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Narratives and Healing: Exploring One Family's Stories of Cancer Survivorship

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This study investigates the narratives of one couple who lived through life-changing events following a cancer diagnosis. The narratives of the cancer survivor and her husband are explored as they struggle to cope with their situation, provide support for one another, and consider their changing personal identities. This research addresses the communication dilemmas that often occur when family members, friends, and providers do not know how to respond to an individual diagnosed with cancer. The rationale for this study is threefold. First, this study advocates the need for learning about the composition of survivor identities over the course of a life-threatening illness. Second, this study seeks to understand how illness survivors and their family members use narratives as a method of communicating their changing identities. Finally, communicating about illness is often perceived as 'taboo', and this study may encourage others to be a part of the participants' stories and learn more about why those stories are often concealed. We learn from these three narratives that supportive relationships are central to healing and that it is through communication among family members that identities are composed and recomposed throughout the illness journey. This research affects communication, social support, identity, and emotion literature and is aligned with human appraisal theories as well. Finally, it offers insights into the ways in which we talk about, hear about, and learn about illness.

Facing the possibility of death associated with a critical illness produces an emotional life-changing experience for those affected by its anguish. When an individual receives the news that his or her time may be limited, attitudes change, ques-

tions are asked, and emotions heighten, not only for the patient but also for family and friends. Frank (1991) explained that "illness takes away part of your life, but in doing so it gives you the opportunity to choose the life you will lead, as opposed to living out the one you have simply accumulated over the years" (p. 1).

This study investigates the narratives of one couple who lived through life-changing events following a cancer diagnosis. We explore the narratives of the cancer survivor and her husband as they struggle to cope with their situation, provide support for one another, and consider their changing personal identities. First, we address the need for learning about the composition of survivor identities over the course of a life-threatening illness. Second, we seek to understand how illness survivors and their family members use narratives as a method of communicating their changing identities. Finally, this study may encourage others to be a part of the participants' stories and learn more about why those stories are often concealed. This article offers the stories of a cancer survivor and her husband, and we invite you to think with their story rather than think about it (Frank, 1995).

CONSTRUCTING NARRATIVES: DIFFERENT VERSIONS OF DIFFERENT STORIES

Cancer may lead individuals into a maze of different identities, such as the sick role (Parsons, 1978), a victim, a warrior, or a survivor. The roles are not sequential, and many issues and experiences affect those identities, such as confronting death, coping with the illness, dealing with the social expectations that guide emotional expression, and even being labeled a "patient." A broad range of research has focused on the identity work of members of varied cultural communities as they face injury, illness, and disease, including athletes (Sparkes, 1996, 1997, 1998), chronically ill individuals (Charmaz, 1987, 1991, 1994, 1995), and individuals diagnosed with cancer (Frank, 1991; Lorde, 1980; Ott, 1999), or generally on the healing powers of the stories we tell over the course of illness (Pennebaker, 1992; Pennebaker, Kiecolt-Glaser, & Glaser, 1988).

Brody (1987) suggested that stories and narratives may help ascertain explanations for illness, which is important for both patients and their families. Geist and Dreyer (1993) explained that accounts let us "discover new ways to talk about and account for ourselves, our relationships, and the contexts within which we manage our identities" (p. 97). This understanding of accounts can be applied to the stories told and heard throughout the illness experience. Each time the story is told, identities are altered, changed, discovered, or abandoned.

Telling Others About Illness

Every day of their lives, individuals decide whom to tell and not tell about their illness. Some individuals may only tell their relatives and a few close friends, and

others may find solace in inviting many people to share in their experiences. Benjamin (1987) advised cancer patients to “tell everyone you want to know, and don’t tell anyone you don’t want to know” (p. 173). However, this approach implies that constructing and telling stories about the illness experience are easy tasks to achieve.

