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Personal Identity Changes of Female Cancer Survivors in Southern Appalachia

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PERSONAL IDENTITY CHANGES OF FEMALE CANCER SURVIVORS IN SOUTHERN APPALACHIA

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ABSTRACT

Navigating personal identity changes through the cancer journey can be challenging, especially for women in a culture that places emphasis on traditional gender roles and values close-knit families. Drawing on a story circle approach, this study examined the intersecting identities of female cancer survivors in southern Appalachia. Stories of 29 female Appalachian cancer survivors from Northeast Tennessee and Southwest Virginia were collected via a mixed methods approach in either a day-long story circle (N=26) or an in-depth interview (N=3). Transcripts from both phases were audio-recorded and transcribed verbatim; NVivo 8.0 facilitated qualitative content analysis of the data. Inductive analysis revealed that women in this study appeared to struggle with 1) maintaining place in the family, 2) mothering, and 3) navigating physical changes. Ideas of family versus self appeared to overlap and intertwine with how women in Appalachia navigate personal identity changes through the cancer journey.

INTRODUCTION

A cancer diagnosis can damage a person's assumptions about herself, her safety in the world, and her connectedness to others, disrupting the survivor's life and her sense of identity (Doyle, 2008). Further, the entirety of the cancer experience likely affects the survivor's body and self-concept, potentially impacting her place within her family. Consequently, in addition to surviving cancer, survivors may also have to "survive" the onslaught of personal questions and doubts about their ability to be both independent and useful in their family (Sherman & Simonton, 2001).

Appalachian Women and Family

Denham, Meyer, Toborg, and Mand (2004) found that many Appalachian women find themselves in charge of most family affairs and are central figures in their families. In this central position women are often in charge of both reproductive and emotional labor, as well as responsible for preserving the culture and being family health experts (Oberhauser, 1995; Patton, 2005). This powerful position is one that Appalachia women surviving cancer may not want to abdicate; yet, when diagnosed with cancer, her identity as central caregiver, and the associated power, may be threatened, subsequently requiring a redistribution of familial roles (Hilton, Crawford, & Tarko, 2000; Holmberg, Scott, Alexy, & Fife, 2001).

What is missing from existing literature is a clear focus on intersecting and conflicting identities (e.g., family, personal, and/or cancer related) female survivors in Appalachia may face. Women may find themselves struggling to balance their precancer position within the family versus their needs to survive cancer.

Identity Changes

Mathieson and Stam (1995) noted that cancer survivors experience "dynamic psychosocial events" (p. 287) that can lead to: personal distress; personal, family, and financial stress; stigma; and threats to precancer identities. Moreover, when combined these events may lead to a forcible change in one's identity.

Physical changes. Physical changes play a large role in the identity changes of cancer survivors, especially since such changes are typically noticeable. Women reported in Holmberg, et al.'s (2001) study no longer feeling sexy or attractive because of changes in appearance (e.g. hair loss, surgical scars, or the loss of a breast). Changes to the body, often caused by cancer treatments or surgeries, threaten a survivor's sense of personal identity. Even temporary changes like chemo-induced hair loss (alopecia) impact a survivor's sense of self because it may symbolizes no longer being healthy, and, arguably, impact perceptions of gender and class (Münstedt, Manthey, Schachsse, Vahrson, 1997); therefore, the loss of one's hair during chemotherapy can forcibly reshape a woman's ideas about her multiple and overlapping identities (e.g., physical sense of self, health identity).

Familial identity changes. Psychological changes during the cancer journey also impact survivors' identities. Women surviving cancer have reported feeling inadequate, a loss of control, and a general sense of confusion. Furthermore they reported struggling with an increased dependence on family members due to their precancer identity of *caregiver* (Helgeson & Cohen, 1996; Peterson, Kruckek, & Shaffner, 2003). That is, the women go from being a caregiver to a *care-receiver*. An Appalachian cancer survivor may experience unique challenges in regards to her personal identities through the cancer journey. Since cultural norms in Appalachia support women having authority over most family matters (Oberhauser, 1995; Patton 2005), women may find identity renegotiation during the cancer journey even more challenging because of the power their position holds within the family and the culture.

