

1-1-2012

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

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Citation Information

Duvall, Kathryn L.; Dorgan, Kelly A.; and Hutson, Sadie P. 2012. Navigating Family Cancer Communication: Communication Strategies of Female Cancer Survivors in Central Appalachia. *Business Research Yearbook*. Vol.XIX(1). 263-270.
<http://www.iabdnnet.org/>

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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, 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 Moln, 2000). Helgeson 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, Kruckek, 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, & Kinsler, 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 I, women were divided into two groups and asked to share their stories of cancer survivorship 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.

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, each lasting approximately twenty minutes.

Participants in this study varied in age, gender, education, and income. In addition to age, cancer diagnosis, time since diagnosis, and education, demographic information was collected to protect participants' confidentiality. Participants self-reported a cancer diagnosis and the year they were diagnosed. No specific malignancy was reported. Researchers recruited participants to capture various perspectives on cancer. The table below shows participant reported cancer types represented in the study.

TABLE 1. CANCER TYPES

Cancer Type
Breast
Ovarian
Thyroid/Breast
Multiple Myeloma
Ovarian/Breast
Colon
Fibrosarcoma
Malignant Melanoma
Stomach/Liver
Cervical Cancer*
Unknown/Unreported

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

Analysis

After the story circle data were transcribed, the data were used to conduct an inductive analysis (Crabtree & interview) were read in their entirety to allow for a rich understanding of participants' experiences. QSR NVivo 8.0 software was used to analyze the transcripts. The coding process was based on Corbin and Strauss (2008). Axial coding allowed the researchers to uncover themes. Incidents were compared within transcripts, between transcripts, and across story circle groups and in-depth interviews. To support the themes below (Berg, 2009). Illustrations of themes and readability; edited quotes are indicated by brackets. The asterisk indicates about whether it came from an interview participant.

RESULTS

The analysis revealed five family cancer communication themes: 1) family cancer diagnosis stage if cancer was suspected worse than 2) selective family cancer communication or 2) selective family cancer communication, 2) limited family cancer communication. The data suggested that family

ion may be furthered challenged when the emotional support for others while at the same time (Letherby & Letherby, 2001; Van der Molen, 2000). Other survivors want emotional support, especially women typically look first towards someone in the family (Ersen, Kruckek, and Shaffner (2003) noted that survivors are satisfied with the quantity and quality of the communication since families too experience difficulties (Ersen, 2003).

Communication prior to the diagnosis is often a precursor to family communication (Ersen, 1994). As such, survivors or family members often communicate cancer-related concerns in an effort to seek support (Duvall, Dorgan, & Kinser, 2012). The act of seeking or distressed communication for female survivors is often a precursor to family communication.

Various studies focusing on how family cancer communication has noted the importance of communication (Welch, 2012) for many Appalachians. One study on cancer communication in Appalachia may be

researchers collected the stories of 29 female survivors in Tennessee and southwestern Virginia via a focus group. The study was recruited through use of oncology nurses, and the study consisted of survivors participating in a focus group (A, 2008). Story circles typically begin with a facilitator (A and SPH) invited a keynote speaker who is a survivor to share her survivorship story. Then the participants in sharing their stories. Once the participants are engaged in open discussion to ask questions for support (RCLA, 2008).

Participants were recruited for Phase I were unable to share their stories of cancer communication sessions with the assistance of a facilitator. The study was audio-recorded and transcribed verbatim, and provided written informed consent.

Participants recruited to participate in a single semi-structured interview (participants recruited for Phase I were unable to share their stories about living with cancer), we necessary to avoid omission of key stories and let participants based on reasons they cited for not seeking cancer treatments, financial challenges to communication (KLD) conducted the three Phase II

interviews in the participants' respective homes; these lasted between sixty to one hundred-twenty minutes.

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 1. CANCER TYPE IN PHASE I & II

Cancer Type	Number
Breast	15
Ovarian	3
Thyroid/Breast	2
Multiple Myeloma	2
Ovarian/Breast	2
Colon	1
Bladder Cancer	1
Malignant Melanoma	1
Stomach/Liver	1
Cervical Cancer*	1
Unknown/Unreported	1

*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

tion may be furthered challenged when the emotional support for others while at the same time (Letherby & Letherby, 2001; Van der Molen, 2000). Cancer survivors want emotional support, especially from family members. Typically, family members look first towards someone in the family (Letherby & Letherby, 2001). Letherby, Kruckek, and Shaffner (2003) noted that family members are typically not satisfied with the quantity and quality of the communication since families too experience difficulties (Letherby & Letherby, 2001).

Communication prior to the diagnosis is often a precursor to family communication (Letherby & Letherby, 1994). As such, survivors or family members often communicate cancer-related concerns in an effort to reduce family distress (Duvall, Dorgan, & Kinser, 2012). The act of communicating or distressed communication for female survivors is often a precursor to family communication.

