

1-1-2012

Barriers to Family Cancer Communication in Southern Appalachia

Kathryn L. Duvall

East Tennessee State University, duvall@etsu.edu

Kelly A. Dorgan

East Tennessee State University, dorgan@etsu.edu

Amber E. Kinser

East Tennessee State University, kinsera@etsu.edu

Follow this and additional works at: <https://dc.etsu.edu/etsu-works>



Part of the [Appalachian Studies Commons](#), and the [Gender, Race, Sexuality, and Ethnicity in Communication Commons](#)

Citation Information

Duvall, Kathryn L.; Dorgan, Kelly A.; and Kinser, Amber E.. 2012. Barriers to Family Cancer Communication in Southern Appalachia. *Business Research Yearbook*. Vol.XIX(1). 287-293. <http://www.iabdnnet.org/>

This Article is brought to you for free and open access by the Faculty Works at Digital Commons @ East Tennessee State University. It has been accepted for inclusion in ETSU Faculty Works by an authorized administrator of Digital Commons @ East Tennessee State University. For more information, please contact digilib@etsu.edu.

Barriers to Family Cancer Communication in Southern Appalachia

Copyright Statement

© 2012 International Academy of Business Disciplines. This document was published with permission from the publisher. It was originally published in the *Business Research Yearbook*.

BARRIERS TO FAMILY CANCER COMMUNICATION IN SOUTHERN APPALACHIA

Kathryn L. Duvall, East Tennessee State University
Duvall@etsu.edu

Kelly A. Dorgan, East Tennessee State University
Dorgan@etsu.edu

Amber E. Kinser, East Tennessee State University
Kinsera@etsu.edu

PUBLIC POLICY

ABSTRACT

This study examines cultural issues surrounding family cancer communication in Appalachia, providing insight into participants' communication choices regarding their illness within their families. Stories of 29 female Appalachian cancer survivors from Northeast Tennessee and Southwest Virginia were collected via a mixed methods approach in either a day-long story circle (N=26) or an in-depth interview (N=3). Qualitative content analysis was used to identify unique barriers to family cancer communication in Appalachia. Two barriers emerged: 1) the health of other family members and 2) cancer in a "taboo" area. These findings suggest that Appalachian female cancer survivors struggle with similar issues as survivors outside of the region regarding family cancer communication. However, there appear to be additional barriers to family cancer communication for Appalachian women that may be a result of cultural norms of the region.

INTRODUCTION

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

Family, Cancer, and Communication

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

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

alking about their illness to family

apeutic and aid in the understanding
Although the literature points to the
& Davis, 1997), this task can be
there are young children involved.
reby keeping family members at a
or minimize negative emotions. As
ndisclosure regarding cancer-related
ppalachia, women may choose to not
bers so that they do not have to carry
nal support for family members who
women might well be sensing and
Family support.

concerns is often key to garnering
urvivors typically look first towards
ang and Siminoff (2003) and Knight
experience difficulties with cancer
es in Appalachia due to health beliefs
chia.

z. Although Appalachia is a diverse
s, arguably, interplay with the cancer
Appalachian self-reliance, potentially
ans for information regarding health
on friends and family members may
eds ahead of their own health needs
feel ambivalent about pursuing their
time away from their family to visit a

udies focusing on how family cancer
search on cancer in Appalachia has
y help remedy those disparities in the
wever, one gap that appears in the
ppalachia may be different from other
ral issues surrounding family cancer
hy and how participants choose to

Appalachian cancer survivors from
ed methods, multi-phasic approach.
ncology nurses, local cancer centers,
rticipating in a day-long story circle

(n=26). For this event, women were divided into two groups and asked to share their stories of cancer survivorship in Appalachia during two 4-hour sessions. Phase II consisted of additional survivors participating in in-depth interviews (n=3). In Phase II, researchers used purposive sampling to select participants based on the reasons cited for story circle non-attendance (i.e., ongoing cancer treatments, financial/transportation issues, and work conflicts.) Interviews were conducted in the participants' homes and lasted between 60-120 minutes.

All participants were asked open-ended questions to probe for what makes the cancer experience in Appalachia unique. Participants self-reported a cancer diagnosis and ranged from being a 4-month to a 50-year survivor of cancer. No site-specific cancer was required for participation in the study to collect stories from individuals who might have varying cancer survivorship experiences. For example, a breast cancer survivor may have a story vastly different from an ovarian cancer survivor because breast cancer is more common among women, resources are more readily available, and the survival rates are higher (American Cancer Society [ACS], 2008). Table 1 shows cancer type and representation in the study.

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

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

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

Analysis

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

RESULTS

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

Health of Other Family Members

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

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

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

Cancer in "Taboo" Areas

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

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

DISCUSSION

This research supports current research that women who struggle with similar barriers as women in this study may have a different understanding of family cancer communication barriers cited by the participants of the "taboo" areas.

These barriers may be linked to cultural norms in Appalachia, more pronounced extended families, more pronounced extended families, more pronounced extended families, disproportionate health and cancer disparities (Huang, et al., 2002), arguably increasing the consequence, family members may have a different understanding of the family, further challenging family communication.

