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Omnibus Survivorship Narratives: Multiple Morbidities Among Female Cancer Survivors in South Central Appalachia

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**OMNIBUS SURVIVORSHIP NARRATIVES: MULTIPLE MORBIDITIES AMONG
FEMALE CANCER SURVIVORS IN SOUTHERN CENTRAL APPALACHIA**

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ABSTRACT

This study examines the illness narratives of female cancer survivors living in Southern Central Appalachia. Stories of 29 female Appalachian cancer survivors from northeastern Tennessee and southwestern 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 guide an inductive analysis of the transcripts. What emerged was that as participants survived cancer, they also survived other health conditions, their intersecting stories yielding an omnibus survivorship narrative.

INTRODUCTION

Over half of the U.S.-American population lives with a chronic disease (Clark, 2011), so it is not surprising that an emerging area of scholarly interest focuses on people living with multiple morbidities, or multimorbidities (Hacker et al., 2011; Schoenberg, Kim, Edwards, Fleming, 2007; Tarasenko & Schoenberg, 2011). Arguably, multimorbidities may be more prevalent in Appalachia due to the "disproportionately high rates of chronic disease" (Appalachian Regional Communication, ARC 2010). At the time of this writing, though, there is little patient-centered research about cancer survivors who experience multiple health problems prior to and concurrent with their cancer experience.

Intersection of Communication, Illness & Gender in Appalachia

In his seminal book, Kleinman (1988) wrote, "Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability" (p. 3). This characterization of illness as an interactive experience is an important one, highlighting the communicative component of any illness episode. The illness experience, therefore, includes the physical manifestations of sickness, as well as how people see and talk about their sickness.

In terms of chronic illnesses, cancer has received a great deal of attention because of disproportionate cancer rates in Appalachia (ARC, n.d.; Paskett, et al., 2011). Additionally, communication-related aspects of the cancer experience have been explored in an effort to further understand the existing health disparities documented throughout the region (Dorgan, Hutson, Gerding, & Duvall, 2009; Hutson, Dorgan, Duvall, & Garrett, 2011; Hutson, Dorgan,

Phillips, & Behringer, 2007). While there is growing interest in the exploration of multiple morbidities in the Appalachian region (Tarasenko & Schoenberg, 2011), there has been little to no exploration of how regional participants talk about surviving multiple health conditions. Therefore, this study examines the illness narratives of female cancer survivors' living in Southern Central Appalachia, focusing on the presence of multiple health conditions in their narratives.

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 mixed methods, multi-phasic approach. Participants of this study were recruited through use of oncology nurses, local cancer centers, and snowball sampling. Phase I consisted of survivors participating in a day-long story circle (n=26). 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; 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

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

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

Analysis

After the story circle data were transcribed, the data (transcripts and interview) were read in their entirety to identify themes. QSR NVivo 8.0 software was used to analyze the transcripts. The axial coding allowed the researchers to understand the incidents were compared within transcripts, between story circle groups and in-depth interviews. The data were used to support the themes below (Berg, 2009). Illustrative quotes and readability; edited quotes are indicated by brackets about whether it came from an interview participant.

RESULTS

What emerged from participants' cancer narratives was often rooted in a host of other illness narratives in effect "rooted" larger (i.e., omnibus) survivorship narrative.

Omnibus Survivorship Narratives (OSNs):

Cancer's not the first passenger on the bus
 did not necessarily begin with their cancer diagnosis. Cancer narratives were often rooted in a host of other illness narratives. For example, a myeloma survivor's story offered insights to her life faced prior to being diagnosed with cancer. She described her life before her cancer diagnosis (SC1). After her diagnosis, she experienced overlapping symptoms. "I was in acetaminophen." Her omnibus survivorship narrative included gallstone, leading to gallstone removal surgery; kidney stones, leading to renal failure; and breast

owing interest in the exploration of multiple (Schoenberg, 2011), there has been little to know about surviving multiple health conditions. The experiences of female cancer survivors living in the presence of multiple health conditions in their

utson, 2008) about cancer survivorship among researchers collected the stories of 29 female cancer survivors in Tennessee and southwestern Virginia via a purposive sampling. Phase I consisted of survivors who were recruited through use of snowball sampling. Phase I consisted of survivors who were recruited through use of snowball sampling. Phase I consisted of survivors who were recruited through use of snowball sampling.

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Participants were invited to participate in a single semi-structured interview. Participants recruited for Phase I were unable to share their stories about living with cancer, we were necessary to avoid omission of key stories and to select participants based on reasons they cited for seeking cancer treatments, financial challenges to accessing care (KLD) conducted the three Phase II interviews; these lasted between sixty to one hundred-

minutes ranging from their early 20s to early 70s. Other demographic information, including parental status, other demographics were not collected. All participants were asked open-ended questions and ranged from being a 4-month to a 50-year cancer survivor; in fact, participants were asked to share their cancer survivorship experiences. Table 1 provides a list of cancer types in this study.