METHODS

Researchers collected the stories of 29 female Appalachian cancer survivors from Northeast Tennessee and Southwest Virginia via a mixed methods, multi-phasic approach. Participants of this study were recruited through use of oncology nurses, local cancer centers, and snowball sampling. Phase I consisted of survivors participating in a day-long story circle (n=26). For this event, women were divided into two groups and asked to share their stories of cancer survivorship in Appalachia during two 4-hour sessions. Phase II consisted of additional survivors participating in in-depth interviews (n=3). In Phase II, researchers used purposive sampling to select participants based on the reasons cited for story circle non-attendance (i.e., ongoing cancer treatments, financial/transportation issues, and work conflicts). Interviews were conducted in the participants' homes and lasted between 60-120 minutes.

All participants were asked open-ended questions to probe for what makes the cancer experience in Appalachia unique. Participants self-reported a cancer diagnosis and ranged from being a 4-month to a 50-year survivor of cancer. No site-specific cancer was required for

participation in the study to collect survivorship experiences. For example, from an ovarian cancer survivor because resources are more readily available, and [ACS], 2008). Table 1 shows cancer type

TABLE 1. CANCER TYPE

Cancer Type	Number
Breast	15
Ovarian	4
Thyroid	2
Multiple Myeloma	2
Colon	1
Fibrosarcoma	1
Malignant Melanoma	1
Cervical Cancer*	1
Unknown	1

Upon analysis of the data, the cervical cancer survivor's story was removed from the study. However, her story was not removed from the study.

Analysis

After the story circle data were collected, they were used to conduct an inductive analysis. Themes emerged including the focus on the cancer journey. From the initial microanalysis, a need took place to further investigate changes. After interviews had been transcribed, all transcripts were their entirety to allow for a general understanding. Software was used facilitate management. Corbin and Strauss' (2008) grounded theory approach researcher to uncover common themes. The researcher to grasp meanings of several focus on a single case (Corbin & Strauss) between story circle groups, between in-depth interviews. Illustrative quotes in the text and participant number follows each quote for readability; edited quotes are indicated by brackets.

RESULTS

What emerged during this study was overlapping, and often contradictory perceptions to add to the complexity of identity renegotiation. 1) challenged their post-diagnosis personal identity, mothering, and 3) navigating physical changes. In separate sections, it is important to note that these are mutually exclusive.

focus on intersecting and conflicting experiences of cancer survivors in Appalachia may face. The precancer position within the family

and how survivors experience "dynamic" stress; personal, family, and financial stress, when combined these events may

lead to changes in the identity changes of cancer survivors. Women reported in Holmberg, 2008, that because of changes in appearance (e.g., changes to the body, often caused by cancer treatments) their personal identity. Even temporary changes in a survivor's sense of self because it may affect perceptions of gender and class. Moreover, the loss of one's hair during chemotherapy about her multiple and overlapping

experiences during the cancer journey also impact survivors' reported feeling inadequate, a loss of self, and reported struggling with an increased responsibility of caregiver (Helgeson & Cohen, 2002). Women go from being a caregiver to a patient and face unique challenges in regards to cultural norms in Appalachia support systems (Patton 1995; Patton 2005), women may find it more challenging because of the

Appalachian cancer survivors from a qualitative methods, multi-phasic approach. The oncology nurses, local cancer centers, and participants in a day-long story circle sessions and asked to share their stories of their experiences. Phase II consisted of additional interviews. Phase II, researchers used purposive sampling for story circle non-attendance (i.e., no-shows and work conflicts). Interviews were approximately 120 minutes.

Interviews to probe for what makes the cancer journey a cancer diagnosis and ranged from general to site-specific cancer was required for

participation in the study to collect stories from individuals who might have varying cancer survivorship experiences. For example, a breast cancer survivor may have a story vastly different from an ovarian cancer survivor because breast cancer is more common among women, resources are more readily available, and the survival rates are higher (American Cancer Society [ACS], 2008). Table 1 shows cancer type and representation in the study.

