family member's illness or after a fam-

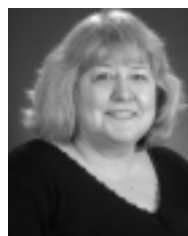
ily member dies and stressed the need for healthcare workers to be flexible and creative when working with this population. Lewis (1986) went further by writing that "linear staged models of the family's response to cancer as espoused in the clinical and theoretical literature, need to give way to more dynamic models that depict the family moving through multiple transitions each of which are characterized by such things as uncertainty, role changes, existential concerns, tensions, and emotional strain" (p. 271).

Continuity of Care Model

During the past 10 years, I have developed a continuity of care model that meets these expectations of a more dynamic model similar to the one described by Lewis (see Figure 1). Through feedback from the children asking to return to programs and classes, we felt that they should be allowed to come back as often as they needed throughout the illness continuum. We serve more than 250 children each year. As I tell parents when they first call me to get information about our programs, life is full of change and loss. Even though they wish they could spare their children this difficult journey, they have no choice but to embrace it as an opportunity for growth. The following describes the different components of the continuity of care model that I designed as part of children's programming at Arthur G. James Cancer Hospital.

Kids Can Cope, Too!

This is a six-week program designed to help children cope with the serious illness of a loved one from the point of diagnosis through end of life. We serve children aged 2–19 and separate them within age-related groups: ages 2–7, 8–12, and 13–19. Although the majority of the children have parents, grandparents, or siblings with cancer, the group is open to any child who is experiencing serious illness in the family. We have had families with AIDS, diabetes, and heart disease, among others. Also, patients with cancer do not need to be treated at the Arthur G. James Cancer Hospital for their children



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King is the 22nd recipient of this lectureship, which recognizes a healthcare provider who has made a substantial contribution to the psychosocial aspects of cancer care.

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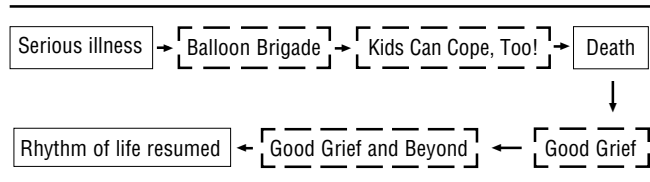


Figure 1. Continuity of Care Model

to participate. A support group for adults is conducted at the same time that the children are in session with their groups.

Kids Can Cope, Too! evolved through feedback obtained from children and their families. When we first started the program, we thought that the children and their families would come to one six-week program and then would be able to go on and cope effectively with the illness. Instead, the children begged their parents to return again and again throughout the continuum of illness. It was a safe place for them to share their fears and to be with other children who were going through the same experience. When they came to the group, they no longer were different from the children they had contact with at home or at school. The majority of children attend several consecutive programs throughout the illness continuum to end of life and even postdeath. In effect, children have different requirements for support throughout the continuum of illness. They have a need for knowledge at the time of diagnosis and coping and adaptation needs when a parent loses his or her hair, when a parent is fatigued or in pain, or when they will not see a parent for three months because of a bone marrow transplant.

Children need and want to know how to adjust to the myriad of changes they will encounter along the illness continuum. One young boy, after attending the second session of a program, said, "You know, I didn't want to come here, but now I feel like a bowling ball left my stomach." Another little boy cried every day in the corner of his classroom after he learned that his mother had cancer. After attending only one session, his teacher reported that he never cried in the corner again. The adults in the children's lives report that when their children attend the group, their grades improve, developmental regression such as incontinence decreases, and they have less acting-out behavior, separation anxiety, fear, and anger.

We teach the parents how children grieve and how to help them cope with their emotions and fears. The adults become an extended family for each other, going out for coffee, attending to each other's children when necessary, and calling each other between group meetings. Although this needs to be researched systematically, we have found that the children and adults who have attended the program throughout the illness continuum adjust and cope better when a family member dies than when they enter the program at the end-of-life stage or postdeath. A mother of two stated,

Other people are blown away by how openly I talk with my children about the illness and then the death. I've learned that it's important to be open with my children. Otherwise, they are all alone with their feelings and fears. They still know that something serious is happening, but they are being left out and feel isolated. We need support and so do they.

Balloon Brigade

This monthly event is a hands-on tour of the Arthur G. James Cancer Hospital to explain cancer and its treatment to

children. We also teach cancer prevention with antitobacco messages, skin cancer prevention, and the role of healthy eating and exercise in preventing cancer. Polaroid pictures are taken of the children in each area and are pasted into their "charts," which detail what we cover on the tour and cancer prevention information. The chart becomes a personal memento and a review of the material presented during the tour.

