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The Story Deepens: Female Cancer Patients Respond to Their Own Experiences with Hair Loss

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Introduction

Storytelling, as a means of sharing experiences, forming relationships, and making sense of our lives is perhaps as old as language itself (Puchner, 2018; Society, 2020). In clinical medicine, a reliable accounting of the history of the present illness is still our most effective diagnostic tool (Peterson et al., 1992). Recently, the exploration of personal illness narratives has become an increasingly accepted method for advancing patient-centered healthcare (Charon, 2006; Kleinman, 1988). Working with this frame, a health care provider can enter a patient's life story in the same way a reader enters the life of a character in a novel. As the listener receives the narrative, she calls upon her own associations, memories, creativity, and interpretations (Charon, 2001), thereby constructing a shared understanding that is inaccessible through standard diagnostic interviews and scientific surveys.

Chemotherapy induced alopecia (CIA) is understood as one of the most traumatic parts of a woman's cancer treatment (Charon, 2006; Kleinman, 1988; Peterson et al., 1992). However, the experience is difficult to capture through traditional data collection methods. Stripped of their hair, women often feel as if they have lost their femininity, sexuality, attractiveness, self-esteem, and personality (Carpenter & Brockopp, 1994; Hesketh et al., 2004; Rosman, 2004). Fear of hair loss can lead a patient to refuse chemotherapy altogether (Hesketh et al., 2004; Saraswat et al., 2019; Trüeb, 2010). Interventions to ease the experience of hair loss exist, such as wigs and scalp cooling. Still, wigs do not appeal to many women (Batchelor, 2001; Rosman, 2004), and scalp cooling has limited efficacy (Dunnill et al., 2018; Nangia et al., 2017). Furthermore, these solutions focus exclusively on physical appearance and fail to address the deeper implications of hair loss on identity.

While some studies have used quantitative measures to assess the effect of hair loss on quality of life and body image (Carpenter & Brockopp, 1994; Münstedt et al., 1997), studies using qualitative measures show more promise for capturing the psychosocial and quality-of-life impact of CIA (Hesketh et al., 2004; Rosman, 2004; Trüeb, 2010; Williams et al., 1999; Zannini et al., 2012). Our study had three specific aims. First, we hoped to collect patient stories to better define how CIA affects a woman's identity and quality of life. Second, we hoped that unifying those stories into a reflective essay would reveal previously inaccessible aspects of hair loss. Finally, we intended to explore for the first time patients' attitudes towards narratives written about their illness experiences.

Part 1: Collecting the Stories

Women diagnosed with cancer who had lost or were expected to lose their hair to

chemotherapy were informed of the study by their oncologist. One of the authors met with these women and invited them to participate in two semi-structured interviews. Since the IRB granted this study exempt status from the Federal Policy for the Protection of Human Research Subjects, participants were required to provide verbal consent only.

One of the authors approached four women, all of whom consented to be enrolled in this study, and conducted the first round of interviews which focused on cancer diagnosis and hair loss (Table 1). All participants (ages 24, 40, 41, and 61 years) had been diagnosed with breast cancer. These interviews were audio recorded and transcribed verbatim.

Table 1

Open-ended questions for first interview.

- Tell me how you found out you had cancer.
- Tell me about your hair loss.
- Tell me about some of the most difficult parts of this process.
- Tell me about some of the best parts of this process.
- How has your life changed since your diagnosis?
- What is your greatest wish right now?
- How has it felt to tell me your story?

Two authors separately coded each transcript and then met to compare codes. Coding processes, definitions, and categories were discussed in a constant comparison approach, and a final codebook was developed in an iterative fashion and reapplied to all transcripts (Author et al., 2019; Crabtree & Miller, 1992). The coded data were then reviewed to identify patterns and themes.

Cancer and Hair Loss in Their Words: Key Themes

Mom as Protector

Three of the four participants were mothers. All three felt compelled to put up strong fronts and maintain a sense of normalcy for their families during the cancer experience. One woman described her diagnosis as “scary because [I felt I needed] to keep up a big front for the whole family...[I] felt like [I] had to maintain a nice image on the outside so you don’t scare them to death.” A second woman echoed these feelings and said her kids did very well during her cancer experience “probably because I acted like it was going to be fine. I try not to bring my cancer up too much. I don’t want them to see any side of me being sad.” A third woman took a different approach: “I didn’t want to hide anything from [my kids]. The more involved it’s gotten, the more upfront we’ve been.” While this

last participant's response reveals that protection took different forms, ranging from concealment to full disclosure, protecting family was clearly a high priority for each mother.

