Achieving Balance: A Case Study Examination of an Adolescent Coping With Life-Limiting Cancer

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A single-case study approach was used to provide an in-depth examination of the special events that take place in an early adolescent's family as the adolescent attempts to adapt to living with life-limiting cancer. Through symptom control, hope, denial, and the achievement of developmental tasks such as peer group identification, independence, and autonomy, the early adolescent was able to demonstrate positive coping and adaptation. In the context of the Calgary Family Systems Model, the adolescent achieved individual system balance, which in turn enabled his family's systems to balance. The health care professional played an integral role in enabling the adolescent to accomplish his developmental tasks, which translated into facilitating adaptation.

Key words: *adolescent, coping, palliative care*

This single-case study examines an early adolescent's efforts to cope with the experience of life-limiting cancer. A conceptual model is presented, coping is defined, and developmental considerations for dying adolescents are offered. The case study looks at the coping strategies used by the adolescent, along with the role of the health care professional in enabling his coping.

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Life-Limiting Cancer in Adolescents

Cancer in the adolescent years is rare, but each year, 1330 Canadian children and teenagers are diagnosed with cancer for an occurrence rate of 16 per 100 000 children and teenagers (Public Health Agency of Canada, 2002). Cancer is the leading cause of disease-related death in North America. Of all children diagnosed with cancer, 25% to 33% will eventually die from their disease (Hinds, Pritchard, & Harper, 2004).

Adolescent Development in Life-Limited Teens

Adolescence is a rich, tumultuous period of life encompassing dramatic changes in physical appearance and the awakening of self-esteem, independence, social skills, and awareness. Adolescence spans the ages of 10 to 20 years, with early adolescence comprising ages 10 through 14. In early adolescence, the central developmental focus is a shift in attachment from parents to peers. Cognitive skills begin to develop; however, the advancement of logical thought does not usually occur until middle adolescence, ages 15 through 17.

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Normal development is profoundly altered in dying adolescents. It has been posited that an ill adolescent is a paradox of emerging capabilities and diminishing possibilities (Freyer, 2004). Terminal illness interferes with the critical life experiences necessary to achieve developmental goals. Chief among these goals are the development of personal independence and self-confidence, which would be acquired through gradual separation from parents and successful functioning in groups beyond the family, such as peers and school.

The physical changes normally associated with puberty are often delayed, and unwelcome physical changes frequently result from treatment. These physical effects diminish the adolescent's potential to achieve peer identification, healthy self-image, and self-acceptance. Physical condition, frequent medical appointments, hospital stays, and home medication regimens alter the teen's normal routines, leading to decreased school attendance and social isolation. These changes and interruptions frequently contribute to a poor self-image and a perception of being radically "different" from peers (Freyer, 2004).

The increased demands of illness threaten the adolescent's ability to establish a sense of identity and self-understanding and to maintain peer relationships. Developmental tasks such as achieving normalcy and self-identity often compete with an adolescent's illness care. An adolescent who strives to be normal and accepted by his or her peers will be tempted, for example, to "forget" doses of medications with appearance-altering side effects. The sense of immortality and freedom that normally shapes an adolescent's future is often replaced by increasing dependence and the reality of what will never be achieved (Christian, D'Auria, & Moore, 1999).There are large gaps in literature describing coping in adolescents with life-limiting cancer, and there is a lack of evidence on interventions to improve the adjustment of dying adolescents (Contro & Scofield, 2006). A single-case study approach was used to provide a clearer understanding of the events that take place for an adolescent and his family as they attempt to adapt to living with life-limiting cancer.

Family and Clinical Case Details

This case study focuses on the Smith family. The mother, Marie, previously a professional, left her job and has worked exclusively in her home since her son's initial cancer diagnosis. The father, Louis, was employed outside the home and has worked 3 days each week since his son's diagnosis. The sister, Melanie, aged 17 years, was a 12th-grade student who taught dance part-time and wanted to become a veterinarian. The focus of the case study, Seth, had been diagnosed with relapsed metastatic Ewing's sarcoma and was 14 years old. Pseudonyms and changes in identifying characteristics were used to protect the anonymity of the family.

Seth was initially diagnosed at age 12, with a primary lesion of the rib. He underwent 42 weeks of chemotherapy, radiation, and surgery and achieved complete remission. Less than 12 months after completion of therapy, he developed recurrent disease in the rib, with metastases to the long skeletal bones, lungs, and brain. Seth was asymptomatic at the time of relapse, but as his tumors grew, he developed significant bone pain in his legs and pleuritic pain in his chest.

