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Surviving Cancer in Appalachia: A Qualitative Study of Family Cancer Communication and
Changing Personal Identities Through the Cancer Journey

A thesis

presented to

the faculty of the Department of Professional Communications

East Tennessee State University

In partial fulfillment

of the requirements for the degree

Masters of Arts in Professional Communications

by

Kathryn L. Duvall

May 2010

Dr. Kelly Dorgan, Chair

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Keywords: Appalachian Women, Cancer, Family Communication, Identity Changes,

Psychosocial Oncology

ABSTRACT

Surviving Cancer in Appalachia: A Qualitative Study of Family Cancer Communication and Changing Personal Identities Through the Cancer Journey

by

Kathryn L. Duvall

The Appalachian region is known for its beautiful mountains, close-knit communities, and health care disparities including higher rates of cancer and premature mortality. Being diagnosed with cancer in the region may present a unique experience for survivors in regards to family cancer communication and changing personal identities. In a multiphasic study, the stories of 29 female Appalachian cancer survivors were collected through either a day-long modified story circle event (n=26) or an in-depth interview (n=3). Qualitative content analysis was used to identify emergent themes in the data. The analysis revealed 5 types of family cancer communication and five barriers to family cancer communication. The analysis additionally revealed the identity struggle women experience between maintaining traditional Appalachian gender roles and surviving cancer. These findings suggest that female Appalachian cancer survivors appear to have additional challenges that may make the cancer experience in Appalachia unique.

ACKNOWLEDGEMENTS

This thesis would not have been completed without the help of many people in the past 18 months. First and foremost I must say thank you to the women who shared the experiences of their cancer journey. I learned so much about life, strength, and endurance from all of you. Second, this thesis would not be what it is without the guidance, encouragement, and wisdom of Drs. Kelly Dorgan, Sadie Hutson, and Amber Kinser. I would also like to thank my mother, Mary Ann Duvall, for her unwavering support through this process. I would be remiss without thanking my coworkers, Dr. Ronnie Gross, Donna Lockaby-Morrow, Mitzi Martin, and Chris Strode for their reassurance and understanding. Finally I would like to acknowledge the funding from the East Tennessee State University Research Development Committee.

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CHAPTER 1

INTRODUCTION

Purpose of Research

An illness diagnosis, especially a cancer diagnosis, forces many changes in a woman's life. She must come to terms with uncertainty about her future and her family's future, tests and treatment options, and side effects, as well as changes with her family's communication dynamics. A cancer diagnosis not only affects the survivor but also her family, making a cancer diagnosis a family issue (Ballard-Reisch & Letner, 2003). It is a challenging time for families because they are thrust into crisis and must learn to communicatively negotiate the sudden changes (Carlick & Briley, 2004; Ell, 1996). In Appalachia, this may be especially challenging for survivors and families due to the well-documented cancer disparities (Appalachian Regional Commission, ARC, 2009; Huang et al., 2002) and cultural traditions (Denham, Meyer, Toborg, & Mand, 2004; Garvin, 1995); therefore, a cancer diagnosis may impose unique challenges regarding family cancer communication. One avenue to explore these challenges is through storytelling. The region has used storytelling for many generations to educate younger generations about culture, history, and social norms (Hutson, Dorgan, Phillips, Behringer, 2007; Kellas, 2005). For female Appalachian cancer survivors, storytelling may be a comfortable and familiar way to talk about the challenges of surviving cancer in the region. This study examines the stories of female Appalachian cancer survivors and what they reveal about family cancer communication and changing personal identities of female cancer survivors in central Appalachia.

The Appalachian Region

The Appalachian region includes approximately 400 counties spanning 200,000 square miles from New York to Mississippi. Of the 23 million residents living in the region, 42% live in rural areas and the majority are white (Behringer et al., 2007; Denham et al., 2004). It becomes challenging to discuss the culture of Appalachia without over generalizing and thus further marginalizing the region. Appalachia is often stereotyped, and these stereotypes tend to focus on “poverty, mountainous terrain, isolated communities, coal mining, and subsistence agriculture” in the region (Oberhauser, 1995, ¶ 9). These stereotypes support long held negative beliefs regarding the region as well as causes others to overlook the tremendous diversity within the region. Dorgan, Hutson, Gerding, and Duvall (2009) note that often researchers need a cultural map “highlighting values, norms and beliefs” (p. 1). However, there is a danger of further marginalizing the region by defining the culture by a set of manageable traits. Although studying the region becomes challenging due to concerns of marginalizing the population further, it is important to look closely at disparities, like cancer, within Appalachia. As stated earlier, cancer is a family issue; therefore, by failing to understand how Appalachian families communicate about cancer, there exists a risk of not understanding the complexity of cancer within Appalachia. This could, in turn, hinder understanding the cancer disparity in the region or the potential cause thereof. Stories from female Appalachian cancer survivors may help uncover how cancer impacts family cancer communication in Appalachia.

Cancer Disparities in Appalachia

The topography of the land, although beautiful, can present challenges to the people who live there. Rural communities within the Appalachian Mountains are often isolated and only accessible by mountain roads that may be impassible during harsh weather. Huttlinger, Schaller-

Ayers, and Lawson (2004) noted that many studies have looked at barriers and access-related issues that are believed to play a large role in the cancer disparity of Appalachia. For example, Lengerich et al. (2005) identified that greater distance to cancer treatment centers is associated with lower survival rates. In Appalachia, traveling to treatment centers may require taking off work, losing wages, and then driving to the nearest center (Dorgan et al. 2009). The lower socioeconomic status of the region has resulted in many un- or underinsured individuals who may not be able to afford medical care or prescriptions. Patton (2005) noted that this has resulted in Appalachians typically seeking acute care rather than preventative health care.

Within the region many families have been touched with cancer in one way or another, but they often do not have the same resources available to them as in other parts of the nation. Rural Appalachia has significantly higher cancer death rates especially for cervical, colorectal, and lung cancer (ARC, 2009; Huang et al., 2002). Documented health-related challenges in Appalachia include being uninsured or underinsured, a shortage of health care providers, lack of cancer knowledge, financial constraints, and limited access to treatment centers (Behringer, Mabe, Dorgan, & Hutson, 2009; Hall, Uhler, Coughli, & Miller, 2002; Lengerich et al., 2004). These researchers have attributed the cancer disparity to geographic isolation, lower socioeconomic status, and the culture in Appalachia.

The Appalachian culture has also contributed to cancer disparities. Patton (2005) noted that there is a general lack of access to and up-to-date knowledge about primary and preventative care. Many Appalachians rely on friends and family members for health information and advice instead of consulting healthcare professionals. This has contributed to the lack of health knowledge in the region (Behringer & Friedell, 2006). Furthermore, McNeill and Dorgan (2005) found that the influences of media messages and social networks of friends and family members

are more persuasive than healthcare providers in affecting screening behaviors of Appalachian women. Although many people within the region are impacted by the cancer disparity, research shows that women may be further disadvantaged. One way to address the needs of the women in Appalachia would be to understand the challenges they face in the context of their culture. The stories of female Appalachian cancer survivors provide insight to these challenges and the unique culture of the region.

Women of Appalachia and Cancer

Although a cancer diagnosis is not an easy adjustment for anyone, Appalachian women may face different challenges than women from outside of the region. Appalachian women, especially women in rural areas, might experience more challenges than their male counterparts. Garvin (1995) posited that Appalachian women are further disadvantaged than men in the region because rural women are even less likely to have medical insurance and transportation. Hicks (1990) found that even urban Appalachian women with health insurance or financial resources have poorer health status than urban women outside the region due to lack of access to care and services. Appalachian women are also faced with limited access to health information and other resources as well as geographical isolation. However these issues may just be symptomatic of deeper cultural norms and expectations of women in Appalachia.

Cancer research, especially pertaining to women, tends to focus on breast cancer because it ranks second in cancer deaths among women (American Cancer Society, ACS, 2008a). However, the experiences of breast cancer survivors may be different from other cancers, and these other experiences may be left out of cancer research due to the abundance of breast cancer research. This study examines the whole cancer experience of women in Appalachia irrespective of the site or stage of diagnosis. By including all types and stages of cancer a stronger picture of

family cancer communication and changing personal identities through the cancer journey can be found.

Appalachian women and over-generalizations. As previously noted, Appalachia is a diverse area that has suffered from over generalizations. Dorgan et al. (2009) argue that it is challenging to study the area without marginalizing the people of Appalachia; therefore, it becomes difficult to characterize what makes Appalachian women different from other women in the nation. Garvin (1995) contends that Appalachian women, especially low-income Appalachian women, are often misrepresented. Researchers must be careful to not further marginalize the region when attempting to uncover the differences in the culture. Although research regarding Appalachia has greatly increased with concerns over health disparities (Behringer & Friedell, 2006; Coyne, Demian-Popescu, & Friend, 2006; Dorgan et al., 2009; McMillan et al., 2007), fewer studies have focused on women in Appalachia.

Appalachian women and their roles within the family. Appalachian women often play a central role in their families. Denham, Meyer, Toborg, and Mand (2004) found that many Appalachian women are in charge of most family matters and are central figures in their families. Oberhauser (1995) noted that traditional roles for Appalachian women include reproductive labor as well as providing emotional and material support for the family. The minimal resources in the region make the provision of essential household tasks (feeding, clothing, and cleaning) as well as providing the emotional support for the family even challenging for Appalachian women. However, it should be noted that Appalachian women do have a powerful position within their families. Women are seen as the providers of emotional strength, are responsible for preserving the culture, and are viewed as experts in health care (Patton, 2005). This powerful position is one that Appalachia women surviving cancer may not want to give up.

Patton (2005) noted that the Appalachian culture signals many women to put their families' daily needs ahead of their own health needs. This results in women choosing acute care over preventative care when health concerns arise. However, when an Appalachian woman is diagnosed with cancer, it may require her to put her needs first, thereby contradicting the social norms of the region. Women may have to change or adjust their identity as central caregiver for the family while recovering from surgery or going through chemotherapy or radiation treatments. This requires a redistribution of familial roles, new routines, and negotiation about communicatively negotiating illness-related concerns among family members (Hilton, Crawford, & Tarko, 2000; Holmberg, Scott, Alexy, & Fife, 2001; Lewis & Hammond, 1992).

An existing gap in the literature is the manner in which female Appalachian cancer survivors renegotiate their identity within the family after their diagnosis, thus affecting family communication. Women may find themselves struggling to balance expected gender roles in the region versus their needs to survive cancer. The change in family roles not only affects the survivor but other family members as well. Female Appalachian cancer survivors may be concerned about further stress for their family. They may also be concerned that if family members are upset, then they are responsible for providing the emotional support to the family while they are surviving cancer; therefore, they may not want to give up control of their role in order to protect their families and themselves from further perceived stress. Unfortunately, the desire to protect family members may also cause dissatisfaction regarding communication about cancer for the survivor (Gotcher, 1993).

Introduction to Study

Appalachia is an understudied region that has well-documented health disparities including high rates of cancer incidence and mortality (Behringer & Friedell, 2006). Research is underway to determine how to better meet the health needs of this region. As part of this effort, this study seeks to better understand family cancer communication in Appalachia and how a female cancer survivor's identity is shaped through that communication.

Family Communication

Cancer has the ability to change the life of each individual it touches. In other words, a cancer diagnosis affects the entire family, not just the individual bearing the diagnosis (Carlick & Biley, 2004). Ell (1996) noted that a cancer diagnosis is a challenging time for family members and the survivor because it propels the family into crisis by disrupting routines and communication as well as causing worry and fear among all members. Family members must renegotiate traditional familial roles such as a spouse or child taking on the responsibility to shop for groceries or cook meals. Along with renegotiation roles, families also face the challenges of communicating about cancer.

