Wish Fulfillment: Palliative Care and End-of-Life Intervention

Bonnie Ewing

Children with life-threatening illnesses are subjected to numerous treatments and procedures. They endure enormous physical and emotional pain as attempts are made to prolong their lives. These children require sensitive care by pediatric nurses who recognize the importance of the child’s need to grow and become. A way to satisfy the child’s desire is the fulfillment of a special wish, which provides a sense of future, a way to be something more. The fulfillment of the wish is a palliative care and end-of-life intervention that can ease suffering and sorrow for the child and family. It is essential to understand, however, that the child has complex emotions as the wish is fulfilled. The provision of care must, therefore, include psychological support, empowerment, and communication with the child and family to assist with life-threatening illnesses as they experience suffering within the tension of living and dying.

One of the greatest challenges for pediatric nurses is providing care for children with life-threatening illnesses. They endure complicated treatments and complex procedures, and experience physical and emotional pain as efforts are made to extend their lives. Children with life-threatening illnesses require sensitive care by pediatric nurses who promote healing knowing that death is a possibility. The fulfillment of special wishes for children with life-threatening illnesses is palliative care and an end-of-life intervention that will enhance the life of the child in the process of both living and dying.

Hope and Joy
The fulfillment of special wishes is a means of giving children with life-threatening illnesses a chance to become. They can be whomever they want or obtain something they thought to be impossible. Wishing for something engenders the hope that the wish will come true. Future possibilities are intertwined with hope, a sense that life is worth living. Hope is fundamental to survival and is an important underlying element in the child’s will to live (Hinds, 2004; Kübler-Ross, 1983).

Drawings by children with life-threatening illnesses who had their special wishes fulfilled were a way for them to share what they could not express in verbal language. Ewing (2007) conducted a hermeneutic inquiry to discern the meaning of having a special wish fulfilled for children with life-threatening illnesses. Children were asked to draw their experiences at a holiday gathering where they could respond freely. Art provided a way to give voice to elements they were trying to understand but were having difficulty expressing in words. Complexities revealed in the form of symbols and images in drawings are often too difficult for children to express verbally because their language is unsophisticated. Their drawings were unspoken expressions that contained images, symbols, and configurations (see Figure 1). Children are in a prime position to be misunderstood by adults (Garbarino, Stott, & the Faculty of the Erikson Institute, 1992); therefore, visual text was used to discern the language of their drawings. A dialogue with the drawings revealed themes and patterns that were interpreted.

These children comprised a culture of their own, and they shared experiences of how it was to have a special dream fulfilled while living with a life-threatening illness. A trip to Walt Disney World, a computer, and a pinball machine were among the special requests chosen by children. Symbols of hope and joy in the form of smiles and rainbows can be seen in their pictures.

The children’s artwork, however, unveiled even more about their experiences. A divided dark sun with a smile half upturned and half downturned, uncontrolled lines, a computer on a desk without the child present, and a thin Mickey Mouse with missing body parts lying on the ground in front of Magic Kingdom were some of the constructs that revealed another dimension of their reality. The children expressed darkness, anxiety, isolation, and bodily disturbances as they had a dream come true (Ewing, 2007). Their drawings were expressions of an unspoken language created for others to understand that they experienced complex emotions while they had an ultimate wish become a reality. They lived with the tension of living life to the fullest while being saddened and pained by disease that threatened their lives.

Suffering and Sorrow
Children with life-threatening illnesses suffer low self-esteem as disease takes hold of their bodies (Hynson, Gillis, Collins, Irving, & Trethewie, 2003). They develop an awareness that they are changing and becoming different from other children, resulting in loneliness and isolation. They suffer pain and become aware when their illness progresses to...
the point that they are dying (Bluebond-Langner, 1978). Their daily activities have changed, and their relationships with peers may no longer be the same. Suffering from feelings of loneliness, they often have difficulty expressing their emotions. Moustakas (1961) states that feelings of loneliness are often hidden in childhood. They are frightening and distressing, and therefore, are restricted, controlled, denied, or if expressed, rapidly resolved or eliminated through busy activities and goals.

