

Talking With Death at a Diner: Young Women's Online Narratives of Cancer

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The current focus on young adult patients with cancer (patients aged 20–39 years at diagnosis) began with Bleyer (2002), who highlighted the deficits in the care and survival of adolescents and young adults with cancer. Young adult women survivors share similar concerns as other cancer survivors, such as lingering late effects of treatment, need for general social support, and access to healthcare services for general surveillance purposes. Because of patients' ages at diagnosis, special emphasis is placed on needs concerning reproduction and fertility worries, lack of adequate health insurance, risk of secondary malignancy, and disruption in educational and career attainment.

Although definitions vary regarding the age range associated with cancer in young adults, the focus of this study was on those aged 20–39 years at diagnosis (Geiger & Castellino, 2011). Bleyer helped to define this range when he first identified the disparities in cancer survival, as well as the unique psychosocial challenges that members of this age group share (Bleyer, 2002; Bleyer & Barr, 2009). Because of the general lack of age-specific support groups, many young adults are unable to fully engage in traditional clinic-based support groups because of what they perceive as age differences among themselves and other participants (StupidCancer.org, 2010). As a result, many young adults begin social networking through blogs and social media sites such as Twitter and Facebook to connect online. The online community for young adults with cancer is thriving, with many patients exchanging information and sharing their narratives through individual illness blogs that often act as diaries of the illness experience.

Background

Internet support groups and resources, including patient-initiated cancer blogs, have recently emerged among patients with cancer and are used in a number of different ways (Thielst, 2007). Some use the blog to

Purpose/Objectives: To gain a unique perspective of the experiences of young women with cancer (age 20–39 years at diagnosis) through analysis of their online illness blogs.

Design: A qualitative analysis of online narratives based on hermeneutic phenomenology.

Setting: Online illness blogs found through young adult cancer Web sites and social media sites such as Twitter.

Sample: 16 women, aged 20–39 years, who self-identified as being diagnosed with cancer and who initiated and maintained an illness blog based on their cancer experience.

Methods: Ethnographic immersion in online culture, thematic analysis based on line-by-line coding, and construction of themes and meanings.

Main Research Variables: Transitions from diagnosis, through treatment, to long-term survivorship.

Findings: Themes were identified as the women processed their diagnosis: living in the middle, new normal, urgency, and transition into the abyss.

Conclusions: The narratives shared on illness blogs offer an online place for expression of emotion, information exchange, and online social support. Emotional catharsis in the young women's narrative elucidated the experiences of transition through diagnosis, treatment, and survivorship that allow a better understanding of their emotional and psychosocial needs.

Implications for Nursing: Illness narratives are a naturalistic form of inquiry that allow nurses to understand the experience of the patient beyond the traditional clinic setting. This initial study provides a point for understanding the content of online narratives and has vast implications for nursing-based interventions.

share their own health-related narrative (Thielst, 2007), others initiated the blog as a way to keep family and friends updated on their care, and some began their blog as a way to promote advocacy and knowledge among the population of young adults with cancer. Uses of illness blogs also include seeking opinions about or validating information given by health providers and preparing information for upcoming visits

to healthcare providers (Kim, 2009; Narimatsu et al., 2008). Online communities are growing support options for young adults (Treadgold & Kuperberg, 2010). Treadgold and Kuperberg (2010) found that 95% of adults age 18 or older with cancer have used or want to use Internet sites that offer age-appropriate cancer education or support, and, in general, 86%–95% of all young adults (aged 18–45 years) go online on a daily basis (Zickuhr, 2010).

To the authors' knowledge, the content of young women's cancer blogs have not been previously analyzed. The purpose of this qualitative study was to gain a unique perspective of young women with a diagnosis of cancer through analysis of their online illness blog. This approach privileges the voice of young women in understanding their lived experiences of cancer.

Methods

Sample

Prior to study initiation, the lead author spent several months immersed in the online culture of young adults with cancer. She followed blogs, Twitter accounts, and listened to podcasts of those diagnosed in young adulthood to understand what topics were discussed, how patients communicated and networked with one another, and how online spaces were used to share the illness narrative. The inclusion criteria focused on women, 20–39 years of age, who blogged about their personal experience following a diagnosis of cancer. Only English-language content was included. Blogs written by women from countries outside the United States were excluded because of the differences in healthcare systems, as well as cultural differences related to illness. Women with stage 0 disease (i.e., diagnoses with ductal carcinoma in situ or lobular carcinoma in situ) also were excluded; however, all other cancer types and stages were included.