A cancer diagnosis may further challenge relationships when the patient provides care for others, like women often do in their families. Exley and Letherby (2001) noted that women often have to manage strong emotions like grief or fear while at the same time struggling to make themselves and others feel reassured about the cancer diagnosis and prognosis. Although men struggle with strong emotions after a cancer diagnosis, female survivorship may be unique as women must often balance their needs against the needs the individuals to whom they provide care. Women must negotiate providing support for others while at the same time trying to make the situation bearable for themselves (Van der Molen, 2000). In the Appalachian region where

social norms tend to signal women to provide emotional support for their families, cancer survivors may struggle to find ways to talk about their illness-related concerns to family members. This forces women to put themselves ahead of family members and requires members of the family to take on more wife/mother specific responsibilities.

Research has demonstrated that 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. Appalachian women play a central role in their family since they are typically responsible for household management, family health, and family matters (Coyne et al., 2006; Garvin, 1995). Due to this central role, female Appalachia cancer survivors may have a unique experience regarding family cancer communication. It may be harder for the family to adjust to changing family roles, uncertainties regarding treatment and outcomes, and caring for the wife and or mother.

A woman, along with her family, must navigate through the challenges of discussing cancer within the family. Discussing cancer within the family can be very therapeutic and aid in the understanding and healing for both the survivor and family members (Shapiro, Angus, & Davis, 1997). Although the literature supports discussing cancer within the family, this task can be overwhelming, especially if there are young children in the family. Hilton (1994) found that how a family communicates prior to the diagnosis is often a precursor to the communication style postdiagnosis. However, families may communicate differently after a life-altering event like a cancer diagnosis. Sometimes communication styles change to protect one another from fears they have regarding the diagnosis, treatment, or outcomes. Some families choose to engage in some type of “buffering” in an attempt to prevent family members from worrying or being upset. As such families may choose not to disclose or communicate cancer-related concerns in an

effort to protect other family members from perceived stress. In Appalachia women may choose to not discuss cancer-related thoughts or feelings with family members so they do not have to survive cancer and provide emotional support for family members who are upset about the diagnosis.

The act of protecting one another may lead to unsatisfying or distressed communication for female survivors. Petersen et al. (2003) noted that female cancer survivors often report feeling dissatisfied with the quantity and quality of the communication regarding the illness within their family. Ell (1996) identified that a cancer diagnosis can catapult families into new lifestyles and family roles. Because a cancer diagnosis and the resulting treatments may force new routines in families, these changes may impact how the family communicates with one another. Not only do the survivors have to worry about treatments, insurance (or the lack thereof), and their health; they also must navigate possible changes in family communication dynamics (Petersen et al., 2003).

What is currently lacking in the literature are studies focusing on how family cancer communication may be unique in Appalachia. MacAvoy and Lippman (2001) noted that the most significant relationships for many Appalachians are those within the kin group, with the most important of those being relationships with members in the nuclear family. 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 et al., 2009; Huttlinger, Schaller-Ayers, & Lawson, 2004; Lengerich et al, 2005). However, one gap that appears in the research is how family cancer communication in Appalachia may be different from in other regions of the United States.

Storytelling and Cancer

One way to understand family cancer communication in Appalachia may be through the stories women tell about their survivorship experiences. Exley and Letherby (2001) noted that the best way to learn about experiences is through hearing the experience from the individual. Storytelling allows individuals to pass on traditions, reshape and understand identities, learn social norms, and come to terms with difficult life experiences (Kellas, 2005). Storytelling has long been a part of Appalachian culture as a way to pass down ideas, customs, and history to younger generations (Hutson et al., 2007; Kellas, 2005), therefore making it an effective way to learn about family cancer communication and changing personal identities through the cancer journey in Appalachia. The stories reveal deep cultural roots that link the people to the land. Ross (2006) noted that many Appalachians began receiving this oral education as infants, and individuals can have thousands of stories in their repertoire by the time they reached their sixties. Considerable research has demonstrated the positive effects of storytelling for individuals experiencing traumatic life events like a cancer (Carlick & Biley, 2004; Frank, 1995; Kellas, 2005).

This study addresses the gap in literature about family cancer communication in Appalachia and how a female cancer survivor's personal identity is impacted by the cancer communication. At the time of this writing, this study is the first to explore Appalachian family cancer communication and changing personal identity.

CHAPTER 2

LITERATURE REVIEW

Impact of a Cancer Diagnosis on Family Communication

Research has revealed that a cancer diagnosis can be a challenging time for not only the cancer survivor but also the survivor's family members. Ballard-Reisch and Letner (2003) argue that a cancer survivor cannot be detached from her family so a cancer diagnosis should be seen as a family issue. Cancer has the ability to challenge relationships and affect all members of a family as they learn to cope, take on new roles within the family and experience lifestyle changes (Carlick & Briley, 2004; Hilton et al., 2000; Mystakidou, Parpa, Tsilika, Katsouda, & Vlahos, 2004; Petersen et al., 2003; Van der Molen, 2000).

Family changes might be even more extreme when the mother and or wife in the family is diagnosed with cancer. Petersen et al. (2003) argue that the cancer diagnosis of the central female caregiver places more stress upon the family as well as makes the family more vulnerable to changes as a result of the diagnosis. A woman's cancer diagnosis requires the family to develop new routines, redistribute roles, provide emotional and physical support to the woman, as well as redefine normalcy within the family (Lewis & Hammond, 1992; Hilton et al., 2000; Holmberg et al., 2001). It may also require family members to reevaluate themselves, other family members, and how they will share concerns and fears with each other (Baider, 2008). In the Appalachian region women are responsible for family and household issues (Denham et al., 2004). This is a powerful position for many women, and they may not be comfortable letting other family members take on some of their responsibilities. For survivors and families in this region, a cancer diagnosis of the wife and or mother might be especially challenging due to the cultural traditions and beliefs in Appalachia.

It is important to discuss cancer within the family context because when the individual is diagnosed all family members are impacted. Lewis (1990) argued that family members, not just the patient, experience the stress of the cancer experience. Families also provide the context of adjustment in which the survivor responds to her disease. How a family responds and communicates about a cancer diagnosis can have positive and or negative effects on the survivor. Research has shown the positive effects of open cancer communication for both the survivor and family members (Ell, 1996; Porter, Keefe, Hurwitz, & Faber, 2005; Zhang & Siminoff, 2003). This study examines what the stories of female Appalachian cancer survivors reveal about family cancer communication in Appalachia and how a female cancer survivor's identity is shaped through that communication.

Benefits of Cancer Communication Within Families

A cancer diagnosis of a family member brings a level of uncertainty to the family. Family members may be expected to not only nurture one another but also are expected to provide caregiving. The survivor may also feel uncertainty regarding the possibility of recurrence or death. Doyle (2008) noted that a survivor's life is potentially affected forever once the diagnosis has been made. One way to overcome this uncertainty may be through communicating about cancer within the family. Baider (2008) defines effective family communication as "the exchange of information of all its members about feelings of self and others, allowing permissiveness and acceptance of independent and diverse thought" (p. 609). This type of communication goes beyond disclosing the diagnosis to the family since disclosure focuses on "interactions between at least two individuals where one intends to deliberately divulge something personal to another" (Greene, Derlega, & Mathews, 2006, p. 411).

Porter et al. (2005) posit that the amount of cancer communication within families is likely to impact the survivor's wellbeing. For example, conversations about cancer may aid the survivor in feeling assured of her health. After the diagnosis, the cancer survivor and her family members must "construct, redefine, negotiate, and renegotiate" their interactions during the illness (Baider, 2008, p. 608). For example, Ell (1996) suggested that communication within the family can aid both the family and the survivor in adapting to the illness. Research has shown that some of the positive effects of communicating about cancer within the family are better adjustment, lower levels of psychological distress, and greater understanding of the survivor's illness experience (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Porter et al., 2005; Zhang & Siminoff, 2003).

Benefit to Survivor

One way for families to navigate the tumultuous changes is through maintaining open family cancer communication. Hilton (1994) noted that open communication occurs when family members can share feelings and fears with one another. Families with a closed communication style believe that not talking about feelings and fears is more helpful and would rather discuss the facts of the situation. For the survivor, open family cancer communication aids in better adjustment to life after a cancer diagnosis, lower levels of psychological distress, and better quality of life. Porter et al. (2005) noted that survivors who were able to openly discuss cancer within the family had fewer emotional and physical complaints. Those survivors also had higher levels of self-esteem and perceived control. Furthermore, Cordova et al. (2001) found that female breast cancer survivors who were able to discuss cancer-related thoughts within their families reported less depression and greater sense of wellbeing. Disclosure of thoughts and feelings

validate the survivor's experiences as well as help her find meaning in the experience (Porter et al., 2005).

Benefit to Family Members

An illness diagnosis like cancer can thrust family members into an “unfamiliar environment where they have little or no time emotionally and psychologically to incorporate the diagnosis of a life-threatening illness into their lives” (Baider, 2008, p. 608). Hilton (1994) suggested that as difficult as it is for a cancer survivor to learn to live with cancer, it may be even more challenging to learn to live with a loved one's cancer diagnosis. Family members may have more struggles accepting the diagnosis and adjusting to routine changes as well as dealing with cancer-related fears and worries. Lewis (1990) noted that family members experience elevated levels of distress and tension after a cancer diagnosis resulting from the unpredictability and uncertainty of a life after a cancer diagnosis. As previously stated, family members must develop new routines, redistribute roles, provide emotional and physical support to the woman as well as redefine normalcy within the family (Hilton et al., 2000; Holmberg et al., 2001; Lewis & Hammond, 1992). Families must cope with emotional strain, fear of the survivor's death, altered roles and lifestyles, as well as financial strain and physical demands (Ell, 1996).

Family members may also benefit when the family is able to openly discuss cancer and, because cancer is a family issue, the benefits a family member experiences also impacts the survivor. The cancer experience can shift family goals and priorities, identity, and spiritual values (Sherman & Simonton, 2001). As stated above, open communication allows family members to share thoughts and fears with one another (Hilton, 1994). This openness allows the family unit to heal from abrupt changes in their lives as well as facilitate the family's adjustment to the cancer diagnosis (Anderson & Martin, 2003; Hilton, 1994). Porter et al. (2005) found that

the cancer survivor's partner experienced lower levels of caregiver strain because the partner has a better understanding of the survivor's physical and emotional needs. Open cancer communication may increase levels of relationship functioning and decrease negative or unhelpful partner responses that may prevent the survivor from discussing cancer-related fears and concerns.

Benefit to Families in Appalachia

Family has long been central to many Appalachians throughout the generations. Even today family remains an important component of Appalachian culture and society. Many people from Appalachia value strong, close-knit families (Burns, Scott, & Thompson, 2006). Older generations in Appalachia historically viewed a cancer diagnosis as a death sentence in part due to late-stage diagnosis and disparities and cancer mortality in the region. Cancer stories passed from one generation to the next often included fears and anxiety about cancer. These stories have influenced health and cancer perceptions as well as health beliefs in the region (Behringer et al., 2009; Dorgan et al., 2009; Hutson et al., 2007).

Discussing cancer within the family has the potential to alleviate fears as well as clear up misconceptions about cancer in Appalachia (Anderson & Martin, 2003; Hilton, 1994; Porter et al., 2005); therefore, open family cancer communication in Appalachia may aid in dispelling fears survivors or family members experience during the cancer journey. One way to open the lines of family cancer communication may be through illness narratives or storytelling. This avenue may be especially beneficial in Appalachia as the region enjoys a rich storytelling tradition.

Illness Narratives and Family Communication

Storytelling, the act of telling one's experience or event in life, is one of the most basic forms of human communication (Atkinson, 1998). Stories can be especially useful for individuals who are diagnosed with an illness like cancer. Atkinson (1998) noted that people think and talk in story form as well as bring meaning to their lives through stories. Chelf, Deshler, Hillman, and Durazo-Arvizu (2000) noted that storytelling is a common way to learn about life and it allows the diverse meanings of life to be woven together. They provide a richly-textured and detailed understanding of an individual's lived experiences (Shapiro et al., 1997). Oxendine (2006) noted that storytelling was historically used for entertainment, education, and cultural preservation. For the Appalachian region storytelling has been a long-standing and vibrant part of the culture. Storytelling in Appalachia began as a way for families to pass along ancient stories to younger generations (Leonard, 2006). For many Appalachians stories were heard during family gatherings, at community events, and at the workplace; therefore, storytelling may be an ideal avenue to understand the complexity of family cancer communication in Appalachia. Illness narratives serve an important function among survivors and with their family cancer communication. Illness narratives allow the survivor to make sense of her life changing event and aid in healing. Furthermore, they provide a way for others to better understand the cancer experience for female Appalachian cancer survivors.

