

Experience of an Adolescent Living With and Dying of Cancer

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Objective: To provide a unified description of an adolescent's experience of living with and dying of cancer.

Design: Qualitative analysis using phenomenological methods.

Setting: Izaak Walton Killam Health Centre, Halifax, Nova Scotia, Canada.

Patient: A 15-year-old boy who was diagnosed as having osteosarcoma in 2003 and died of his disease 1 year later.

Intervention: Analysis of his 90-page journal that spanned 3 months just before his death.

Main Outcome Measures: Identification and clustering of key themes to capture the essence of his experience.

Results: Five main themes that surfaced during analysis of the journal were adolescent development, escape from illness, changing relationships, symptoms, and spirituality.

Conclusion: A single case study can provide valuable information in a field such as pediatric palliative care in which the patient's perspective may be difficult to access or ascertain.

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PEDIATRIC PALLIATIVE CARE aims to provide the best quality of life for infants, children, and adolescents faced with life-threatening conditions: "The goal is to add life to the child's years, not simply years to the child's life."^{1(p353)} It is widely accepted that pediatric palliative care should be integrated with curative therapies at the time of diagnosis and continued throughout the course of illness.² Unfortunately, several barriers continue to prevent the delivery of optimal palliative care in this population.³⁻⁶ This has prompted increased support for research to examine the quality and effectiveness of pediatric palliative care programming.¹ Tomlinson et al⁷ described several ethical and recruitment challenges to participation in this type of research. A primary concern is placing undue burden on an already vulnerable population. This is one of the many reasons why there is a scarcity of published data illuminating the experiences of children and adolescents facing terminal illness.

I was privileged to be given the opportunity to examine the journal of an adolescent boy with advanced cancer. Ed was 15 years old when he was diagnosed as having osteosarcoma in 2003. He was treated aggressively with various chemo-

therapeutic agents but had a poor response. His first journal entry on February 3, 2004, was 1 year after his initial diagnosis and coincided with the realization that his disease was not regressing. On March 19, 2004, Ed began his final hospital admission, during which he wrote regularly in his journal. His last entry on May 22, 2004, was less than 1 week before his death. Before Ed died, he graciously offered his journal for the benefit of others. He clearly stated in his journal that it should be made available for "anyone who wants to read" (**Figure 1**).

The primary objectives of this project were to analyze Ed's 90-page journal using qualitative methods and to identify key themes. The aim was to provide a unified description of Ed's experience of living with and dying of cancer.

METHODS

This study was approved by the Research Ethics Board at Izaak Walton Killam Health Centre, Halifax, Nova Scotia, Canada. Permission to use the journal was given by Ed before his death, and his family later signed a consent allowing the use of his journal, including direct quotations, for research and educational purposes. Within the diverse tradition of qualitative research, there are various theoretical

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frameworks.^{8,9} This is a case study that uses the method of phenomenology, which explores the nature or meaning of everyday experiences. I was guided in my approach by Moustakas, who stated that the first step in a phenomenological study is to “set aside our prejudgments, biases, and preconceived ideas.”^{10(p85)} This allowed me to interpret Ed’s journal without prejudice. Next, I set out to transcribe the journal in its entirety. I then examined the text in detail using the line-by-line approach described by Van Manen, who instructs the researcher to ask, “What does this sentence or sentence cluster reveal about the phenomenon or experience being described.”^{11(p93)} I identified 27 themes and grouped these into 5 broad categories to capture the essence of Ed’s last few months of life. All themes were reviewed by research clinicians familiar with the journal, and their interpretations were consistent with my analysis; however, Ed’s words will allow the reader to make his or her own judgments.

RESULTS

The 5 main themes that surfaced during analysis of Ed’s journal were adolescent development, escape from illness, changing relationships, symptoms, and spirituality. These are illustrated below by quotations taken directly from the text of the journal. **Figure 2** shows a schematic representation.

ADOLESCENT DEVELOPMENT

Ed was trying to navigate through adolescence while fighting a serious illness, which presented some unique challenges. Like most teens, Ed fought for independence from his parents, but this became increasingly difficult as his mobility worsened and he was forced to rely heavily on his family. Ed also asserted his independence in the realm of medicine: “. . . is my nurse today. That’s cool. Had her before. Only bad thing is she hovers when you take your pills. So that’s gonna be annoying really quick [April 4].” Sometimes Ed remarked that his wishes regarding his care were not taken seriously: “No one would listen to me as usual. That’s getting really annoying [April 30].” However, when he contributed to treatment decisions, he took the responsibility seriously: “Umm, they told me that they don’t think the radiation did anything. Or that the tumor is still growing. So they gave me my options again. . . . I think I might do another IV round of chemo then switch to the pill [April 8].” As the journal progressed, Ed became more responsible for his health and well-being.