Potential blog sites were sampled using criteria that ascertained that at least three of four randomly selected blog entries specifically related to their cancer experience, and the blog title or biography of the blog author specifically described that the blog was related to the cancer experience. From this point, a modified snowball convenience sample was obtained starting with a cross-section of listed blogs found at the StupidCancer.org (2010) blogroll. Nine blogs were included from this step. Simultaneously, the lead investigator began following young adult cancer survivors on Twitter and connected to their blogs, adding three more blogs for analysis. From the starting blogs, the lead investigator chose subsequent blogs that met sampling criteria based on those who were followers and connected to each other virtually, adding four more blogs for analysis of a total of 16 blogs.

Data Collection and Analysis

Institutional review board approval was submitted and exempted because all of the blogs used for analysis were public Web sites. Ethical considerations are evolving as use of this form of data continues to grow, but the primary investigator was careful to consider the ethical considerations prior to the study initiation, which focused on informed consent, privacy, and confidentiality. A decision was made by the lead investigator that if an e-mail address for the blog author was accessible on the blog, the author would be contacted for permission to be included in this study. Five of the 16 blogs had e-mail addresses available, and the blog authors were contacted for permission to be included.

The textual data were analyzed nonconcurrently, meaning the analysis began at the earliest online posting and moved forward in time to the most recent post on the blog. The analysis was guided by hermeneutic phenomenology, which describes the meaning of lived experience while exploring the structure of consciousness in those experiences (Cohen, Kahn, & Steeves, 2000; van Manen, 1994). The textual data from the blogs were analyzed by immersion in the data (reading it several times and then fully interpreting the context of the blog entry including photographs and other documents from each blog) and line-by-line analysis and data reduction of the textual data (Cohen et al., 2000). Tentative categories were listed with each line of data. After line-by-line analysis of all blogs, categories were grouped together with tentative themes (Cohen et al., 2000). Categories and themes were reviewed by both authors, and data saturation were achieved when no new categories or themes emerged. Reflective journal entries and field notes maintained by the lead investigator also were included for analysis at this point in the process.

Bias control, or trustworthiness, was handled in several ways: (a) making aspects of the study design open for review by the members of the research team; (b) keeping a journal and reflecting on prior assumptions and beliefs about the research; and (c) allowing for open peer review for decisions made (as a part of the audit trail) and reviewing the decisions made for developing thematic content, which was done once every two weeks throughout data collection and analysis (Cohen et al., 2000; Lincoln & Guba, 1985).

Findings

Sample

A total of 16 blogs were included in this analysis. The age at diagnosis ranged from 23–39 (\bar{X} = 31.7, median = 30.5 for those reporting an actual age and not a decade). The average length of the time the women wrote in the blog was 27.4 months (median = 25 months); therefore,

the majority of the women had an established connection with their online blog lasting a number of years. The diagnoses of the women included breast cancer (n = 4) (two inflammatory and two non-inflammatory), colorectal cancer (n = 3), Hodgkin lymphoma (n = 3), ovarian cancer (n = 3), sarcoma (n = 2), and melanoma (n = 1). The overwhelming majority of the women who identified their stage had advanced-stage cancer (III or IV) at initial diagnosis (n = 14), with only one young woman diagnosed at stage I. All of the women underwent systemic treatment (either chemotherapy, radiation therapy, or a combination of the two), and many also had surgery. Two of the women died prior to the initiation of this study, and their blogs were kept on the Internet in memoriam.

The major finding of the study was the young women's experience of transition, limbo, the distortion of time, and confrontation of mortality following diagnosis, through treatment, and beyond. Their experiences can be understood in terms of several themes: living in the middle, new normal, urgency, and transition into the unknown.

Themes

Living in the Middle

From the moment they were diagnosed with cancer, many participants had an intuitive understanding that their lives were forever changed. One woman described the harsh transition by redefining Biblical terms suggesting that, to her, B.C. and A.D. represented "before cancer" and "after diagnosis." She was acutely aware that her life was never going to return to the "carefree days" she experienced before she was diagnosed with cancer. From the onset of diagnosis, the distortion of time began as the waiting and uncertainty built:

The cancer surgeon took a skin biopsy and seven core biopsies from my right breast yesterday morning. I came home and rested, read your messages of hope and cuddled my children close. As the pathologist cultures the cells and reads the results, I wait. The words are not coming easily now, but they are coming.

Some of the women described the period of time surrounding diagnosis as surreal, as if the rest of the world stopped and suddenly their lives are put on hold. During those moments, time felt as if it was standing still and vivid details were accounted with excruciating detail. Others experienced a literal and figurative heaviness following diagnosis. As one woman described it, the "cloud of cancer," suddenly and without warning, became ever-present. Almost as soon as the diagnosis was given, the women expressed their sense of wanting things to return to normal. One

woman who expected her colonoscopy results to come back normal, and instead received a diagnosis of late-stage colorectal cancer, expressed the shock of this period of time.