Sense-Making for the Survivor

Kellas (2005) noted that humans are by nature storytellers and the primary reason for telling stories is for the creation and evaluation of self. Stories help people organize experiences, increase communication, and bring a greater sense of understanding for others including family members (Carlick & Biley, 2004). Frank (1995) stated that the ill "need to become storytellers in

order to recover the voices that illness and its treatment often take away” (p. xii). That is, illness and treatment have the potential to take away a survivor’s voice and perhaps identity.

Storytelling allows the survivor to find voice and begin reconstructing their changing identity.

Stories allow survivors to understand and make sense of changes they are experiencing (Carlick & Briley, 2004). Stories allow the storyteller to discover the deeper meaning of the events through reflecting and telling (Atkinson, 1998; Bell, 2002; Frank, 1995; McCormack & Milne, 2003; Riessman, 1993), and for ill patients these stories help diminish a sense of isolation, helplessness, and marginalization they might feel (Rosenblatt, 2006).

Therapeutic Nature of Storytelling for Survivors

Storytelling has the potential to be a healing experience for cancer survivors because it can help them navigate and make sense of the illness experience. A cancer diagnosis has the potential to destroy the ideas the survivor once had about herself, but storytelling can aid in repairing the damages of illness and help the individual redefine their life after a cancer diagnosis (Carlick & Briley, 2004; Frank 1995). Furthermore, stories provide a way for the teller to create continuity and wholeness for a life torn apart by illness as well as come to terms with life changes (Charmaz, 1999). Stories “play a therapeutic role in the healing of the rupture in the autobiography due to cancer” (Shapiro et al., 1997; p. 549).

Although the benefits and needs of family cancer communication have been well documented, not all families are able to engage in open communication regarding cancer. The following section discusses potential barriers to communication including specific barriers in Appalachia.

Barriers to Cancer Communication Within Families

For individuals with an illness like cancer, the ability to discuss illness-related concerns is often key to the emotional support they need. Helgeson and Cohen (1996) found that most cancer survivors want emotional support – to talk with someone about their illness-related fears and concerns. Cancer survivors typically look first towards someone in the family to provide that support. Unfortunately, cancer survivors are not always able to discuss their cancer-related thoughts within the family. In fact, Gotcher (1993) found that women with cancer were actually dissatisfied with communication within their family about their illness. Furthermore, Zhang and Siminoff (2003) found that not only women, but families too, experience difficulties with family cancer communication. The researchers interviewed 37 lung cancer patients and 40 caregivers representing 26 families. Within those families, Zhang and Siminoff revealed that two-thirds of the families experienced some type of communication problem. Discussing cancer within families appears to be challenging for many families. However, there may be additional challenges in Appalachia due to health beliefs of the region and the expectations of women within Appalachia.

Despite the potential benefits of discussing cancer-related thoughts and feelings, there are a number of barriers that prevent both the survivor and family members from disclosing to one another. These barriers include protecting family members and self, concerns over psychological distress, and positive-only thinking (Charmaz, 1997; Porter et al., 2005; Zhang & Siminoff, 2003). Sherman and Simonton (2001) noted that communication barriers are harmful to families because they leave individuals feeling isolated from one another at a time when greater family cohesion is needed. In Appalachia there may be additional barriers to open family cancer communication. As noted by Garvin (1995) women are often the primary caregivers for families

and tend to put the needs of their families ahead of their own. Additional barriers may be present in Appalachia due to the culture of the region. These barriers may include health beliefs of the region as well as cultural norms.

Barrier #1- The Need to Protect

Examination of the literature revealed two types of protective communication in which families engage: 1) protective buffering and 2) mutual protection. First, protective buffering occurs when one member of the family tries to protect another member by not discussing cancer. Zhang and Siminoff (2003) found that cancer-related fear and anguish prevented survivors and their family members from communicating about cancer. Some women attempted to protect family members like elderly or ill parents by not disclosing the diagnosis at all (Holmberg et al., 2001). Porter et al. (2005) noted that in other families the cancer survivor's spouse engaged in "protective buffering" (p. 1031). For example, family members protect the cancer survivor by not discussing cancer-related thoughts and concerns such as fears regarding treatment because they believe it would be harmful to the survivor to hear.

For Appalachian survivors, they might be protecting families to protect themselves. Because Appalachian women tend to provide emotional support within the family (Oberhauser, 1995), they may be concerned that they would be responsible for providing emotional support to a family member who was upset about the diagnosis. The survivor may feel that she would be unable to care for herself *and* provide emotional support; therefore, she may decide to protect the family from her cancer-related thoughts and concerns in order to protect herself.

Second, mutual protection occurs when all the family members chose to not discuss cancer because of the concern of upsetting other family members (Baider, 2008; Zhang & Siminoff, 2003); therefore, no one in the family discusses any of their cancer-related fears or

concerns. However, Hilton et al. (2000) noted that this buffering interferes with communication, increases energy expenditure, and causes added stress with misconceptions that cannot be clarified. The need to protect one another might lead to limited forms of communication within the family. The cancer survivor may feel alone because she does not feel comfortable discussing cancer with another family member. Also, family members may feel confused or scared since they are not fully aware of what is happening with the cancer survivor.

Women often resist asking for help and attempt to maintain precancer routines in an effort to reduce future perceived stress on their family and avoid further changes in their family system (Petersen et al., 2003). Anderson and Martin (2003) noted that “communicating about illness is often perceived as ‘taboo’” (p. 133), and family members may just not know what to say to the survivor. Exley and Letherby (2001) found that sometimes the awkward reactions from family members or friends made it difficult for cancer survivors to talk about their cancer-related thoughts and feelings. Worse yet was when people “forgot” or ignored the cancer experience making the survivor feel further isolated; therefore, women are often left to understand and cope with their illness by themselves. Unfortunately, Ell (1996) noted that protecting one another from cancer-related thoughts and fears had harmful effects on survivor recovery because the survivor was more likely to feel depressed, isolated, or out of control.

Barrier #2 – Psychological Distress

Discussing cancer-related thoughts and concerns may cause psychological distress to survivors or the survivors’ families. Zhang and Siminoff (2003) found that for their participants discussing cancer-related fears was just too emotional or difficult. Not only do they have to cope with cancer-related stress but also with the stress of communicating with family members about cancer-related stress. They viewed it as a depressing subject and speaking about it made them

feel sad or upset. The participants were also worried that family members would feel sorry for them, and they did not want to further upset their families. A study by Exley and Letherby (2001) further supported the problems of communication within the family after a cancer diagnosis. In their study of 19 terminally ill patients, the participants discussed how it was easier to talk with the interviewer about their illness than their family members. They stated that because they did not love the interviewer, they did not have to worry about managing emotions or upsetting the interviewer like they would with a family member. If family members are worried about causing psychological distress among one another, they may engage in either protective buffering or mutual protection, therefore, linking the need to protect barrier and psychological distress barrier.

Furthermore, Lewis (1990) noted that family members do not always know the best way to emotionally support the cancer survivor. They may feel as if they are not able to help the survivor process cancer-related thoughts and feelings. This uncertainty about how to respond may lead to awkward interactions between family members and the survivors. As previously noted, these awkward interactions make it difficult for survivors to feel comfortable discussing cancer-related thoughts and feelings with their family members. However, avoiding or ignoring the survivor's cancer experience can make her feel isolated and alone. As such, the woman must understand and cope with her illness by herself.

Barrier #3 Positive-Only Thinking

Optimism and a positive outlook through the cancer journey have documented advantages to the survivor and ultimately their family. Research has demonstrated that a positive outlook helps both the survivor and the family have better psychological adjustment to the diagnosis over time (Aspinwall & MacNamara, 2005). However, there are times when positive-

only thinking can be detrimental to the communication between survivors and their families. When only positive thinking is allowed, it provides no space for cancer-related fears and concerns to be vocalized. Zhang and Siminoff (2003) found that some families choose to engage in positive-only thinking. For these families, positive-only thinking may feel more like a prison because the survivor and family members have no way of expressing fears and concerns with one another resulting in self and other censorship (Sherman & Simonton, 2001). With this barrier, family members and survivors are fearful that discussing negative emotions could impede the survivor's recovery process (Sherman & Simonton, 2001; Zhang & Siminoff, 2003). Survivors and family member choose to only think positively about recovery at all costs. Survivors engage in positive only thinking by keeping a positive attitude about self and not giving in to being sick (Charmaz, 1997). Families can further encourage the positive-only thinking by changing the subject whenever someone begins discussing cancer-related fears and concerns (Sherman & Simonton, 2001). This barrier impedes communication because it does not allow for all thoughts to be discussed, just positive-only thoughts. Survivors and family members are unable to voice cancer-related fears and concerns they experience thus limiting cancer communication within the family.

Barrier #4 – Health Beliefs in Appalachia

Ballard-Reisch and Lenter (2003) stated that beliefs have the ability to impact family cancer communication. Although Appalachia is a diverse region with a complex culture, some of the health beliefs in the region may be attributed to the higher cancer incidence and mortality rates as well as hinder communication about cancer within families.

Some health beliefs in Appalachia differ from beliefs held outside of the region. One of these beliefs appears to be that friends and family are a reliable source of health information. As

previously stated, Appalachians often have strong family ties. These strong ties have led many Appalachians to turn to friends and family rather than from health care practitioners for health information (Crissman, 1989; McNeill & Dorgan, 2005). Dorgan et al. (2009) posited that these strong family ties intersect with Appalachian self-reliance resulting in women relying on family instead of physicians for information regarding health. This reliance on friends and family members may also be a result of Appalachian women putting the family's needs ahead of their own health needs (Patton, 2005). Appalachian women may feel guilty spending money and or taking time away from their family to visit a health care practitioner; therefore, by asking friends and family instead a woman can learn health information without feeling like she is neglecting her family. Unfortunately, as noted by Behringer and Fridell (2006) this information may be outdated and incorrect which potentially causes family cancer communication in Appalachia to be centered upon outdated and incorrect information.

The Appalachian culture encourages women to place their families' needs above their own including their health needs (Garvin, 1995; Patton, 2005). Garvin (1995) found that women in Appalachia consider themselves to be strong. In her study, Garvin conducted six focus groups to talk with 44 women regarding the information needs and wants of women in the Appalachian region of Virginia. The women described themselves as strong women due to financial hardship like limited employment opportunity and geographical isolation. They are typically the primary decision-makers about health needs and services for their families. Garvin (1995) found in her study that Southwest Virginia women recognize the need for preventative care. However, those female participants chose not to seek preventative care due to health care costs, stigma of social assistances, and the implication that they are being selfish by putting their needs ahead of their

families. If Appalachian women believe their families' needs come first, then they may also feel selfish by discussing their health needs and concerns with family members.

Summary

Family cancer communication helps survivors and family members not only make sense of a cancer diagnosis, but it also helps them adjust to life after the diagnosis. Because a cancer often requires changes in family roles and responsibilities, it may also impact a survivor's identity. This may be especially true for women in Appalachia because women play central roles within their families and often the family caregivers.

With this in mind, this proposes the following research question:

RQ #1: What do the stories of female Appalachian cancer survivors reveal about family cancer communication in Appalachia?

