



Building a Legacy for Children and Adolescents With Chronic Disease

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Children and adolescents who undergo extensive health-related treatment benefit from sharing their experience. Here, we describe how one institution established a legacy program for patients during their chronic disease treatment and how their journeys were symbolized with the distribution of beads. The legacy bead program was designed to be individualized according to the patient's journey and treatment experiences. A bead program offers a concrete, tangible method for patients to share their treatment journeys while building legacies on which they can reflect.

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CHILDREN AND ADOLESCENTS who experience chronic illnesses find meaning in sharing their stories with others. Described as illness narratives, these stories provide patients with opportunities to share their illness experiences through narratives that symbolize their journeys, coping, and ultimate resilience (Sakalys, 2003). The therapeutic process of sharing their stories provides children and adolescents an opportunity to share feelings, process challenges, and find ways to deal with their ongoing medical experiences and the changes associated with their developmental ages.

Children, adolescents, and parents not only want to share their stories but also want to build a legacy to ensure that their stories will not be forgotten. One means to share, process, and cope is through a legacy program. Here, we describe how our child life specialists have created a legacy-building bead program utilizing Erik Erikson's psychosocial stages as a framework for children, adolescents, and their families as they journey through life-threatening illnesses.

Review of Literature

Legacy has been described as transmission of self, values, and beliefs that may be conveyed through actions or behaviors and artifacts or concrete items (Hunter, 2008). Legacy building through a bead program has also been defined as a program directly involving the patient and family in meaning-based coping through construction of a lasting memento (Allen, 2009). These programs have been found to have appeal across pediatric age groups and across gender (Foster et al., 2009).

In creating a comprehensive story for the patients and families, the legacy bead program should incorporate professional disciplines throughout the health care organization. This allows development of an in-depth legacy item to vividly detail the patient's health care journey and story. Incorporating both good and bad experiences during the journey allows the patient and family to evaluate their life experience with balance, making an effective life review (Ando, Tsuda, & Morita, 2007).

Wholihan (1992) and Dunn, Haight, and Hendrix (2002) suggest that offering a structured chronological life span approach empowers patients to determine the direction in

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which they wish to review their life, increasing their focus on emotional needs accordingly. In addition, creating a legacy with a celebration perspective through the journey assists in maintaining an individual's sense of self and pride (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008), allowing patients to recount their significant milestones in treatment and accomplishments, thus providing a sense of satisfaction with their journeys (Ando, Tsuda, & Morita, 2007). Therefore, two patients with the same treatment plan will create unique legacy bead strands because the emphasis becomes on how the child or adolescent feels and perceives his or her individual experience.

The self-renewal, self-awareness, and personal growth phase of meaning making is theorized by Lee (2007) to emerge specifically in cancer patients when limitations from a cancer diagnosis are integrated into a new life concept that offers the patient a sense of order and purpose. Utilizing beads for legacy building contributes to this phase of meaning making by assisting patients in creating this sense of order and purpose by documenting their journeys and tangibly seeing their personal accomplishments during the process. Furthermore, families participating in legacy building with a child or adolescent patient are creating a coping mechanism in which they might find comfort should the child be given a poor prognosis. Callister (2006) finds pediatric legacy work to be "an important supportive intervention to assist the family in accepting the reality of death." It has been our experience that parents become intently focused on completing legacy projects once end-of-life discussions have been introduced. They become intimately involved in commemorating the legacy of their child and the time they spend together. Thus, legacy building benefits the patient and family, providing a legacy to their personal journey (Ives-Baine, 2010).

Legacy Bead Program Background

Previously at our institution, when children encountered a task they deemed difficult, they were given the option of choosing a small toy from a treasure chest. The toys were similar to those received at a fast-food restaurant and would often follow tasks such as a blood draw, intravenous start, assessment of blood pressure, and other invasive procedures. The toys served as an emotional band-aid after the undesirable procedure for the child and for health care providers who requested the procedure. Over time, the nurses, physicians, and child life specialists began to question if repeatedly providing toys, even small ones, promoted a culture of extrinsic motivation and masked the child's accruing accomplishments.

In 2008, interdisciplinary discussions began to consider a developmentally appropriate program that would foster feelings of accomplishment and provide a history of the journey. During these discussions, the child life program suggested the creation of a legacy program. Child life



Figure 1 Patient sharing legacy bead journey with her mother.

specialists are specifically trained to incorporate activities aimed at assisting children in reflecting on their thoughts, emotions, memories, and even physical appearance while striving to reflect these constructs into an item that will endure, such as art, pottery, or photography. Following discussions with child life, nursing, and nursing administration, we used these opportune moments to encourage legacy building by creating a legacy bead program.

The aim of the legacy bead program is to provide a means of acknowledging the patients' accomplishments while they undergo treatment, provide a platform for patients to tell their treatment stories, and allow patients to create legacy items that reflect their thoughts, emotions, and memories with representation of their coping during their treatment journey. Although bead program concepts are utilized at other institutions, the legacy bead program was created to address and adapt to the unique needs of any specific population. The legacy bead program is available to all patients, including those with newly diagnosed disease, in active therapy, or after the completion of therapy. Parents of children 5 years or younger are required to sign a waiver for participation, agreeing to assume responsibility for their child's beads because the beads are small and can be considered a choking hazard. The primary diagnoses served at our institution include oncology, hematology, and infectious diseases, and the legacy bead program we describe is specific to these chronic illnesses. However, the development and implementation of a legacy bead program is applicable to any chronic or life-threatening illness (Figure 1).

Program Initiation

Prior to program initiation, hospital staff was provided an overview of the bead program, with educational presentations to all nursing units, clinics, and departments with direct patient contact. The educational overview emphasized the importance of multidisciplinary participation and the importance of understanding the program as a representation of the child's or adolescent's journey experience and should not be used as a reward for compliance. Patients and families were informed of the program with flyers throughout the hospital, and an article was published in the monthly Parents newsletter sharing the importance of legacy building during the treatment journey.

Program initiation featured a kickoff event with tables stocked with assorted bead-making supplies. At each table, child life staff assisted the patients in making their

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