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Navigating Family Cancer Communication: Communication Strategies of Female Cancer Survivors in Central Appalachia

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NAVIGATING FAMILY CANCER COMMUNICATION: STRATEGIES OF FEMALE CANCER SURVIVORS IN SOUTH CENTRAL APPALCHIA

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ABSTRACT

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 including both pre-diagnosis and post-diagnosis cancer communication strategies.

INTRODUCTION

A cancer diagnosis is often 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). 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). For example, cancer narratives can be transformative, providing opportunities for family members to heal (Anderson & Geist Martin, 2003). Yet, openly discussing a cancer diagnosis may be problematic, emotionally taxing, or uncomfortable for the survivor and family members, or both. In Appalachia, this may be especially challenging for survivors and families due to the well-documented cancer and health disparities (Appalachian Regional Commission [ARC], n.d.) as well as cultural traditions and norms (Hutson, Dorgan, Duvall, & Garrett, 2011; Hutson, Dorgan, Phillips, & Behringer, 2007; Welch, 2012); therefore, a cancer diagnosis may impose unique challenges regarding family cancer communication.

Family Communication

A woman, along with her family, must navigate the challenges of communicating about cancer within the family. After diagnosis, a cancer survivor and her family members must "construct, redefine, negotiate, and renegotiate" their interactions during the illness (Baider, 2008, p. 608). Discussing cancer within the family can be very therapeutic and aid in the understanding and healing for both the survivor and family members (Anderson & Geist Martin, 2003; Shapiro, Angus, & Davis, 1997). Furthermore, the amount of cancer communication within families is likely to impact the survivor's wellbeing (Porter et al., 2005).

Although literature supports discussing cancer within the family, this task can be overwhelming. The diagnosis and prognosis may cause strong feelings of grief or fear for
everyone involved. Family cancer communication may be furthered challenged when the survivor finds herself negotiating providing emotional support for others while at the same time trying to make the situation bearable for herself (Exley & Letherby, 2001; Van der Moelen, 2000). Hedge son and Cohen (1996) found that most cancer survivors want emotional support, especially about their fears and concerns. Cancer survivors typically look first towards someone in the family to provide that support. Unfortunately, Petersen, Kruckeke, and Shaffner (2003) noted that female cancer survivors often report feeling dissatisfied with the quantity and quality of the communication regarding the illness within their family since families too experience difficulties with family cancer communication (Zhang & Siminoff, 2003).

The ways in which a family communicates prior to the diagnosis is often a precursor to the communication style post-diagnosis (Hilton, 1994). As such, survivors or family members may strategically choose not to disclose or communicate cancer-related concerns in an effort to protect other family members from perceived stress (Duvall, Dorgan, & Kinser, 2012). The act of protecting one another may lead to unsatisfying or distressed communication for female survivors.

What currently lacks in the literature are studies focusing on how family cancer communication may be unique in Appalachia. Various scholars have noted the importance of kinship (MacAvoy & Lippman, 2001) and families (Welch, 2012) for many Appalachians. One gap that appears in the research is how family cancer communication in Appalachia may be different from other regions of the United States.

METHODS

As part of an omnibus study (Dorgan & Hutson, 2008) about cancer survivorship among females living in Southern Central Appalachia, researchers collected the stories of 29 female Appalachian cancer survivors from northeastern Tennessee and southwestern Virginia via a multi-phasic approach. Participants of this study were recruited through use of oncology nurses, local cancer centers, and snowball sampling. Phase I consisted of survivors participating in a day-long story circle (n=26). Story circles are useful for investigating patterns and similarities (Research Center for Leadership in Action, RCLA, 2008). Story circles typically begin with a primer story. In this case, the investigators (KAD and SPH) invited a keynote speaker who is a breast cancer survivor and practicing oncology nurse to share her survivorship story. Then participants sit in a circle and the facilitator guides the participants in sharing their stories. Once the stories are shared, the participants may engage in open discussion to ask questions for clarification or to generate themes among the group (RCLA, 2008).

In Phase II, additional survivors were invited to participate in a single semi-structured interview (n=3). Upon recognizing that several participants recruited for Phase I were unable to attend the story circle (despite their interest in sharing their stories about living with cancer), we, the researchers, determined Phase II was necessary to avoid omission of key stories and experiences. We used purposive sampling to select participants based on reasons they cited for not attending the story circle event (i.e., ongoing cancer treatments, financial challenges to transportation, and work conflicts). One of the authors (KLD) conducted the three Phase II interviews in the participants’ respective homes over twenty minutes.

