Legacy Making Through Illness Blogs: Online Spaces for Young Adults Approaching the End-of-Life

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Little is known about young adults with cancer at the end-of-life, but life review and legacy making may be important modalities to process the emotions associated with anticipatory grief. The study analyzed the illness blogs of five young women (aged 25–39 years) at the end-of-life using a narrative approach. Key elements of legacy making and grief processing were explored. The women had varying experiences before their death, but uniform posthumous occurrences with the use of the blog for a space of grief for loved ones. The use of online blogs among adolescents and young adults with advanced cancer is an area of needed further study.

Keywords: young adult oncology, end-of-life, illness blogs, legacy making

DESPITE THE ATTENTION THAT ADOLESCENTS and young adults (AYAs) with cancer have received in the past decade, young adults (aged 20–39 years) with advanced cancer remain an understudied population.¹ Very little is known about the healthcare experiences of young adults with cancer approaching the end-of-life.^{2–5} Previous research indicates that it is a period where anticipatory grief and confrontation of mortality elicit a sense of urgency to complete developmental tasks and life milestones of young adulthood.^{6,7} Because of this unique developmental period, the concept of therapeutic life review has been described as a modality that can enhance patients' existential and spiritual processing and may help diminish anticipatory grief as patients approach the end-of-life.⁸ Legacy making, or the effort to preserve memories and confirm that they will be remembered, is often undertaken by children and adults at the end-of-life, but has received little empirical attention.⁹ Illness blogs offer a unique opportunity to utilize and study the concepts of therapeutic life review and legacy making through the act of memorializing words, stories, and photographs among young adults who are approaching the end-of-life.

Illness blogs, or online blogs (diaries) that were initiated by the user to document their experience with a specific disease, have many purposes and benefits,¹⁰ but one such purpose is the use of expressive writing to facilitate a form of life review and emotional processing during the illness.¹¹ To understand better how illness blogs can be used in future research and intervention among young adults with advanced cancer, a nested secondary analysis was conducted to explore the illness experience at the end-of-life among young women with

cancer who maintained online illness blogs during their cancer trajectory and subsequently died.

Methods

Study participants

This nested sample included women, aged 25–39 years, who initiated an illness blog following their diagnoses with cancer and subsequently died from their disease. Sampling criteria from the parent study is described elsewhere.^{10,12–14}

Data collection and analysis

The University of Virginia Institutional Review Board approved this study. The study was considered exempt because the data were obtained from publically accessible websites. Of note, ethical considerations involving the use of public data derived from the internet are evolving, and the lead author was careful to consider issues regarding informed consent, privacy, and confidentiality related to online data prior to study initiation.¹⁵ Two of the five participants displayed their full names and email addresses and were contacted for permission to be included in this study. Due to the private–public continuum on the internet (i.e., the personal expectation of privacy based on identifiers that are present), those participants were not contacted who (1) used only first names or (2) did not have their email addresses visible on their blogs.¹⁰ Additionally, the researchers were passive, and no attempt was made to direct the content of the blog in any way. Finally, no attempts were made to contact the partner or

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parent (who added content to the blog) after the participant died.

As a part of the parent study, the analysis of textual data from the blog occurred non-concurrently, beginning at the time of diagnosis and moving forward in time to the most recent blog post. For this focused analysis, the blog data from the 6 months that preceded death, as well as any posts from family members left posthumously, were the key entries analyzed. Textual data were obtained from the blogs then placed in Dedoose, a qualitative data management software.¹⁶

Data analysis was guided using a focused descriptive narrative approach.^{17,18} Descriptive narrative research can reveal how participants construct their situation in the context of life events and evaluation of those life events. The goal of this focused narrative approach was to gain insight into how the study participants understand and process their lives at the end-of-life through their own illness stories shared publicly. The textual data were analyzed by: (1) immersion in the data, reading it several times and fully understanding the overall context of the entry; (2) line-by-line analysis and data reduction of the text and development of tentative categories; and (3) grouping categories into a meta-narrative or overarching theme.¹⁹ At this point in the process, the lead author's reflective field notes and journal entries were also included in the analytic process. Trustworthiness, or bias control, was addressed in the following ways: making all aspects of the study design open to members of the research team, keeping a journal and "bracketing" or reflecting on prior assumptions and beliefs about the research, allowing for open peer review for decisions made during the process, and independent review of final qualitative findings by all co-authors.²⁰

Results

Five blogs were included in this analysis. The young women were on average of 31.8 years of age at the time of their cancer diagnoses and blogged for an average of 35.6 months, or nearly 3 years in total. The range of cancer diagnoses can be found in Table 1. The overarching theme, or meta-narrative, was the importance of the online space for legacy making and grief processing, both before death and posthumously. Exemplars for each participant can also be found in Table 1.