There are several studies focusing on how family cancer communication varies. Various scholars have noted the importance of family communication (Welch, 2012) for many Appalachians. One study noted that cancer communication in Appalachia may be different from other regions.

Johnson (2008) about cancer survivorship among researchers collected the stories of 29 female survivors from Tennessee and southwestern Virginia via a focus group. The participants were recruited through use of oncology nurses. Phase I consisted of survivors participating in a focus group. Phase II consisted of survivors participating in a focus group for investigating patterns and similarities (Johnson, 2008). Story circles typically begin with a facilitator (Johnson & SPH) invited a keynote speaker who is a survivor to share her survivorship story. Then the facilitator asks the participants in sharing their stories. Once the facilitator has heard the stories, she asks questions for clarification (RCLA, 2008).

Participants were grouped and asked to share their stories of cancer survivorship. The sessions with the assistance of a facilitator were audio-recorded and transcribed verbatim. Participants provided written informed consent.

Participants were recruited to participate in a single semi-structured focus group. Participants recruited for Phase I were unable to share their stories about living with cancer, we were unable to avoid omission of key stories and participants based on reasons they cited for not participating in cancer treatments, financial challenges to cancer treatments. The authors (KLD) conducted the three Phase II

interviews in the participants' respective homes; these lasted between sixty to one hundred-twenty minutes.

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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?" (SC1). 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'" (SC1). As illustrated by the quotes, these 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 want to give family members something to worry about until they knew if there was something to worry about. When a breast cancer survivor (SC2) 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 (SC1) 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 support. Some women reported feeling uncomfortable talking with husbands or other family members. They felt other cancer survivors would understand and they would be able to offer a comparative analysis (e.g., "I've been through this with a lump).

Post-diagnosis Family Cancer Communication

Post-diagnosis family cancer communication styles, but included one additional style. Post-diagnosis family cancer communication styles included 1) open family cancer communication, 2) selective family cancer communication.

Open family cancer communication. Participants who engaged in open family cancer communication. For example, one woman reported sharing information with her children. "My father [from the doctor or from receiving treatment] would discuss what was going on." Another participant reported not talking with family members about the cancer until she had talked about within the family, then family members went to preventative screening.

One reason survivors seemed to use open family communication was to help family members to help the survivor through the cancer journey. One woman said to her husband, "we're going to talk about it, and I'm crying... That's what helps" (SC2).

Selective family cancer communication. Selective family cancer communication within their families may have been open with family members or selective in the family. Some women reported thoughts or feelings. An ovarian and breast cancer survivor would not have survived her cancer journey without talking about her experience she would not have had if she had not talked to her husband and daughter-in-law but selective communication was quite as involved... they didn't deal with it quite as involved.

Those engaging in selective communication after diagnosis to family members. For example, one woman described needing time to absorb the diagnosis and wanted to figure out how I was going to deal with it before I could help you else and figure out how they were going to help me.

Limited family cancer communication. Limited family cancer communication with family members. These women reported protection during the cancer journey. A breast cancer survivor reported going through the cancer journey by herself: "Chemotherapy I do on my own. There were a lot of things I just did on my own. I was so focused on going through the cancer journey that I was dating to leave during her treatment period. I was pushing people away from her during cancer treatment."

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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 addition 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 knew 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 (IntP) 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 no 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 women 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/or 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 for life in the midst of the challenges presented by the culture. Their stories are worthy of future research to understand the complexity of family cancer communication within Appalachia.

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ght into family cancer communication for
study is not intended to definitively answer the
lanchian culture, our findings do suggest an
xperience. The culture of the region tends to
ir families (Welch, 2012), and it also signals
r own health needs (Denham, Meyer, Toborg,
raditional gender roles may appear to make
powerful position for many women. These
ivors communicate about cancer.
absorb and understand their cancer diagnosis
ncommunicate about those feelings and concerns
in the family, both pre- and post-cancer
is study. The women cited multiple family
diagnosis that included: 1) pre-diagnosis open
family communication, 3) post-diagnosis open
family communication, and 5) post-diagnosis

families regarding cancer is challenging for
style, allowing survivors to tailor their
as well as to their internal goals. The women
aging in open, selective, and/or limited) may
and selective styles can afford survivors with
ir ambivalence and reconcile themselves to
vivors with opportunities for uncertainty-
y member assess a new symptom) and for
d survivors with the opportunity to seek out
e protecting more vulnerable members of the

f scholarly inquiry that needs to be further
le Appalachian cancer survivors. This study
s pronounced extended families, traditional
nily cancer communication in the following
ia that contribute to the unique experience of
ould be heard and acted upon to improve
Appalachian women understand how to fight
the culture. Their stories are worthy of future
cer communication within Appalachia.

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Note: This research was funded by the East Tennessee State University Research Development Committee.

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