Nobody Wants to Wear a Wig

For three of the four women, purchasing a wig was an instinctive and immediate solution to their hair loss. However, only one woman decided to wear her wig nearly full-time: "anytime I was around anyone outside of family, I wore it. I wouldn't wear the wig walking around the house." For the other three women, wigs were not a satisfying solution. One woman bought a \$500 wig and threw it into a box as soon as she brought it home. She said that while "being in control was important to me...wearing the wig made me someone I wasn't." Instead, she took control of her hair loss by shaving her head regularly. Overall, acquiring and—in some cases—wearing wigs was seen as a necessary, if ultimately unsatisfactory, coping strategy. As their cancer experiences unfolded, the women developed more individualized coping mechanisms to deal with their loss of control, including embracing humor, focusing on their work, and cultivating an intentionally positive mindset.

The Jo March Reaction

In the book *Little Women* by Louisa May Alcott, the protagonist Jo March cuts her long, thick hair and sells it to make money to care for her ill father, much to the dismay of her family. Her sister Amy declares that Jo has lost "her one beauty." Jo maintains her composure in front of her family but sheds tears later that night for the loss of her beautiful hair. While there was a similar Jo-like tendency among participants to minimize their hair loss—"it will grow back"—it remained clear that all women struggled as a result. Each of the participants in our study expressed that hair loss took a toll on their sense of identity and self-efficacy. As one woman stated, the "hardest part of losing hair [is] not feeling like yourself." Another woman said, "losing hair meant I had cancer," and concluded that hair loss is "a symbol of all these things that you're going to lose," such as job, independence, and sensation of taste and touch. Two women identified hair as a source of pride, which was lost when it fell out. One woman said that "people knew me by my hair," and another, "I was really mad and upset [by my hair loss] because it's taken me two years to get it long, and it was longer than my husband had ever seen it." One woman said, "the loss of the eyebrows bothered me worse than the head, because that's where your expression is."

Three Pillars

The participants described three main supports that helped them through their cancer diagnosis and treatment: romantic partners, family and friends, and faith. All four women referred to their romantic partners as their primary sources of

support. One woman said, “I always knew he loved me, but you see it in a different way.” Another woman recounted how her husband would say, “you look so beautiful without hair.” He would shave her head every three days so that it stayed smooth. Three of the four woman described faith as a central coping mechanism: “with Christianity, I don’t feel alone as much...God gives me peace, and it’s reassuring that someone higher loves me and wants what’s best for me.”

Living with Gratitude

All four participants spoke of silver linings from the cancer experience, of which the most notable included: renewed love and appreciation of family and friends, increased gratefulness for life, and the ability to help other people diagnosed with cancer. One woman said that her cancer experience “makes you see more things in your family and friends and community—that’s a positive.” Another woman described this same sentiment as “a glimmer of light in this dismal world we live in.” One woman had promised herself to “fill this year with good memories” and spoke of the trips she made with her fiancée and the concerts seen with her grandma. The last woman stated that her cancer has “made me stronger in everything—in life, in love, in friendship. You don’t take nothing for granted.”

Scarred and Haunted by Dreams Deferred

All four participants expressed feeling diminished, both physically and emotionally. One woman said, “I won’t ever be the same. Too much goes on in your head, at least for me. I would hope that I could be somewhat close to what I was, but I won’t be the same.” These women felt as if they had lost part of their youth and the opportunities that come with that: “[I] gave up my job, living on my own, gained a lot of weight on steroids, lost my taste, I get horrible hot flashes and night sweats because my body is on menopause.” One woman said that after chemo, her hair grew back white, and she felt like “the white hair took a lot of my youth away.”