The constraints placed on stories of the illness experience affect individuals’ identities. For example, people who feel victimized may shy away from full disclosure of their story because avoidance helps them deal with their feelings of stigmatization. On the other hand, warriors (e.g., Lorde, 1980; Metzger, 1992) may feel that telling more people about their illness will help in their fight to conquer the disease. The individuals responding to the illness stories may shape the context for future disclosure; if people feel their stories are validated and acknowledged by a family member or close friend, they may be willing to share more in the future. In contrast, a negative experience in sharing an illness story may hinder future disclosure.

Acknowledging Narrative’s Health Effects

Illness for many of us is an opportunity to pay more attention to our body’s signals, and “we can actually learn something from illness that helps to bring us back into alignment with our potential wellness” (Rossman, 1989). Brody (1987) contended that “storytelling as an activity is central to medicine” (p. 12) and that “suffering is produced, and alleviated, primarily by the meaning that one attaches to one’s experience. The primary human mechanism for attaching meaning to particular experiences is to tell stories about them” (p. 5). Narratives serve as a method of working through the anguish and suffering brought on by life-threatening illness.

Narratives may function as a paradox in the illness experience. Some individuals may find that telling their account repeatedly increases the stress and anxiety brought on by the illness. Lorde (1980) explained this paradox as she discussed the strain of wanting to feel strong and talk about her cancer but at times feeling only sorrow and weakness. In those times of weakness, storytelling may prove harmful rather than beneficial. Individuals may feel cornered and obligated to disclose their narrative in every interaction. Benjamin (1987) suggested that “when cancer patients discard the feelings of shame and embarrassment, they tear down another barrier to living life as it was before the illness” (p. 76).

On the other hand, narratives may function as medicine for the ill person. Telling their stories becomes a form of control for individuals, allowing them to gain greater understanding of themselves and their relationships (Brody, 1987). It is compassion, in the sense of experiencing and sharing another’s perspective, that allows us each to become transformed into real, dimensional, embodied selves, rather than selves defined solely by a physical characteristic, an illness, or a disease (Leder, 1990). Communication can be a vehicle for transformation,

for experiencing compassion, and for crossing the boundaries between embodied and disembodied selves.

Healing Stories: Communicating Transformation

Narratives reflect people's lives and the changes in identity they experience when they become ill or as they grapple with their "spoiled identities," allowing others to glimpse the experiences and emotions of persons who feel embodied or disembodied in some way. Stories as identity work represent an overarching type of narrative that might also be described as a journey (Jackson, 1989), a performance (Denzin, 1997), or a ritual of community (Richardson, 1997). Identity work for persons who are ill involves articulating what it means to live a life circumscribed by illness (Mathieson & Barrie, 1998). From the moment they are diagnosed with an illness or begin some type of physical or psychological therapy, individuals are faced with a process of composing and renegotiating their identities with family, friends, co-workers, and health care providers (Mathieson & Stam, 1995).

Narratives become the means to negotiate our changing identities (Coles, 1989; Hanne, 1994). Through stories we explain, exemplify, recount, and account for our decisions (Fisher, 1987). We can think of narratives as something we construct for ourselves and with others to make sense of our lives (Bruner, 1987; White, 1981). Narrative is a mode of reasoning used to make sense of or apprehend the world, and it is a mode of representation we use to tell about the world (Richardson, 1997). The boundaries between narrative and scientific knowledge are permeable, and both forms of reasoning arrive in packages that are inseparable aspects of the same thing—both frame and picture (Czarniawska, 1997).

METHOD

We turn now to one family's experience with cancer. This single case study is part of a larger corpus of narratives about cancer survivorship (Ott, 1999). In-depth interviews were used as the method of data collection. In the original study, a total of 20 interviews were conducted with nine illness survivors and 11 family members of survivors over 8 months. We have juxtaposed excerpts from one couple's narratives, in order to see the similarities and differences in perceptions about the illness experience, the moments of strained communication, the epiphanies that arose, and reflective feelings about the experience. We also see how shared stories serve as catharsis for those who have suffered from life-threatening illnesses. Lindlof (1995) stated that "the qualitative interview creates an event in which one person (the interviewer) encourages another person to articulate interests or experiences freely" (p. 163). In what follows, Ivy speaks of her experiences as a cancer survivor. Next, Ivy's husband, Jack, describes his experiences. The juxtapositioned ac-

counts permit discovery of what would be otherwise difficult, and even impossible, to obtain (Hammersley & Atkinson, 1995).

