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Barriers to Family Cancer Communication in Southern Appalachia

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BARRIERS TO FAMILY CANCER COMMUNICATION IN SOUTHERN APPALACHIA

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PUBLIC POLICY

ABSTRACT

This study examines cultural issues surrounding family cancer communication in Appalachia, providing insight into participants' communication choices regarding their illness within their families. 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). Qualitative content analysis was used to identify unique barriers to family cancer communication in Appalachia. Two barriers emerged: 1) the health of other family members and 2) cancer in a "taboo" area. These findings suggest that Appalachian female cancer survivors struggle with similar issues as survivors outside of the region regarding family cancer communication. However, there appear to be additional barriers to family cancer communication for Appalachian women that may be a result of cultural norms of the region.

INTRODUCTION

Cancer has the ability to change the lives of survivors and their family members by propelling the family into crisis, disrupting routines, and causing anxiety among all members (Carlick & Biley, 2004). This study examines cultural issues surrounding family cancer communication in Appalachia, providing insight into participants' communication choices regarding their illness within their families.

Family, Cancer, and Communication

Research suggests females diagnosed with an illness might face more challenges than men who are diagnosed (Petersen, Kruczek, & Shaffner, 2003) because female responsibilities tend to be more focused on families. Women often have to manage strong emotions while simultaneously struggling to reassure themselves and others about the cancer diagnosis and prognosis (Exley & Letherby, 2001).

Arguably, female survivors face some unique challenges, especially since Appalachian women often play a central role in their family, such as being responsible for household management, family health, and family matters. Since cultural social norms tend to direct women toward providing emotional support in their families (Patton, 2005), cancer survivors may

struggle to find ways to seek emotional support (e.g., talking about their illness to family members).

Barriers to Family Cancer Communication

Discussing cancer within the family can be very therapeutic and aid in the understanding and healing for both the survivor and family members. Although the literature points to the therapeutic benefit of discussing cancer (Shapiro, Angus, & Davis, 1997), this task can be overwhelming to survivors and their families, especially if there are young children involved. Some families may choose to engage in "buffering," thereby keeping family members at a distance throughout their cancer experience to prevent and/or minimize negative emotions. As such, families may strategically use both disclosure and nondisclosure regarding cancer-related concerns in an effort to protect others and self. That is, in Appalachia, women may choose to not discuss cancer-related thoughts or feelings with family members so that they do not have to carry the double burden of surviving cancer and providing emotional support for family members who are upset about the diagnosis and its implications. These women might well be sensing and responding to what Arrington (2009) notes are the limits of family support.

For survivors, the ability to discuss illness-related concerns is often key to garnering emotional support (Helgeson & Cohen, 1996). Cancer survivors typically look first towards someone in the family to provide that support. Yet, as Zhang and Siminoff (2003) and Knight (2009) found, women and their family members all experience difficulties with cancer communication. However, there may be additional challenges in Appalachia due to health beliefs of the region and the expectations of women within Appalachia.

Health Beliefs and Cultural Norms in Appalachia. Although Appalachia is a diverse region with a complex culture, some regional health beliefs, arguably, interplay with the cancer experience. For example, strong family ties intersect with Appalachian self-reliance, potentially resulting in women relying on family instead of physicians for information regarding health (Dorgan, Hutson, Gerding, & Duvall, 2009). The reliance on friends and family members may also be a result of Appalachian women putting family needs ahead of their own health needs (Patton, 2005). Subsequently, Appalachian women may feel ambivalent about pursuing their own health care needs (e.g., spending money and/or taking time away from their family to visit a health care practitioner).

What are currently lacking in the literature are studies focusing on how family cancer communication may be unique in Appalachia. Much research on cancer in Appalachia has focused on health and cancer disparities and steps that may help remedy those disparities in the region (Behringer, Mabe, Dorgan, & Hudson, 2009). However, one gap that appears in the research relates to how family cancer communication in Appalachia may be different from other regions of the United States. This study examines cultural issues surrounding family cancer communication in Appalachia, providing insight into why and how participants choose to communicate about their illness within their families.