TABLE 1. CANCER TYPE AND REPRESENTATION IN PHASE I & II

Cancer Type	Number	Percentage
Breast	15	51%
Ovarian	4	13%
Thyroid	2	6%
Multiple Myeloma	2	6%
Colon	1	3%
Fibrosarcoma	1	3%
Malignant Melanoma	1	3%
Cervical Cancer*	1	3%
Unknown	1	3%

Upon analysis of the data, the cervical cancer survivor may have had cervical dysplasia rather than cervical cancer. However, her story was not removed from the study because she perceives herself as a cervical cancer survivor.

Analysis

After the story circle data were transcribed, accepted qualitative data analysis procedures were used to conduct an inductive analysis (Corbin & Strauss, 2008). Through this process many themes emerged including the focus of this study: changing personal identities through the cancer journey. From the initial microanalysis of the story circle transcripts, theoretical sampling took place to further investigate changing personal identities. Once all data from the in-depth interviews had been transcribed, all transcripts (story circle and in-depth interview) were read in their entirety to allow for a general understanding of survivorship experiences. QSR NVivo 8.0 software was used to facilitate management of the data. Analysis of the transcripts was based on Corbin and Strauss' (2008) grounded theory approach. Open and axial coding allowed the researcher to uncover common themes throughout all transcripts. This coding technique allows the researcher to grasp meanings of seemingly obscure events as well as counter the tendency to focus on a single case (Corbin & Strauss, 2008). Incidents were compared within transcripts, between story circle groups, between in-depth interview, and between story circle groups and in-depth interviews. Illustrative quotes in the section below will be used to delineate the findings and participant number follows each quote. Quotes have only been edited to promote clarity and readability; edited quotes are indicated by [...].

RESULTS

What emerged during this study was that participants struggled with intersecting, overlapping, and often contradictory personal identities; moreover, cultural influences did appear to add to the complexity of identity renegotiation. Specifically, three (3) factors emerge that challenged their post-diagnosis personal identities: 1) maintaining place in the family, 2) mothering, and 3) navigating physical changes. Although these categories are described in separate sections, it is important to note that they interplay with one another; they are not mutually exclusive.

Maintaining Place in the Family

Several participants highlighted the importance of maintaining their place in their family while surviving cancer. For example, P7 described mowing the lawn prior to her cancer diagnosis. After her chemotherapy treatments she stated that her energy levels were not the same, but she wanted to be useful. Against the wishes of her husband and mother she was determined to mow the lawn. "I got the lawnmower out ... and I got to the end of the yard ... I couldn't get back over to the porch.... I did not have any energy in my hands and my legs." P7's story was one of several stories provided by participants who wanted to maintain their place in the family even at the expense of their own health.

Fear of abdicating or delegating. Across story circles and interviews, participants seemed hesitant to delegate all or some of their familial responsibilities to other family members. This hesitance may be a result of perceived fears of being useless to their families and/or maintaining a sense normalcy. Part of maintaining place in the family also appeared to be about the important duty of protecting their families as illustrated by P12: "You know it's that trying to protect your children and your husband and your family. You're always the woman."

When there was tension between the conflicting identities of survivor and family caregiver, participants repeatedly indicated that Family consistently won over Survivor. Ultimately, what emerged in this study was that female Appalachian cancer survivors may feel at a loss for who they are if they are no longer the central caregiver, the central protector of the family.

Mothering

Participant identities also seemed to interplay with perceived ideas about mothering, as many repeatedly reported concern over transitioning from being the caregiver to needing caregiving, particularly if they had young children at the time of diagnosis.

Young mothering. Survivors who were mothers of children under 18 years old described fears that cancer would take away their ability to mother, resulting in someone else taking over as "mother." For example, P18 had just had a baby when she was diagnosed with cancer which left her fearing her place within her family as well as her ability to care for her children. "I can't get run down. I have children. I have a husband. I have to do this, you know. I felt like somebody was going to take my place." As noted by Kinser (2008) women, their body, and their children are closely linked, and women use their bodies as part of mothering. Cancer can make changes to the body that in turn can change how a woman uses her body to mother. After P18's mastectomy she was unable to breastfeed her daughter which appeared to heighten her sense of failing as a mother.

