

Grief and Gracefulness Regarding Cancer Experiences Among Young Women

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Purpose/Objectives: To gain a unique perspective of young women with cancer aged 20–39 years who are experiencing challenges with fertility and parenting through analysis of cancer blogs.

Research Approach: A secondary analysis of online narratives using a focused thematic analysis approach, comparing women who were mothers prior to diagnosis with women who are exploring the possibility of motherhood after diagnosis.

Setting: Blogs found through websites and social media venues for young adults with cancer.

Participants: 10 women aged 20–39 who maintained blogs about their cancer experiences.

Methodologic Approach: Thematic analysis using line-by-line coding. Construction of comparative themes and meanings were guided by the analytic framework of the stages of grief.

Findings: Themes emerged along the grieving trajectory of denial (maintaining routines and discussing “eggs”), depression (losing motherhood and anticipatory grief), and acceptance (finding joy moment to moment and hope for pregnancy).

Conclusions: Motherhood and infertility are unique experiences for young women with cancer but are expressed similarly through the stages of grief: denial, depression, and acceptance.

Interpretation: Understanding the grief trajectories of young women with cancer will help nurses to develop screening tools and supportive interventions.

The challenges for young women with cancer aged 20–39 years are complex and include disruptions in identity development and barriers to reaching life milestones, such as family initiation and parenthood (Love & Donovan, 2014). The difficulties are similar to those for young adults in general, but young women are faced with compounding challenges because of their roles as single women, wives, and/or mothers. Often, young women desire to begin or grow their families, but those aspirations are placed on hold while the multitude of decisions surrounding cancer treatment takes precedence. Therefore, women who may become infertile because of cancer treatment and those who balance parenthood with cancer treatment begin the process of grieving. While desiring to have a child and caring for a child are not the same, these groups of women still have important similarities and differences. This study will explore their unique experiences through a secondary analysis of an ethnographic study of blogs of young adult women with cancer (Keim-Malpass & Steeves, 2012).

Blogs are a continually evolving medium young adults are using to seek support during cancer diagnosis, treatment, and survivorship. Use of an online medium for support has several benefits. It allows women to talk about their experience candidly without the emotional exposure present in face-to-face conversations. In addition, the online environment removes the physical distance and difficulties associated with transportation, neutropenia, cancer- and treatment-related fatigue, and other barriers preventing women from attending support groups in person. Another very pertinent benefit of blogging is that it can be done whenever it is convenient for the woman (Treadgold & Kuperberg, 2010). Young women with cancer work to balance their lives with doctors' appointments and treatment schedules, and online blogging can be a way to express themselves without the constraints of time. Despite the need for research involving young women with cancer, literature examining the use of cancer-illness blogs is limited.

Background

About 69,000 adolescents and young adults aged 15–39 are diagnosed with cancer each year (National Cancer Institute, 2014) and, by age 39, 1 in 51 women has been diagnosed with cancer (Canada & Schover, 2012). Of the difficulties facing young women with cancer, those related to motherhood and infertility are central to their identities and a focus of their disease-related grief experience.

Women aged 20–39 years are in the prime of their childbearing years. Many face the cultural expectation that their life story should include becoming a mother, or at least wanting children. A cancer diagnosis results in a disruption of feminine social roles, of what it means to be a woman. At the time of diagnosis, women must deal with “existential questions at the meaning of life without the desired goal of motherhood, while making complex decisions about treatment and fertility preservation” (Kirkman et al., 2014, p. 512).

Infertility can be a result of the cancer itself or of chemotherapy- and radiotherapy-related damage to the reproductive system. In addition to the complications of infertility, women may experience psychological distress and loss of hope for future fertility if they have not succeeded in fertility preservation (Perz, Ussher, & Gilbert, 2014). Literature in this area focuses on the uncertainty of a woman's journey through cancer treatment, fertility preservation options, assisted conception techniques, and pregnancy and motherhood, all of which carry some level of uncertainty for young women (Halliday & Boughton, 2011). In addition to the emotional difficulties of

infertility, women can experience financial stresses, such as the expense of fertility preservation, which is not nationally mandated and is expensive without insurance (Canada & Schover, 2012). The financial, emotional, and physical difficulties of infertility play significant roles in the grief trajectory of young women with cancer.