On several occasions, Ed lamented the fact that his left leg and groin were becoming more swollen. This did not seem to diminish his self-esteem; instead, he was able to maintain a strong sense of pride throughout the course of his disease. Ed was proud of everything, from his successes in video games to simple everyday tasks made challenging by his illness. However, it was pride that kept him from asking for help when he needed it the most: “Too stubborn. Didn’t want to admit I needed help. Look at where that got me [April 18].”

ESCAPE FROM ILLNESS

As Ed’s journal unfolds, it becomes apparent that his illness pervaded almost every aspect of his life. Fortu-

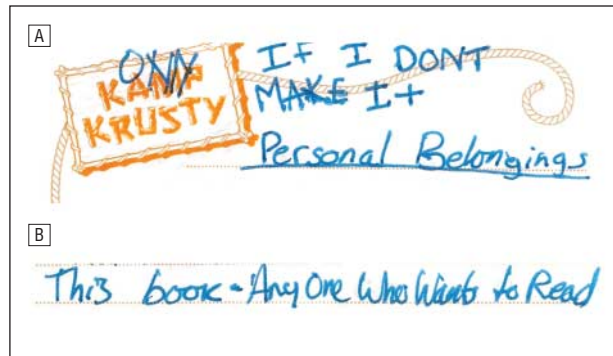


Figure 1. From the original text at the end of the first journal (A and B).

nately, he found various ways to escape this. First and foremost was his passion for video games. On occasion, Ed would devote an entire journal entry to discussing his likes and dislikes for certain games and how he planned to conquer a particular level. Throughout most of the journal, it is clear to the reader that playing video games consistently lifts Ed’s spirits. However, in the last entry that makes reference to video games, Ed’s mood parallels his difficulties on screen: “My game of warriors of might and magic is over. Can’t pause in the level without the game freezing so I don’t think I’ll be able to go the whole level and it’s running really slow. I think my spirits are getting low. I know they’re getting low but I think I may be getting to a point where I’m getting depressed. It sucks [April 26].”

Another outlet for Ed was his sense of humor, which was primarily sarcastic. In this quotation, Ed is talking about his stuffed animal Ernie and his ex-girlfriend: “Really glad Ernie is here. He’s a big help. Just to hold on to. Kinda like [my ex-girlfriend] was last year. Only Ernie doesn’t argue or back talk either. It’s nice [March 28].” Ed was even able to joke about his difficulties with toileting: “Oh yeah, I made a commode pillow. Venom’s on it. Then it says ‘take a load off and have a seat’ [April 5].” Ed also used humor to deal with the concept of death and dying. At the end of his will, he stated, “If there are any arguments over who gets what then a fight to the death will be used to determine . . . so hand to hand, no weapons, must take place at Bayers road bowling alley [April 28].”

The journal was also an escape for Ed: “I feel a lot better already just writing down all this stupid stuff. Nice to just sit and think [March 16].” As time passed, Ed began to confide in the journal as he would a friend. Ed also used his journal to outline his plans for various creative projects that he had in mind. Most notably, he wanted to write a book about “a kid who’s always picking his nose . . . they then discover that he had some rare disorder . . . where the brain seeps into the nose and can be removed by picking [March 25].”

Sleep played an equally important role for Ed. He used sleep primarily as an escape from pain: “But I gotta go get outta pain and get some sleep [April 22].” As Ed’s condition worsened, he spent more and more time sleeping: “I think my spirits are getting low. . . . Haven’t been eating or drinking much cause of it. No urge to talk to people. Just kinda wanna sleep all the time [April 26].” However, if Ed was not sleeping, he was probably find-