Participants in this study varied in age, than age, cancer diagnosis, time since diagnosis collected to protect participants’ confidentiality questions. Participants self-reported a cancer diagnosis year survivor of cancer. No specific malignancies were recruited to capture variation shows participant reported cancer types represent.

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Multiplied Additive</th>
<th>Multiplied Additive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>Multiplied Additive</td>
<td>Multiplied Additive</td>
</tr>
<tr>
<td>Ovarian</td>
<td>Multiplied Additive</td>
<td>Multiplied Additive</td>
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<tr>
<td>Multiple Myelomas</td>
<td>Multiplied Additive</td>
<td>Multiplied Additive</td>
</tr>
<tr>
<td>Colon</td>
<td>Multiplied Additive</td>
<td>Multiplied Additive</td>
</tr>
<tr>
<td>Melanoma</td>
<td>Multiplied Additive</td>
<td>Multiplied Additive</td>
</tr>
<tr>
<td>Stomach/Liver</td>
<td>Multiplied Additive</td>
<td>Multiplied Additive</td>
</tr>
<tr>
<td>Cervical Cancer*</td>
<td>Multiplied Additive</td>
<td>Multiplied Additive</td>
</tr>
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</table>

*Upon analysis of the data, the cervical cancer survivor n cancer. However, her story was not removed from the analysis.

Analysis

After the story circle data were transcribed, they were used to conduct an inductive analysis (Coding and interview) were read in their entirety to allow for experiences. QSR NVivo 8.0 software was used to analyze the transcripts. The analysis was based on Corbin and Strauss (1990). axial coding allowed the researchers to uncover new themes and support the themes below (Berg, 2009). Illustrations and readability, edited quotes are indicated by whether it came from an interview participant.

RESULTS

The analysis revealed five family cancer communication during two (2) two and one-half hour sessions with the assistance of a facilitator (KAD and SPH). Each story circle was digitally audio-recorded and transcribed verbatim, yielding 227 pages of transcripts. All participants provided written informed consent.

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Participants in this study varied in age, ranging from their early 20s to early 70s. Other than age, cancer diagnosis, time since diagnosis and parental status, other demographics were not collected to protect participants' confidentiality. All participants were asked open-ended questions. Participants self-reported a cancer diagnosis and ranged from being a 4-month to a 50-year survivor of cancer. No specific malignancy was required for participation; in fact, researchers recruited participants to capture varying cancer survivorship experiences. Table 1 shows participant reported cancer types represented in this study.

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>10</td>
</tr>
<tr>
<td>Ovary</td>
<td>3</td>
</tr>
<tr>
<td>Thyroid-Brass</td>
<td>2</td>
</tr>
<tr>
<td>Multiple Myeloma</td>
<td>2</td>
</tr>
<tr>
<td>Ovarian-Brass</td>
<td>2</td>
</tr>
<tr>
<td>Colon</td>
<td>1</td>
</tr>
<tr>
<td>Rectal-Brass</td>
<td>1</td>
</tr>
<tr>
<td>Malignant Melanoma</td>
<td>1</td>
</tr>
<tr>
<td>Other LP</td>
<td>1</td>
</tr>
<tr>
<td>Cervical Cancer*</td>
<td>1</td>
</tr>
<tr>
<td>Adolescents (Child)</td>
<td>1</td>
</tr>
</tbody>
</table>

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

Analysis

After the story circle data were transcribed, accepted qualitative data analysis procedures were used to conduct an inductive analysis (Corbin & Strauss, 2008). Transcripts (story circle and interview) were read in their entirety to allow for a general understanding of survivorship experiences. QSR NVivo 8.0 software was used to facilitate management of the data. Analysis of the transcripts was based on Corbin and Strauss' (2008) grounded theory approach. Open and axial coding allowed the researchers to uncover common themes throughout all transcripts. Incidents were compared within transcripts, between story circle groups, interviews, and between story circle groups and in-depth interviews. Liberal use of participant quotes are offered to support the themes below (Berg, 2009). Illustrative quotes were edited only to promote clarity and readability; edited quotes are indicated by [...]. Each quotation is followed by a notation about whether it came from an interview participant (IntP) or story circle participant (SC1, SC2).

RESULTS

The analysis revealed five family cancer communication strategies. During the pre-diagnosis stage if cancer was suspected women appeared to engage in either: 1) open family cancer communication or 2) selective family cancer communication. Once the diagnosis was confirmed, there appeared to be a slightly wider range of 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...
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about how to communicate about cancer, reactions to how family members responded to the survivor, or the prior family communication style.