TABLE 1: CANCER TYPE IN PHASE I&II

Cancer Type	Number
Breast	15
Ovarian	3
Thyroid/Breast	1
Multiple Myeloma	2
Ovarian/Breast	1
Colon	1
Fibrosarcoma	1
Malignant Melanoma	1
Stomach/Levor	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

What emerged from participants' cancer stories was an omnibus survivorship narrative. That is, other illness narratives in effect "rode" side-by-side with cancer narratives, yielding a larger (i.e., omnibus) survivorship narrative.

Omnibus Survivorship Narratives (OSNs): Cancer's Just One of Many

Cancer's not the first passenger on this omnibus. Participants' survivorship narratives did not necessarily begin with their cancer diagnosis. Instead, the beginning of survivorship narratives were often rooted in a host of other health conditions. For example, one multiple myeloma survivor's story offered insights to the persistent and long-term health conditions she faced prior to being diagnosed with cancer. She "had a heart attack [at] 39 years old," four years before her cancer diagnosis (SC1). After her heart attack, she continued experiencing mysterious and overlapping symptoms. "I was in so much pain. I was popping ibuprofen and acetaminophen." Her omnibus survivorship narrative detailed the following health problems: gallstone, leading to gallstone removal surgery and "reconstruction surgery" on her intestines; kidneys, leading to renal failure; and breast health problems, leading to a mammogram and a

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(Hutson, 2008) about cancer survivorship among researchers collected the stories of 29 female cancer survivors in Tennessee and southwestern Virginia via a snowball sampling. Phase I consisted of survivors' story circles are useful for investigating patterns (Lincoln & Guba, 2008). Story circles typically involve an investigator (KAD and SPH) invited a keynote facilitator (oncology nurse) to share her survivorship experiences. The facilitator guides the participants in sharing their stories. Participants may engage in open discussion to ask questions of the group (RCLA, 2008).

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

Participants were invited to participate in a single semi-structured interview. Participants recruited for Phase I were unable to share their stories about living with cancer, we were necessary to avoid omission of key stories and to select participants based on reasons they cited for seeking cancer treatments, financial challenges to accessing care. Authors (KLD) conducted the three Phase II interviews. These lasted between sixty to one hundred-

minutes, ranging from their early 20s to early 70s. Other demographic information, including parental status, other demographics were not collected. All participants were asked open-ended questions and ranged from being a 4-month to a 50-year cancer survivor. Informed consent was required for participation; in fact, the purpose of this study was to explore cancer survivorship experiences. Table 1 summarizes the data from this study.

TABLE 1: CANCER TYPE IN PHASE I & II

Cancer Type	Number
Breast	15
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biopsy of a benign tumor. After these health challenges, she had a "bone marrow biopsy and it came back that I had multiple myeloma" (SC1).

While it may be tempting to focus on the negative aspects of having multiple health conditions, what emerged was a potential positive: Persistent health problems guided some survivors toward their cancer diagnosis. One breast cancer survivor shared, "I had fibrocystic disease, and so I had an excellent gynecologist and he told me how my breasts should feel." Subsequent changes in her breasts triggered her to seek screening (SC2). Likewise, another breast cancer survivor's narrative detailed how regular monitoring of fibrocystic tissue in her breast helped her monitor changes in her body.

I went for my mammogram. I have, always have, benign cysts you know, fibroids, and always had to have another mammogram every time. [...] Well, it came back and there was a questionable spot [...] I knew this wasn't what I had before. It was different (SC2).

Another survivorship narrative detailed how a melanoma survivor "went for knee replacement and they found, in pre-op they found a spot on my lung" (SC2).

All aboard the omnibus! The omnibus survivorship narratives revealed that while surviving cancer, several participants are also surviving multiple health problems concurrent with their cancer experience. Survivorship narratives captured women's struggles with depression (SC1) and a lack of stamina (SC2). One survivor said, "shoot, some weeks, I didn't get out of bed" (IntP). Others had to contend with mysterious symptoms post-diagnosis that required attention. Two different multiple myeloma survivors reported perplexing symptoms they had to investigate with one saying:

My blood pressure went up, and I spent a whole lot of time researching and trying to figure out what to do. I didn't know anybody else with multiple myeloma (SC2).

OSNs captured the struggles with illnesses, including cancer, but they also captured the struggles with cancer treatment-related health problems. For example, two separate interview participants mentioned having to deal with scar tissue from their treatments that resulted in chronic pain and impaired bladder emptying.