Forging a New Life Story

All four women stated that their initial greatest fear was hair loss. However, the importance of hair loss faded for all women as they proceeded through their cancer treatments. As one woman said, “I would much rather lose my hair than my life.” The woman who set out immediately to buy a \$500 wig after being diagnosed now believes, “it’s okay to be without hair—that doesn’t define you.” All women described journeys that began with shock, anger, and devastation at their diagnosis. These journeys moved towards gratefulness, varying degrees of acceptance, and a hope that their children would not have to experience what they’ve endured. For the one woman who did not have children, her greatest wish was to become a mother. Each participant felt differently about sharing her journey. It was hard for one, “good therapy” for another, and “normal” for a third.

Part 2: Writing the Narrative

One of the authors used the content of the initial interviews as the basis for a creative non-fiction essay. The author reflected on the emotional content of the interviews and relied on this lived, shared experience to capture the holistic and human core of the stories. She employed literary techniques to combine the women's accounts into a unified essay, which was reviewed and edited by a separate author. The essay writer's own mother lost her hair during chemotherapy, and she drew significantly on her personal experiences throughout the writing process.

In order to compare the content of the essay to the source material, two different authors completed a thematic analysis of the essay. Among the essay's five major themes, two—*Mounting Losses* and *The Meaning of Hair*—corresponded directly to the *Dreams Deferred* and *The Jo March Reaction* themes from the initial interviews. The remaining three themes—*Resilience through Protection* (the protective instinct becomes a form of resilience), *The Cancer Curtain* (so much of the cancer experience remains obscure to those around the patient), and *Self-Knowledge Through Writing* (the effect of writing on the author)—revealed depths of analysis and insight not present in the individual interviews.

The narrative can be found here: <https://hekint.org/2020/06/19/tracing-wisps-of-hair/>

Part 3: Responses to the Narrative

Nine months after the initial interviews, participants completed a second interview by phone. Prior to the interview, one of the authors (not the essay writer) read the final essay to each participant and then asked a set of open-ended questions regarding participants' attitudes towards the narrative (Table 2).

Table 2

Open-ended questions for the second interview.

How do you feel after hearing the story?

Tell me what you liked about the story.

Tell me what you didn't like about the story.

How did it feel to have your story combined with other women's stories?

How do you think this story could help you or other women diagnosed with cancer?

If you think this story could help other women diagnosed with cancer, what do you think are good places for it to be (print-out from your doctor, on a website, in a magazine)?

Was there something that could have made this story more helpful to you?

Two authors applied the same thematic analysis to the second interviews as to the first.

The Women Respond to the Narrative: Key Themes

One Thousand and One Stories

In *One Thousand and One Nights*, the Sultan is distraught by the discovery of his wife's infidelity and in a dark revenge plot, resolves to marry and kill all of the kingdom's women. In an effort to save her own life and the lives of all the other women, Scheherazade marries the Sultan and begins to tell him stories. Her tales are so engrossing that each morning, the Sultan is too eager to hear the next part of the story and consequently can never execute her or any other woman. In this collection of tales, Scheherazade – and more broadly, storytelling – serves the role of savior. Similarly, the women's responses to the essay highlighted the therapeutic potential of being able to tell their stories, to have them written down, and to hear them reflected back. As one participant put it, "just being chosen to have my story written about with other women who are going through the same thing and who are brave, you know...it just made me feel special." Another woman described the story as "heartwarming," and a third participant stated that the essay made her feel "thankful that I have the life I have right now." Having their stories written down by someone else validated their difficult experiences. The narrative provided these women a place to reflect on what they have endured and be proud of what they have accomplished. Like Scheherazade's 1,001 tales, the story itself proved to be a source of strength and resilience.

Scheherazade's Woven Tapestry

The power of Scheherazade's stories lies in how each story builds seamlessly from the next. In this way, she captivates the Sultan's attention to such a degree that he cannot afford to execute her or any other woman in the kingdom. The integration of similar, yet diverse, narratives can add a great deal of depth that would otherwise be lacking in an individual story told on its own. Two of the four women expressed comfort at having their stories combined with other women's stories. One participant said that the essay helped her realize that "it's not just me, that this is ongoing, this is millions of women that...have the same feelings." Seeing their stories as part of a larger community helped these women normalize their difficult experiences with cancer and feel less alone. Another participant appreciated "hearing other people's stories" and said that she "always finds them intriguing." Each illness experience takes on new meaning when told in conjunction with other illness narratives.