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 discussing their cancer survivorship in Appalachia during the past year. Survivors participating in in-depth interviews were selected based on ongoing cancer treatments, financial/transportation issues, and were conducted in the participants' homes and communities. All participants were asked open-ended questions about their cancer experience in Appalachia unique. Participants ranged from being a 4-month to a 50-year survivor. The purpose of the participation in the study to collect stories of cancer survivorship experiences. For example, a participant shared her story 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 was removed from the study. However, her story was not removed from the study.

Analysis

After the story circle data were transcribed, they were used to conduct an inductive analysis. Themes emerged including the focus of the cancer journey. From the initial microanalysis, a plan took place to further investigate changing themes. All interviews had been transcribed, all transcripts were read in their entirety to allow for a general understanding. NVivo software was used to facilitate management of data. Corbin and Strauss' (2008) grounded theory approach was used by the researcher to uncover common themes that emerged. The researcher to grasp meanings of seemingly different data. The focus on a single case (Corbin & Strauss, 2008) was used between story circle groups, between in-depth interviews. Illustrative quotes in the text and participant numbers follow each quote to enhance readability; edited quotes are indicated by []

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(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 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 numbers follow each quote. Quotes have only been edited to promote clarity and readability; edited quotes are indicated by [...].

RESULTS

This study focuses on two emergent barriers to Appalachian family cancer communication not previously identified in the literature: 1) health of other family members and 2) cancer in "taboo" areas.

Health of Other Family Members

The first Appalachian family cancer communication barrier that emerged focused on the health of family members. That is, another family member's health problems limited a survivor's open communication about her cancer experience within her family. Survivors in this study repeatedly expressed resistance to burdening an already ill family member.

Participants often appeared strategic and mindful about avoiding cancer-related disclosures in an effort to lessen their own discomfort or the discomfort of others. For example, P10's mother had a mammogram scheduled on the same day as her breast biopsy. "I did everything I could to dodge her. She didn't know I was going over there...Because I did not want to give her something to worry about unnecessarily." Similarly, P26 expressed her desire to not tell her parents before her diagnosis was confirmed because her father had been diagnosed with prostate cancer: "My father had had seeding for prostate cancer the day before. And I had been hiding from my parents all week because I didn't want them to know." These stories suggest that these survivors mindfully made communication choices to avoid contributing to the burdens ill family members already faced. This may be due to their need to protect family members, but it may also be explained as their exercising agency in self-protection. That is, containing information about their own illness may in fact reduce the emotional labor for which they feel, and are often held, responsible.

Even if a survivor discussed cancer with her family, she may have been motivated to avoid focusing on her diagnosis because another member was also ill. For women in the region, talking about their cancer-related thoughts and concerns may make them feel like they are being selfish by putting their needs first. For instance, P14 was caring for her husband who had been diagnosed with cancer before she was diagnosed with cancer. She described feeling guilty because she was getting sick and she "had to be strong for him because they had told him that he... wouldn't survive."

Cancer in "Taboo" Areas

The second Appalachian family cancer communication barrier that emerged focused on the survivors' type of cancer. If a survivor was diagnosed with cancer that was in a "taboo" area (e.g., cervical or colon cancer), they reported limiting cancer communication with family members. After her cervical cancer diagnosis, P29 acknowledged her desire to not discuss her cancer. "It was my own personal private thing, and I didn't want to talk about it." Furthermore, P29 reported that her family never discussed preventative screenings in "embarrassing" areas of the body until her stepfather was diagnosed with and died from stage 4 colon cancer. Ultimately, survivors reported that certain cancers like cervical cancer and colon cancer further impacted their communication with family.

For women in Appalachia it can be challenging to talk about the cancer journey when the cancer is in a taboo part of the body like the cervix. P29 felt that her family was closed-minded and avoided discussing anything that had to do with sex. This may also preclude any discussions of preventative screenings or any type of cancer diagnosis in a taboo area of the body.

DISCUSSION

This research supports current struggle with similar barriers as women. Our current understanding of family cancer barriers cited by the participants of the "taboo" areas.

These barriers may be linked to families, more pronounced extended disproportionate health and cancer disparities (Huang, et al., 2002), arguably increasing consequence, family members may have the family, further challenging family.