It was all so surreal and horrible. I felt numb yet stuffed full of jagged glass. Forget dinner out, any plans we made beyond that moment were irrelevant, obliterated by the sucking black hole that had suddenly taken over our lives. All I wanted to do was get home and nurse my baby, try to somehow reclaim a single shred of the normalcy that used to be my life.

For many of the young women, this period of time was described using images of heaviness, clouds, black holes, and jagged glass. Their emotions following diagnosis were raw and unedited as they continually processed the changes expected to occur as treatment commenced. Uncertainty regarding their future started to emerge as another woman aptly described the agony of this period by writing a blog titled *A Case of the Cancerous Maybes*.

The maybes are the sickness that spreads. The hypothetical continues to plague my thoughts and those of anyone close. I would like to know if this pain growing inside me will be my downfall. I would like to know, grieve, and get the hell on with it. I hate indecision. I hate the middle.

New Normal

As soon as treatment began for the young women, sentiments of living in the middle transitioned to a more pronounced period of limbo, where time became stagnant and all energy focused on fighting the disease. Limbo allowed the young women to break free from the heaviness and cloud that came with the initial diagnosis and move forward with a plan of treatment. With this period of limbo came a new normal for many of the young women; days that were previously consumed by school, work, and relationships soon became dictated by treatment, laboratory results, appointments with the oncologist, countdowns marking the last day of chemotherapy or radiation therapy, and dates of the next scan.

In contrast to the uncertainty that surrounded the period of diagnosis, most of the women described their early days during active treatment as ritualistic and predictable. In some ways, less uncertainty occurred during this phase compared to the time surrounding diagnosis because the women quickly learned what to expect from treatment, and it was early enough that they had not yet failed any treatments or received any negative scans. The women became accustomed to the familiarity of their cancer centers, the nurses and physicians who treated them, the precise steps of chemotherapy or radiation therapy, the side effects to

expect, and exactly how many days they would feel physically depleted and then better again. Much of their physical and emotional energy was focused on fighting the disease and getting through the daily ritual of treatment. The women often described feelings of being a “permanent patient” as their new normal, and they were not able to imagine their lives would ever return to the one they knew before cancer.

My monotony and normalness is living my days thinking almost nonstop about my guts, my blood, my side effects, my prescriptions, my schedule of emptying my bowels, my money and lack thereof. I spend my days off doing doctors appointments, infusions, procedures, transfusions, waiting rooms, blood tests, scans, and scopes.

My life now is hooked to an IV 24 hours a day, five days a week. My life is nausea, my life is too tired to speak. My life misses the comfort of fingertips along my back, taking my mind off of the pain. These days I am not touched without gloves. My life is now a ritual of treatment, my place of worship the hospital. Every Sunday offering up my blood to white-robed oracles and praying my counts will be OK.

A majority of the women also expressed gratitude for having family members and friends for support; however, alternatively, for some, it was upsetting and uncomfortable to feel so dependent on others. During this period of treatment, the women described a loss of identity that accompanied the new normal because their identity was now encompassed by that of patient. Some felt very lucky that they were able to work for a period of time and keep their life as interruption-free as possible.

I really never considered not working during my cancer treatment. From the moment I was diagnosed, I knew that if I could physically do it, I would keep my life as normal as possible. Over these past five months, I’ve learned that normal doesn’t exist, and I’m happy about that. Normal is boring. Instead, let’s say that I’ve been able to keep my life as uninterrupted as possible and being able to continue with my career has certainly helped that.

As the new normal began to take shape, the young women were acutely aware of the importance of living and embraced the everyday moments that were previously taken for granted. This was embodied in many ways, but often it was described as reflecting on idyllic moments that had the power to let them forget about their cancer briefly. As the importance of embracing idyllic moments persisted, time slowed down for many of them to take note of the moments.

When Daddy came home, he found us dancing in the rain, singing a silly made-up song together and

moving around like airplanes in slow motion. His eyes lit up too, happy to see me happy, and happy to see [me] feeling so much better than I had in the past few days. He put down his laptop, dropped his work burdens, and began to dance with us. In the garage, in the rain, in the moment. And for a moment, we were happy and carefree, dancing together in the rain.

However, the sentiment was not uniformly expressed. One young woman described how she wished she had those idyllic moments, but often felt depleted and unfulfilled in her new identity.

