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MOTHERED, MOTHERING, AND MOTHERIZING IN ILLNESS NARRATIVES: WHAT WOMEN CANCER SURVIVORS IN SOUTHERN CENTRAL APPALACHIA REVEAL ABOUT MOTHERING-DISRUPTION

BY KELLY A. DORGAN, KATHRYN L. DUVALL, SADIE P. HUTSON, AND AMBER E. KINSER

Informed by a mothering-disruption framework, our study examines the illness narratives of women cancer survivors living in Southern Central Appalachia. We collected the stories of twenty-nine women cancer survivors from northeast Tennessee and southwest Virginia using a multi-phasic qualitative design. Phase I consisted of women cancer survivors participating in a day-long story circle (n=26). Phase II consisted of women cancer survivors who were unable to attend the story circle; this sample sub-set participated in in-depth interviews (n=3) designed to capture their illness narratives. Participants' illness narratives revealed the presence of: (1) mothering-disruption whereby cancer adversely impacted the mothering role; and (2) mothering-connection, whereby the cancer experience motivated mother-survivors. Participants' illness narratives reflected that the role of mother was the preeminent role for mother-survivors and whenever there was oppositional tension between the roles of mother and survivor, the women-survivors seemed to linguistically relocate away from the survivor role and toward the mothering role. As a result, women-survivors seemingly rejected medicalization of their identities by emphasizing their mothering responsibilities, something we term motherizing.

Good mothering is a lofty, culturally sanctioned aspiration (Hays 1996;

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Runquist and Baker 2008) that tantalizes and beckons even after the onset of chronic illness (Elmberger, Bolund, and Lutzen 2000; Elmberger, Bolund, and Lutzen 2005; Vallido, Wilkes, Carter, and Jackson 2010). For example, when cancer disrupts their lives, women who are mothers must simultaneously struggle with conflicting demands, devastating emotions, and fluctuating identities (Elmberger et al. 2005; Elmberger, Bolund, Magnusson, Lutzen, and Andershed 2008). While they may have been mothers for years, the role of "patient" might be thrust upon them, requiring that they negotiate new challenges to carework and identity.

Many mothers find caring for their children to be a central part of their identity and are motivated toward carework as an "authentic expression of self" (deMarneffe 2004, 8), including mothers facing debilitating health conditions (Elmberger et al. 2008; Malacrida 2009; Vallido et al. 2010). Still, we know little about how chronic illness interrupts mothering. As Bell and Ristovski-Slijepcevic (2011) argue in their study of Canadian mothers living with metastatic cancer, research literature generally remains "uninterested" in mothers' experiences, largely, and almost resolutely, focusing on the impact on dependent-aged children (633). Even in Southern Appalachia, a region with a well-documented history of illness-related morbidity and mortality (Appalachian Regional Commission 2004) and cancer disparities (Behringer and Friedell 2006; Tennessee Comprehensive Cancer Control Coalition 2009), research largely remains silent about chronic illnesses' disruption of parenting. Women of the region have been described as having "unshakable authority over many family affairs" (Welch 2012, 108), tending to play a central role within families in matters of health (Denham, Meyer, Toborg, and Mande 2004; Patton 2005; Stephens 2005). Yet, at the time of this writing, there has been no exploration of mothering-disruption within Appalachia. The purpose of our study, then, is to examine what women cancer survivors living in Southern Central Appalachia reveal about mothering and illness disruption.

Conceptual Framework

Informing this study is a mothering-disruption framework (e.g., Elmberger et al. 2000, 2005, 2008; Vallido et al. 2010). Previous research shows us that cancer survivors face myriad family-related challenges, including radical transformations of identity and family (Doyle 2008; Elmberger et al. 2000, 2008); threats to perceived usefulness to family (Shapiro et al. 1997; Sherman and Simonton 2001); and increased dependence upon family members (Petersen et al. 2003). Additionally, mothering itself can be "interrupted" by cancer, as Elmberger et al. (2005) explored in their interview-based research with lymphoma survivors in urban Sweden (257). Despite the physical, emotional, and psychological realities of being diagnosed with

cancer, following a diagnosis, mothers reportedly work to meet the demands of caring for their children (Elmberger et al. 2000; Elmberger et al. 2005; Elmberger et al. 2008).