The pediatric palliative care team, including a palliative care physician, a clinical nurse specialist, a clinical research associate, a music therapist, and a bereavement coordinator, became involved after Seth's disease failed to respond to salvage chemotherapy. The palliative care team shifted the focus of his care to "living fully." The Smiths began to discuss Seth's wishes and to plan for his remaining quality of life and comfort. A do-not-resuscitate order was completed 3 months after his relapse. Subsequently, his disease failed to respond to 2 palliative chemotherapy regimens, and a third regimen was initiated 5 months after relapse. The third regimen provided some local tumor growth control and noticeable symptom relief, especially in regard to pain.

Ewing's sarcoma is the second most common bone malignancy in childhood, but its incidence is rare, occurring in 2.1 per 1 million children. Cure rates of localized disease, which Seth was initially diagnosed with, are 50% to 70% (Hellston, 2005). Primary lesions of the rib fare better. Recurrent disease is indicative of a poor prognosis, with a 5-year survival rate of 30%. Prognosis upon relapse is related to a number of factors: the aggressiveness of initial treatment, the length of time between end of treatment and relapse, and age, with more favorable outcomes for children younger than 11 years old. None of these factors were in Seth's favor. Disease progression through salvage and 2 palliative chemotherapy protocols indicated that Seth's disease was incurable and that he would ultimately succumb to the disease.

Conceptual Model

Wright and Leahy's (1994) Calgary family systems model was used to guide this case study. This framework conceptualizes the nested hierarchy of family and societal contexts as they relate to adaptation to chronic illness. The model defines a system as a complex of elements in mutual interaction. The systems in which the family is embedded include subsystems such as parent and sibling and larger suprasystems such as school and the community.

Interaction and reciprocity are central tenets of the model. It is theorized that parts of the family cannot be understood in isolation from the rest of the system. When an individual member adapts and is able to maintain balance, the rest of the family is better able to adapt and maintain their balance. Family outcomes can thus be viewed as a function of the complex interplay among components of the system (Wright & Leahy, 1994).

Coping

Lazarus and Folkman's (1984) seminal work defines coping as the constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are determined to be taxing or as exceeding the resources of the person. Coping methods are classified as emotive focused or problem focused.

A life-limiting condition is a diagnosis that affects the whole family. The responses of the child, parents, and siblings are highly interdependent. Seth, Melanie, Marie, and Louis lived within a reciprocal and closely intertwined family system. Their family coping was composed of all their roles in the family system.

In order for the family to be balanced, the well-being of each individual needed to be understood and maintained as much as possible. The family systems model allowed identification of family strengths, problems, and areas amenable to intervention. Strategies for these areas were promoted to facilitate family members' adaptation and balance. The remainder of this case study focuses on these strategies.

Adolescent Coping and Adaptation

Coping is related not only to the nature of the stress but also to the perception of meaning of that stress for an individual, as well as the coping methods chosen (Lazarus & Folkman, 1984). It became very clear, early on, that Seth perceived meeting developmental tasks as his most important goal. It was within his developmental context that he coped: meeting developmental goals was his coping.

Seth's coping method was problem focused as it was used to manage and alter a problem amenable to change (Lazarus & Folkman, 1984). Seth was unable to change the course of his illness, but it was evident that he chose to use this coping method to alter his illness experience.

Maintaining Peer Group Identification and Normalcy During Adolescence

Seth's opportunities for peer group identification were limited by poor health. While enduring chemotherapy in the hospital during the period of his relapse, Seth was isolated from his peers. Along with hospitalization, his peer links were also lost via school absence and through friends being overwhelmed by his illness and compromised abilities. However, Seth pushed himself to participate in as many normal activities as he could. He determinedly participated in his peers' Halloween activities. He loved music and doggedly attended keyboard lessons and enjoyed having his friends over to use his electronic keyboard-synthesizing program: he once commented, "I like friends to come and play my keyboard with me and stuff."

Seth also loved being home to carry on family routines as normally as possible. He liked to be home when his sister, Melanie, got home from school and enjoyed hanging out with her and her friends. When asked what his favorite part of home was, he would reply with a grin, "I don't know. I like it all. Every part of it." Seth loved his golden retriever and enjoyed being home to care for his dog: "I went to the beach with Dad and Duke (dog). We told him to go chase the ducks. . . . Yep, that's one of my favorites [things to do]."