Pre-diagnosis Family Cancer Communication
For a subset of participants, their family cancer communication style originated before a cancer diagnosis. For example, some women experienced symptoms (e.g., a lump), causing them to be suspicious about what would eventually be diagnosed as cancer. From the time their cancer speculation occurred, this subset of participants had to decide how to share cancer information with family members. Women varied how much they shared and with whom within their families. Two main types of family communication strategies were seen in participants who suspected cancer prior to their diagnosis: 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 pre-diagnosis was rare; only a few women reported openly sharing cancer suspicions with family members. This strategy was most prominent in the breast cancer survivor participants, arguably because symptoms for breast cancer are more easily detected due to visible or tactile changes in the breast. In addition to engaging in open family communication about their cancer suspicions, some participants engaged their family members in a kind of informal diagnosis (e.g., asking family members to look at or touch the lump).

What these findings suggest is that open communication allowed women to gain a degree of certainty by confirming their suspicions. Several participants solicited help from husbands, with a breast cancer survivor saying, "I asked my husband, does my left one look like my right one to you?" (SCI). Others asked mothers for help to confirm suspicions, like a breast cancer survivor 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'" (SCI). As illustrated by the quotes, women appeared to want validation about their cancer suspicions. What is potentially important is that husbands and mothers were often the recipient of open family cancer communication, suggesting that women were still mindful about whom they confided, especially given that verbal discussion combined with physical exploration of a highly intimate area (e.g., the breast), arguably magnifying the feelings of vulnerability.

**Selective family cancer communication.** Prior to a cancer diagnosis, the primary reason cited for selective communication centered around protecting family members from perceived undue stress. Participants stated that they did not wish to give family members something to worry about until they knew if there was something to worry about. When a breast cancer survivor (SCI) found her lump she reported not telling her parents until she had confirmation. Participants repeatedly reported avoiding family members, particularly their mothers, until they had more accurate information. For example, while one breast cancer survivor (SCI) eventually disclosed her diagnosis to her mother, she also acknowledged telling her mother that she was going to pay "light bills" when she was actually going for her mammogram.

Those engaging in selective communication may be adhering to culturally prescribed rules about putting families first (Welch, 2012) by protecting them from worry. Another possibility is that women may not feel able to cope with suspecting they have cancer and also provide emotional support for a family member upset about the suspected cancer. They appeared to not want to make certain family members, especially parents, anxious or worried, which again may be linked to concerns about providing emotional comfort while protecting family members from worry about the suspected cancer. They appeared to not want to make certain family members, especially parents, anxious or worried, which again could be linked to the overall desire to protect family members.

Post-diagnosis Family Cancer Communication
Post-diagnosis family cancer communication styles, but included one addition style. Post-diagnosis family cancer communication, 2) selective family cancer communication.

**Open family cancer communication.** For example, a subset of participants engaged in open family cancer communication. For example, a breast cancer survivor 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'" (SCI). As illustrated by the quotes, women appeared to want validation about their cancer suspicions. What is potentially important is that husbands and mothers were often the recipient of open family cancer communication, suggesting that women were still mindful about whom they confided, especially given that verbal discussion combined with physical exploration of a highly intimate area (e.g., the breast), arguably magnifying the feelings of vulnerability.

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Limited family cancer communication. For example, one breast cancer survivor was so focused on going through the cancer journey by herself that she didn't reach out to her family until after she made some decisions about her care. "When I was diagnosed, I wanted to figure out how I was going to deal with it on my own. I wanted to do what was best for me and not consult with others." (SC1). These findings suggest that open communication allowed women to gain a degree of certainty by confirming their suspicions. Several participants solicited help from husbands, with a breast cancer survivor saying, "I asked my husband, does my left one look like my right one to you?" (SCI). Others asked mothers for help to confirm suspicions, like a breast cancer survivor 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'" (SCI). As illustrated by the quotes, women appeared to want validation about their cancer suspicions. What is potentially important is that husbands and mothers were often the recipient of open family cancer communication, suggesting that women were still mindful about whom they confided, especially given that verbal discussion combined with physical exploration of a highly intimate area (e.g., the breast), arguably magnifying the feelings of vulnerability.

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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 offer a comparative analysis of sorts (e.g., compare her breasts pre-lump and
with a lump).

Post-diagnosis Family Cancer Communication

Post-diagnosis family cancer communication had similar strategies to pre-diagnosis
styles, but included one additional style. Post-diagnosis family cancer communication included: 1)
open family cancer communication, 2) selective family cancer communication, and 3) limited
family cancer communication.