In addition, parenting during cancer treatment cancer presents challenges. Young women are more likely to experience greater levels of stress during treatment than older women, and even more so in young mothers (Arès, Lebel, & Bielajew, 2014). Women used to devoting themselves to their children must learn to prioritize their needs over their children's (Semple & McCance, 2010). Parents, in contrast to those without children, experience depressive symptoms related to parental stress as well as the stress of disease and treatment (Schlegel, Manning, Molix, Talley, & Bettencourt, 2012). Parents also fear that experiencing the emotional roller coaster of the cancer journey will have a lasting impact on their children (Coyne & Borbasi, 2006). Practical challenges these women experience include talking to children about what to expect during treatment and maintaining routines of daily life, including discipline (Semple & McCaughan, 2013). The challenges of parenting contribute to the grief trajectory in these women.

In an effort to explore the grief trajectory in these women, the stages of grief (Kübler-Ross, 1969) were used as an analytic framework. *On Death and Dying* (Kübler-Ross, 1969) provided the initial introduction to the stages of grief: denial, anger, bargaining, depression, and acceptance. This current article highlights three of those stages as experienced by young women with cancer—denial, depression, and acceptance.

Denial is a coping mechanism that occurs after realizing a loss, allowing a person to handle the immediate period of grief. Depression is a deep state of sadness and often one of the longer-lasting stages. It is considered maladaptive when depression is not experienced. Acceptance is an understanding of the reality loss.

The existing framework of the stages of grief was chosen after the completion of the thematic analysis, as the most prominent themes naturally fell into the stages of denial, depression, and acceptance. The prominence of those particular stages over anger and bargaining reflected a spirit of gracefulness as the young women experienced grief.

The purpose of this study was to gain a unique perspective of young women with cancer experiencing challenges with fertility and parenting through analysis of blogs. This study also explored the process of grief in young mothers and aspiring mothers as they experienced cancer diagnosis and treatment.

Methods

Sample

This analysis was a part of an overall parent study that examined the experiences of young women with cancer through their online narratives. Blogs were chosen in the parent study based on several inclusion criteria, including blogs written by women in the United States with a cancer diagnosis during young adulthood, to avoid differences in healthcare systems and cultural routines related to the diagnosis. Women with stage 0, or in situ cancers, were excluded. Potential blogs were purposefully sampled based on criteria that three of four randomly selected blog entries would directly be related to the cancer experience. In addition, each blog title or author biography specifically described that the blog was related to a young woman's cancer experience. A modified snowball convenience sample was obtained on the StupidCancer.org blog roll. Followers of those blogs were located and added to the analysis if they met the criteria. Also, the lead researcher of the original study began following young adults with cancer via Twitter and added several blogs to the analysis.

For the secondary analysis, the author chose blogs based on the criteria of the women being either mothers prior to diagnosis ($n = 6$) or exploring the possibility of motherhood as demonstrated by their discussion of issues related to infertility after diagnosis ($n = 5$). One participant fell into both groups and was analyzed once for each group.

Data Collection and Analysis

For the primary study, institutional review board approval was submitted and was exempt as the blogs used for analysis were all in public access. From the original body of data included in the study, a subset was chosen for this thematic analysis. The data set for this analysis were chosen by identifying a particular area of analytic interest and including all instances in the textual body where the analytic interest was indicated (Braun & Clarke, 2006). In this case, the data set was chosen based on references to motherhood, aspiring motherhood, or infertility.

The research analyzed textual data from the blogs in a line-by-line fashion, and grouped categories together to develop potential themes. During the process of line-by-line coding, the authors identified the analytic framework of Kübler-Ross's (1969) stages of grief and used it to guide further thematic analysis. Both authors reviewed the categories and themes and found no new categories or themes after review. They kept reflective journaling as well as field notes to minimize potential bias. Additional methods used

to minimize bias were open peer review of analysis by members of the research team and maintenance of an audit trail to review the decisions regarding thematic development.