Scheherazade's Talking Cure

Each night that Scheherazade continues her tales symbolizes another life saved. Over the course of 1,001 nights, she employs her wisdom and creativity to transform the Sultan's constant, disastrous threats of execution into a series of fantastical tales. After what translates as a little less than three years, the Sultan ultimately relents on his revenge plot, and all of the kingdom's women are saved. The women in our study found themselves at the center of a similar narrative arc. The participants emerged from the cancer experience changed in both expected and surprising ways. Each woman came to acknowledge hair loss more as "only a symptom of cancer," rather than a primary loss. The participants felt that the essay could help other women diagnosed with cancer "mentally prepare for what's actually to come" instead of focusing predominantly on hair loss, as they did. In this way, they take on elements of Scheherazade's role, as the lived experiences of these four women serve as both guide and guardian for other women embarking on similar journeys. One woman stated, "that's a story I would have liked hearing a little bit earlier on." These women's stories have the potential to educate other women and prevent future hardship surrounding other women's hair loss.

Enriched Perspective

Two women described the narrative as a means of adopting an alternate perspective of their illness. One participant used the essay as a way to "think [about] how my kids are thinking" and thought that it "could help [other women with cancer] realize a child's perspective." Participants thought that this enriched understanding could help them better talk about their illness with their families: "I think [the essay] can help a lot of moms out there who don't know how to tell their family [about their cancer diagnosis] and what to do with their family whenever they're going through it." Another participant stated that she "could feel [the author] as a daughter." The essay could help moms step into their children's shoes and ease the struggle that moms face when communicating with their children about their disease.

Persistence of Pain

Listening to the narrative brought back painful and sad memories for all of the participants. One woman said, "[The narrative] takes me back to a place when I first got diagnosed, and the things I lost, and the things I still continue to find that are lost." The interview question *how did you feel after hearing the story?* elicited "heartbroken," "teary," and "emotional and sadness." While there was clearly a cathartic aspect to hearing their own stories, listening to the essay also required the women to confront one of the most painful parts of their lives.

Discussion

The Story Deepens

One of the primary aims of our study was to use a narrative framework to reveal rarely accessible aspects of a women's experience with chemotherapy induced alopecia (CIA). Consistent with prior research, all four participants identified hair loss as their greatest initial hardship. However, participants revealed that other losses—such as loss of job, family time, role in family structure, and fertility—had a far greater impact on their lives and identities.

While previous studies relied on both surveys (Carpenter & Brockopp, 1994; Münstedt et al., 1997) and interviews (Batchelor, 2001; Rosman, 2004; Zannini et al., 2012), our study was unique both in its use of the narrative form and in revealing more nuanced attitudes towards CIA. This finding suggests that the narrative approach, by providing a structure through which to organize, compare, and unify diverse experiences, may capture the complexity of experience in a way that questionnaires, scales, and even semi-structured interviews cannot.

Themes that emerged from our initial interviews mirrored those described in other qualitative studies of CIA; namely, that hair loss was associated with a diminished sense of identity and seen in retrospect as a harbinger of future losses. The subsequent combination of the women's stories, and the addition of the author's own, enabled participants to regard their experiences in a new light. Hearing the essay prompted each woman to consider parts of the cancer experience that had not surfaced initially. It is striking that, during the final stage of our study, hair loss no longer appears among the key themes. In its place, broader considerations highlighting the value of shared experience emerge.

Narrative as Tool for Enhanced Communication

This study was partly motivated by the personal experiences of one of the authors, who grew up with a mom who had cancer. For this author, her mom's hair loss was one of the most difficult parts of her mother's illness. After her mother's death, she sought to better understand the psychological toll that hair loss takes on women and families.

The study's findings that hair loss may be less defining than other losses for women with cancer diverge substantially from the author's expectations. This divergence points to the disconnect between the preconceptions of this author, a child at the time of her mother's hair loss, and the lived experiences of four adult women. Three key themes from the initial interviews—*Mom as Protector*, *Nobody Wants to Wear a Wig*, and *Scarred and Haunted by Dreams Deferred*—offer insight into possible causes of the disconnect between mother and child with

respect to hair loss. In different ways, the participants who were mothers did their best to protect their children from their own fears surrounding cancer. For two out of the three mothers, this meant projecting false confidence and shielding children from the most troubling physical and emotional losses. That children regard hair loss as one of the most striking aspects of the experience may be due in large part to their mothers' designs.