In the survivorship narratives, chemotherapy became almost a second disease that the women had to survive, echoing previous work about cancer narratives (Frank, 1995):

The illness sets in, and the chemo sets in, and you're sick [...] I can't shower. I can't even get to the shower. [...] You know those are things that hurt (SC1).

One described chemotherapy as "the worst thing that I'm ever going to do" (SC2). The cancer treatment rendered survivors vulnerable in profound ways that sometimes impacted more than just their health. A breast cancer survivor's narrative revealed when she was in "the middle of me having [...] chemo," she was "was sicker than a dog." Moreover, she claims during all this "the manager of my business embezzled all my money" (SC1).

Other OSNs detailed the health problems they faced due to chemotherapy, including violent, nearly incapacitating vomiting (SC1). Still others indicated that chemotherapy negatively impacted their mental and cognitive health: "for a year out I could not read a book. You know, I

love to read. I have a passion for reading but (SC2). Another survivor explained:

...my physical therapist calls it chemobrain. It's a little better because now I can get through it. The other time I still can't (SC1).

Omnibus Survivorship Narratives (OSNs):

Frequent riders on the survivorship omnibus that survivors of cancer were also survivors of a subset of survivors emerged: Repeat Health Challenges. One survivor that had numerous significant health conditions began telling her story by detailing all she had to deal with: high blood pressure, broken bones/sprains, shingles, and other health issues with me besides the cancer (SC1).

An ovarian and breast cancer survivor shared her experience: "emphysema in both lungs" and is "a recovering alcoholic for a really long time. Almost 20 years" (IntP). She also mentioned "infection, [and] my veins blowing."

RHCS: Painful Medication Management that repeat survivors may have unique challenges related to medication. One survivor's narrative revealed that she had to deal with pain medication. You sit there and tell [healthcare providers] that you're diagnosed with blood clots, including one near your heart, and you're getting overlooked. "If something's wrong, first you get up with pain medication and hope that it goes away."

A survivor of fibrosarcoma (cancer of the connective tissue) experienced challenges related to medication management:

[I] started going to all these doctors and they said, "I know, I was taking 15 Xanax a day [...] for my fourth child. So the guilt of putting [myself] on those drugs that I, all I did was sleep, and medication is worse than anything [...] I had to deal with" (SC1).

Notably, highlighted in some survivorship narratives, especially regarding pain medication. One participant shared that pain medicine [...] as soon as I got out of the hospital, it's gone anymore. You know, it hurt but [...] I wanted to get it. Seemingly, what emerged in some survivorship narratives was that pain medication can be especially challenging for RHCS. Some survivors shared that persistent health problems with medications (SC1) can be almost a badge of honor to actively resist certain

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now. The other time I still can't (SC1).

Omnibus Survivorship Narratives (OSNs): Repeat Health Condition Survivors (RHCS)

Frequent riders on the survivorship omnibus. As previously discussed, OSNs revealed that survivors of cancer were also survivors of other health conditions. Yet, among participants a subset of survivors emerged: Repeat Health Condition Survivors (RHCS). These were survivors that had numerous significant health conditions. For example, one multiple myeloma survivor began telling her story by detailing all she had survived, including: heart attack, high blood pressure, broken bones/sprains, shingles, and a miscarriage, declaring, "There are other health issues with me besides the cancer (SC1).

An ovarian and breast cancer survivor explained in her survivorship narrative that she has "emphysema in both lungs" and is "a recovering alcoholic," adding, "Praise the Lord I've been sober a really long time. Almost 20 years" (IntP). In addition, this survivor had problems "with infection, [and] my veins blowing."

RHCS: Pain[ful] Medication Management. What this sub-set of OSNs suggested was that repeat survivors may have unique challenges managing medication and interactions about medication. One survivor's narrative revealed: "I've had to go to the ER a thousand times [...] You sit there and tell [healthcare providers]. And it goes in this ear and out this one." She was diagnosed with blood clots, including one near her lung, but she alleged that the problem kept getting overlooked. "If something's wrong, find out what's wrong and try to fix it. Don't cover it up with pain medication and hope that it goes away" (IntP).

A survivor of fibrosarcoma (cancer of the muscle) also revealed that post-diagnosis she experienced challenges related to medication management:

[I] started going to all these doctors and everybody was giving me the Xanax [...] You know, I was taking 15 Xanax a day [...] when I found out, I was pregnant [...] with my fourth child. So the guilt of putting [my child] through this and then getting so hooked on drugs that I, all I did was sleep, and made my 11 year old take care of my kids. That guilt is worse than anything [...] I had to go to [residential treatment] to get off the Xanax (SC1).