I spend my evenings pretending I’ve found that new perspective on life that makes me enjoy all the little things that much more, when mostly I’m gluing on that smile and going through the motions of who I knew myself to be before the me I am became the permanent patient.

For this young woman, the despair and unhappiness of her current situation was emotionally taxing, and she was honest in her account of not being able to force something that she was not able to perceive.

Urgency

Almost immediately after beginning treatment, many of the women remained positive about their prognosis; however, as treatment moved forward, another distortion of time began. The women felt a sense of urgency to complete milestones in their lives that were previously less of a priority.

Although I feel like I accomplished a lot this week, I am ashamed to admit that it is in part because I feel such an urgency about the things I really wish to accomplish before I leave this Earth. I suppose that’s the cancer talking.

The sense of urgency she described often coincided with a greater uncertainty of the future once the reality of the diagnosis had been fully accepted. At this stage, the cumulative effects of the treatment wreaked havoc on their bodies and minds, and, in some cases, initial treatments failed to clear the disease completely, or “no evidence of disease” was achieved but short-lived. Senses of urgency oscillating with stagnation and depletion, as well as dichotomies of emotions (fear and hope, anger and gratitude, fighting and healing) marked the transition. Limbo often inhibited the young women from accepting the future as something they would be able to fully participate in. For one woman, it was very difficult to make plans a year in the future, and she described how it was an act of faith for her to buy a calendar for the next year.

I still am afraid. I still flinch when I hear my friends talk about “next summer,” because for me it seems

so binary—Will I be alive and vibrant again, laughing, and taking my children to swimming lessons? Or . . . I can't finish that last statement. All I can do is take the chemicals, rest, and pray. Pray that once again we will have joyous days together as a family, and a day without the omnipresent threat of cancer.

The women began to conceptualize their own mortality and come to terms with their own death. Their disdain of living in limbo became more pronounced as they thought about death.

Remember lying amidst the savage darkness, the hollow sound of idleness, waiting to either live or die, but only waiting. Wishing fate had a backbone. The feeling of your body plotting against you, wanting to reach in and exhume your disease, to tear apart tendons and scrape the bone clean. Oh, to be clean. Fevers like little deaths, dying only to be painfully reborn again by surprise, watching that glowing orange eye rise and wink, upon which you realize the world must be mocking you. You'd rather end than watch the cruel parody of daybreak again. The sky is insufferable.

Women who wrote about confronting their own mortality demonstrated a graduate shift in comfort. For many of them, the thought of cancer taking their life began with fear; however, over time, the idea was less fearful. One of the women who died noted that she was never afraid of dying. She was only afraid of treatment and not being able to tolerate the side effects. As a mother of six, she also was fearful of how her family would handle it; however, outwardly, she was very accepting of her prognosis. Another young woman wrote about a dream she had that exemplifies the growing acceptance.

Realistically though, one must confront the possibility of not-so-favorable outcomes. One must confront death. I had a dream a couple of nights ago in which I did just that. You see, I had a conversation with death. At Denny's no less, which I can only assume signifies purgatory or Hell or some other horrid sterile place. We sat at a booth and had a cup of coffee. I had a sense death was a man, but with no discernable body. Just fuzzy blackness. I never looked directly at him, just stared at the speckled beige tabletop. We worked it out. We've reached an understanding. I'm not going to die anytime soon. I was conscious that it was a dream, but still terrified in the beginning, as if thinking about it would usher death in. It was like a nervous first date, I slowly became more comfortable as the conversation progressed.

Transition Into the Abyss

For those who entered a period with no evidence of disease and began long-term survivorship, the transi-

tion back to the normalcy of their precancer life was not always an easy one. Physically, their bodies were still recuperating and, sometimes, had lasting late effects of treatment. Emotionally, they were required to transition away from fighting the disease to resuming their previous life roles. Mentally, many suffered lasting anxiety about recurrence. One of the young women entitled a blog passage during this period as "transition into the abyss," which accurately described this time of struggle and renewed hope. Entering post-treatment, the young women had to reenvision their lives.

A friend [with cancer] sent me an email a few months back, asking for advice. She had prepared herself for death, was comfortable with its immanence, had presumably tied up all those loose ends with one's self. And then, a second chance, balloons and bouquets and be off your merry healthy way! What the f___ do I do now? The transition between death and the "second life" we've been given is massively confusing and distressing, almost as much as the task of readying oneself for death. I don't really have an answer for her. Now that school is done, forever, I have the task of rebuilding all those hopes and dreams that I abandoned when I was bracing myself for a premature death.