Children with life-threatening illnesses are often afraid to let others know how they feel. They fear dying and fantasize about what life would be like without parents, brothers and sisters, and the comfort of home and friends (Davies, Collins, Steele, Pipke, & Cook, 2004; Kübler-Ross, 1983). Wondering if there will be anything after death, they feel anxiety, terror, anger, despair, and depression.

These children often reveal an edited version of their internal life. They may regress physically, socially, and emotionally, which varies during the course of illness (Kübler-Ross, 1983). To counterbalance sorrowful feelings, they seek to go to faraway places, meet someone special, or possess a special item.

Family

The fulfillment of the wish is a means of bringing children with life-threatening illnesses closer to their families. The experience of participating in the fulfillment of a wish is, for many families, a respite, an opportunity to get away from hospitals and day-to-day burdens. Parental responses strongly affect the dying child’s reaction to illness and impending death (Bjork, Wiebe, & Hallstrom, 2005). Parents must be sensitively supported through their experiences so that their dying child may be able to receive love that is desperately needed (Davies & Connaughty, 2002).

Including the siblings in the fulfillment of the wish helps them feel more a part of the family. Research has shown that siblings suffer from isolation and trauma if they are excluded and uninvolved in the care of the dying child (Rollins, 1990). Siblings who share in the care of the ill child can understand and communicate at a different level than if they had not participated. If siblings are involved closely in the care of the dying child, they are able to accept the death of the child more peacefully (Giovanola, 2005).

Palliative and End-of-Life Care

Wish fulfillment is a palliative care intervention that provides children with an opportunity to carry out something as normally as possible. Palliative care is the provision of interventions that relieve physical and emotional distress that comes about with a life-threatening illness (Feeg, 2005; Field & Berman, 2003). Combined with curative care, palliative care that includes complementary and alternative medicine will enhance the child’s ability to endure difficult treatments with an improved hopeful outlook (Matzo, Sherman, Penn, & Ferrell, 2003; Rollins, 2002). Palliative care is a way for children and their families to gain a sense of normalcy in the face of life-threatening conditions.

Figure 1.

A 6-year-old girl with leukemia, who requested to go to Disney World, drew herself standing alone and smiling beside Minnie and Mickey. In contrast, stick-like figures with missing facial expressions are drawn in a pool. Water can be dangerous to a child, but also may be a form of play and fun that is spiritually healing.
The fulfillment of the wish gives children a way to rise above a life of problems and sorrow. Children can transcend the reality of their complex existence and come closer to becoming true children again. This sense of being a child embodies deep meaning because it is the means for children to continue to live and grow. The fulfillment of a wish is a way of recapturing how it is to simply enjoy living in a healthier and happier state of mind.

Having a special wish come true can be provided as an end-of-life intervention that focuses on preparing for anticipated death (Ferrell & Coyle, 2002; Field & Berman, 2003). Research by Wolfe et al. (2000) indicates that children who die of cancer receive aggressive treatment, and many suffer substantially in the last month of life as attempts to control symptoms are often unsuccessful. Greater attention to the overall well-being of the child may ease suffering. End-of-life care strategies that help children and their families in their final days feel comforted and peaceful as death approaches should be included in the child’s plan of care (Davies & Connaughty, 2002; Malloy, Sumner, Virani, & Ferrell, 2007). Adolescents may need special considerations to accommodate their developmental issues (Freyer, 2004). The fulfillment of a wish can provide an immediate and may help ease the transition to death. For example, an adolescent who had cancer was near death. He was in the hospital and had chest tubes in place. As he lay dying, he asked if he could leave the hospital to attend the Super Bowl. The physician honored his wish and removed the chest tubes and intravenous lines. He left the hospital, and had a wonderful time seeing his favorite team play. Three weeks later he died. His death was not easy for his parents, but the lasting memories are still talked about today (Ewing, 2007).

Psychological Support, Empowerment, and Communication

The care of the child before, during, and after a wish is fulfilled necessitates that practitioners are holistically attuned to the needs of the child and family (Ewing, 2007). Health care providers must understand the importance of providing psychological support, empowering the child, and opening up communication with the child and family.

Psychological support. Superimposed on all physical challenges that the child experiences are complex emotional issues that need to be addressed. If the child chooses a trip, such as on a cruise ship to a far off island, health care providers must help the child and family know how to recognize significant physical and emotional symptoms, and notify appropriate medical personnel when help is needed.