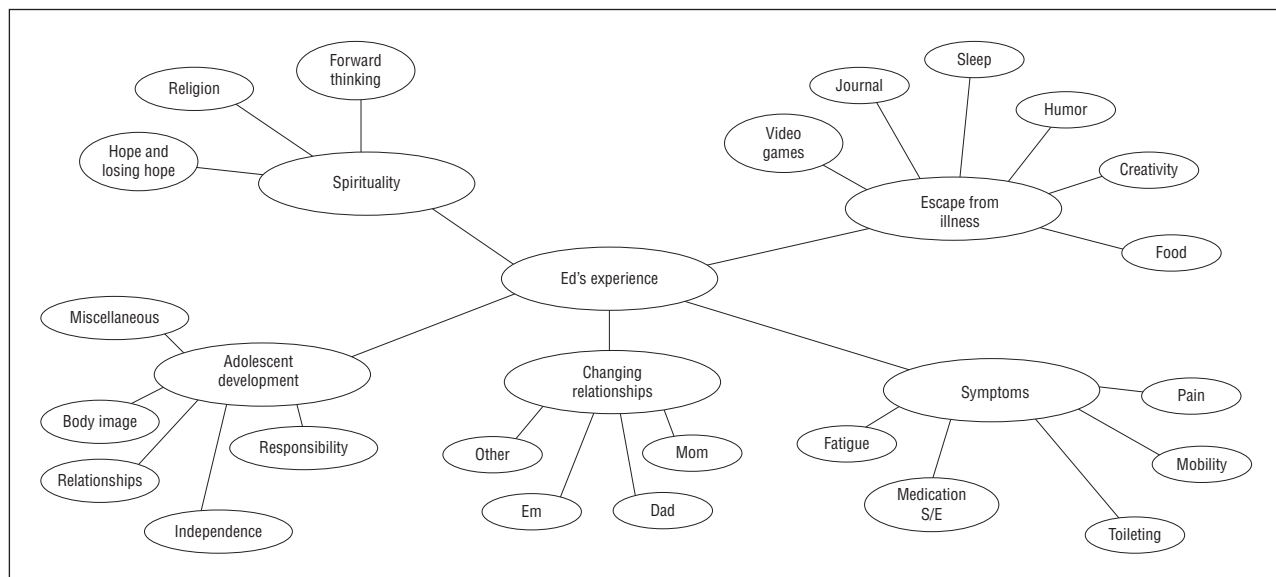


Figure 2. Schematic representation of 5 major themes and various subthemes derived from analysis of the text. S/E indicates adverse effects.

ing refuge in food: “So time to eat poutine and chocolate tart, pudding, and some green apple candies [April 27].” He always found joy in food and often wrote about his overindulgences.

CHANGING RELATIONSHIPS

Throughout the journal, Ed reflects on his relationship with his parents and his sister, whom he affectionately refers to as Em. Ed spent the most time detailing his relationship with his mother, which was volatile yet full of love and compassion: “We had a little scrap tonight. Didn’t handle it well. I told her to shut up or get out. Can’t believe I did it [March 28].” It is clear that Ed’s mother made every effort to be at her son’s side, but this put some strain on their relationship. Ed also worried about her constant presence: “Mom kinda makes me wonder why she’s here everyday cause she doesn’t do much. I appreciate the moral support and all, it’s just she could be out working and making money for herself . . . it would ease my worries with her [April 25].” Despite their differences, Ed writes that his mom was the first person to read through his journal before he died.

While Ed’s mother seemed to spend the most time with him toward the beginning of his illness, it was his father whom he talked about the most as his symptoms progressed: “I love it when Dad stays. Things go so much smoother and it’s just easier [April 16].” Ed wrote about how his father gave him strength and had the courage to help him manipulate his leg: “Mom’s scared to do anything with my leg. Dad’s a little better. He can stretch my leg for me anyway [April 25].” In his last few journal entries, Ed often wrote about finding comfort in his father’s presence.

Ed also had a close relationship with his sister. He seemed to pride himself on his role as her protective big brother. When he found out that his tumor was still growing, despite radiation therapy, he expressed the need to shield Em from the news: “I just gotta tell Dad. Nor-

mally no prob. But Em is here till Monday. So gotta wait till she’s outta ear shot [April 8].” As his symptoms worsened, he wrestled with the dilemma of desiring her company but not wanting her to see him in pain or exhausted.

One element that Ed seemed to be missing was a more intimate connection: “Last time I was sick it was easy. I had [my ex-girlfriend]. I really thought we were going to be together forever. This time I don’t have that comfort to see me at the end. I’d like to get involved again but I think I’ll wait in case something happens. Not gonna put anybody else through this too [February 3].” Ed understood the burden that a terminal illness can have on a relationship and was able to put the needs of others above his own.