Children put on masks and gowns and scrub up for the operating room where they "operate" on an anatomically correct dummy and learn terms such as incision, excision, benign, and malignant. They tour the radiation therapy department and learn how this treatment kills cancer cells. In the chemotherapy clinic, they get "hooked up" to an IV and try on wigs while learning what the words "immune system" and "chemotherapy" mean and the importance of handwashing. In the laboratory, they look at cancer cells through a teaching microscope in addition to insects, hair, and dollar bills. They relax with a snack while we cover the importance of healthy eating and exercise. This part of the program is an adjunct for children who attend Kids Can Cope, Too! but it also is well suited for children who live too far from the hospital to attend any other programs.

Good Grief

This program, also six weeks long, is designed to help children cope with the death of a loved one from long-term illness, suicide, car accident, heart attack, and even war. Because grief is a family experience, an adult support group also is offered while the children are in session.

Besides learning about the grief experience and how to cope with it, each child makes a remembrance quilt out of pictures, clothing, and other personal mementos that belonged to their loved one or that have special meaning to the child. The children use their remembrance quilts to comfort themselves by sleeping with them or putting them up on the walls of their rooms. Following the directions given by the children as to where they want things to be placed and their ideas for the general design, a professional quilter finishes the quilts by the sixth session when they are awarded to each child. To see their faces when they receive their quilts is something to behold. The quilts continue to comfort them in their grieving and help them to remember and honor their loved ones throughout life. One child brought in some very nondescript seashells. When we asked him what these shells meant to him, he told us that he and his dad had seen the ocean for the first time a few years earlier and it was a day that he would never forget. He said, "We were so happy that day, running up and down the beach, and that is when we picked up these shells." Our quilter affixed them to the quilt with ribbons so that the child could take them off to play with them. Another child brought in a ragged piece of piano music that had hand-written annotations by his mother. He played the piano, as well. The quilter laminated the piece of music and affixed it to the quilt with hook-and-loop tape. The remembrance quilts offer many wonderful stories, but the importance of these quilts is that they are a child's view of what was important about the relationship with his or her loved one at the time of death.

Children are much more natural and instinctual about grieving once they understand the process. We use the metaphor of waves to help them identify the feelings and emotions of grieving. We explain that when their loved ones first die, they might feel like the waves are hitting them frequently and hard, but as time passes, the waves will hit less frequently and less hard. Nevertheless, grief is a lifelong process and you never

know when a wave will hit you. We tell the children to use those moments to remember and honor their loved ones.

We urge parents to cry with their children. One father told me that he tried to be strong and protective by not crying in front of his children. He said, "One night when it was clear that my wife was not going to make it, I was rocking both of them on my lap and I started to tear up. My little girl looked up at me and said, 'Daddy! You're sad, too?'" Adults need to cry with their children. It gives the children permission to cry and to talk about their fears.

Good Grief and Beyond

After completing Good Grief, children are invited to attend Good Grief and Beyond, a monthly support group that is designed to help them honor their loved ones through the year's events, holidays, and anniversaries such as Thanksgiving, Christmas, Mother's Day, Father's Day, or the first day of school. An adult group also meets with this program.

This group has become an extended family. The children love coming each month because they fear they will forget the people who died. Some of these children have been together for five years and are great friends. The children's group is involved in activities such as having dinner together, checking up on any new occurrences in their lives, giving honor to their loved one through art that is focused on the seasonal anniversaries, and participating in a closing ceremony that includes the releasing of balloons. We feel that it is important to find ways to honor the people who have died using life's yearly rhythm. Initiating new family rituals gives the family a new life rhythm, which is one of the goals of the grieving process.

The children must learn to contend with changes. Mom might start to date or contemplate remarriage. This may involve the new spouse's children entering the family unit. The children have fears such as "I already lost my Dad, and if my Mom remarries, will I lose her, too?" Or they may wonder if the new spouse is going to love them or exclude them. The majority of the adults involved are ages 30–45. They struggle with their own unfamiliarity with dating, whether the children will be able to handle their dating, the guilt of yearning for someone else in their lives, and whether they are being disloyal to their deceased spouses. It is rewarding to help these families deal with the aftermath of great loss and to see them go on with their lives.

A Higher Level of Being

Children who have experienced the threat of death or the actual death of a family member seem to achieve a more mature emotional intelligence that shows itself in a heightened awareness of others' needs and the development of compassion at an earlier age. They see themselves as experts in coping with illness and death because of the support they have received and want to help other children who may not have the advantage of the same resources.

The trauma literature demonstrates that if you help others get through trauma similar to what you have experienced, your capacity to heal is far greater than those who have not had the experience. For instance, in one of our groups, the 8- to 12-year-olds were feeling powerless by the cancer in their families. With discussion, they came up with the idea that they wanted to raise money for cancer research so that they might prevent other children from having to go through the experience. They decided to have a "rockathon," and each gathered sponsors who

pledged so much money for every hour that they would rock in a rocking chair. We rocked together during the group while eating popcorn and watching a movie. The staff members were very supportive and thought that if the group could raise even \$100, it would be beneficial. The children raised \$2,100! During our last session of this group, the children and their families gathered in one of our research laboratories. The researcher was studying the effects of berries as an anticarcinogen. After a tour of the laboratory by the researcher, he and our chief executive officer accepted an oversized check to support the Berry Fund. Our kids were so proud and honored.