There were vastly different pre-death illness experiences that were described among the participants. For example, Susan and Angela were both parents in their late 30s when diagnosed with inflammatory breast cancer (IBC) and had early and consistent palliative and hospice care provided to them. Both women exhibited anticipatory grief over the lost future with their partners and children. At times, impending death felt very heavy and ever-present, but there was also an ease and acceptance that was truly unique to their experiences. Susan had significant pain issues due to the metastasis to her bones, yet maintained a sense of adventure and control over her own narrative. Angela was able to use poetry as an outlet for her pain and grief. They were both able to plan for their death, and Angela specifically wrote a blog post that was intended to be posted after her death, while also noting that she wrote birthday cards to her six children for the next two years.

Karin exhibited a form of life review on her blog, but interestingly it only focused on the cancer experience. She described how naïve she felt looking back on her original posts close to the time of her original diagnosis, remarking

how she was going to "fight" the disease and "battle" her cancer. Her metaphors shifted over a long treatment course of multiple chemotherapies, clinical trials, two stem-cell transplants, and finally an experimental salvage therapy. Her later writings revealed an ease about her trajectory and the personal growth she made during her cancer experience. She used humor to share the account of her own end-of-life discussion with her healthcare team and jokingly remarked that all she could think about was how badly she had to pee. These writings provided key points of reflection and an overall sense of optimism and love, even during difficult times.

Becca and Shannon expressed very different narratives during their end-of-life trajectory. Becca was in her mid-twenties, single, living with roommates, and would often describe how isolated she felt. She felt abandoned by many of her friends, but through her blog was able to meet other cancer survivors online and was able to develop rich friendships with people who "understood her." Becca was a regular blogger during her early cancer treatment, but abruptly stopped blogging for almost 2 years prior to her death. Uniquely, her mother posted entries from Becca's journal, written poetry, and Facebook messages to the blog posthumously that allowed for an insight into Becca's experience prior to death. Exhibiting a stark contrast in her illness trajectory, Shannon had a very rapid escalation in care and spent most of her time blogging from the hospital. She remarked that the blog made her feel more connected while she was there and separated from loved ones, but overall she remained fearful about her treatments. Her death occurred suddenly in the intensive care unit with very little time for life review or anticipatory guidance. It was unclear if palliative care was involved for Becca or Shannon.

While the pre-death experiences varied, posthumous blog experiences were universal. In every blog included in this analysis, the partner or parent drafted a eulogy of remembrance for their loved one. Angela's husband wrote several updates focusing on how he and his children were coping with grief and loss. Becca's mom shared the video of her memorial service, while Karin's husband developed a book of quotes and stories from her blog postings to memorialize her words. The postings of eulogies, pictures, and videos allowed for followers of the blogs to offer condolences and shared grief.

Discussion

It has been previously described that anxiety related to death is proportional to each person's perception of their "unlived life," meaning those who feel as though they have lived a rich life experience less anxiety as they approach death.⁵ This concept has numerous implications for young adults with advanced cancer due to the need to condense many years of unlived life into a short amount of time. This analysis demonstrates that illness blogs may offer a modality for young adults with advanced cancer to engage in therapeutic life review and legacy making through engagement with expressive writing on their illness blogs. Additionally, because "being remembered" is central to legacy making,⁹ blogs offer a unique opportunity to be remembered through public sharing of words, pictures, and life experiences.

Experiences that were shared among the young women through their illness blogs varied in terms of levels of anticipatory grief. Fear, sadness, and uncertainty of the future were all uniformly expressed, but embedded within some of