SYMPTOMS

Pain is frequently highlighted in cancer narratives; unfortunately, Ed was no stranger to this experience. At the beginning of the journal, Ed describes how pain was the first sign of his relapse: “I guess I knew I was getting sick again. . . . Slowly I started getting pains again [February 3].” Once in the hospital, Ed had to cope with the adverse effects of his cocktail of pain medications: “They have played with my pain med doses again. I feel better. The only thing is they’re making me really tired and drowsy. But it’s worth it [March 22].” Over time, the pain becomes so significant that it begins to affect his relationships: “Gonna be cross with Em cause of all my pain. Oh well she’ll learn to understand that. I always try to apologize [April 21].” By the end of the journal, Ed’s pain is virtually constant, and he requires sedation for dressing and position changes. Ed’s final entry, written by a relative, is a single line, but it is clear that pain has prompted him to turn to his journal a last time: “Butt and legs hurt, don’t know what’s causing it [May 22].”

Ed’s mobility was also compromised as a result of his illness. Just a few lines into his first entry, he remarks,

“Sometimes I feel like a burden to people. I’m not very mobile any more and the pain is now visible on my face [February 3].” Everyday tasks became increasingly hard for Ed. An important consequence of Ed’s limited mobility was difficulty with toileting: “Still can’t pee laying down again yet. Kinda annoying. Perfected it and all [March 16].” Despite his struggles, it became a topic that he seemed to enjoy writing about, not unlike many teenage boys. He spent several pages detailing and drafting a “bed pan cover that should provide a lot of relief on my sore spots [May 2]” (**Figure 3**). Nevertheless, he also took his troubles seriously and went so far as to write “Pee (if not take pills to do so) [April 23]” on his “To Do List” (one of many).

Fatigue was another illness experience that significantly affected Ed’s quality of life and his interactions with others: “Don’t know if I want Emmie here. Sure, I love hanging out with her and just chillin’ but I don’t want her to see me like this either. I don’t wanna get really mad at her cause I’m in pain or don’t wanna sleep the whole time she visits [April 22].” Although sleep was an escape for Ed, there were times when he fought against fatigue: “Hard to keep my eyes open now, guess I’m really going. Bedtime. 8:30 PM (PATHETIC) [April 5].” Entire days were sometimes lost: “Well the day is over. Been drifting in and outta sleep today [April 21].”

SPIRITUALITY

Ed’s first journal entry reveals that he is struggling to find meaning and purpose in his life: “Sometimes I just wonder if it would be easier to give up. Then I think of everyone I would let down or all the things I would miss. I’ve been thinking a lot about who gets what if I were to die [February 3].” More than a month passes before Ed revisits his journal, but he returns with a renewed sense of hope and self-worth: “[H]opefully this is the turning point for me again. No more bad thoughts. I know I can beat it again [March 22].” Ed is sending a strong message that he is in control and has the power to conquer his illness single-handedly.

As the journal continues, Ed begins to understand that he can no longer continue to fight on his own. Ed learns that faith can be an important source of strength, but initially this concept was met with resistance: “Today I found out Father Robertson was supposed to come over. Wouldn’t really mind it if I knew him and had something to talk about with him. But I don’t. He just seems like another person from school that ‘has’ to see you cause your sick. . . . I don’t believe in all this catholic stuff and it feels like beliefs are being imposed on me and such [March 27].”

As Ed’s symptoms progress, his sense of hope and search for meaning become more grounded in religion. On one particularly difficult day, Ed calls on the power of prayer to give him the strength to carry on: “I think the tumor is growing REALLY fast or the swelling has gotten worse. . . . Maybe I just need more drugs. I don’t really want to be on more drugs. Each time I go up a drug or get a new one makes me wonder who’s winning. All I can do is get chemo and radiation and hope for the best. I pray every night for some strength and the strength to get through this [April

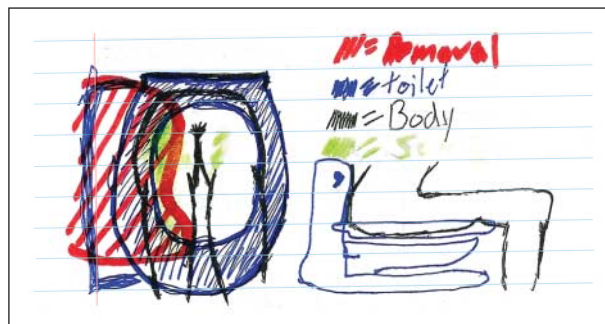


Figure 3. Ed’s version of the perfect bedpan cover, from the second journal (May 2).