Normalcy was something that Seth yearned for, but struggled to achieve, due to the competing demands of his illness care. He did not find the pumps administering pain medication to be conspicuous. However, he resisted using corticosteriods for pain control because he was afraid of what his peers would think if he developed a cushingoid appearance as a side effect. Participating in regular teen and family activities allowed Seth to feel as normal as possible and contributed both to the development of self-identity and his perception of gaining independence. Peer interaction was essential to minimize his growing illness experience–induced feelings of separateness and isolation.

Equilibrium From Symptom Control

Seth and his family experienced a state of equilibrium when his symptoms were under control. The symptom control that Seth achieved from palliative chemotherapy was critical in facilitating his participation in normal activities. Seth decided that the 10 days spent in the hospital for each palliative chemotherapy cycle were worth the next 10 quality days at home. The pediatric palliative care team also worked diligently to implement a tailored pain control regimen for Seth. During the time of this case study, Seth received and self-administered at home continuous intravenous infusions of both hydromorphone and ketamine via a CADD pump, which he kept in a small knapsack. These infusions were complemented with oral gabapentin, methadone, and dexamethasone for pain control, as well as oral Ritalin (sustained and immediate release) to combat narcotic-induced drowsiness. Two months after his relapse, Seth had 2 hospital admissions for pain. Without expert symptom control, he would not have been able to remain at home or participate in activities: "Yep. I have normal leg muscle pain. Not tumor pain!" The elimination of tumor pain and the ability to participate in activity causing normal muscle strain were enormous accomplishments for Seth.

Independence

Terminally ill teens, like Seth, are forced to rely on their family and health care professionals at an age when they long to be independent and in control of their own lives (Craig, 2006). Even "healthy" teens strive for independence, and Seth was no different in his attempts to maintain his independence. One month into his third palliative chemotherapy regimen, when he was feeling quite well, Seth stated that he wanted to return to school after an 8-week absence. At that time, he continued to be fatigued after short exertions such as stair climbing and was sleeping until early afternoon. His parents confided that they were anxious about Seth's ability to physically attend school and to integrate normally. In such situations, parents of life-limited children often have anxiety that their children will not manage and that they may experience harm, disappointment, or failure (Craig, 2006). Seth's parents were not prepared to accept the risks associated with him attending school at this stage of his illness.

Recent evidence suggests, however, that health care professionals and parents should support teens to attend school and to see friends (Craig, 2006). The team focused on the significance of developing independence in adolescence and encouraged Marie and Louis to help Seth to be as independent as he wanted to be.

Layered with struggles for independence are exceptionally complex relationships between teens and their parents. By virtue of their illness, adolescents such as Seth are required to rely on their parents more and must cope with 2 conflicting realities: the need to be independent of parents and the need to be supported by parents (Craig, 2006). Seth's illness began at age 12, before he had developmentally achieved separation from his parents; therefore, this conflict was not perceived to be a critical issue. However, Seth was showing signs of wanting to be more independent in select areas of his life, particularly related to his disease and treatment.

Control, Mastery, and Autonomy

As an early adolescent, Seth was able to understand and contribute to care decisions. He often sought ways to actively control and gain mastery of his care. The team members were careful to include Seth when discussing treatment choices in an effort to grant him as much autonomy as possible, even though it would be easier and less time-consuming to address his decision-making parents. Allowing this control encouraged his feelings of competence and independence, which are important developmental tasks for the adolescent.

Seth's previously noted recognition of the difference between his tumor pain and exercise-related leg pain demonstrated that Seth had attained mastery over symptom assessment. Managing his symptoms independently gave him control over his body, and the sense of autonomy that ensued contributed to positive coping.

Denial

Denial is a well-documented coping method that allows an adolescent to take in information at his or her own pace (Klopfenstein & Young-Saleme, 2002). Seth often moved in and out of the cognitive-processing state of denial to control the amount of information presented to him. Understanding how Seth communicated nonverbally was just as important as listening to his verbal messages. While in hospital, if he were unprepared or unwilling to hear information from a professional or parent, he would turn away and focus on the television, ignoring the adult and family. He was stating, in a developmentally driven and appropriate manner, that he was not able to cope with the information being presented. Often, he would eventually be ready to hear out the professional or parent and would actively listen to their dialogue.

Sustaining Coping Through Hope

Seth possessed new and emerging early adolescent cognitive skills. However, he had not yet achieved a middle adolescent's developmental capacity for abstract thought or reasoning. In relation to hope, a complex and multifaceted phenomenon, Seth often relied on and adapted his parents' hope and emotive-focused coping as his own.