REVEALING CHANGING IDENTITIES: BRAVE SOULS, SHARED STORIES, AND CHANGED LIVES

There's Strength in Ivy

It was a regular gynecology appointment. The nurse practitioner sat across the room. She looked at me. "So tell me about your neck." I said, "What about my neck?" "You seem to have an area that's a little larger." She sent me to my physician who referred me to an endocrinologist who sent me to have a scan. The doctor wanted to do a needle biopsy, which is about 90% accurate.

I became very organized before surgery because I thought I was dying. I cleaned drawers and cupboards and put my clothes in order because I wanted things to be right and taken care of. I really did think the chances of my dying during surgery were very great. I had no control over what was happening to me. Even though I could not control what was happening to me, I could control my son, Brandon. I didn't want to give him a lot of information because I didn't want him to worry. A mother's role is to protect her child. Brandon was at an age where he really didn't need protecting. I know he was worried about me. I couldn't protect him from the knowledge of it, but I could protect him from the details. I wrote out some letters to Brandon and my husband, Jack. I think they said, "If I die, please read this, otherwise please don't." The only way I could have control was to write these letters saying what I wanted done if I died.

I remember waking up after the surgery. Jack just kind of bent down and said, "You're OK but it's cancer." I just knew it was going to be cancer. The doctors thought they'd only have to take half of my thyroid. But they did the biopsy and the surgery showed that it was cancer. It was starting to go into the muscle tissue as well so they removed it all.

There was a time when I thought I was never going to be well again. But there was also part of me that said, "I'm still gonna grow that garden and that's important to me." Despite my motivation, I was still worried about my future. There was a disease within me and that disease was all encompassing. I ate a lot. I cried a lot, I shed a lot of tears, and I talked a lot. How dare I allow it to happen? Being without the thyroid, all I felt like doing was staying in bed. I could not walk around the house or the outside of my house. The emotions went up and down, up and down. I talked to Jack and he listened. There was a point where Jack's optimism got to me. It was like stop, you're not listening to me. I could die, stop. But Jack needed to hear, "I'm really gonna fight, I'm gonna conquer this, I'm gonna go forward." I needed to be a warrior for Jack.

They kept me off all thyroid medication for about a month after the surgery. I got really, really weak and very tired. I didn't feel good. The hormone level was as low as they could get it so I could have another iodine scan. The next week I went to the hospital for two or three days. Being in a hospital was a very hard thing for me to do. I was put into a room. There were signs on the door that everyone who went into the room had to sign their name and how many minutes they were in the room. They put paper on the floor and I could only walk on the paper. None of the nurses wanted to come into the room because I was radioactive. Whatever I brought into the room had to be thrown out. Jack had to stay in the hall and we talked to each other back and forth. It was dehumanizing and very lonely.

Jack was able to show me the humor in it all. So in spite of everything, we were laughing together—him being out in the hall and me being in this room that was lined with lead, and talking back and forth. The iodine treatment came back negative. It took quite a while to get my thyroid medication regulated. A year later I had to be scanned again to see if there was cancer growing again. They had to take me off the thyroid medication. I became very tired and weak.

I wear my scar as a badge of courage but I've never thought of myself as a courageous person. But I am, I am a courageous person. People notice the scar. But you know I don't mind the scar. I feel, looking back, I feel like I did the best that I could do and I'm proud of that. Years ago, I decided that I wanted to change my name, to pick out who I wanted to be. Ivy came to mind because I liked the plant. It's a vine, it is strong, you can cut it down and it comes back. There's a lot of strength in Ivy. I want to be like Ivy so no matter how many times I might be cut down I'm coming back. I'm not there yet. Becoming Ivy's a life process.