In another example, the children wanted to write and produce art for a book that would help other children feel less isolated by grief. The outcome of this effort was a book called *Honoring Pain* (see Figure 2). The book was dedicated to the children affected by the events of September 11. The governor of Ohio sent it to the governor of New York. He, in turn, sent it to Mayor Michael Bloomberg of New York City, who requested that 500 copies of the book be placed in a private viewing room at Ground Zero. The books were available to the children affected by the events of September 11 on the first anniversary of the event, and our children were ecstatic to have had a role in helping those children.

The Comfort Card Project was yet another way that our children wanted to help others. We recognized that manufacturers did not make cards to give children at the time of the death of a loved one. We told them that they were the best ones to come up with sympathy cards for other kids because they knew what another child may want to hear at a time of great loss, having gone through this themselves. Working with artists and poets, the children designed cards and wrote sentiments that were very different from adult sympathy cards. Some of the cards were simple but profound: "After this difficult time, I hope you have a life full of hot chocolate," or "When you are feeling sad, just remember to take a hot bath." Older children expressed themselves this way: "Don't let tears invade your life—Someday all will be alright. There might be a scar in our heart. Now you have a fresh new start. I know what you feel like, I really do. You should know everyone loves you. That is all I have to say, the sun will rise every day." And yet another child wrote, "No one ever leaves all the way. They leave little pieces for family and friends to find and discover." We are planning to have these cards available to the public in the next few months.

Discussion

We live in a society where death is denied as part of a normal life experience. We are a youth-oriented society. Older members of the family die in nursing homes, families are geographically spread out so that they may not witness a loved one's illness or death, and our medical institutions see death as the enemy and as a failure. No wonder struggling with a serious illness can be isolating. If adults no longer know how to grieve, they will not be able to help their children with their grief. This programming helps children find ways to express themselves and also helps the adults in their lives to be open to the children's sometimes-difficult questions and to know that it is good to cry as a family.

From our experience, we believe that the intensity and comprehensiveness of the support and bonding that occurs among the hospital staff, children, and families throughout the continuity of care is necessary to provide a long-term therapeutic impact within this population. Programs that meet for a few hours or

People grow, and everything is not always perfect in life. The flower has a shield of silver around the heart to guard it. The heart is stitched together to help heal the pain. The gold drops represent the pain leaving. The blue represents all the bad and the yellow, good. With all the bad, good things will come out, if you give it time. Lightning bolts in the sky are sudden events that pop up out of the blue. It might scare you, but if you let the sun shine through, everything will be all right.

J.N.C., age 17



A weeping willow is sad because it lost someone. It never wants to blow in the wind anymore. All it wants is to be alone. Still it wants someone to be around.

D.E.P., age 10



The dragon was fighting the alien dragon and the alien dragon won. So, the alien dragon flew back to his planet Jupiter. The dragon flew after the alien dragon, used his fire, and beat him. The dragon was fighting cancer. He used fire that really was radiation to beat the cancer.

A.M.H., age 8



First time in my house, mom told me she had cancer, I went outside and cried, and thought what if my mom would die.

J.C., age 6

Figure 2. Sample Pages From *Honoring Pain*

Note. From *Honoring Pain* (pp. 6, 9, 12–13), 2002, Dallas, TX: Children Writing for Children, Inc. Copyright 2002 by Children Writing for Children, Inc. Reprinted with permission.

once a month may be useful for crisis intervention purposes but may not be sustaining enough to give children and their families the skills needed to help them through multiple transitions that are characteristic of a long-term illness.

Sometimes, a long-term relationship is needed to help a child feel safe opening up. Eight-year-old Alex's mother was away from him for three months while going through a bone marrow transplant. She died a year later. During the first six months, everything that he drew about his inner feelings, be it a picture or a mask of how he felt inside, looked like him on the outside—calm and in control. Finally, after an ongoing relationship with the group leader, Alex was asked to draw a picture of himself experiencing his most intense emotion about his mother's death. He drew a dramatic picture of himself with his head

screwed onto his body, his eyes as dazed circles, his hair electrified and standing on end, and all of his feelings moving in erratic scribbles in his upper chest. When asked what emotions he was feeling in the picture, he replied, "I feel weird and confused." When I shared the picture with his father, he asked us what could he do about it. I said, "Nothing can be done except to be there for him and honor his pain. He now knows that you are a witness to his pain, so it will be easier for him to talk with you when he is ready." Afterward, it was much easier for this child to access his emotions about his mother's death and to do the work of grieving that he needed to do.

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