Findings

Upon comparison of fertility and parenting in young adult women with cancer, the major alignments with the grief trajectory include denial, depression, and acceptance as expressions of grief.

Denial

Kübler-Ross's (1969) stages of grief are denial, anger, bargaining, depression, and acceptance. Denial is necessary to maintain well-being and deal with overwhelming stressors (Stephenson, 2004). Denial may be a subconscious process when "physical health, important relationships and sense of control [are] threatened" (Stephenson, 2004, p. 985). Denial is a complex internal process, but additional exploration may help to better understand young women's experiences with their initial cancer diagnosis. Young mothers demonstrate denial by assuming that life and routine are normal rather than confronting their fear of cancer. Use of the word *eggs* allows aspiring mothers to remain lighthearted about the very serious threat of infertility and, thereby, deny their fear. The findings of denial in each group of women are as follows.

Young mothers: Maintaining routines: After a cancer diagnosis, young mothers work to maintain normalcy, a coping mechanism that falls into the category of denial. According to one young mother,

Six days before my biopsy, I took the children to the park. We laughed, we played, we had a snack. Just an ordinary day—except that when I lifted the boys, my right arm twinged and I had to put them down.

For hours, she could pretend as if everything would move forward as normal, but her body briefly reminded her that would not be the case. The desire to be selfless, which often accompanies mothers, does not suddenly shut off when they are diagnosed with cancer. They strive to keep moving forward for their families.

The analysis indicated that children recognize when their parents are sick but use language they understand to describe it. A young child, excited to see his mother at circle time in preschool, asked her if she could pick him up. When telling him that she could not, he asked if she could still drive him to school. Then she realized that, to him, taking him to school and picking him up meant that she was feeling better.

Those little normal moments, like pick up and drop off from school, or even making them dinner, have become so monumental for me and as a result for the kids. I feel their excitement when I'm the one to get their sippy cup. I feel their relief . . . "Now Mommy's okay." And I want to cry. If only it were true.

The children saw that their mother was doing everyday tasks on a good day and believed that she was feeling better. This analysis demonstrated that young children associate normal activities with hope for the future, a future in which their mother can care for them, which is an important part of maintaining routine and denying current difficulties. One mother addressed when and how she would feel better by describing apples, a concept that a child would be able to understand.

I think about apples a lot these days.

"When will Mommy be better?" asks David.

"When the apples turn red and we can eat them," says Michael.

We try to use concrete things to explain the cancer to the kids. Mommy's hair will get thin again. She'll wear more hats. Mommy will get tired and not pick you up from school as often. Mommy will be better when it's Halloween and we'll dance and we'll dance and we'll dance.

"Is Halloween tomorrow?"

"No, Sweetie, Halloween is in October. Jeremy will be 3. You'll be back in school."

"And the apples will be ready to eat."

I need to remember that those apples will become red in turn, and we will eat them. I need to think of time and the future and an end to chemo.

Denial continues in terms of the mother's appearance. Children get confused and often upset at the sight of their mother without hair. Bearing the discomfort of hair loss and the itchiness of wearing a wig, mothers strive to look normal for their children. In addition to the hair loss, mothers do not want to appear distressed in front of their children.

They see me and know that I suffer. I fantasize about having a superpower that would allow me to freeze time for them so that I could go off and get better without them having to witness the pain of treatment. In this daydream, I would return as basically my same self and we could resume our family life without this nightmarish interruption.

Maintaining a normal appearance is as important to young mothers with cancer as maintaining the routines of their own lives and the lives of their families.

Aspiring mothers: Discussing "eggs": Denial presents itself in aspiring mothers in their discussions of future children. Afraid to consider that not having a child is a possibility, they discuss their fertility by using the term *eggs*. It is a very literal and lighthearted word, and using it keeps them from having to discuss their changing identity. One young mother talked to her eggs and apologized for not planning for the chance of infertility.