Emotive-focused coping is directed at decreasing emotional distress when it is appraised that there is nothing that can be done to modify a stressor (Lazarus & Folkman, 1984). As they could do nothing to alter Seth's dying process, Marie and Louis used this coping strategy to shift from hope for a cure to hope for more quality time together as a family of 4. Marie initially hesitantly confided, "I don't know what. . . . I don't know what I should hope for." Through normalizing and encouragement to reframe, she began to state, "We are hoping for more quality time together . . . not for a cure." Marie often verbalized her hope with Seth present, and Seth's nonverbal language, such as affirmative nods and soft smiles, would indicate that he agreed with her. Literature demonstrates that being hopeful is important to parents, even in the face of drastic changes in a child's condition. Hope adapts over time as the child's disease progresses and treatment options change. Parents want to focus on hope and living, no matter how short the time for "living" may be (Antle, Barrera, Beaune, D'Agostino, & Good, 2005). Interactions with health care professionals directly influence the nature of families' hope and the manner in which hope affects their response to life-limiting illness. As an advanced practice professional, I played a role in supporting this family's hopefulness by providing them with a safe space to verbalize, frame, and encourage hope.

Thoughts on Dying

Adolescents with a terminal prognosis normally experience feelings such as grief, anger, guilt, and fear. Yet, most teens develop effective coping strategies (Freyer, 2004) such as those expressed by Seth. Adolescents older than 12 years realize that death is irreversible, universal, and inevitable. Adolescents understand death in terms of personal significance and its effect on others. Dying teens are most concerned about those that they will leave behind. Adolescents are very aware of their parents' distress and often try to protect their parents by hiding their fears and concerns (Klopfenstein & Young-Saleme, 2002). Dying teens who do not wish to discuss painful matters and seemingly put on a brave front may, in fact, be seeking to protect their loved ones from further turmoil for which they may feel responsible (Work Group on Palliative Care for Children, 1999).

Seth had not yet reached a point where he wanted to discuss his feelings about death with an adult. Because of the adolescent propensity to protect parents from emotional pain, when Seth wants to talk, he will need an adult whom he trusts. Literature indicates that teens have specific concerns regarding dying and want to know answers to specific questions (Klopfenstein & Young-Saleme, 2002). Does dying hurt? Will I be alone? Do I have to do it in the hospital? Will my family be all right without me? Who will get my things? It will be critical for Seth to know that he has someone whom he can confide in, beyond his family and peer group, when he wants to know the answers to some of these questions.

Implications: A Continuing Struggle for Adaptation and Balance

There are limited studies that guide our supportive practice with teens and their families as they face life-limiting illness. Therefore, it is essential to explore case study learning opportunities to help us understand strategies focused on enhancing adolescent and family support. Seth was able to demonstrate positive coping and adaptation to his health situation via symptom control, the use of denial, and the achievement of developmental tasks such as peer group identification, independence, and autonomy. Although this case study focused exclusively on strategies to support Seth's coping, there also was much work being done for Marie, Louis, and Melanie. Building on strengths of the family, such as their supportive relationships with one another, buffers the stress of their experience.

The Rebalancing Act

Approximately 6 weeks into his third palliative chemotherapy regimen, Seth stated to his mother, "I don't want to go back to the hospital [for chemotherapy]." Adolescents with cancer expected to eventuate in death often reach a point where the burdens stemming from continued treatment seem, from the teenager's perspective, to outweigh its benefits (Freyer, 2004). Seth had likely reached this perspective. After a fragile and tenuous phase of quality time, the family system was again overwhelmingly unbalanced.

All of the named problem-focused coping strategies, including normalizing, reframing hope, achieving last developmental tasks, and protecting Seth's autonomy, will be relevant for advanced practice nurses and health professional teams as they help Seth and his family adapt, yet again, to another phase in Seth's life. Finally, Seth's story will also be valuable for health care professionals as they assume care for future adolescents with life-limiting cancer.

Conclusion

In summary, there is little information available regarding how to support and improve the adjustment of families living with an adolescent's life-limiting condition. This case study highlights the critical importance of early identification of family systems, strengths, and coping mechanisms. Supporting strengths and preferred coping mechanisms can facilitate positive adjustment. Due to the nature of life-limiting illness, any period of adjustment is fragile and time limited. Channelling strengths and coping mechanisms into the management of uncertainty may help to offset disequilibria. Listening, enabling, and encouragement are essential tools for use along the way.

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