The importance of hair loss is not the only aspect of the cancer experience on which mothers' and children's attitudes differ. As mothers develop resilience by protecting their children and maintaining normalcy, so much of the cancer experience remains obscure to their children. The author's mom had cancer for 10 years, yet they rarely talked about her illness. This author and her mom did not know how to communicate on this issue. Similarly, participants in this study described the struggles they faced in deciding what and how much to share about their cancer with their children. Taken together, these findings suggest that mothers diagnosed with cancer might appreciate more guidance on how to talk with their children about their illness.

In response to the narrative, participants expressed a greater understanding of how their kids might be thinking about their illness. Having a better sense of the knowledge gaps between mother and child can help mothers decide how they want to discuss their cancer with their children. As the participants suggested, the essay created for this study, and others like it, could be useful tools to start conversations between mothers and their children.

Participants' Attitudes towards the Narrative

The participants responded to the narrative in both formal and informal ways. During their second interviews, three out of four participants expressed appreciation at having their stories combined with the others. They felt a sense of both solidarity with the other women in the essay and community with others who have suffered from cancer. One of the participants was much younger than the others and felt that combining her story with other women's stories made her uncomfortable because "my story is so different just because many of my concerns are different." Her discomfort was caused by what she considered to be a simplification of her story. She voiced a desire for the narrative to include more, not fewer, details of her story and those of the other women. Still, she appreciated the opportunity to share her story.

Less formally, each participant responded to hearing the narrative in a unique and heartfelt way, indicating that the essay resonated strongly with her. One woman sent one of the authors a picture of her in her wedding gown and wrote, "I married my high school sweetheart during the pandemic with little hair. There is life after

cancer, and I'm choosing joy. I'm incredibly grateful for all the people who have taken care of me during my journey. Thank you for sharing my story." Another sent photos of her with a shaved head, surrounded by family, with the caption: "It's hitting me hard at the moment. Hoping to bounce back at least one more time, always one more time." One woman wrote, "I am doing great right now and continuing my recovery."

Limitations & Future Directions

While some might consider the sample size of this study to be a limitation, the number of participants was kept small deliberately due to the nature of our methods. Writing a cohesive narrative such as the one in this study requires intensive reflection of deeply personal experiences and can therefore be better accomplished by limiting source material. Focusing on a small number of stories helps the writer stay true to the original accounts. The more specific and authentic the story is, the more universal its impact. On that note, the inherent subjectivity of the writing process, as well as the author's decision to include details of her personal experience with her mother's cancer, might seem at odds with the principle of objectivity so important in science. This was far from a blinded study, after all! However, the author's presence in the essay as both an actor and thinker provided a lens through which participants were able to view their own experiences more clearly. Ultimately, this study reminds us that an intentionally subjective exploration is both as valid and as likely to yield new insights as a rigorously objective approach.

Future research studies are needed to address questions raised by our study findings. First, taking advantage of a participant group with more diverse racial, ethnic, and socioeconomic backgrounds would provide an enhanced understanding of the importance of hair loss relative to other aspects of a woman's cancer experience. Second, further studies examining children's attitudes towards their mother's cancer diagnosis and hair loss would be helpful in providing additional interventions to facilitate how mothers communicate with children about their illness.

Conclusion

The current study suggests that the generally accepted toll of hair loss on female cancer patients may be exaggerated compared to other losses endured, primarily because conventional tools used to measure patients' experiences do not allow for the deepest form of inquiry. The essay form is an underutilized tool for synthesizing and consolidating knowledge gleaned from qualitative interviews, for helping patients cope with illness and forge new identities, for strengthening relationships between patients and healthcare providers, and for improving communication between parents and children.

Declarations

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Competing Interests

The authors have no competing interests to declare.

Ethics approval

The IRB granted this study exempt status from the Federal Policy for the Protection of Human Research Subjects.

Consent to participate

Based on the study's exempt status, all participants provided verbal consent to participate in this study.

Consent for publication

All participants have consented to having their data published.

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