As mentioned earlier, a cancer diagnosis is challenging for the entire family. Both the survivor and her family must learn to cope, adjust to altered lifestyles and family roles, and provide emotional support for one another (Baider, 2008; Hilton, 1994; Hilton et al., 2000). Ell (1996) suggested that open family cancer communication, where families share cancer-related fears and concerns, helps families and survivors adapt to the changes cancer brings to families. Although research documents the benefits of open family cancer communication, barriers like protection, psychological distress, and positive-only thinking can impede open communication. In Appalachia, some cultural beliefs like who to trust for health information as well as the belief that women should put their family's needs above their own may impede family cancer communication in Appalachia.

Family Cancer Communication and Changing Identities

As previously discussed, a cancer diagnosis turns one's world upside down and can destroy a person's assumptions about herself, her safety in the world, and her connectedness to others (Shapiro et al., 1997). Doyle (2008) argues that cancer is an extreme experience not only disrupting the survivor's life but also her sense of identity. Furthermore, Fitch (2008) noted that cancer survivors struggle through changing roles and responsibilities within their families as well as alterations in self-image and body functioning. This idea is seen in Mathieson and Stam's (1995) study of identity renegotiation through cancer narratives where one participant said:

The focus on the things I think about are entirely different now...all your plans are future oriented...and that is taken away from you...my body keeps letting me down in various ways...I feel like it's betrayed me sort of, I guess...Some people who I was quite close with just kind of disappeared...I know cancer patients are chronically ill, but I feel useless, because I can't do anything any more. I can't work properly. (p. 294)

Women diagnosed with cancer must make decisions that will affect her body, ideas about herself, and her reproductive options. Her decisions impact her identity and her role within her family; therefore, it is no surprise that these women report a heightened sense of self-awareness. The changes may cause the survivor to not only question her sense of usefulness in her family as well as her autonomy (Shapiro et al., 1997; Sherman & Simonton, 2001).

Challenges of Changing Identities

Often the physical changes play a large role in the identity changes of cancer survivors. Women reported in Holmberg et al.'s (2001) study no longer feeling sexy or attractive because of changes in appearance like hair loss, scars from surgery, or the loss of a breast. Other changes,

like altered hormonal states, loss of libido, and fatigue from treatment affected sexual functioning and impacted perceptions of the women as sexual beings. The physical effects of cancer as well as the diagnosis and treatment experience impact how a woman perceives herself. At the time of this study, no research has been conducted in the Appalachia region regarding changing personal identities through the cancer journey. Due to family roles and cultural beliefs, women in this region may experience different challenges than women outside of the region face.

Mathieson and Stam (1995) noted that cancer survivors are in the midst of “dynamic psychosocial events” (p. 287). These events can lead to personal distress; personal, family, and financial stress; stigma; and threats to their precancer identities. These authors also argue that when combined these events lead to a forcible change in one’s identity. Shapiro et al. (1997) reported that female cancer survivors had an increased sense of vulnerability and uncertainty after their cancer diagnosis. Women may also struggle to deal with increasing dependence upon family members because they are use to the identity of caregiver (Peterson et al., 2003). Charmaz (1997) argues that “dependency spurs identity questioning” (p. 102). In societies such as Appalachia where cultural norms place women in caregiving roles, this can be especially challenging. These challenges are expressed by a participant in Charmaz’s (1997) book *Good days, Bad Days*.

I was totally physically depended on Norma [her lover] and I didn’t like it. I didn’t like it. That was worse than the treatment. I think I can face anything again but that feeling of total dependency. You lose yourself. (p. 102)

Helgeson and Cohen (1996) noted that cancer survivors may feel inadequate and have a sense of loss of control and a general sense of confusion. In Appalachia these feelings may be increased due to the culture of the region and roles of the women in the region.

A cancer diagnosis not only impacts family communication but also impacts identity. Little, Paul, Jordens, and Sayers (2002) stated that they believe that surviving cancer produces changes in personal identity. Identity is described as the “sense of being this person, with attributes, acquisitions, and capabilities which condition interactions and between the person and the social systems in which he or she lives” (Little et al., 2002, p. 171). Cancer has the ability to change those attributes, acquisitions, and capabilities. Mathieson and Stam (1995) noted that cancer survivors are in the midst of “dynamic psychosocial events” (p. 287). These events can lead to personal distress, family stress, financial stress, stigma, and threats to precancer identities. These authors also argue that when combined these events lead to a forcible change in one’s identity.

Changes to the body, often caused by cancer treatments or surgeries, threaten a survivor’s sense of personal identity. Women have to make decisions that will impact their body as well as their reproductive options (Shapiro et al., 1997). Even temporary changes to the body like chemo-induced hair loss (alopecia) impact a survivor’s sense of self because for many it symbolizes no longer being healthy. The participants in Mathieson and Stam’s (1995) study struggled with how the hair loss changed them. One participant noted:

I’ve never lost my hair but there was a time I thought, ‘Forget it,...I’d rather die than just kind of go out with such a visible thing.’ The hair thing...would have marked me as a cancer patient. (p. 295)

Many women struggle with alopecia due to what hair symbolizes in society and because hair is often tied to identity and a sense of self. Münstedt, Manthey, Schachsse, and Vahrson (1997) stated that hairstyles have the ability to indicate one's gender, class, occupation, and social beliefs. Hair may also represent ideas about one's self-concept and self-identity; therefore, the loss of one's hair during chemotherapy can quickly start reshaping a woman's ideas about her body and her identity and may cause higher levels of depression and anxiety. It is also important to remember that survivors are renegotiating their identity in the midst of family responsibilities making the identity negotiation that much more challenging.

Summary

Cancer survivors may find that their identity both as an individual and as a family member is impacted by the cancer diagnosis. Shapiro et al. (1997) reported that female cancer survivors had an increased sense of vulnerability and uncertainty after their cancer diagnosis. Women may also struggle to deal with increasing dependence on family members because they are accustomed to the identity of being a *caregiver*. Often cancer requires role redistribution in families, meaning that sometimes the woman goes from being the caregiver to being cared for. These new family roles and how a family communicates about these changes may impact survivors' identity changes during cancer. In Appalachia women play central roles within their families (Coyne et al., 2006; Denham et al., 2004; Garvin, 1995). An Appalachian cancer survivor may experience unique challenges in regards to her personal identities. This study also proposes the following question:

RQ #2: What do the stories of female Appalachian cancer survivors reveal about their changing personal identities?

A cancer diagnosis brings challenges to not only the survivor but her family as well. Together they must all learn to cope, adjust to change, and provide emotional support for one another (Baider, 2008; Hilton, 1994; Hilton et al., 2000). Research supports that open family cancer communication is beneficial to not only the survivor but the family members as well (Ell, 1996; Porter et al., 2005; Zhang & Siminoff, 2003). Also, during the cancer journey survivors must negotiate identity changes as they experience changes in their body as well as psychological changes. Further stress may be added for women who must negotiate their changing identity within their family. In Appalachia, an area noted for close-knit family groups and often traditional gender roles, negotiating family cancer communication as well as their identity may provide additional challenges.

CHAPTER 3

METHODOLOGY

Purpose of Research

The purpose of this study was to understand family cancer communication and changing personal identities through the stories for female Appalachian cancer survivors. The researchers chose a qualitative approach to explore the experiences of female Appalachian cancer survivors. The qualitative research paradigm lends itself well to this study because qualitative research attempts “to understand the meaning or nature of experience of persons with problems.” It also is used to explore phenomena for which little is known, and can be used to obtain intricate details that would be difficult to gather through more objective research methods (Strauss & Corbin, 1998, p. 11).

Methodological Approach

Data for this study were collected through a mixed-methods approach including story circles and in-depth interviews. Each data collection style was selected as a way to gain descriptive accounts of the female cancer survivor’s experience in Appalachia. After an initial review of the story circle data, family cancer communication and changing personal identities emerged as primary themes among participants. Theoretical sampling was used to collect additional data to explore the emergent themes. Corbin and Strauss (2008) describe theoretical sampling as a data collection method where data are collected from places, people, or events to maximize opportunities to develop concepts found in existing data. To maximize opportunities to develop family cancer communication and changing personal identities additional participants were selected for in-depth interviews. This mixed-method collection approach allows for a deeper and richer understanding of the themes. Although this work may not be generalizable to

the entire population, it may have value for southern female Appalachia cancer survivors making sense of their family cancer communication and changing personal identities.

This qualitative study was a two-phase study exploring survivorship and the unique needs of female Appalachian cancer survivors. Data for Phase I were collected through a day-long story circle event (Dorgan & Hutson, 2008). The goals for the study were as follows:

1. To define survivorship from the perspective of female Appalachian cancer survivors;
2. To identify unique needs among female Appalachian cancer survivors; and
3. To identify possible strategies for addressing female Appalachian cancer survivors' needs.

Some survivors were unable to attend the story circle event due to treatments, financial or transportation issues, and work conflicts; therefore, additional data were collected through in-depth interviews for Phase II. This allowed for the exploration of diverse cancer experiences.

Phase I

Participants

The stories of 26 women were collected in September 2008 during a day-long storytelling event. Participants were identified through a variety of techniques. Two oncology nurses assisted in recruiting participants who either were in or had been in treatment. Participants were also identified through places of worship, support groups and therapists, senior centers, libraries, healthcare providers (i.e., oncologists and oncology nurses), and clinics. Snowball sampling was used as well to identify potential participants; both participants and local health care providers were involved in indentifying potential participants. Forty possible participants were mailed an invitation to participate in a day-long story circle event focused on collecting the stories of female Appalachian cancer survivors.

Twenty-six women agreed to participate in the story circle event, and these individuals were given participant numbers P1 through P26. All women were from the Northeast Tennessee (NETN) and Southwest Virginia (SWVA). All had been diagnosed with cancer 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. By not limiting the type of cancer, the researchers were able to collect stories from individuals who might have varying cancer survivorship experiences. For example, a woman surviving breast cancer may have a story vastly different from another woman surviving ovarian cancer because breast cancer is more common among women, resources are more readily available, and the survival rates are higher (ACS, 2008b). No medical records were collected, so all women self-reported their cancer diagnosis. Table 1 shows cancer type and representation in the study.

Three participants were dual cancer survivors, meaning they had survived two different types of cancer. Two participants had both thyroid and breast, and one participant had stomach and liver cancer. However, only the first cancer diagnosis was included in the numbers. For this study participants were oversampled to ensure approximately 30 women participated in the story circle event. Researching cancer survivors in Appalachia can present challenges. First, depending on where the individual is along the cancer survival continuum, the survivor may have been undergoing treatments thus causing a physical inability unable to participate. In Appalachia some survivors face transportation issues as well as concern over the money lost from missing a day of work, therefore, making it challenging for women to attend. Fourteen women were unable to participate due to treatments, transportation or financial issues, or work-related reasons.

Table 1

Cancer Type and Representation in Phase 1

Cancer Type	Number	Percentage
Breast	15	58%
Ovarian	2	8%
Thyroid	2	8%
Multiple Myeloma	2	8%
Colon	1	4%
Fibrosarcoma	1	4%
Melanoma of the lung	1	4%
Unknown	1	4%

Data Collection Procedures

Data collected from the event were recorded and transcribed verbatim, resulting in 161 single-spaced pages. Women who participated in the event received breakfast and lunch as well as a \$25 gas card to offset the cost to travel to the story circle location. Prior to starting the event, all women were asked to read and complete the Institutional Review Board (IRB) consent forms. The women were divided into two groups (n=15 and n=11) and asked to discuss their stories of cancer survivorship in Appalachia during two 4-hour blocks. Groups were larger during the morning sessions (n=15 and n=11) than in the afternoon sessions (n=11 and n=9) because some participants had to leave early due to prior obligations like doctor’s appointments, child care issues, or a funeral. If half day attendance was expected, those women were asked to tell their stories first. Each group had one faculty researcher as a moderator and one research assistant to

take participant observation notes to capture descriptions of the environmental surrounding, participants' behavior, and verbal and nonverbal cues. The observation notes became part of the audit trail for the study.