Mature mothering. Women with adult children at the time of diagnosis expressed fears of increasing dependency. P27 had three adult children when she was diagnosed with cancer and expressed concern about burdening them with her need for financial help or care. "My goal was getting back to that office as quickly as possible. I couldn't be a burden to my children.... I'm not ready to take their help at this point." Similarly, P14 shared that her three adult children were helpful and supportive during her cancer journey, adding, however:

You have to put limits on what you are going to let them do for you. You cannot sit there like a knot on a log and let them do everything. All three of my kids worked, they had their life. They couldn't spend every waking minute with me (P14).

Again, when there was a conflict, it appeared to be granted greater weight by the family.

Navigating Physical Changes

Some findings underscored that physical changes within the broader family context, they had concerns and doubts about their self and body changes.

Visible physical changes. For many participants, visible physical changes (such as surgical scars) were the noticeable physical changes (such as surgical scars). P11 described being unattractive and likened it to that of her prepubescent daughter. "I was without any breasts, oh my God. That hair loss was a journey."

Chemo-induced alopecia affected many participants' journeys, and they cited hair loss as one of the most difficult aspects of cancer. P11 was "mentality ill" over her hair loss. "It happened to her, even worse than losing her hair as a person. P26 described her red hair as a source of pride. "I was born with this red hair and when I lost it, it was like me that it would come back... That was a challenge. She stated that she felt the chemo-induced alopecia with her supportive family, she reported that she would not go out. "I'm going to tell you when I lost it I felt like I wouldn't go out. Wouldn't do anything. Physical changes caused her to withdraw from the community."

Professional identity and physical changes. For many participants, there was some evidence of how physical changes triggered, in part, by physical changes. For example, P26 to her new image during the time of the diagnosis. "I was a professional ... to be like this, well, I don't know who wants a one boobed, no hair woman. I'm still worthy of employment because she was once associated with being professional. Her hair loss about supporting her family because she was diagnosed."

Intersecting Identities

Cancer has the ability to turn lives upside down and have about themselves. Changes to place within the family had an impact on our participants' identities and relationships with one another. Physical changes, like alopecia, can hold her daughter thus making her fear for her daughter. For P28 her hair loss and mastectomy made her concerned about ability to financially support her family.

Participants in this study reported that physical changes and their place within the family were interconnected.

Again, when there was a conflict between Survivor and Mother, the mothering role appeared to be granted greater weight by participants.

Navigating Physical Changes

Some findings underscored that while women in Appalachia are experiencing cancer within the broader family context, they also continue to be women with the private struggles and doubts about their self and body changes.

Visible physical changes. For many participants, the most notable changes in identity were the noticeable physical changes they experienced through the cancer journey (e.g., alopecia, surgical scars). P11 described being unnerved at looking at her body after her mastectomy and likened it to that of her prepubescent nephew. She stated, "The first time I looked at myself without any breasts, oh my God. That had to be ... life-altering."

Chemo-induced alopecia affected many of the participants (n=12) during their cancer journeys, and they cited hair loss as one of the most challenging parts of being a survivor. P12 was "mentality ill" over her hair loss and described it as "probably the worst thing" that happened to her, even worse than losing the breast, because her hair was a part of who she was as a person. P26 described her red hair as part of her identity as illustrated in the following quote: "I was born with this red hair and when it fell out, I about freaked, because they couldn't assure me that it would come back... That was very traumatic, because that was part of me." P28, too, stated that she felt the chemo-induced alopecia was the worst part of her cancer journey. Even with her supportive family, she reported not leaving the house until her hair had grown back. "I'm going to tell you when I lost it I felt bad. I didn't go out of the house. Quit going to church. Wouldn't go out. Wouldn't do anything." P28 not only struggled with physical changes, but her physical changes caused her to withdraw from her place in the family and her place in the community.