Open family cancer communication. Post-diagnosis, some participants appeared to use
open family cancer communication. For example, a colon cancer survivor (SC1) described
sharing information with her children. “My family know everything... When I’d come home
from the doctor or from receiving treatment all three [children] would come over, and we
would discuss what was going on.” Another participant (SC1) described 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.

One reason survivors seemed to use an open style was to promote healing by allowing
family members to help the survivor through the cancer journey. One survivor described telling
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” (SC2).

Selective family cancer communication. Survivors who had selective family cancer
communication within their families 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. An ovarian and breast cancer survivor (SC2) stated that she believed she
would not have survived her cancer journey without her family, and if she 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.”

Those engaging in selective communication also focused on how to disclose their
diagnosis to family members. For example, one dual cancer survivor (breast and thyroid)
described needing time to absorb the diagnosis before telling her family members, stating, “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” (SC1).

Limited family cancer communication. A few women chose to share little to
information with family members. These women may have been engaging in self and other
protection during the cancer journey. A breast cancer survivor (SC1) described her desire to go
through the cancer journey by herself: “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.” 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. Likewise, a fibrosarcoma survivor (SC1) described
pushing people away from her during cancer treatments.
DISCUSSION

Previous research has provided little insight into family cancer communication for Southern Central Appalachian women. While this study is not intended to definitively answer the question about whether there is a "unique" Appalachian culture, our findings do suggest an interplay between cultural norms and the cancer experience. The culture of the region tends to place women in central caregiving roles within their families (Welch, 2012), and it also signals them to put their family's daily needs ahead of their own health needs (Denham, Meyer, Toborg, & Mande, 2004; Patton, 2005). Although these traditional gender roles may appear to make woman powerless, in Appalachia it is actually a powerful position for many women. These norms may have an effect on how families and survivors communicate about cancer.

Following diagnosis women must not only absorb and understand their cancer diagnosis and treatments, they must also decide how to communicate about those feelings and concerns within the family. Communication about cancer in the family, both pre- and post-cancer diagnosis, were challenging for the women of this study. The women cited multiple family cancer communication styles in both pre- and post-diagnosis that included: 1) pre-diagnosis open family communication, 2) pre-diagnosis selective family communication, 3) post-diagnosis open family communication, 4) post-diagnosis selective family communication, and 5) post-diagnosis limited family communication.

Deciding how to communicate within families regarding cancer is challenging for survivors; yet, there are also benefits to each style, allowing survivors to tailor their communication to each interaction, family member, as well as to their internal goals. The women in our study illustrated that a blended approach (engaging in open, selective, and limited) may help them in a number of ways. First, the limited and selective styles can afford survivors with the opportunity to "buy time," to sort through their ambivalence and reconcile themselves to uncertainty. Second, open styles can afford survivors with opportunities for uncertainty-reduction (e.g., disclosing to and having a family member assess a new symptom) and for emotional healing. Third, blending styles can afford survivors with the opportunity to seek out the most fitting family communication partner while protecting more vulnerable members of the family (e.g., children, ill parent).

This research catapults into a rich field of scholarly inquiry that needs to be further analyzed in order to understand and support female Appalachian cancer survivors. This study revealed that Appalachian culture, which includes pronounced extended families, traditional gender roles, and close-knit family units, impacts family cancer communication in the following ways: There may be additional aspects in Appalachia that contribute to the unique experience of surviving cancer. The stories of these women should be heard and acted upon to improve services to the Appalachian region. These strong, Appalachian women understand how to fight surviving cancer. The stories of these women should be heard and acted upon to improve services to the Appalachian region.

REFERENCES


Aging in open, selective, and limited (Welch, 2012) may appear to make powerful position for many women. These survivors communicate about cancer: absorb and understand their cancer diagnosis, and communicating about those feelings and concerns in the family, both pre- and post-cancer is study. The women cited multiple family communication patterns that included: 1) pre-diagnosis open family communication, 3) post-diagnosis open family communication, and 5) post-diagnosis family communication in the following ways and healing: Exploring one family’s experience in rural Appalachia. Their stories are worthy of future research into family cancer communication for scholars. Our findings do suggest an experience. The culture of the region tends to its families (Welch, 2012), and it also signals to an other health needs (Denham, Meyer, Toborg, & Mantle, 2004). Providing health education to Appalachian populations. Holistic Nursing Practice, 16, 293-301.


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