I am pretty mournful about losing these little eggies. I also want to apologize to them for not having frozen a few for a rainy day. I had no idea a thunderstorm was coming. I'm sorry, little guys.

That is not to say that these young women are not taking the issue of fertility seriously, but that discussing eggs instead of fertility helps them cope with the loss.

Another aspiring mother asked her oncologist whether she should have her eggs "fried, scrambled or fertilized." Despite the levity of the question, she worried that her oncologist would say that she had no time to wait before beginning chemotherapy and that egg freezing would not be an option for her. She conceded that she had never hoped to make such a decision.

[It's either] risk waiting these next few weeks before starting to kill the cancer cells multiplying within me or risk the chance that we'll . . . be able to enjoy the miracle of having our own biological children.

The situation is stressful, and one that a newlywed and newly diagnosed woman with cancer may cope with by using denial.

Holding it all together, maintaining normalcy for the sake of their relationships and families, and attempting to gain some control over the uncontrollable that accompanies a cancer diagnosis lead young women with cancer to use denial. But as with most who grieve, they will move through the stages of the grieving process on their own terms. Each group copes in unique ways and yet has many similarities, such as sharing the same experiences of motherhood and infertility through the stages of grief.

Depression

No two people experience grief the same way, and people often move back and forth between the stages of grief as necessary. However, many experience depression following the initial reactive responses of denial, anger, and bargaining. Helplessness and lack of control over cancer progression or treatment can increase the severity of depression (Kulpa, Kosowicz,

Stypula-Ciuba, & Kazalska, 2014). Young mothers experience depression as they realize that they are losing the motherhood they had pictured for themselves, and in some cases, they prepare for the ultimate loss of motherhood through death. Aspiring mothers experienced depression in terms of anticipatory grief. This section highlights several similarities and differences between young mothers and aspiring mothers as they experience depression in their grief trajectory.

Young mothers: Losing motherhood: Depression can easily take hold when mothers grieve in anticipation over what may come during and after treatment. The fear of death, intensified by a cancer diagnosis, can increase the worry of losing motherhood.

I worry. I don't want to leave my little boys mommyless. No one can mommy them like me. And I don't want to talk about it (because it's NOT going to happen), but it still nags me in the back of my mind. They're too young to even remember me, should the worst happen. SO I CAN'T LET IT HAPPEN.

Often women believe, in part to denial and in part to optimism, that if they have something very important to live for, then they will not die. However, this feeling lasts only for a period of time. The fear of imagining someone else raising their children, whom they loved and raised until that point, is terrifying and depressing.

The hardest part about this cancer is dealing with the possibility that I might not beat it, that I might not survive to be their mama through their baby years, their preschool years, grade school, and beyond. That someone else would raise them, with only pictures and stories to tell them about the mama that loved them so much.

The depression extends beyond fearing death and what may happen after death; it also presents itself in identity loss, when women who spend their lives selflessly caring for their families now must make themselves a priority. It is more than simply balancing the priorities of caring for themselves and their families; it is a dramatic shift of putting themselves first. Feeling a pull to do what her children needed but not having the strength or physical capabilities to do so, one mother said,

I feel tired and weak, but I must be strong for my son. I feel nauseated, but I must help him eat his chicken nuggets and try new foods. I feel like curling up in my bed and crying, but I must help him to go sleep instead, keeping him company until he drops off to dreamland. I feel insecure, alone, and afraid, but I must reassure him that I am always here for him, and I will always keep him safe.

Another mother shared, "The kids still seem stressed and sad. I have not had much time to reassure them that everything will be ok. It is hard to do that when I do not even know myself if things will in fact be OK." The confusion over adopting new roles, which feel selfish, can lead to sadness. Women feel like they do not recognize the mothers they used to be.

The realization I came to last night is that I have spent the last 17+ years trying to protect my children from pain. All types of pain. I am a mommy. A boo-boo kisser. I have done everything in my power to insulate them from the pain they are all in now. The hardest part is knowing that I am the cause of all their distress. I just feel like such a jerk. Watching them mope about with fake smiles. Knowing that their brave faces thinly veil the sadness underneath.