Jack: Discovering Ivy's Strength

I remember the day she came home and she said she had some nodules. It didn't really alarm me. I was just, "Oh, you know, OK, it's just one more thing we have to take care of." The worst emotional strain for me was the fact that Ivy had to go through another crisis. She had previously dealt with so much else. She was quite afraid that she wasn't going to come home. She was really nervous about the general anesthesia. She has a real problem with losing control. We went into surgery thinking it was 90% chance that it wasn't anything bad. But the surgery day was hard. We went in early and again, the thinking early in the day was let's get through the surgery, get half the thyroid out, it'll be benign, and we'll worry about the rest later. I was with her for pre-op and the anesthesiologist came in, we discussed things and I could tell she was really, really nervous but she did fine.

Jennie (my sister) and Laurie (my niece) stayed with me. The surgery took about three hours. After about three hours, the doctor came down and he said, "She's doing fine. She's in post-op." Then he was about to leave! I said, "Well, was it benign?" And he said, "Oh, no, it was cancer." Very matter-of-factly. These guys

deal with it every day. I was just devastated. He asked me, "Do you want me to tell her or do you want to tell her?" So I said, "I probably should tell her." Some tears dropped. Jennie and I went for a walk. It was very hard to tell her, and when I told her, she was very down. Ivy and I tried to not dwell on it any more than necessary. With the reassurances of all the physicians, we were well founded in that things would turn out fine. I tried to keep life as normal as possible while dealing with the problem, which is probably the best way for me to cope. I tried to be as positive as possible. It's very easy to go right down the dunker and for both of us to be depressed. I tried to keep her up as much as we could. We talked a lot about it. I was her sounding board, which has not been an unusual role for me.

The biggest problem occurred between surgery and the scan. It was about a month between them, and she didn't have any thyroid medication. As the month went along, she got to the point where she could hardly do anything. She'd wake up in the morning and take a shower, and she'd have to sit down and rest for an hour before she could dress herself. That left some more things for me to do which she did in our normal every day life. In that scan they computed somehow how much thyroid tissue was left in her body. And we're talking 1% or more and you've got to do something. After the scan, the doctors decided that she needed to be treated; that there was enough thyroid tissue left that she had to be treated. She went into the hospital for a radioactive iodine treatment. The thyroid uses iodine to produce the hormone. This was a special kind of iodine that the thyroid tissue reads as being regular iodine, but yet when it takes it up then it kills the tissue. During the scan, nobody wanted to be in contact with her and they weren't supposed to be because she was radioactive. Each nurse when they brought the food or something, they signed their name, time in, time out. It was a minute or less. I couldn't come in and see her. It was hard to leave her there, because she really did feel like an outcast. She spent two days with virtually no other person being around her. And as soon as she had a low enough level of radiation, then they let her go.

We learned a lot about illness. We're the type that when something presents us, we find materials to read about it. We did that. I learned a lot about thyroid cancer, which hopefully we'll never need to know about again. More importantly, I just learned how resilient she is, more so than I think she realizes. It even strengthened our relationship more going through it.

DISCUSSION: THE PARADOX OF COMMUNICATING IDENTITY IN ILLNESS SURVIVORSHIP

The stories shared in this article provide a great deal of insight into the power of narratives as an opportunity for healing. Each person's story brings us one step closer to understanding the impact that a cancer diagnosis has on the communication among

family members, the difficult and enlightening moments throughout the journey, and how those moments affect our perceptions of self as we grow older.

During her experience with cancer, Ivy struggled to figure out how the illness happened to her at a time when she was in control in her life and doing everything "right." Her physicians approached the illness as a simple process of surgery followed by taking medication the rest of her life. Ivy found herself becoming segmented, because the illness did not allow her to fulfill her role as a mother, a wife, and a friend. She dealt with people's blinders to her illness because they simply did not understand what was happening to her. Jack needed her to be a warrior and fight her illness, but there were times when she could not align herself with those expectations. Ivy's scar is a badge of courage, and a reminder that the illness did not win.