Perhaps adding to the existing research on cancer communication barriers. For these participants, talk about cancer when the cancer was diagnosed in "taboo" areas may be embarrassed or ashamed to communicate. This may feel similarly toward cancer in the family, implies that these survivors have even more fears within the family, requiring survivors to vocalize their story may be dangerous to their health. Screenings due to the embarrassing nature of the cancer.

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

Further research is needed in the area of Appalachia cultural norms may further inform this topic. Women may have been strategic in their communication within the family to lessen the double burden of cancer and support to others struggling with their own cancer. Future generations knowledge about cancer communication barriers.

REFERENCES

- American Cancer Society (ACS). (2008). [http://www.cancer.org/docroot/P/content.jsp](http://www.cancer.org/docroot/P/content.jsp?CID=2000)

DISCUSSION

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

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

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

Although this research provides needed insight to family cancer communication in Appalachia, it is not without its limitations. The participants of this study were recruited through use of oncology nurses, local cancer centers, and snowball sampling; therefore, the study is not a random sample and only represents southern Appalachian women. All participants were self-reported cancer survivors, and no medical records were collected to verify cancer diagnosis. After analyzing data collected from the cervical cancer survivor, suspicions were raised as to whether the cervical cancer participant had been diagnosed with cervical cancer or cervical dysplasia which is often referred to as pre cervical cancer. Due to the participant perceiving herself as a cervical cancer survivor, her story was not removed from the data. Finally, this study failed to address Appalachian populations that face layers of marginalization (e.g. black Appalachian women). Due to the layers of marginalization their survivorship experience in Appalachia may be different from what was reported in this study.

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

REFERENCES

- American Cancer Society (ACS). (2008). Cancer statistics 2008 presentation. Retrieved from http://www.cancer.org/docroot/PRO/content/PRO_1_1_Cancer_Statistics_2008_Presentation.asp

- Appalachian Regional Commission (ARC). (n.d.). Appalachian region. Retrieved from <http://www.arc.gov/index.do?nodeId=2>.
- Arrington, M. I. (2009). "She's right behind me all the way": An analysis of prostate cancer narratives and changes in family relationships. *Journal of Family Communication, 5*(2), 141-162.
- Behringer, B., Mabe, K. H., Dorgan, K. A., Hutson, S. P. (2009). Local implementation of cancer control activities in rural Appalachia, 2006. *Preventing Chronic Disease, 6*(1). Retrieved from http://www.cdc.gov/pcd/issues/2009/jan/08_0064.htm
- Carlick, A., & Brily, F. C. (2004). Thoughts on the therapeutic use of narrative in the promotion of coping in cancer care. *European Journal of Cancer Care, 13*, 308-317.
- Carlick, A., & Brily, F. C. (2004). Thoughts on the therapeutic use of narrative in the promotion of coping in cancer care. *European Journal of Cancer Care, 13*, 308-317.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.
- Dorgan, K. A., Hutson, S. P., Gerding, G., & Duvall, K. L. (2009). Culturally tailored cancer communication, education, and research: The highways and back roads of Appalachia. *Preventing Chronic Disease, 6*(2). Retrieved from http://www.cdc.gov/pcd/issues/2009/apr/08_0194.htm
- Exley, C., & Letherby G. (2001). Managing a disrupted lifecourse: Issues of identity and emotion work. *Health, 5*, 112-132.
- Helgeson, V. S., & Cohen, S. (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology, 15*, 135-148.
- Huang, B., Wyatt, S. W., Tucker, T. C., Bottorff, D., Lengerich, E., & Hall, H. I. (2002). Cancer death rates—Appalachia, 1994-1998. *Morbidity and Mortality Weekly, 51*, 527-529.
- Knight, K. (2009). In his time of dying: Communication and silence in family illness and death. *Qualitative Inquiry, 15*(10), 1612-1624.
- Patton, C. M. (2005). Rural Appalachian women: A vulnerable population. In M. de Chesnay (Ed.) *Caring for the vulnerable: Perspectives in nursing theory, practice, and research* (pp. 277-282) Sudbury, MA: Jones and Bartlett.
- Petersen, L., Kruckek, A., & Shaffner, A. (2003). Gender roles in the family life cycle: The case of women with cancer. *Journal of Feminist Family Therapy, 15*, 99-119.
- Porter, L. S., Keefe, F. J., Hurwitz, H., & Faber, M. (2005). Disclosure between patients with gastrointestinal cancer and their spouses. *Psycho-Oncology, 14*, 1030-1042.
- Shapiro, S., Angus, L., & Davis, C. (1997). Identity and meaning in the experience of cancer: Three narrative themes. *Journal of Health Psychology, 2*, 539-554.
- Zhang, A. Y., & Siminoff, L. A. (2003). Silence and cancer: Why do families and patients fail to communicate? *Health Communication, 15*, 415-429.

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

PERSONAL IDENTITY CHANGES IN SOUTH

Kathryn L. Duvall

Kelly A. Dorgan

Sadie P. Hutson

ABSTRACT

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

INTRODUCTION

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

Appalachian Women and Family

Denham, Meyer, Toborg, and Mendenhall (2005) state that in themselves in charge of most family decisions. In a culture where central position women are often in charge of family decisions and responsible for preserving the culture and traditions (Doyle, 2008; 2005). This powerful position is one that is often abdicated; yet, when diagnosed with cancer, a woman's power, may be threatened, subsequently leading to a loss of power (Crawford, & Tarko, 2000; Holmberg, S.