Perhaps adding to the existing cancers. For these participants, talk about when the cancer was diagnosed in "taboo" may be embarrassed or ashamed to communicate. They may feel similarly toward cancer in the family, implies that these survivors have even more fears within the family, requiring survival vocalized story may be dangerous to screenings due to the embarrassing nature.

Although this research provides Appalachia, it is not without its limitations. The use of oncology nurses, local cancer centers, random sample and only represents some reported cancer survivors, and no men. After analyzing data collected from the study, whether the cervical cancer participants had dysplasia which is often referred to as pre-cancer, herself as a cervical cancer survivor, he failed to address Appalachian population (Appalachian women). Due to the lay understanding of Appalachia may be different from what is known.

Further research is needed in the Appalachia cultural norms may further complicate the topic. Women may have been strategic within the family to lessen the double burden of support to others struggling with their future generations knowledge about cancer.

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DISCUSSION

This research supports current literature that female Appalachian cancer survivors struggle with similar barriers as women outside the region. However, this study may help expand our current understanding of family cancer communication in Appalachia through the additional barriers cited by the participants of this study: the health of other family members and cancer in "taboo" areas.

These barriers may be linked to the culture of the region because of historically close-knit families, more pronounced extended families, and traditional gender roles. Appalachia has disproportionate health and cancer disparities (Appalachian Regional Commission [ARC], n.d.; Huang, et al., 2002), arguably increasing the likelihood of another family member being ill. As a consequence, family members may have to simultaneously navigate multiple chronic illnesses in the family, further challenging family cancer communication.

Perhaps adding to the existing communication challenges is the existing stigma of some cancers. For these participants, talk about cancer appeared to be made even more complicated when the cancer was diagnosed in "taboo" areas of the body. Survivors or their family members may be embarrassed or ashamed to communicate in general about these areas of the body, and so may feel similarly toward cancer in these areas. The desire not to discuss cancer in taboo areas implies that these survivors have even fewer opportunities to discuss cancer-related thoughts and fears within the family, requiring survivors to be strategic about their disclosures. This lack of vocalized story may be dangerous to younger generations who would refuse preventative screenings due to the embarrassing nature of the screening in these taboo areas.

Although this research provides needed insight to family cancer communication in Appalachia, it is not without its limitations. The participants of this study 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. 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 cervical cancer participant had been diagnosed with cervical cancer or cervical dysplasia which is often referred to as pre cervical cancer. Due to the participant perceiving herself as a cervical cancer survivor, her story was not removed from the data. Finally, this study failed to address Appalachian populations that face layers of marginalization (e.g. black Appalachian women). Due to the layers of marginalization their survivorship experience in Appalachia may be different from what was reported in this study.

Further research is needed in the area of family cancer communication in Appalachia. Appalachia cultural norms may further challenge communicating about an already challenging topic. Women may have been strategic by not discussing their cancer-related thoughts and fears within the family to lessen the double burden of surviving cancer and providing emotional support to others struggling with their cancer diagnosis; however, non-disclosure may impact future generations knowledge about cancer and decisions regarding preventative screenings.

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PERSONAL IDENTITY CHANGES IN SOUTH

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Sadie P. Hutson

ABSTRACT

Navigating personal identity changes, especially for women in a culture that values close-knit families. Drawing on a storied history of female cancer survivors in Appalachia, cancer survivors from Northeast Tennessee used a day-long methods approach in either a day-long or two-day format. Transcripts from both phases were analyzed using facilitated qualitative content analysis of the data. The study appeared to struggle with 1) navigating physical changes. Ideas of how women in Appalachia navigate personal identity changes were explored.

INTRODUCTION

A cancer diagnosis can damage a woman's sense of self, her world, and her connectedness to others (Doyle, 2008). Further, the entirety of a woman's life and self-concept, potentially impacting her ability to survive cancer, survivors may also have doubts about their ability to be both a mother and a survivor (Simonton, 2001).

Appalachian Women and Family

Denham, Meyer, Toborg, and Mendenhall (2005) state that themselves in charge of most family decisions. In a central position women are often in charge of the family responsible for preserving the culture and traditions (2005). This powerful position is one that is often abdicated; yet, when diagnosed with cancer, a woman's power, may be threatened, subsequently leading to a loss of power (Crawford, & Tarko, 2000; Holmberg, S.