7].” Reading the Bible gradually becomes a regular part of Ed’s daily routine, with an increasing sense of urgency as time passes: “Always gotta get in bible time [April 27].” Just over a month before his death, he wrote, “I know everyone here is doing everything they can and all my family are rooting for me and for the first time I feel safe and I do believe that there is a God and he is watching over me and protecting me [April 23].”

At the end of Ed’s first journal is a personal will that he drafted with the title “ONLY IF I DONT MAKE IT: Personal Belongings.” Mostly, it details to whom his expansive collection of video games will go, but he requests that certain items should be blessed and buried alongside him and that his Bible should be given to his sister. Ed then started his second journal but was able to write only 6 entries spanning his last 4 weeks of life. Each entry during this period describes the significant pain and fatigue that Ed endured on a daily basis, but surprisingly none of these entries makes mention of God, prayer, or the Bible, yet Ed remained hopeful in spite of it all.

COMMENT

A small body of literature examines palliative care in the adolescent population.¹²⁻¹⁴ Most of these articles emphasize the unique developmental considerations that arise in this age group and how normal physical and psychological changes are profoundly altered in the context of terminal illness. In early adolescence (10-14 years), illness most significantly affects the development of self-image and peer relations. In middle adolescence (15-17 years), illness often leads to a compromised sense of autonomy and interferes with attraction of a partner. Toward the end of adolescence (≥ 18 years), illness may disrupt career aspirations and affect family planning.¹⁴ Ed was navigating through middle adolescence when he was diagnosed as having osteosarcoma. As expected, Ed struggled with his parents for independence but found refuge in their presence as his condition deteriorated. He also yearned for an intimate relationship but was selfless enough to recognize that it would be a difficult journey for a partner to embark on. Undoubtedly, each patient will have his or her unique experiences, but commonalities are likely to emerge.

Unfortunately, there is little published literature looking at the experience of adolescents living with and dying of cancer. Hinds et al¹⁵ conducted a review of the literature

to identify articles that sought patient-reported outcomes from pediatric oncology patients at the end of life. Only 4 of 26 identified publications included patient-reported outcomes. Several articles examined the experiences of parents and health care providers, but these do not provide the reader with a patient perspective. Bingley et al¹⁶ identified a growing number of published and unpublished narratives in which individuals describe the experience of facing death. These enable us to better understand the needs and views of persons approaching the end of life; however, most accounts were written by adults. Sourkes¹⁷ wrote extensively about the psychological effect of life-threatening illness on the lives of children and their families but did not address the experience of the adolescent. Hurwitz et al¹⁸ described the interview of a 13-year-old boy named Frank in the terminal phase of acute leukemia, revealing that much can be learned from the experience of just one patient. Furthermore, a few young patients at the end of life have had their journals or memoirs published directly, but publications like these are uncommon.^{19,20}

Suzuki and Beale²¹ analyzed the home pages of 21 adolescents with cancer. Part of their study involved the identification of common themes from diary entries found on several of the Web sites. The themes they observed included humor, anger and fear, treatments, physicians, body image, death, home pages, and finding meaning in their lives. Many of these topics arose in Ed's journal, suggesting that some of his experiences parallel those of other adolescents living with cancer. Suzuki and Beale also noted that several youth used humor and spirituality as a means of coping with their disease. Similarly, Ed's sharp and often sarcastic sense of humor enabled him to endure tremendous pain, compromised mobility, and constant fatigue. He also found solace in spirituality and his belief in the existence of God. Having access to Ed's rich narrative is a rare occurrence, but home pages such as these in our technology-savvy society may shed additional light on the experiences of youth with cancer and other life-threatening illnesses.

Ed's experience with osteosarcoma shaped his reality and forever changed the lives of those who knew him. By offering to share his story with a greater audience, Ed has given others the opportunity to understand his journey and to appreciate that many of his experiences are reflected in the lives of youth faced with similar challenges.

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