Mothering might be disrupted in part because illness provokes a tension between realistic and ideal states of mothering. Deeply rooted moral responsibilities require that mothers protect their children from the realities of illness while also meeting the ideals associated with “good mothers” (Elmberger et al. 2005, 259). Consider, for example, that illness narratives feature a sometimes stark reality whereby cancer survivors live with a disease and treatments that weaken bodies and encumber minds (Frank 1995). However, broad social discourses emphasize mothering ideals, in which mothers remain eternally and eagerly present—emotionally, physically, and financially—for their children (Hays 1996). Indeed, assumptions abound that equate motherhood with self-sacrifice (Pollitt 1998; Horwitz 2011) with mothers often responding to what deMarneffe (2004) calls the “supermom ideal.” The fantasy that if mothers “work hard enough to get everything ‘right,’ they will not lose anything” (10 - 11).

Among the general U.S. population, mothering ideals proliferate, promoting prescriptive norms (Hays 1996; Douglas and Michaels 2004). Normative prescriptions for good motherhood persistently prove unrealistic, impossible to follow, and out of synch with contemporary families (Green 2004; Horwitz 2011). However, equally impossible is the rejection of these norms and ideals. As Runquist and Baker (2008) argue, “women continue to strive to be ‘good’ mothers in the ideological sense, because often the only other option available to them is to be a ‘bad’ mother” (85). Given the ways in which womanhood and motherhood have been conflated through U.S. history (Kinser 2010), falling short in motherhood might translate into falling short in womanhood (Green 2004; Kinser 2010; Runquist and Baker 2008).

Grounded in an essentialized notion of maternal instinct as innate rather than a socialized notion of maternal thinking as acquired through discipline and practice (Ruddick 1995), there is the broad cultural assumption that only the biological mother is able to truly meet the child’s needs (O’Reilly 2006). Furthermore, children’s “needs” in U.S.-American culture are framed by social discourse in ways that may have much less to do with children’s well-being than with institutional regulation of family life (Kinser 2012). Therefore, even while surviving cancer, many mothers might resist relying on others to provide for their children—They alone must put aside their needs in favor of their children’s needs. Based on such an assumption, the mother’s health is placed second, at best, relative to what are perceived to be her obligations to their children (Pollitt 1998). Like the mothers who experienced fatigue after childbirth in a study by Runquist and Baker (2008), women surviving cancer may experience a profound “frustration as they

[struggle] to negotiate between the reality and ideology of caregiving" (83). Frustration is understandable because ideal mothering is "both unachievable and blaming," especially so for women whose bodies and minds are disabled (Malacrida 2009, 100), further impairing an already impaired balancing act between real and ideal.

Of relevance to the discussion of mothering-disruption is de-contextualization, a transformative process examined in feminist analysis scholarship. For example, in their study of images of mental health, and in particular constructions of gender, sexuality, and race in the psychiatric chart, Daley, Costa and Ross (2012) contend that de-contextualization involves the "removal of social context, including contributing social causes and meaning-making from women's accounts of madness" (962). Various scholars have explored how dominant narrators in modern medicine, such as psychiatrists, reduce patients' complex health experiences to categories (Coker 2003; Daley, et al. 2012), medicalizing complicated phenomena instead of situating them in broader social and cultural contexts. In essence, women patients become oversimplified by the dominant narrator, rather than being featured as having multifaceted identities as produced by intersecting categories (e.g., gender, race, sexuality, class). Of note to our study is that de-contextualization is realized through dichotomization whereby women are linguistically located in mutually exclusive and oppositional categories (Daley et al. 2012), as with the good mother/bad mother dichotomy.

The mothering-disruption literature hints at a kind of de-contextualization by mothers themselves. Mothers facing depleted bodies and interrupted strength struggle to attend to that well-ingrained "ideology of caregiving" (Runquist and Baker 2008, 83) and strive to meet the demands of ideal mothering (Malacrida 2009). Instead of medicalizing their identities, then, these women may be motherizing. Langellier and Peterson (2004) argue that "disease converts a person to a patient, the body to an assembly of fixable or replaceable parts, and the personal narrative to a medical report or clinical history" (190). Similarly, "motherizing" converts the whole person to exclusively or predominately a mother, the body to a driven or obligated nurturing relation, and the personal narrative to a parenting report or a past and unfolding history whereby childrearing decisions can be scrutinized.