TABLE 1. EXEMPLAR STUDY ELEMENTS

<i>Age and length of blog time</i>	<i>Diagnosis</i>	<i>Elements of legacy making and grief processing</i>
Karin; diagnosed at age 25; blogged 58 months after diagnosis	Hodgkin's lymphoma	<p><i>Pre-death</i></p> <ul style="list-style-type: none"> – “Cancer” review—shared key moments in cancer trajectory – Photographs of times with loved-ones shared, overwhelming feeling that her life was inherently rich – Shared end-of-life meeting – Importance of shared writing through blog posts, developed scripts, etc. <p><i>Posthumous</i></p> <ul style="list-style-type: none"> – Husband shared obituary, loving comments from readers – Crowdsourcing project to create a book of Karin's most poignant blog entries
Susan; diagnosed at age 34; blogged 54 months after diagnosis	Inflammatory breast cancer (IBC)	<p><i>Pre-death</i></p> <ul style="list-style-type: none"> – Expectation of life as an adventure – Involvement of hospice nurses to help alleviate pain to participate in key events and holidays – Course was unpredictable, but not permanent – Awareness and action related to IBC, key purpose of sharing story – Reflection of milestones and memories with children and husband <p><i>Posthumous</i></p> <ul style="list-style-type: none"> – “Goodbye” post from husband with links to IBC research efforts that were important to Susan, loving comments from readers, communication via Twitter
Becca; diagnosed at age 26; blogged 44 months after diagnosis	Colorectal cancer	<p><i>Pre-death</i></p> <ul style="list-style-type: none"> – Becca stopped blogging regularly ~2 years prior to her death <p><i>Posthumous</i></p> <ul style="list-style-type: none"> – YouTube video of Becca's memorial service – Becca's mom began posting entries from her journal, poems, and Facebook messages that exemplified the emotions she was experiencing as she approached her death. Key themes included loneliness and being forgotten – Her mother included her own grief reactions on the blog
Angela; diagnosed at age 39; blogged 14 months after diagnosis	IBC	<p><i>Pre-death</i></p> <ul style="list-style-type: none"> – Waves of acceptance of impending death, heaviness of death close to her – Elements of being a mom and having a terminal illness; worries over suffering of family – Grief of lost future (anticipatory grief) – Forgiveness – Poetry about pain and hospice – Writing birthday cards to her six children for the next 2 years <p><i>Posthumous</i></p> <ul style="list-style-type: none"> – A final post written close to death but posted on the blog after she passed; “final thoughts” – Blog continues by husband; updates on coping with grief
Shannon; diagnosed at age 35; blogged 8 months after diagnosis	Melanoma	<p><i>Pre-death</i></p> <ul style="list-style-type: none"> – Importance of staying connected while in the hospital and intensive care unit (ICU) – Fear – Posting pictures of previous happy memories <p><i>Posthumous</i></p> <ul style="list-style-type: none"> – Eulogy from husband

those narratives was also acceptance, peace, love, and ease. As Steeves and Kahn²¹ explain, when someone is suffering, but not incapacitated by suffering, they are likely to have experiences of meaning. While these emotions may be difficult, they are still considered positive, and individuals are better equipped to face suffering when they are also enriched with experiences of meaning.^{21,22} Publically sharing experiences of meaning online through narrative expression, photographs, videos, and other digital media represents an innovative modality for AYAs to engage of the catharsis of expressive writing¹¹ while also having the additional benefits of social

support⁶ and legacy making. These modalities and concepts must be explored further through further research. It is posited that blogging could be a therapeutic option for patients with advanced cancer.

The narratives of the women with early initiation of palliative and later hospice care were notably different from the narratives of the other women. Life review is a common approach enacted in palliative and hospice care to allow for existential and spiritual processing, and it is possible that these women were more comfortable with coping with their anticipatory grief of a lost future because of palliative and

hospice involvement.^{8,23} Uniformly, illness blogs offered a unique opportunity for family members and loved ones to commemorate the loss of their loved one in a public way, contributing to the act of legacy making.

While there are several advantages to using this method for qualitative inquiry,¹⁰ there are also notable limitations. Results may lack generalizability due to the qualitative nature and very small sample size. There may be unique personality characteristics among women who blog that are very different from women who do not share their story through an illness blog. Of note, the women in this study had extremely high levels of health literacy and writing ability. Additionally, because blogs were used as the source data, it is impossible to validate reported diagnoses or specific disease-related experiences that were shared. Even so, the advantages of using illness blogs are multifaceted, including the ability to study the experience longitudinally through the use of the participant's own words.

Conclusion

In general, very little is known about the trajectories of young adults with cancer as they approach the end-of-life.² Because of the unique lens that illness blogs provide, this study offers novel insight into their shared narrative during this understudied period.¹⁰ This approach allowed for an exploration that is often unavailable due to perceived distress and burden during a time where very few participants are recruited into psychosocial research.²⁴ Additionally, because participants blog about topics that are meaningful to them, the naturalistic approach allows researchers to understand a patient-centered experience. There is a defined need to research further the concepts outlined in this study (legacy making as a form of life review through illness blogs) and empirically study the utility in specific populations, such as AYAs with advanced cancer, who are already comfortable with online technologies.

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