Mothers cannot embrace new roles and identities in the stages of denial and depression. They must continue to move through the stages of grief to accept who they are becoming as both mothers and patients with cancer.

Aspiring mothers: Anticipatory grief: Depression often arises in aspiring mothers in identity loss and the loss of the hope of the mother they thought they would be. The sadness is so poignant when these women, who had dreamed of motherhood, feel those dreams diminishing. One mother confessed, "As thankful as I was to be in good health, and done with chemo, I am saddened by this loss, the loss of my fertility." Another woman described the moment when she realized that not only did she have cancer, but she was no longer able to have children: "I really hadn't given much thought to the fact that in the process of saving my life, I would become barren."

Depression is compounded by uncertainty. Not knowing or understanding the future, especially a future completely different from the one originally pictured, can lead to further depression.

What does my constant crying mean, if anything? Am I, after all this, still whole? I know what all the docs said at the beginning and I eventually accepted it (or so I thought) but things keep happening to contradict them, so: Will someone please just tell me if I will ever to be able to have babies again?

Uncertainty can be consuming and increase the distress already present during cancer treatment. "When you are a mom who lost her fertility to her cancer treatment, every ultrasound looks like an empty womb, even if they're just scanning an enlarged lymph node in your neck." A woman desiring normalcy and the ability to grow her family, as she believes she

should be allowed to do, will experience depression as she moves forward in the stages of grief.

Acceptance

Through the progression of grief, women often find themselves accepting their new identities and situations, allowing themselves to revel in joy and hope. Both mothers and aspiring mothers were optimistic in their situations, resulting in acceptance of their circumstances.

Young mothers: Finding joy moment to moment: Experiencing joy in parenting is an exercise in balance and allowing oneself to temporarily “let go” of cancer. It happens when mothers process grief and allow themselves to feel joyful.

I do not feel particularly sick today as I had the awesome golden acupuncture yesterday. Maybe today is my day. Today I am not going to die. Today I am not “sick.” Today with Jacob I am a fat bald mommy. And I am going to spend the rest of today forgetting I have cancer.

A woman allows herself to feel joy not merely by forgetting the cancer but by delighting in her family.

There was some happy salsa music playing and Renee began to groove. Joe saw it and began to bust some serious moves as he shouted, “Renee dancing!” and “Mommy dance!” So I got into it and Keith, on the bench between Babu and me, started channeling complicated 80s pop moves . . . complete with the worm.

By now Joe was demanding everyone dance. “Babu! Daddy!” He was punching one arm in the air. He made all of us follow his “cool” moves. He pushed me over on the bench and sat next to me. Babu ended up in her original chair and we all bopped along. Renee, pleased as punch that everyone was dancing, smiled and grooved. . . . With Joe shouting orders, we seemed a bit like a Richard Simmon’s show, but we were super happy. Everyone. You can’t ask for more than that.

In parenting, joyful moments are not always momentous but simply everyday occurrences that foster happiness.

This afternoon, I lay quietly on the hammock with my baby, and let the world wash over me and around me. The leaves rustled with the slightest breeze. The bees and butterflies set about pollinating the overgrown mint borders and the dying tomatoes in the garden. The hammock swung gently as I pushed us ever so softly through the air.

In caring for children and in quiet moments of reflection, women can experience joy. These moments

reflect an acceptance of the disease, of new roles, and of the new limitations of motherhood.

Aspiring mothers: The hope of pregnancy: Just as moments of joy reflect acceptance in motherhood, so the hopefulness of new life can reflect acceptance in women experiencing infertility. Hope keeps women moving along through their treatment. Some women with cancer have strong desires to have children and fear that their dreams of being mothers will not be fulfilled, but women find hope in the possibility of pregnancy after cancer. With this hope, women are able to accept their disease and cope with the difficulties of impending infertility.

We went in there ready to pull the plug on this ordeal knowing that we gave it our best shot. But this time the bright, white room felt illuminated and refreshing. This experience has been nothing less than a roller coaster ride—the kind where your feet dangle unprotected below you. . . . We now have four mature follicles to work with, each of which could possibly contain an egg.