The medical team needs to understand that this intervention is palliative and promotes quality of life during a time when a child is suffering. Some children have dreams while having their wish fulfilled or shortly thereafter. Children often struggle to live while wishing to die and die while wanting to live. It is important to address spiritual needs to promote a sense of wholeness and unification of the self (Furman, 2000).

Traditional curative care views death as a phenomenon to fight against, prevent, and overcome, which places a burden upon children with life-threatening illnesses at the cost of causing emotional and physical pain. The children are caught in between, trying to survive while professionals attempt to save their lives. Children may want to relinquish the pain, sorrow, and sadness that come with dying.

Wish fulfillment may provide an opportunity, if even for a short duration, to live life fully, being physically, emotionally, cognitively, and spiritually unified. It offers a way to balance the child’s tormented life of struggling with pain and torment by promoting an experience that is hopeful as the child moves toward death. Balance is a way of staying in control physically, emotionally, and spiritually. It has an ontological meaning that is related to healing. Balance is the sense of peacefulness that one can attain through integration of mind, body, and spirit (Dossey & Guzzetta, 2005). It does not necessarily mean that balance brings about a cure, but it can bring about a sense of peace in which healing can occur.

Empowerment. By exploring desires and empowering children to make decisions about how to create a dream and make it a reality, nurses can help children discover inner strengths at times when they experience sorrow and hopelessness. If children have meaningful projects that help them experience a sense of future, they remain hopeful (Field & Berman, 2003; Hinds, 2004). When children participate in the creation of their wish, they are involved and in control, enabling them to verbalize desires, make choices, and influence decisions. As their wishes are fulfilled, some children might express choices in treatment options as well as how they might want to die.

Communication. The wish offers a way to understand how the child and family are coping by listening to adaptation patterns and coping skills (Wolfe, 2004). The nurse can assist the child to communicate meaningful aspects of the experience. Having a child tell a story about the dream that came true opens the way for the child to communicate about life and illness that may help the child move toward a healthier state or transition toward death. If the family took pictures or movies of the experience, the nurse can open up questions that may help them to reveal the special moments that were meaningful.

Children’s stories of their wish experiences provide an opening for discussion about joy and sadness and other dreams that the child might have. Drawings by children of the fulfilled wish as well as about other wishes and dreams will enhance their stories by offering an additional avenue to gain insight into the child’s reality. Through metaphorical thinking, children use symbols and images in their drawings to represent elements in a situation they are trying to understand. Embedded meanings are manifested in symbols and images that may be interpreted as expressing what the children are unable to articulate (Rollins, 2005; Skybo, Ryan-Wenger, & Su, 2007; Welsh & Instone, 2000).

Emotions that are healing as well as those that are painful become unveiled. Including the family in the discussion will encourage an exchange with parents and siblings that will provide an opportunity to share their feelings for one another. By exploring the child’s thoughts, ideas, and emotions, the child and family may be helped to accept what they believed to be intolerable (Kübler-Ross, 1983).

Case Study: Ben’s Story

Ben was a 9-year old boy who had leukemia. His mother learned of the wish-granting organization, The Make-A-Wish Foundation, that grants wishes to children with life-threatening illnesses. Volunteers from the foundation visited the child’s home and conducted an interview (Ewing, 1995).

Ben had two special wishes, but he was unsure which one he wanted to have fulfilled. He wanted to meet either Dolly Parton or some of the players of the Pittsburgh Steelers. As he walked around the room, he spoke of Dolly Parton, but it was

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How does a child qualify for a wish?
The child must have a life-threatening illness in which the child might not outlive the 18th year of life. Ages for fulfilling wishes are generally between 3 and 18 years. Wish requests under the age of 3 years are dependent on request and illness.

Who can make a referral?
A referral can be made through parent/legal guardian, medical professionals, or the potential “wish child” to the wish-granting organization. If a well-meaning friend or family member refers a child, it is suggested that they contact the family, who in turn should place the call. This protects the child who may not be ready to handle such an experience.