Story Circles

Story circles and the methods for conducting them are still relatively new. Pavlenko (2002) noted that it is only in the past 3 decades that the stories people tell about their lives have become the focus of narrative study. The story circle approach has been used in academia to encourage reflection by students as well as in organizations to understand organizational change (Bell, 2002; McCormick & Milne, 2003; Pavlenko, 2002). Story circles typically consist of small groups of 15 individuals or fewer who have shared experiences like surviving cancer in Appalachia (Becker, Randels, & Theodore, 2005; McCormack & Milne, 2003). McCormack and Milne (2003) noted that the moderator plays a less intrusive role with the participants leading the discussion rather than the moderator. Typically the moderator does not have predetermined questions that guide the story in any way. The moderator merely asks the participants to share their experience and may ask questions to help the participants organize the events and factors in their stories (Becker et al., 2005). For this project a modified story circle approach chosen because in Appalachia storytelling is an important form of communication in the region. Stories in Appalachia have been used for generations to pass on traditions and history from one generation to the next (Dorgan et al., 2009; Olson, 1998).

For this study the researchers opted to use a modified story circle method. The researchers were concerned that data would not be comparable between groups and objectives of the study would not be met without modifying the story circle method; therefore, the most useful parts of story circles and focus groups were combined. Like story circles, focus groups allow for

flexibility as well as a large amount of data to be gathered at once. They also allow the moderator to explore unanticipated topics and permit the unique stories of each group member to be told (Berg, 2007). Berg (2007) further notes that a disadvantage of focus groups is that they should ideally be between 30 to 60 minutes. Researchers agreed this timeframe was too short to sufficiently gather the survivors' stories. However, concerns were raised over comparability of data if two groups were asked to talk about their cancer experience without any type of guide; therefore, the moderator's guide was taken from focus group methodology to ensure data collected from both groups would be consistent and comparable. An interactive, semistructured moderator's guide includes a number of predetermined questions but also allows the moderator to digress and probe beyond the standardized questions (Berg, 2007). This allowed the data to be consistent but maintained the spirit of the story circle methodology.

The semistructured moderator's guide was used as a starting point for discussion in the story circles. The open-ended questions were designed to ascertain participants' definition of cancer survivorship in Appalachia, their unique needs in their area, as well as their suggestions to address those needs. The semistructured moderator's guide allowed the moderators to explore unanticipated areas discussed by the participants. Some questions asked in the story circles were What does it mean to be a survivor? What are the needs of female cancer survivors in Appalachian? And What advice would you give a female Appalachian cancer survivor?

Phase II

Participants

Three additional participants were selected for in-depth interviews by using theoretical sampling. The interviewees were given participant numbers P27 through P29. As mentioned before, theoretical sampling is the practice of collecting data from places, people, or events to

maximize opportunities to develop concepts found in existing data (Corbin & Strauss, 2008). The participants were sampled based on the primary reasons for not attending the story circles which included going to treatment appointments, transportation or financial issues, or work-related reasons. As mentioned earlier, women who participated in the story circle event ranged between 4 months and 50 years of survival; therefore, some women invited to attend were undergoing cancer treatments. For the women unable to come, they may have had a treatment scheduled for that day or they were recovering from a treatment earlier in the week or were unable to drive to the story circle location due to lack of transportation or recent surgeries or treatments. Lastly, for many women in Appalachia financial concerns predominate, causing an inability to take a day off of work. However, those women unable to attend also have unique stories that may contribute to how the cancer experience in Appalachia is unique. Not capturing these stories would have resulted in a less complete or comprehensive understanding of the cancer survivorship experience in Appalachia. A large number of participants in the storytelling event were breast cancer survivors, purposeful sampling of nonbreast cancer survivors also took place to provide a more diverse cancer population in the study. One participant from Southwest Virginia participated in the story circle event so one in-depth interview participant was chosen from the SWVA area to strength the region's presence in the study.

Two participants were recruited with the assistance of the coprinciple investigator who is also an oncology nurse (SH). The third participant self-identified as a cancer survivor to the principle investigator (KAD). For the second phase of data collection, one woman was an ovarian cancer survivor, the second an ovarian and breast cancer survivor, and the third a cervical cancer survivor. Women selected for the interviews were women living in Appalachian who had survived cancer. They had been survivors from 18 months to 25 years. Like the story

circle participants, the interviewees were also self-reported cancer survivors, meaning that no medical records were used to verify cancer diagnoses.

Data Collection Procedures

Like the story circle participants, the in-depth interview participants were consented using the IRB approved forms. The interviews were recorded and transcribed verbatim resulting in 66 single spaced pages. Interviews ranged in length from 60 to 100 minutes. All interviews were conducted in the homes of the participants for the following reasons: 1) some potential story circle participants cited ongoing cancer treatments, lack of transportation or financial constraints, or conflicting work schedules as a reason for not attending, 2) participants homes provided a private setting to conduct the interview, and 3) it allowed the researcher (KLD) to work around the participants' schedule. The researcher (KLD) traveled to the homes of the participants, so no compensation was provided to the interview participants. After each interview the researcher (KLD) performed introspective journaling to capture descriptions of the environmental surrounding, participants' behavior, and verbal and nonverbal cues. As with the story circle observation notes, these notes too became part of the audit trail for the study.

After the interview with the cervical cancer survivor, it was thought she may have had cervical dysplasia rather than cervical cancer. It is not uncommon for women to confuse cervical dysplasia with cervical cancer because cervical dysplasia is described as precervical cancer (Palefsky & Handley, 2002). However, the decision was made to include the participant in the study since her underlying perception is that she is a cervical cancer survivor.

In-Depth Interviews

Three additional stories were collected in the spring of 2009 through in-depth interviews. Participants were sampled around the reasons cited for not attending the story circle event. One

participant was unable to attend due to chemotherapy treatments, another could not attend due to lack of transportation or financial constraints, and the third in-depth interview participant had a conflicting work schedule the day of the event. Interviews are a powerful research tool that allow for depth, richness, and vividness of stories to be collected. They typically work around a semi-structured interview guide that is flexible when new ideas emerge (Miller & Crabtree, 2004). In-depth interviews are typically used to collect data regarding specific research questions like the ones this study proposes. Due to the richness of information desired from in-depth interviews, sampling of participants should be purposeful and not random. The original moderator's guide was modified to include questions regarding changes in pre- and postfamily cancer communication. Sample questions include How does your family talk with you about cancer? How do you talk about your diagnosis in your family? and What are the challenges of being a cancer survivor in your family?

Data Analysis

In qualitative research, data collection and data analysis are fluid processes with one influencing the direction of the other. Data analysis begins during data collection, but it is not until the collection is complete that a full analysis begins (Corbin & Strauss, 2008). Inductive analytical approaches aid the researcher in understanding the meaning in the data through the development of themes and categories. Lindsley (1999) describes inductive analysis as the process of discovering categories by grouping categories that relate to the same phenomena. The analysis of this study was influenced by Glaser and Strauss's (Corbin & Strauss, 2008) grounded theory. Grounded theory does not generate a hypothesis but instead focuses on emergent themes, and all categories and subcategories are grounded in the original data. This study was not theory

driven. Instead the researcher (KLD) allowed the data to reveal emergent themes, categories, and subcategories like communication barriers and changing roles in families.

After the story circle data were transcribed, a microanalysis of the transcripts began. Microanalysis of the data allowed the researcher to dig deep into the data and focus on data that seems relevant but the meaning seems elusive (Corbin & Strauss, 2008). Microanalysis consists of “breaking open the data to consider all possible meanings,” and it allow the generation of initial categories (Corbin & Strauss, 2008, p. 59). Through this process many themes emerged including the focus of this study: family cancer communication in Appalachia and changing personal identities through the cancer journey. From the initial microanalysis of the story circle transcripts, theoretical sampling took place to further investigate family cancer communication and 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. NVivo 8 was used facilitate management of the data. Analysis of the transcripts was based on Corbin and Strauss (2008) grounded theory approach. As noted by Shapiro et al. (1996) the theory is fluid and evolves instead of being completed in discrete, linear steps because “data collection and the emerging analysis overlap and inform each other” (p. 542). Open and axial coding allowed the researched to uncover common themes throughout all transcripts.

Open Coding

Open coding was used to analyze and interpret both the story circle and in-depth interview data. It involved a systematic approach of identifying family cancer communication and changing personal identity phenomena. Although open and axial coding go hand in hand,

open coding begins the analysis process and allows for the raw data to be broken down into blocks. An example of this taken from the women's responses: "The hardest thing for me was losing my hair" (P26) and "I almost was mentally ill over my hair" (P12) both fit under the category of "impact of hair loss."

Strauss and Corbin (1998) stated that the blocks of raw data allow the researcher to examine and compare data for similarities and differences. Concepts like fear of burdening family, guilt, and protecting family were similar concepts that were grouped into the family interaction category. Open coding helps the researcher name, label, and categorize data. Category examples from the data include "family interactions," "Guilt," and "Maintaining Familial Role." Berg (2007) offers four guidelines to open coding.

1. Ask the data specific and consistent set of questions
2. Analyze the data minutely
3. Frequently interrupt the coding to write a theoretical note
4. Never assume the analytic relevance of any traditional variable...until the data show it to be relevant (p. 317)

Axial Coding

If open coding involves breaking the data apart into blocks, axial coding is the process of putting the blocks back together. As stated by Corbin and Strauss (2008) axial coding is like using the blocks to build a pyramid. Axial coding is the process of relating categories to subcategories. It helps the researcher understand how the categories interact with one another and provide a better understanding about the concepts found in the data. Throughout the coding process constant comparison took place. For example, the concept of protecting family members was compared between participants within story circles, across both story circles, and with the

in-depth interviews. 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.

CHAPTER 4

RESULTS

The results of this analysis are based on the use of data from the story circles (n=26) and in-depth interviews (n=3) in order to better understand what the stories of female cancer survivors reveal about family cancer communication and changing personal identities in Appalachia.

The analysis revealed family cancer communication styles for both pre- and postcancer diagnosis. During the pre diagnosis stage if cancer was suspected women engaged in either: 1) open family cancer communication or 2) selective family cancer communication. Once the diagnosis was confirmed, women again engaged in the following family cancer communication styles: 1) open family cancer communication, 2) limited family cancer communication, and 3) selective family cancer communication. The data suggested that family communication styles were a result of decisions about how to communicate about cancer, reactions to how family members responded to the survivor, or the prior family communication style. Communication barriers and consequences were seen for all types of family cancer communication styles.

The analysis also revealed that women struggled to maintain or renegotiate their personal identities through their cancer journey. Women cited the following concerns: 1) maintaining family roles, 2) changing mothering role, 3) physical changes, and 4) psychological changes. Interestingly, these concerns also impact family cancer communication style because these women negotiating their changing personality identities in the midst of keeping families together.

Research Question #1

Research question #1 asked: What do the stories of female Appalachian cancer survivors reveal about family cancer communication in Appalachia? The stories gathered from the women indicate that cancer communication styles differ from prediagnosis and postdiagnosis and no one type of family cancer communication works best for all families in Appalachia. What emerged during analysis were two primary themes: 1) prediagnosis family cancer communication and 2) postdiagnosis family cancer communication.

Prediagnosis Family Cancer Communication

A woman's family cancer communication style may start before the cancer diagnosis is confirmed. How to share cancer information with family members seemingly began when participants suspected cancer. Women cited varying degrees of how much they shared and with whom within their families. Women in this study who reported suspecting cancer prior to diagnosis (n=9) like feeling a lump in the breast experienced prediagnosis family cancer communication. Two main types of family communication styles were seen in participants who suspected cancer prior to their diagnosis. These were: 1) open communication and 2) selective communication. Not all participants suspected cancer prior to their diagnosis; therefore, those women did not engage in any type of disclosure or communication of cancer suspicions.