Notably, highlighted in some survivorship narratives was an anti-medication theme, especially regarding pain medication. One participant explained, "I just didn't want to take the pain medicine [...] as soon as I got out of the hospital I thought I don't want the pain medicine anymore. You know, it hurt but [...] I wanted to get my life back as soon as possible" (SC2). Seemingly, what emerged in some survivorship narratives was that medication management can be especially challenging for RHCS. Some felt that healthcare providers were "covering up" persistent health problems with medications (e.g., pain, anxiety), while others felt that there was almost a badge of honor to actively resist certain medication, the exception being chemotherapy.

DISCUSSION

The study documented that participants both survived cancer and other health conditions either concurrently or consecutively, thus creating a more complex survivorship narrative and broadening the scope of what it means to be a *cancer survivor*. What is particularly powerful about these findings is that they were arrived at inductively. Female cancer survivors' stories were the main focus of the interview and story circles; yet, the survivors routinely intertwined stories about their cancer and other health conditions.

Omnibus Survivorship Narratives: Implications for Patient Communication & Support

In his landmark book, Kleinman (1988) argued that medical education curriculum must include teaching medical students how to interpret illness narratives. Survivorship narratives in our study revealed that survivors may be coping with and managing a host of health challenges; healthcare providers may find patient narratives helpful when trying to understand the barriers encountered by their patients, especially when considering treatment regimes. For example, patients facing "illness fatigue" (Tarasenko & Schoenberg, 2011), including those with multiple morbidities, may be more resistant to routine check-ups and multi-faceted, time-intensive treatments.

Providers may also find patient narratives helpful when trying to understand possible opportunities associated with multiple health conditions. For example, by experiencing multimorbidities, patients may become so in-tune with their bodies that they know when there are physical changes related to cancer. Additionally, if patients are already accessing the healthcare system to treat their other health conditions, practitioners may be better able to encourage additional screenings, thereby diagnosing cancer earlier (Tarasenko & Schoenberg, 2011).

One potentially problematic emergent finding was that the RHCSs seemed to perceive pressure to engage in medication management, especially for chronic pain and/or psychological disorders associated with ongoing long-term health conditions. This finding may echo Clark's (2011) contention that "the weaknesses in our health care system are magnified when a person seeks care for more than one chronic condition" (p. 219). If overburdened providers practice in an area characterized by healthcare provider shortages and disproportionately high rates of multiple morbidities, then there may be pressure to manage certain symptoms with medication (e.g., chronic pain, anxiety). Hence, communication may suffer between rushed and overburdened parties with patients being overburdened by their conditions and physicians being overburdened by numerous professional, ethical, and structural responsibilities (e.g., patient load).

CONCLUSION

Little is known about patient management of concurrent conditions (Clark, 2011), including among Appalachian populations (Tarasenko & Schoenberg, 2011). This study suggests challenges with multiple health conditions but also left room for further investigation about how cancer survivors manage simultaneously occurring health conditions (e.g., physically, psychologically, emotionally, relationally).

Arguably, the populations "most burdened by several chronic diseases are those historically overlooked and disadvantaged" (Clark, 2011, p. 220). One question outside of the

scope of this study is the following: How do conditions, especially if they are in overburdened Appalachians? While this study helps shed light on more questions about surviving multimorbidities.

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scope of this study is the following: How do we support patients managing multiple health conditions, especially if they are in overburdened and disadvantaged populations, such as in parts of Appalachia? While this study helps shed light on an under-examined but pressing subject, more questions about surviving multimorbidities, along with cancer, are waiting to be addressed.

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NAVIGATING FAMILY CANCER COMMUNICATION CANCER SURVIVORS IN SO

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ABSTRACT

In a multiphase study, the stories of cancer survivors were collected through either a day-long modified story circle (n=3). Qualitative content analysis was used to analyze the data. Analysis revealed 5 types of family cancer communication strategies.

INTRODUCTION

A cancer diagnosis is often a challenging crisis and must learn to communicatively negotiate (Ell, 1996). Research has shown the positive effects of communication between the survivor and family members (Ell, 1996; Pollock & Siminoff, 2003). For example, cancer narratives provide opportunities for family members to heal (Ell, 1996). Discussing a cancer diagnosis may be problematic for the survivor and family members, or both. In Appalachia, cancer survivors and families due to the well-documented stigma (Regional Commission [ARC], n.d.) as well as limited resources (Duvall, & Garrett, 2011; Hutson, Dorgan, Phillips, & Duvall, 2011) a cancer diagnosis may impose unique challenges.

Family Communication

A woman, along with her family, must learn to communicate about cancer within the family. After diagnosis, a woman may need to "construct, redefine, negotiate, and renegotiate" her identity (Ell, 2008, p. 608). Discussing cancer within the family is essential for understanding and healing for both the survivor and family members (Pollock & Siminoff, 2003; Shapiro, Angus, & Davis, 1997). Family communication within families is likely to impact the survivor's experience.

Although literature supports discussing cancer with family, it is often overwhelming. The diagnosis and prognosis