The transition to survivorship was described as no less abrupt than the transition after diagnosis. It was described as freeing and distressing to assume life roles that had been placed on hold while fighting the disease. Although time seemed much more abundant, it still was met with sentiments that life is precious and health would not be taken for granted. Once the women were more comfortable in their transition, the unknown became more positive, filled with creativity, and full of possibility. Initially, this was overwhelming to them; however, over time, they could let go and re-envision their life. Fear of recurrence was still present, but it often successfully coexisted with happiness and contentment. Some of the women embarked on new projects and flourished in their professions, noting that the experience had given them the courage to try new things, because the possibility of failure seemed far less daunting after surviving cancer. Time continued to simultaneously be wondrously infinite and excruciatingly finite as they broke free from living in limbo and continued on with their second chance at life.

Discussion

Transitoriness, or the awareness of one's own mortality, was experienced in varying capacities by all of the women included in this study. Transitoriness was previously described in a study of patients with

early-stage breast cancer (Shaha & Bauer-Wu, 2009) and among older adult patients with cancer (Shaha, 2003; Shaha, Cox, Hall, Porett, & Brown, 2006). In the current study, the distortion of time was the central action that allowed the participants to experience a wide range of emotions, including transitoriness. When moments were filled with great uncertainty, time was perceived as slow-moving, forcing the young women to confront many of their uncertainties and fears. During the early stages of treatment, more familiarity with treatment routines resulted in less uncertainty for the women. As treatment progressed, time remained stagnant as their identity was consumed by patient and less by previous life roles. Idyllic and everyday moments made time slow down even more and were met with happiness, as well as simultaneous mourning for their previous life lost. Finally, death was accepted as one of many possible outcomes; time sped up, and a sense of urgency was noted to complete many life tasks and goals. With the concept of losing and gaining time as the central theme, transitoriness was sometimes necessary for the women to experience vast dichotomies of emotions (anger and acceptance, hope and fear, fighting and healing, depletion and gratitude) and come to a place that felt most comfortable for them after experiencing the full emotional range.

As Steeves and Kahn (1987) described, when one is suffering to some degree, but not incapacitated by suffering, he or she is likely to have experiences of meaning. The emotions are considered positive, because individuals are not totally fulfilled without them, and they are better able to cope with suffering when they have experiences of meaning in their life (Steeves & Kahn, 1987). In the current article, the women were processing emotions and experiences of meaning with the whole world as their potential audience. For them, their online community, although public, was a safe place to express their dichotomies of emotion, transitions, connection with time, and transitoriness. Morris (2011) suggested that everyone has an inherently narrative brain. Narrative is a basic human cognitive activity, and people do not just tell stories, they live stories (Morris, 2011). For young women who are already regular users and participants in online spaces (Zickuhr, 2010), the narratives became a social support modality because they allowed for an open audience of followers (often other young people with cancer, caregivers, friends, and family) to be a unique part of the journey as well, and offer support as they proceed. The readers, whether they know the person or not, quickly become an engaged part of the narrative (Bach, 2008). The instant connection and feedback in the form of comments is what sets illness blogs apart from diaries or other forms of expressive writing.

Although the clinical benefits of expressive writing and expression of narrative are beginning to be considered

(Laccetti, 2007; Pennebaker & Seagal, 1999; Thielst, 2007), the benefits of expressive writing online and connecting through blogs and social media are not fully understood. This marks a significant area of needed research, particularly for young adults who may not fully participate in clinic-based support groups because of dramatic differences in age at diagnosis (StupidCancer.org, 2010).

Limitations

Several limitations exist in the current study that must be addressed. Because of its qualitative and descriptive nature, results lack generalizability to a larger patient population. In addition, blogs were used for narrative source data, and although blogs have many advantages in providing a naturalistic sense of the experience, they lack the inherent ability to validate the diagnosis, treatment modalities, and symptom-based experiences.

Implications for Research and Practice

Research has determined that young adult patients with cancer are often an overlooked and understudied group (Bleyer, 2007; Bleyer & Barr, 2007). A necessary first step is understanding the experience of the disease among young women through a physiologic and psychosocial lens that the patient describes herself. Online data through illness blogs represent a new and innovative way of capturing the naturalistic experience of the journey outside of the clinic setting. Also, a defined need remains for this population to be addressed in the nursing literature, considering that much of the current work is being done in the fields of medicine. Given the psychosocial needs, emotional transitions, and survivorship goals unique to this population, nurses have relevant and clearly defined roles for providing age-specific nursing interventions to support emotional transitions and confrontation of mortality. The current study offers great implications for future work in offering social support and health literacy interventions that transcend traditional clinic experiences.

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