Open family cancer communication. Women who engaged in open family communication prior to their diagnosis talked with family members about their cancer suspicions. This type of communication prediagnosis was rare as only a few women (n= 4) reported sharing cancer suspicions with family members. This was most prominent in the breast cancer survivor participants because symptoms for breast cancer are more easily detected due to visible or tactile changes in the breast. Women not only talked about their cancer suspicions

among family members, some also asked other family members to look at or touch the area, for example feel the lump in a breast. One reason to talk with others may be confirm suspicions:

I went in and I told my husband, you know, I want you to feel this. And he goes, oh gosh.
(P15)

I said to my husband, I said I think something's really wrong. I said I can feel it. (P7)

I asked my husband, does my left one look like my right one to you? (P10)

Some participants asked known cancer survivors to feel the lump. For example, one story circle participant whose mother was also a survivor asked her mother to feel the lump in her breast. "My mother said 'my gosh that feels like exactly what I've got'" (P7). As illustrated by the quotes, these women appeared to want validation or perception checking about their cancer suspicions. This may be linked back to the culture signaling women to put their needs behind the needs of the family. However, if another family member like a husband can confirm that something looks or feels different it may alleviate their guilt about putting their needs first.

Selective family cancer communication. The primary reason cited for selective communication centered around protecting family members from perceived undue stress. This is similar to the previous findings of Zhang and Siminoff (2003) regarding protective buffering. Participants stated that they did not want to give family members something to worry about until they knew if there was something to worry about. When P20 found her lump she reported not telling her parents until she had confirmation. Some women even went to extreme measures to keep family members like parents from finding out about the cancer suspicions. "When I went for the mammogram, [my mother] called on my cell phone... I told her I was going to ... pay some light bills" (P15). P10 also expressed going to great lengths to keep her mother from learning about her suspected cancer fears.

The day I had my biopsy my mom had a mammogram at the same facility, and 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. (P10)

The selective communicators in this study may be hesitant to discuss cancer suspicions with family members because of the Appalachian culture. As P10's experience illustrates, women in this culture may feel guilty talking about their suspicions to family members because they are putting their needs ahead of the families. Another possibility is that women may not feel able to cope with suspecting they have cancer and provide emotional support for a family member upset about the suspected cancer. These women did not express that they were opposed to telling some family about their cancer suspicions or even opposed to telling family members after they were diagnosed. They appeared to not want to make certain family members especially their parents anxious or worried, which again may be linked to concerns about providing emotional support. The women did appear to be more comfortable talking with husbands or other cancer survivors in their family. This may be because they felt other cancer survivors would understand their concerns and offer advice, and husbands would be able to compare their bodies from before the suspicions.

Postdiagnosis Family Cancer Communication

Postdiagnosis family cancer communication had similar styles to prediagnosis styles, but included one addition style. Prediagnosis family cancer communication included: 1) open family cancer communication, 2) selective family cancer communication, and 3) limited family cancer communication.

Open family cancer communication. Women who engaged in open family cancer communication openly talked with their family about cancer. Women using this style cited that

open communication was best for healing, and it also allowed the family to help the survivor through the cancer journey. Another reason cited by participants was that families had a right to know about a cancer diagnosis. P22 reportedly felt that being open put her and her family on the path to healing. She told her husband “we’re going to talk about it, and we’re going to cry about it if we feel like crying...That’s what helps.” P14 described sharing information with her children. “My family knew everything. I told them everything...every time I would go for treatment or went to the doctor. When I’d come home all three would come over, and we would discuss what was going on.” P7 discussed the potential danger in not talking with family members about the cancer journey. She perceived that if cancer was not talked about within the family, then family members might not be proactive in having preventative screening.

This desire to share with family members may also be part of the storytelling culture in Appalachia. These women may be attempting to protect family members as well as attempting to encourage preventative screenings. Women in this study seemed aware of the cancer disparity in Appalachia and many had been told negative cancer experiences by others. These women may want to break that cycle by telling their experience and encouraging screenings.

Selective family cancer communication. Survivors who had selective family cancer communication within their families cited both open communication with some family members and selective communication with others. They may have either been selective in the content they shared with family members or selective in the family members with whom they shared cancer-related thoughts or feelings. P28 stated that she believed she would not have survived her cancer journey without her family, and if they had not communicated about her experience she would not have had their support. She cited open communication with her husband and daughter-in-law but selective communication with her sons.

My sons weren't quite as involved... they didn't deal with it quite as well, you know, as maybe girls would have. But although they weren't there for the appointments and that sort of thing they were there to cheer me up you know. (P28)

Those engaging in selective communication also focused on how to disclose their diagnosis to family members. For some individuals that was easier than others. P12 described needing to absorb the diagnosis before telling her family members. She stated, "I wanted to figure out how I was going to deal with it myself before I wanted to include anyone else and figure out how they were going to help me deal with it." P12's statement suggests that women in Appalachia may need the time to absorb this information to understand how to talk with family members about the diagnosis. It may also be about preparing themselves for providing emotional support for their family while they are surviving cancer. P12 stated that she knew her mother felt as if she had passed the cancer gene to her; therefore, P12 may have needed time to decide the best way to disclose to her mother without furthering her mother's sense of guilt. She felt conflicted by her need to share versus her need to protect her mother.

Limited family cancer communication. Although about a third of the women (n=10) discussed talking with their families at one point or another during the diagnoses and treatments regarding their cancer-related fears and worries, a few women chose to share little to no information with family members. These women may have been engaging in self and other protection during the cancer journey. "Chemo I wanted to do on my own, and the work I had to do on my own. There were a lot of things I just wanted to do on my own" (P17). She stated that she was so focused on going through the cancer journey on her own that she asked the man she was dating to leave during her treatment period. She also stated she would have driven herself home from her mastectomy surgery if she could. P21 reportedly attempted to complete her

cancer journey on her own as well. She, like P17, described pushing people away from her during cancer treatments.

Both participants had families and may have chosen limited family cancer communication to protect themselves as well as family members. P17 reportedly felt her adult daughter was too young to experience her mother surviving cancer. P21 may have also been protecting family members when she decided not to tell her mother or husband about her surgery until the day before the scheduled procedure. The data support that family is central to the lives of many Appalachian women, and for a vast majority of participants, family was a major influence in how to communicate about cancer within the family. For some women selective or limited communication may have been strategic or intentional to protect self and family.

Communication Barriers

The reasons for engaging in communication styles varied as much as the communication styles themselves did. Three barriers to communication emerged from that data, and these barriers were also seen in review of current literature (e.g. Exley & Letherby, 2001; Sherman & Simonton, 2001; Zhang & Siminoff, 2003). The barriers were 1) the need to protect family members and self, 2) psychological distress of discussing cancer, and 3) positive-only thinking. Two additional barriers also emerged: 1) health of other family members and 1) cancer in “taboo” areas.

Protecting family members and self. One common theme among all three communication styles was concern for family members as repeatedly illustrated in the above quotes. Participants in the study wanted to protect family members even if they preferred the open communication style. Protecting family members may also be a way for survivors to protect themselves. Survivors may not tell family members about cancer-related thoughts and concerns so that the

survivor will not have to provide emotional support for worried family members. Survivors cited concerns about family members worrying about them. “I didn’t want my sisters to worry. They did anyway, but they didn’t have to but they did” (P7). Another woman, P20, was given advice by her aunt to find a nonfamily member to talk to about her cancer concerns and fears. Her aunt, who also was a cancer survivor, told P20 that the family loved her, but it would be easier for the family and herself if she had a nonfamily member for support. This suggests that survivors not only have to negotiate the healthcare system and the physical aspects of their illness, but they also must spend time and energy seeking out social support.

Even women who identified an open family cancer communication style were also concerned about protecting family members. These women did not describe what type of information they shared with their families. There is a possibility that these women were open with facts regarding their cancer journey but not open about cancer-related fears and concerns. As noted by Ell (1996) families protecting one another from cancer-related fears and concerns may harm the recovery of the survivor. The survivor may feel trapped between needing to share and needing to protect. In Appalachia this may be further complicated for women because they often are the central caregivers in their families, and they put their needs below the families (Denham et al., 2004). It may also be about way to reduce emotional labor for the survivor.

Psychological distress. The simple act of discussing cancer within the family can cause psychological distress for the survivor, the family, or both. Zhang and Siminoff (2003) found that their participants cited discussing cancer-related fears too emotional or difficult. Cancer survivors in Appalachia seemed to find it troublesome as well. P21, a four-time survivor of the same type of cancer, was emotional about describing her cancer journey. She stated that she did not talk about her cancer experience within her family. Even though she stated her lack of

communication was to protect them, one might assume that it was also because for P21 talking about her cancer experience caused psychological distress.

Discussing cancer with a family can cause distress for family members as well. P28 noted that her sons, and especially her eldest son, appeared to not handle her cancer diagnoses very well. The son may have been internally struggling with traditional gender roles in Appalachian where men are providers and women are caregivers (Bush & Lash, 2006). For the son, he may have been struggling to deal with the emotions or concerns about taking over caregiving responsibilities. She reported that her eldest son withdrew from her during the beginning of her cancer journey. She stated that conversations were limited to superficial subjects like the weather while he adjusted to the new reality that his mother had cancer. P28 felt that the simple act of discussing cancer with her eldest son was too psychologically distressing for him. She reported that she gave him space and did not attempt to force him to talk with her about her cancer or cancer treatments which in turn allowed her to focus on healing while reducing her need to provide emotional support to her son.

Positive-only thinking. Some women in this study (n=10) felt that positive thinking was one of the best ways to become a cancer survivor. Positive thinking has been shown to increase survival rates for cancer survivors (Sherman & Simonton, 2001). However, there comes a point when positive-only thinking can hinder family cancer communication due to the belief that any type of “overt expression of sadness, pain, and fear of cancer” will weaken the morale and cancer fighting ability of the survivor (Zhang & Siminoff, 2003, p. 424). This type of family cancer communication does not allow space for cancer-related fears and concerns to be expressed. Positive-only thinking may be more about protecting self and other from cancer-related fears and

concerns than simply maintaining a positive attitude. This too may overlap with either the survivor's or the family members concern about psychological distress to one another.

There was a commonly voiced fear among the women that letting doubts and fears creep into the mind would decrease survival chances. P27 stated multiple times during the interview that she had to remain strong and positive during her journey. She stated, "If you let these negative feelings start dwelling in on you it's going to make it harder to cope with anything." P28 also stated maintaining a positive-only attitude through her journey. She chose not to join support groups because she did not want to hear negative stories or horror stories from other survivors. P28 did not "want any negative thoughts creeping in." To keep the negative thoughts from "creeping in," these women stated that they chose not to share cancer-related fears with some or all of their family members. This focus on positive-only thinking may be a by-product of Appalachia culture. The region is known for its rich oral history; however, it is also known for health and cancer disparities. Hutson et al. (2007) found that some women in Appalachia believe that cancer is inevitable and often stories passed to younger generations included fear and anxiety about cancer. Participants of this study did not want to hear negativity or doubt from anyone. This may be due to the negative cancer stories passed from one generation to the next. This may lead female cancer survivors to focus on positive-only thinking because the negative stories are too pervasive.

However, the question left unanswered is what happens when these survivors and their families experience cancer-related fears or worries. If they have a positive-only approach, how do they handle bad days? Women who have the positive-only thinking approach may find they still have open communication with their families. However, the open communication may be

based solely on factual information like treatments, procedures, and positive incidents in their journey but may be void of any of the fears, doubts, or concerns they experience.

Health of other family members. One barrier not seen in the literature but that emerged in the analysis was how the health of other family members influenced family cancer communication. If another family member had a serious illness like cancer either when a survivor suspected cancer or after she received the diagnosis, the survivor seemed even less likely to have open family communication within her family. Participants expressed guilt about burdening that family member with their illness. P26 expressed her desire to not tell her parents before her diagnosis was confirmed because her father had been diagnosed with prostate cancer. She did not want to further worry them with her fears of cancer because her parents were already worried about prostate cancer and treatments. She stated, “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.” P26’s concern about her father’s health suggests that women in Appalachia do not want to cause undue psychological stress upon family members. This may be due to their need to protect family members or engage in self-protecting because not sharing their suspicions may reduce emotional labor.