How is the wish granted?
Trained volunteers visit the child in the hospital or home and ask the child for three wishes. A conclusion regarding the choice is reached after discussion with the child. After obtaining permission from the child’s physician and agreement from the parents/legal guardian, the wish is granted. It is preferred that the wish is fulfilled when the child is in a relatively good state of health to enjoy the experience. However, granting the wish at or near the time of death is considered more important than to have the child die without having the wish fulfilled.

What types of wishes are fulfilled?
Many children ask for a trip to Disney World. Others want to swim with dolphins, go fishing, become a ballerina, or meet a special celebrity. Shopping sprees are favorites for adolescent girls, and other children want computers or new furniture for their room.

How are wishes funded?
Members of the organization in partnership with community groups conduct fundraising events. For example, an entire school may become involved in the fulfillment of a schoolmate’s wish by conducting a car wash, holding a dance, or having a bake sale. Social groups and churches raise money by hosting special events. Some companies provide services, such as trips to airports, airfares, tickets to games, and contacts. Individual, private, and corporate donors may participate actively on boards of chapters of the wish granting organization. The organization may conduct its own fundraising events, such as golf tournaments or dinners.

What are the jobs of volunteers?
Volunteers are necessary to handle all aspects and details of a child’s wish. This generally involves going into the home and spending time with the ill child and the family members. They also contact physicians and hospital personnel to determine the readiness of the child and family. These home care volunteers require specialized training to work with seriously ill children. In addition to handling the activities and fundraising for the child’s wish, they do office work and public speaking for the organization.


The fulfilled dream became a part of his end-of-life care. Ben’s experience was magical for Ben as he met many of his favorite team won. He received a football with the players’ signatures on it, which he kept with him in his hospital bed. Within a few months of having his wish fulfilled, Ben died. As he passed away, the football was near him.

Since Ben died, his story lives on for others to know and understand how this experience became a part of his end-of-life care. Ben’s experience was an appropriate dream for a 9-year-old boy—to meet football players and have a special football signed by them. The team members were very encouraging to him, and he shared his stories with family, nurses, doctors, and classmates. The fulfilled dream became a part of his way of being until his death. His mother, while greatly saddened, expressed having beautiful memories during a most painful time in their lives.

Wish Granting and the Community
Wish-granting organizations, such as the Make-A-Wish Foundation, exist in communities and rely upon individuals and other organizations to provide the means to grant wishes. Hospital, home, and school nurses work with volunteers to identify the needs of the child and family, plan the intervention with wish-granting organizations, and communicate with the family regarding the implementation and completion of the wish.

Through fulfillment of the wish, the child can also become actively involved with the community. Many social groups and churches raise and contribute funds. Other voluntary organizations, such as fire and police departments, offer goods and services to help make the dream become a reality. For example, a young child wanted to be a policeman, so the police department offered to give him a uniform and take him for a ride with the police force.

Many people in the community, including health care professionals, want to refer a child, but they may be unclear about how a child is referred for wish granting and the constraints that exist in fulfilling a wish. Health care providers are often unaware that special requirements must be met before a wish can be granted. A list of frequently asked questions and barriers to wish fulfillment are provided in Tables 1 and 2.

The community’s participation in the fulfillment of children’s wishes is a way to experience the joys of the children, which has a profound effect upon those around them. Adults often look to children for their own enjoyment and glean a sense of the joy of life from them. Seeing smiles and making them feel healthier helps adults to feel better as well.

The fulfilled wish may have a healing effect on those who connect with the child. Children can connect adults to the wonders of life that come with being a child. They represent the future—a way to live on. Providing children with a sense of hope and
future possibilities offers the notion that there may be something hopeful in life and in death.

References


Table 2.
Barriers to the Fulfillment of Special Wishes for Children with Life-Threatening Illnesses

- Physicians may not be willing to approve a wish that the child requests if they believe that the fulfillment of the wish jeopardizes the child’s ability to fight the illness.
- Requests for unsafe items, such as weapons or animals that may cause a risk to the child’s health, are not granted.
- Children may request money that is needed by parents for medical reasons. Wish-granting organizations believe that it is not best for the child to have such a wish granted.
- Parents may influence the child’s desires to have a wish fulfilled. The child’s wish should be honored and not the wish of the parents.
- The child may live in a region where there are no funds to have a special wish granted. The fulfillment of the wish may be accomplished by another chapter of the wish-granting organization.


Additional Reading