Learning how to openly communicate information with one another was central to being able to heal as a cohesive unit. Ivy thought she could control the amount of information given to Brandon so that she could maintain her motherly role and protect her child. Jack felt he had to play the role of the positive, upbeat husband to help Ivy in her coping. By breaking down some of those barriers, the family opened up as a whole, and they were able to better communicate with one another, a process they feel has improved even more since then. We learn from these narratives that supportive relationships are central to healing. Each person learned in whom he or she could confide, and once those ties were established, they became stronger and stronger. This was evident for them going through the cancer journey and also in recounting the experience through these narrative interviews. We can view narratives as both a process and a product. Through the process of sharing their experiences, they discovered more about themselves as they retold the story. As a product, these stories may help others experience their own journeys with cancer and may help others determine the supportive relationships central to their own healing processes.

Hearing the stories emphasized that by letting our guards down and admitting that we need other people, we can find a place for healing. Much of the literature presented in this article advocates for sharing illness experiences as a means of catharsis and healing (e.g., Brody, 1987; Frank, 1991, 1993; Pennebaker et al., 1988). Sharing the experience, in this case, was helpful for the entire family. Once they realized the importance of sharing experience with one another and with others outside of the immediate family, they found it easier to communicate about their feelings. Ivy needed to be nurtured and comforted. Jack needed Ivy to share her feelings and be strong for him. All of these things meant that they would have to break down the walls that inhibited this type of communication, and in doing so, they found that they needed each other much more than they previously realized.

One of the most important implications we glean from these narratives is the impact the experience had on this family's aging process. As we grow older, our likelihood for developing cancer increases. For example, according to the American Cancer Society, between age 45 and 50, the chances of women developing breast cancer nearly doubles. For Ivy and Jack, cancer was one reminder of their

own aging processes. Even though the vast amount of information told them that Ivy's type of thyroid cancer was completely curable, Ivy still believed there was a possibility that she could die. In confronting her own mortality, she felt it necessary to write out her last words to her husband and son. In doing so, she was able to grasp on to the control she so much wanted. Through these narratives, we are able to realize the changes in perceptions toward aging and death.

Learning Through Narratives: Theoretical Implications of This Research

We can theorize about communicating health in our lives and the lives of others through considering the personal complexities revealed in stories. Frank (1995) suggested that theory meets story when we think with a story rather than about it. Focusing on narratives in the contexts of health, illness, and providing care opens up opportunities for understanding and participating in our own health care with greater vigor and freedom. Each of us should consider how useful it is to compare our interpretations with others and to consider the personal, cultural, and political complexities of health care decisions.

The findings presented in this research parallel Kleinman's (1988) and Frank's (1991, 1995) argument that we can best learn about illness through narratives. Not only are narratives told and heard among families while coping with the illness, but also narratives are a primary means of learning about illness in the research process. By eliciting and re-presenting narratives that are focused on families as a unit, we are able to learn how illness is a communicative phenomenon. The narratives presented in this research show that identity composition and recomposition are not unique to the ill individual, and through family communication survivor identities develop. The discoveries that unfold in these stories confirm that renewal of the self comes through the shared experience of illness (Frank, 1991).

Communication literature can apply the conclusions from this study to expand the theoretical acumen concerning how individuals cope with the experience and expression of emotions present in life-threatening illness. Some authors propose that identities can be categorized as victim identities (Lichter, 1987; Parsons, 1978; Verwoerd, 1966), warrior identities (Doka, 1993; Lorde, 1980), and survivor identities (Gotcher & Edwards, 1990; Rossman, 1989). We learn from this research that identity composition and recomposition are a continuous, multifaceted process. The development of the survivor identity does not mark the end of the illness journey; a person can be a survivor one day, a victim the next, and a warrior in between.

We constantly learn from stories of health and illness—the stories others tell, the stories we tell, and the stories we construct in conversation. Critical to learning from stories of health and illness is encouraging people to speak and tell their stories of being silenced, discredited, excluded, and stigmatized as well as to tell their

stories of being heard, encouraged, and included. A desire to learn about, to theorize from, and to understand the personal complexities of our own and another's experience is vital to communicating health as we age.

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