Professional identity and physical changes. Though not a finding that emerged across all participants, there was some evidence of a renegotiation of professional identity, a renegotiation triggered, in part, by physical changes. For example, P28 continued to struggle with readjusting to her new image during the time of the interview and described no longer feeling employable. "I was a professional ... to be like this, well it's like so much for being professional anymore. You know who wants a one boobed, no haired professional?" P28 described questioning if she was still worthy of employment because she no longer possessed the physical characteristics that she once associated with being professional. Perhaps of note, this participant also cited being worried about supporting her family because she had not been able to work due to her two cancers diagnoses.

Intersecting Identities

Cancer has the ability to turn lives upside down and challenge the very ideas that women have about themselves. Changes to place in the family, mothering, and physical appearance all had an impact on our participants' identities. These changes appeared to interweave and overlap with one another. Physical changes, like a mastectomy, impacted P18's ability to breast feed and hold her daughter thus making her fearful her daughter would view another woman as her mother. For P28 her hair loss and mastectomy changed her identity as a professional woman and made her concerned about ability to financially support her family.

Participants in this study reported pushing their bodies to the limits to maintain precancer identities and their place within the family like mowing yards, caring for children, or caring for

ill family members. Sometimes these desires to maintain their place, especially in the instance of caregiving, resulted in hospitalization and or health care providers reminding the women that they could not do it all.

DISCUSSION

Appalachian female cancer survivors in this study revealed that surviving cancer presents unique challenges for Appalachian women and their identities. Participants of this study cited the following challenges to personal identities through the cancer journey: 1) maintaining place in family, 2) mothering, and 3) navigating physical changes. While surviving cancer, participants also attempted to keep families together and maintain precancer identities, sometimes at the expense of their health. Surviving cancer may require the woman to allow others to take on some of her responsibilities like caring for her children or completing household tasks. Appalachian women may find that surviving cancer conflicts with cultural expectations and desires to remain central within the family. This conflict may provide insight into understanding why women fight to maintain their precancer identities, even when it might risk their health.

Physical changes due to cancer treatments appeared to begin the process of identity changes for the participants. As seen in the literature, alopecia appeared to be the most challenging of all physical changes the survivors experienced through their cancer journeys, even more challenging than the loss of one or both breasts. The shock of hair loss may be more about it representing that the woman has cancer rather than the hair loss itself. Participants expressed a desire to be normal or return to normal, but the hair loss was a visible sign they were not normal. Perhaps for female cancer survivors the hair loss was upsetting because it was a constant reminder they are ill. This illness in turn prevents them from maintaining their normal routines within their family; therefore, the loss of identity was also a loss of place within the family.

Although this research provides needed insight into changing personal identities of female Appalachian cancer survivors, it is not without its limitations. Study participants were recruited through use of oncology nurses, local cancer centers, and snowball sampling; therefore, the study is not a random sample and only represents southern Appalachian women from two states. All participants were self-reported cancer survivors, and no medical records were collected to verify cancer diagnosis. After analyzing data collected from the cervical cancer survivor, suspicions were raised as to whether the participant had been diagnosed with cervical cancer or cervical dysplasia which is often referred to as precervical cancer. Due to the participant perceiving herself as a cervical cancer survivor, her story was not removed from the data. This study did not directly compare Appalachian and non-Appalachian populations nor did it address Appalachian populations that face layers of marginalization (e.g. black Appalachian or Hispanic women). Due to the layers of marginalization their survivorship may present additional and unique challenges not addressed by this study.

Further research is needed in the area of identity changes of cancer survivors, especially for women with young children at the time of diagnosis. Participants reported a determination to maintain their place within the family, a decision that was often detrimental to their own health. This may be linked back to the culture of Appalachia and women's desire to maintain their powerful position within families. Without question, surviving cancer is not an easy experience for individuals. However, it does appear that for our participants there are unique aspects to surviving cancer in Appalachian.

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