Even if a survivor discussed cancer with her family, she may have experienced guilt about focusing on her diagnosis because the other member was also ill. As stated earlier, women in Appalachia are often central caregivers in their families, and they tend to put family needs above their own. For women in the region, talking about their cancer-related thoughts and concerns may make them feel like they are being selfish because they are putting their needs first. P14 was caring for her husband who had been diagnosed with cancer when she was

diagnosed with cancer. She described feeling guilty because she was unable to talk with him about her diagnosis prior to her surgery so that he would not be so upset by her diagnosis.

These findings are linked to the concept of psychological distress and protection barriers. As seen in the literature, the often close-knit family units in Appalachia mean that extended families are more pronounced; therefore, one would assume that the likelihood of another member of the family having an illness would be increased. If Appalachian women are concerned about caring for their family and protecting them, they may feel guilty for putting their needs ahead of their family and or choose to protect their ill family members. They may also believe that protecting their family from cancer-related thoughts and feelings will reduce their emotional labor within the family. That, in turn, would allow the survivor to focus her energy on surviving.

Cancer in “taboo” areas. The type of cancer also affected how participants talked with family members. If a survivor was diagnosed with a type of cancer that was in a “taboo” area like cervical cancer or colon cancer participants reported limiting cancer communication with family members. “It was my own personal private thing, and I didn’t want to talk about it” (P29). P29 reported that her family never discussed preventative screenings in “embarrassing” areas of the body like the genitals until her stepfather was diagnosed with and died from stage 4 colon cancer. Even after the family began talking about the necessity of preventative screenings, her daughter still refused to have pap smears or breasts exams due to the embarrassing nature of the screenings.

For P29 and perhaps other 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.

Consequences of Family Cancer Communication Styles

Discussing cancer within a family is challenging for survivors. Not only do they have to deal with what they are experiencing themselves, they must also consider the best way to communicate in the family about their cancer journey. Open, selective, and limited family cancer communication styles are not without consequences.

Open family cancer communication consequences. As stated above, open family cancer communication has benefits to survivors and their families. Participants cited it as a way for survivors and families to help one another as well as heal. However, there are potential negative consequences. For participants choosing open family communication prior to diagnosis they risk worrying family members unnecessarily if the tests reveal they do not have cancer. Postdiagnosis survivors might find they want open cancer communication, but other family members do not. Throughout the interview P28 expressed many times that if it were not for the support of her family she would not be alive. However, her desire to be open about her cancer journey was challenging for her eldest son. P28 described him as withdrawing from her after her cancer disclosure and remaining that way until she was in remission. She reportedly felt that discussing cancer with her son was too psychologically distressing for him.

Selective family cancer communication consequences. Women who chose selective family cancer communication may have either selected what to share or who to share with in regards to cancer. A consequence to this style would be family members not having all the information needed to help the survivor through her cancer journey. Also, some survivors may be surprised to find that family members they talk to about their cancer journey have a different

reaction than expected. P7 described how she ended up consoling her sisters about her diagnosis instead of being consoled by them. This required additional energy and time on P7's part at a time when she stated that family members should be consoling her. This type of reaction may be what many women predict; therefore, they may use selective communication to reduce their emotional labor with family members.

Limited family cancer communication consequences. Women who engaged in limited family cancer communication shared little to no information about their cancer journey with their families. A consequence to this style would be the family not being able to help the survivor through this journey. If family members do not know what is happening to the survivor, they will not understand the best way to help. This may lead to the survivor feeling isolated or even dissatisfied with the family cancer communication within the family. P7 cited another potential consequence of limited family cancer communication. She stated there was a danger in not talking with family members about the cancer journey because family members may not be proactive in preventative cancer screenings if they do not understand about the cancer journey of the survivor.

Summary

Women of this study also saw benefits in their styles of family cancer communication. Survivors who had open family cancer communication described how that style allowed family members to heal as well as help one another. Selective cancer communication allowed survivors and family members to choose members and information they shared. This allowed survivors and family members to protect certain family members from perceived psychological distress. However, sometimes the person with whom the information was shared had a different reaction than expected. Limited family cancer communication was used by survivors who wanted to

protect self and family members or if they had cancer in a taboo area. However, the danger of this style was family members did not know how to help survivors and it may not encourage family members to be proactive in preventative screenings. One benefit of both selective and limited communication is that it may reduce the amount of emotional support a survivor must provide to family members that do not cope well with the diagnosis. For Appalachia, talking about cancer within families may be key to reducing the high cancer incidence and mortality in the region.

Research Question #2

Research question #2 asked: What do the stories of female Appalachian cancer survivors reveal about changing person identities through the cancer journey? As mentioned earlier, a cancer diagnosis has the ability to not only disrupt a survivor's life but her sense of identity as well (Doyle, 2008). In the midst of surviving cancer women find they are negotiating identity changes while holding their families together. One way to navigate these identity changes would be through discussing cancer within the family. However, discussing cancer within families has been shown to cause great difficulties within families (Zhang & Siminoff, 2003). For Appalachian women navigating the identity changes may have added layers of complexity because of close-knit families and traditional gender roles in the region.

A little less than half the women (n=12) described personal identity changes through the cancer journey. Some women felt the journey made them stronger individuals who could tackle feats they never thought possible. These women describe how their personal identities changed as a result of physical changes due to cancer and treatments and psychological changes resulting from the cancer journey.

Changing Personal Identities

A concern among women that may have affected their cancer communication styles are fears about burdening their families and maintaining independence. Women of this study cited four main categories that impacted their changing personal identities: 1) maintaining family roles, 2) mothering role changes, 3) physical changes, and 4) psychological changes. Although these categories are described in separate sections, it is important to note that they do interplay and overlap with one another. For example, mothering role changes can be described as part of maintaining family roles. However, it can also be viewed separately as not all family roles involve mothering and not all families have children.

Maintaining family roles. Several women (n=5) in this study expressed concerns about maintaining roles within their families. Often the roles women have within their families are part of their identity. For example, as stated previously, a role many female Appalachia women have is central caregiver within the family (Denham et al., 2004). This desire to maintain roles may also influence communication styles. A woman may fear that if she shares her cancer-related thoughts or fears, her family may attempt to take over some of her responsibilities which may lead to her losing her place within the family. For Appalachian women this may be especially true as the women are often central caregivers in the family.

P7 described how she helped her husband mow 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. “Well 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.” Her husband took the spark plugs out to keep P7 from mowing the yard during her chemo treatments. P7 was so determined to maintain her role within her family that she risked injuring herself.

Women in this study seemed hesitant to give all or some of their familial responsibilities to other family members. This hesitance may be a result of their perceived fears of being useless to their families. Female Appalachian cancer survivors may feel at a loss for who they are if they are no longer the central caregiver resulting in feelings of useless to their families. This fear of giving up family roles may lead to women to not share cancer-related thoughts or concerns with family, or in the case of P7, risk injuring themselves to feel useful to the family.

Mothering role changes. Cancer has the ability to change mothering roles both physically and psychologically. Women of this study reported concern over going from being the caregiver to needing caregiving especially if they had young children. P14 shared that her three adult children were helpful and supportive during her cancer journey. She jokingly reported that at times they got on her nerves because they did not want her to do anything other than sit at the house and rest. She felt it was important to put limits on what she would allow her children to do for her.

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).

P14 was not ready to let her children care for her, and she wanted them to understand she was still able-bodied. There also was a sense of concern about burdening adult children. This idea is also seen in the story of P27. P27 also had three adult children when she was diagnosed with cancer. She set a goal of getting back to work as soon as possible so that she would not have to rely on her children. "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." She expressed that she felt she was too young to have cancer and especially too young to accept their help.

Women who were mothers of children under 18 years old expressed additional challenges over maintaining their role as mother while at the same time surviving cancer. These women feared that cancer would take away their mother role or that someone else would take their place. P18 had just had a baby when she was diagnosed with cancer. “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.” She worried that if she got sick from her chemo treatments and required help from others, she would lose her place within her family. She stated, “I was afraid that my daughter would think that someone else was her mother.” 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 women uses her body to mother. After P18’s mastectomy she was unable to breastfeed her daughter which appeared to heighten her sense of failing her children. From the stories of the participants, it became clear that maintaining the role within the family was a prevalent concern among participants and especially participants who had children under 18 at the time of their diagnosis.

Physical changes. For many women in the study, the most notable changes in identity were the physical changes through the cancer journey. Often cancer survivors lose their hair during chemotherapy treatments (alopecia), and bodies may be scarred from surgeries or left with different shapes (Holmberg et al., 2001). These physical changes may also impact how women choose to communicate about cancer within their family. The visual changes may be shocking at first and take time to adjust to the new appearance and therefore be difficult or challenging to talking about. 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.” P11 is not just seeing her body. She is using her family to view her new body through their eyes.

P28 was apparently still struggling with readjusting to her new image during the time of the interview. She felt she could no longer be the professional woman she once was. “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 found herself questioning if she was still worthy of employment because she no longer possessed the characteristics that she once associated with being a professional woman. It appears that P28 believed that being a professional woman also allowed her to be the caregiver of her family by providing financial support. She cited being worried about supporting her family because had not been able to work due to her cancers.

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. Chemo-induced alopecia affected many of the participants (n=12) during their cancer journeys. Many of the participants who lost their hair cited that the hair loss as one of the most challenging parts of the journey. P26 described being known for her red hair and reportedly felt that her hair was part of her identity.

The hardest thing for me was losing my hair and looking at the changes in my body.

Because 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. (P26)

P12 also struggled with her hair loss as well and described it as “probably the worst thing” that happened to her, even worse than losing the breast. Hair loss may not be as much

about vanity but the idea of being a woman. Women in this study described that losing their hair resulted in losing their femininity and sense of self. P12 expressed feeling “mentality ill” over losing her hair because her hair was a part of who she was as a person. 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 she had hair again. “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 is not only struggling with physical changes, but her physical changes cause her to withdraw from her place in the family and place in the community. Even the decision to hide during the period of alopecia impacted family communication. She stated that her family tried to encourage her to leave, but she described being not only embarrassed, but tired of being looked at for her lack of hair.

Hair loss may not be so much about the hair itself but what it symbolizes to the participants. The women wanted 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 is upsetting because it is a constant reminder they are ill. This illness in turns prevents them from maintaining their normal routines within their family; therefore, this loss of identity is also a loss of place within the family. P10 described how grocery shopping meant “normal” to her. This may have allowed P10 to regain a sense of her identity and place in the family because Appalachian women are typically in charge of household matters,.

Families may encourage these feelings of not normal. P9 reported that her mother appeared to be upset with her for not wearing a wig. Her decision to not hide her hair loss contradicted her existing family narrative about what is acceptable when you are ill. She described that for her mom’s generation “it’s not how it is, it’s what it looks like.” This mindset

implies to survivors that if they look fine they are fine. However, it also encourages silence in the family about physical changes during the cancer journey.

Psychological changes. Women in the study described how their cancer journey changed the type of person they were. Sometimes the women did not want to change because they were happy with who they were. P12 was angry when she was diagnosed with breast cancer. She had experienced cancer three times prior to her breast cancer diagnosis. She felt happy with who she was as a person and found that the diagnosis put her in a dark and depressed state in her life. When P12 talked with her doctor he gave her what she described as life changing advice that at first upset her.

You're like a broken clay pot. He said, you're going to be molded and you'll go back together. The pieces will all fit back together. But you're never going to be exactly who you were before. And that really made me mad because I wanted to be exactly who I was before. (P12)

Women in the study described how cancer had changed who they were as a person. In the midst of these personal changes they were attempting to hold families together. P27 and P28 described themselves as independent, professional women. However, both found that through their journeys they learned to depend on other people. P27 let friends help her, and P28 allowed her family to help. P11 described finding strength she never knew she had. She stated, "I've done things I never imagined I would do you know. Make decisions I never dreamed I'd have to make." P27 repeatedly prayed for strength and the endurance to continue her cancer treatments. P27 may have focused so strongly for strength and endurance due to her concern about burdening her children. P10 found that she became more authentic with people and light-heartedly warned them not to ask her questions unless you were okay hearing the truth. Her

identity changes during her cancer journey may have allowed her to be open in her communications with her family. P27 described becoming a more empathic person, and P4 became more appreciative of the little things in her life like sunrises. Cancer tends to be viewed as a negative or bad experience. However, the psychological changes these women experience prove that the cancer journey can have a positive side as well. Although these women started they would not have chosen to have cancer, they described feeling like a better person because of the experiences they faced while surviving cancer.