Prior to a fertility appointment, this aspiring mother discussed a feeling of renewal.

It’s appropriate that it’s snowing hard outside our windows. Like a comforting blanket engulfing us in a fresh start. And that comfort is exactly what both Jack and I need.

With the hope of future motherhood, women are able to cope with their disease, believing that on the other side of it is a new life with a growing family.

Discussion

The aim of this study was to explore the experiences of young mothers and aspiring mothers with cancer, and much has been learned about the similarities and differences between the two experiences. This analysis allowed the researchers to understand the complexities of grief experienced by young women with cancer. Each of the participants experienced some level of grief, and some young women with cancer progressed through the stages of grief gracefully. By using a public forum to discuss the cancer experience, women were allowed to express their experiences individually and privately. In a comparison of face-to-face interviews with online blogging, McBride (2011) found that bloggers were able to give and receive support while discussing frank material on sensitive topics.

This analysis revealed some of the inner complexities of the grief experienced by young women with cancer. The stages of grief have been widely criticized as the model has implicated that the stages of grief

are to be experienced in a linear fashion: first denial, then anger, bargaining, depression, and acceptance (Smit, 2015). The stages of grief have become outdated in many ways, making way for models that reflect the intricacy of grief. Although the experience of grief is complex and the discussion of denial, depression, and acceptance offers a simplistic view of the grief trajectory, this analysis showed that the stages of grief have merit. In addition, the prominence of these stages over anger and bargaining demonstrated a gracefulness within the women's grieving process. This is not to say that anger and bargaining were not parts of the grieving process of young women with cancer, but those stages were not as evident in this analysis. This also does not suggest that women should or have to be graceful as they experience grief. The roles of mothers shifted from self-less caregivers to caregivers prioritizing their own needs over others'. Women experiencing infertility had a slow realization of who they were outside the hope of motherhood. Eventually, young women with cancer accepted the inevitable changes cancer and treatment brought into their lives, and demonstrated grief gracefully by adapting to their new roles.

Limitations

The qualitative and descriptive nature of this study decreases its generalizability to a larger population. In addition, blogs provide narrative data, or a naturalistic sense of the experience, but lack the ability to validate cancer diagnosis, motherhood, fertility status, and symptom-based experiences.

Implications for Practice

Acknowledging patients' grief processes allows nurses to provide social support—the information, advice, and aid provided to patients to reduce anxiety and distress. Social support can improve a patient's tolerance of stressful life events (Kinsey & Van Gerpen, 1997). In addition, researchers should expand on grief assessment tools to make them more applicable to this patient population and develop social support interventions.

Young women tend to decline the need for support, while those in their social circles are looking for ways to support them. Nurses should encourage their patients to make a list of those who have offered to help them, and as specific needs arise, suggest that these women reach out to them. By pairing needs with helpers, nurses can help patients maintain a sense of control over their situations (Kinsey & Van Gerpen, 1997).

In addition, when grief leads to maladaptive coping responses and psychosocial distress in women,

Knowledge Translation

- Young women with cancer experience grief in relation to identity change and loss at cancer diagnosis and treatment.
- Grief is compounded by parenting and family planning challenges common among women of this age.
- Understanding these women's grief trajectories will help nurses develop screening tools and supportive interventions.

nurses should offer immediate attention and counseling. Pressure to be optimistic can lead to an internalization of negative feelings in patients, which can impede the grief process. Nurses should encourage these women to discuss their grief (Gonzales, 2012). If a woman is uncomfortable discussing her grief in person, nurses should suggest that she find other ways of expressing her grief and emotions, such as writing a blog. Offering social support, pairing patients with helpers, and educating patients on online support groups are just a few practical ways nurses can help young women through the grief process during cancer treatment.

Conclusion

Motherhood and infertility are unique experiences for young women with cancer. Although different, their individual stories shared many similarities, as they experienced grief with an emphasis on denial, depression, and acceptance.

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