Cancer has the ability to turn lives upside down and challenge the very ideas that women have about themselves. Although physical changes, e.g. loss of hair or loss of breast, can be difficult to see and accept, changes in family roles and mother roles seem the most challenging for women to accept. This may have been especially difficult for women in Appalachia because they tend to play a central role within their families and are often in charge of caregiving responsibilities.

Summary

In summary, discussing cancer in families is challenging for women and their family and cancer has the ability to change personal identities. Women in this study cited different types of communication styles as well as barriers to communicating about cancer within their families. Women engaged in family cancer communication both before and after diagnosis, and from their experiences there is not a best communication style or a style that did not come with barriers. Barriers to family cancer communication were: 1) the need to protect family members and self, 2) psychological distress of discussing cancer, and 3) positive-only thinking. Two additional barriers also emerged in the data that may mean the cancer experience in Appalachia is unique – health of other family members and cancer in “taboo” areas. Although the five barriers were

described separately, they often interplayed and overlapped with one another. For example, survivors wanted to protect ill family members from undue psychological distress.

In addition to navigating family cancer communication, women also navigated personal identity changes. As previously mentioned, women navigated these changes in the midst of holding families together. Women of this study cited four main categories that impacted their changing personal identities: 1) maintaining family roles, 2) mothering role changes, 3) physical changes, and 4) psychological changes. For women of Appalachia there may be an additional layer of complexity due to often close-knit family groups and the cultural norms of women in the region. It is obvious from this study that the cancer journey is a difficult time for both survivors and their families. It is a difficult time for women and not one that has been fully understood.

CHAPTER 5

DISCUSSION

Previous research has provided little insight into family cancer communication and changing personal identities through the cancer journey for southern Appalachian women. Findings of this study reveal that the cancer experience may in fact be unique in Appalachia. The culture of the region tends to place women in central caregiving roles within their families, and it also signals them to put their family's daily needs ahead of their own health needs (Denham et al., 2004; Oberhauser, 1995; Patton, 2005). Following diagnosis women must not only absorb and understand their cancer diagnosis and treatments, they must also communicate about those feelings and concerns within the family. In the midst of adapting to life as a cancer survivor a women's cancer diagnosis may require her to act against long-held regional traditions, therefore, affecting her identity as a women and as a mother in Appalachia.

Communication about cancer in the family, both pre- and postcancer diagnosis, were challenging for the women of this study. The women cited multiple family cancer communication styles in both pre- and postdiagnosis that included: 1) prediagnosis open family communication, 2) prediagnosis selective family communication, 3) postdiagnosis open family communication, 4) postdiagnosis selective family communication, and 5) postdiagnosis limited family communication. Along with communication styles, women also cited barriers to family cancer communication. Three were found in the literature which were: 1) protecting family members, 2) psychological distress, and 3) positive-only thinking (Charmaz, 1997; Porter et al., 2005; Zhang & Siminoff, 2003). Two additional barriers were reported which may make the Appalachian cancer experience unique: 1) health of other family members and 2) cancer in "taboo" areas. Often these barriers overlapped and interplayed with one another when survivors

communicated about cancer within the family. For example, women who had other family members with an illness appeared to be hesitant to use open family cancer communication in pre- and or postdiagnosis periods. They reported concerns about unnecessarily worrying family members as well as their desire to protect them from undue stress. This desire to protect may have also been about protecting themselves. Survivors may have felt they could more fully focus on healing if they did not have to provide emotional support to family members who were upset about the diagnosis.

As the women were surviving cancer, they were also navigating changing personal identities while in the midst of holding their families together. The survivors cited the following as challenges to personal identities through the cancer journey: 1) maintaining family roles, 2) mothering role changes, 3) physical changes, and 4) psychological changes. They also reported not wanting to give up roles in the families or changing their mother role. For women in Appalachia this may be due to cultural norms of the region. If women are expected to be caregivers for their families, they may feel they would be letting families down by not continuing that role. Also, the central position within the family is also a powerful position for women; therefore, they may have been unwilling to give that up. Physical changes due to cancer treatments appeared to be the first changes in identity. Interestingly, chemotherapy-induced hair loss appeared to be the most challenging of all physical changes the survivors experienced through their cancer journeys. This shock of hair loss may be more about it representing that the woman has cancer rather than the hair loss itself. Women also struggled with psychological changes to their identities. Women described being happy with who they were and did not want to experience the changes that cancer bring. However, even if the women did not welcome the changes, they did cite that the cancer experience changed them for the better.

Implications for Family Cancer Communication in Appalachia

Research has revealed that navigating family cancer communication in Appalachia is challenging for female Appalachian cancer survivors. For example, women must negotiate their need to discuss cancer-related thoughts and feelings against their need to protect family members and self. Family cancer communication styles may be further complicated by the culture of the region that values close-knit families, pronounced extended families, and traditional gender roles (Burns et al. 2006).

Communicating about cancer in the family is challenging and not without barriers. Some of these barriers identified in other studies include 1) desire to protect, 2) concern over psychological distress, and 3) positive-only thinking (Sherman & Simonton, 2001; Zhang & Siminoff, 2003). This research supports current literature that female Appalachian cancer survivors struggle with these barriers as well. How this study may help expand our current understanding of family cancer communication in Appalachia is through the additional barriers cited by the participants of this study. These two additional barriers – the health of other family members and cancer in “taboo areas – suggest that cancer in Appalachia may be unique for female survivors in the region.

These additional barriers may be linked to the culture of the region because of often close-knit families, more pronounced extended families, and traditional gender roles. As noted previously, the region has disproportionate health and cancer disparities (ARC, 2009; Huang et al., 2002). These factors combined increases the likelihood of another family member being ill. With the increased likelihood of another ill family member comes the increased likelihood that a female Appalachia cancer survivor would be less likely to communicate about cancer within the family due to her need or desire to protect and or care for ill family members. In addition to ill

family members, cancer in “taboo” areas like the cervix appeared to be a barrier to communicating about cancer within Appalachian families. Survivors or their family members may be embarrassed or ashamed to communicate about cancers in these areas. The desire not to discuss cancer in taboo areas implies that these cancer survivors have even fewer opportunities to discuss cancer-related thoughts and fears within the family. The survivor may not feel support among her family because of the embarrassing nature of the cancer and their desire not to talk about it. This also implies that there are shameful cancers and that the survivor may have done something wrong to develop the cancer. 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.

Implications for Appalachian Scholarship

This research reveals that surviving cancer presents unique challenges for Appalachian women, their identity, and their family cancer communication. In the midst of surviving cancer these women attempted to keep families together and maintain identities sometimes at the expense of their health. As stated previously, the Appalachian culture signals women to be in charge of household matters, put the family’s daily needs ahead of their own, and be the family caregiver (Denham et al., 2004; Oberhauser, 1995; Patton, 2005). In other words, the Appalachian woman and mother is self-sacrificing, but within those self-sacrificing acts Appalachian women have power they may not want to give up. Surviving cancer may require the survivor 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 her desire to remain central to her family. This conflict may explain why women risk their health to maintain traditional gender roles of the region.

Women in this study reported pushing their bodies to the limits to maintain roles like mowing yards, caring for children, or caring for ill family members. Sometimes these desires to maintain roles, especially caregiving roles, resulted in hospitalization and or health care providers reminding the women they could not do it all. If a woman had young children at the time of diagnosis, her desire to maintain her mothering roles appeared to intensify. As stated by Kinser (2008) a mother, her body, and her children are deeply connected. Cancer threatens this connection women have with their children. A mastectomy may make holding or carrying children too painful during the recovery period or make her unable to breastfeed her infant. Cancer treatments may make a woman weak or sick thus preventing her from engaging or connecting with her children the way she could prior to her diagnosis and treatments. This threatened connection may go beyond threatening her connection with her children. It may also threaten her place with her family. This may explain why survivors pushed their bodies so hard to maintain roles in the family, feared of getting sick from chemotherapy, and feared their children forgetting them.

Limitations

Although this research provides needed insight to family cancer communication in Appalachia and changing personal identities of female Appalachian cancer survivors, it is not without its limitations. First, 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. The goal of qualitative research is not to use random sampling or to draw generalizable conclusions of the population. Instead the goal of qualitative scholars is a focus on a representation of concepts (Corbin & Strauss, 2008). Second, 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. Fourth, not all participants of this study were born in Appalachia. Some participants had been born outside the region and had moved to Appalachia. Third, this study did not directly compare Appalachian and non-Appalachian populations. 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.

Future Research

This study, along with many others, supports that women have an additional burden of maintaining family roles while surviving cancer especially if they are mothers. As stated above, the family unit is central to the lives of many Appalachians with the women often being the central caregiver in the family. Additional research is needed to discover how female cancer survivors communicatively negotiate caring for their family and themselves when Appalachian values signal women to place their family's needs above their own. Women in this study were still apt to put their family's needs above their own by attempting to maintain the same level of care they provided prior to their diagnosis. Questions that remain unanswered include: 1) What are the consequences to female cancer survivors and their families when survivors attempt to put family needs above their own during the cancer experience? 2) How are family cancer communication and changing personal identities different for minorities in Appalachia? and 3)

How are the experiences of survivors with young children different from survivors with grown children at the time of diagnosis?

Based on this study, more research is needed to consider family perspectives for Appalachian cancer survivors. Ballard-Reisch and Letner (2003) argued that cancer is a family issue because it affects not just the survivor but her family as well. In Appalachia where families are a central component of the society and culture this may be especially true. If women in the region are told to place their family's needs ahead of their own, how do they negotiate placing their needs ahead of their family's need when surviving cancer? Also, this negotiation may affect how female cancer survivors discuss their needs within the family. If they do not want to burden or worry family members, they may choose a communication style like limited or selective communication. However, family members may not know how to appropriately respond and support the survivor because they have limited information about what is happening with the survivor. Further research is needed to more effectively provide support for women fighting in Appalachia.

Conclusion

This research steps into a rich field of information that needs to be further assessed and analyzed in order to understand and support female Appalachian cancer survivors. Deciding how to communicate within families regarding cancer is challenging for survivors. Each communication style – open, selective, limited – has benefits and consequences for survivors and their family members. In the Appalachian region there may be an extra layer of complexity added to family cancer communication style due to cultural norms. Due to communication barriers found in the data, female Appalachian cancer survivors may find they are dissatisfied with the level of family cancer communication. There may be feelings of isolation or guilt that

talking about their needs would mean neglecting the needs of family members. This study revealed that on top navigating family cancer communication, women are also navigating changing in their personal identities while holding families together. Survivors with young children describe additional challenges due to fears of their children forgetting them as their mother.

Overall, recommendations are to further study how a cancer diagnosis makes cancer in Appalachia unique. This study revealed that Appalachian culture, which included pronounced extended families, traditional gender roles, and close-knit family units, impacts family cancer communication. There may be additional aspects in Appalachia that contribute to the unique experience. This study also suggests that further research is needed in the area of identity changes of cancer survivors, especially for women with young children at the time of diagnosis. Women of this study reported a determination to maintain family roles which was sometimes to the detriment of their own health. This too may be linked back to the culture of Appalachia. Without question, surviving cancer is not an easy experience for individuals. However, it does appear that for women there are unique aspects to surviving cancer within Appalachian

The stories of these women should be heard and acted upon to improve services to the women of the Appalachian region. These strong, Appalachian women understand how to fight for life in the mist of the challenges presented by the Appalachian region. Their stories are worthy of future research to understand the complexity of family cancer communication and changing personal identities within Appalachia. This research steps into a region that has received little attention until recent years.

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2007 – present

Publications:

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