Because of the concerns feminist scholars raise about dominant narrators offering simplified depictions of women (Daley et al. 2012), in this study we sought to have women tell their illness narratives, using their own language choices (Stevens 1993). What is critical about the nature of our study is that findings about mothering-disruption emerged from the data. That is, while the subject of mothering was not the primary focus of the story circles or interviews, participants raised the issue, unprovoked, regardless of the data collection strategy.

Methods

This study was part of an omnibus qualitative research project aimed at: (1) defining survivorship from the perspective of women cancer survivors living in Southern Central Appalachia; (2) identifying any unique needs of survivors in this region; and (3) identifying communicative strategies for addressing those needs (Dorgan and Hutson 2008). Following approval by our university's institutional review board, we collected the stories of twenty-nine Appalachian women cancer survivors from northeast Tennessee and southwest Virginia using a qualitative descriptive, multi-phasic approach. The analysis of this study allowed for inductively derived findings (Corbin and Strauss 2008). Participants of this study were recruited through use of referral by oncology nurses, local cancer centers, and snowball sampling. Prior to data collection, two authors (KAD and SPH) conducted a bracketing interview with a community member and cancer survivor to mitigate the effects of any preconceived ideas we had about the topic that may have biased the results (Tufford 2012).

Phase I

Responding to the "culture of storytelling" (Olson 1998, 73) in the southern region of Appalachia, we implemented a story circle approach in Phase I which consisted of women who were cancer survivors participating in a day-long story circle (n=26). Story circles gather individuals in an open-participation collective experience, during which participants are encouraged to speak "heart-to-heart" about a given topic. Story circles are useful for investigating patterns and similarities; they also represent a productive approach that empowers the participants (Research Center for Leadership in Action [RCLA] 2008).

First, a story circle typically begins with a primer story (RCLA 2008). In this case, we, the primary investigator and co-investigator (KAD and SPH), had invited a keynote speaker who is a woman living in Southern Central Appalachia, a breast cancer survivor and practicing oncology nurse who shared her survivorship story. Second, the participants sit in a circle and the facilitator guides the participants in sharing their stories, enabling participants to decide how to tell their stories and what language to use in the telling (Stevens 1993). The story circle facilitators (KAD and SPH) were community members and were trained and experienced in qualitative data collection procedures. Additionally, our familiarity with the community and culture arguably helped improve the credibility of the data (Shenton 2004) in that we were able to foster a connection with the participants based on shared language, experiences, and values.

We divided participants into two groups and asked them to share their stories of cancer survivorship in Appalachia during two sessions, each

session two and a half hours long, with the assistance of a facilitator (KAD and SPH). In determining which participants were assigned to which story circle (SC1 or SC2), we tried to ensure that types of cancer were represented across groups and that survivors who were related were able to attend the same story circle, thereby promoting participant comfort. We obtained informed consent prior to the beginning of the story circles. Each story circle was digitally audio-taped and transcribed verbatim, yielding 228 pages of transcripts. Participants were provided with a gift card for twenty-five dollars to a local grocery store that also sells gas; we did this to offset transportation costs by participants traveling to the data collection site from rural surrounding counties. Participants' stories were captured by using open-ended queries (Stevens 1993), including: (1) "Tell me about becoming a cancer survivor"; (2) "What does it mean to be a cancer survivor"? (3) "What does it mean to be a cancer survivor in your community?" Questions were designed to permit participants to direct the nature of their cancer survivorship narratives.

Phase II

Phase II consisted of a semi-structured interview approach (n=3) to capture a fuller story (Pederson 2013) about surviving cancer in this region. We used purposive sampling in Phase II to select interview participants based on reasons cited by recruited story circle participants for not being able to attend the story circle event (i.e., ongoing cancer treatments, financial challenges to transportation, and work conflicts). One of us (KLD) conducted all three Phase II interviews in the participants' respective homes; these interviews lasted between sixty to 120 minutes.

Following each data collection method, the research team recorded descriptive, subjective, methodologic, and analytical memos (Berg 2009), sensitizing ourselves to dynamics (e.g., between participants, between participants and moderators), emerging findings, and problems (e.g., difficulty recruiting the most economically marginalized members of the population). We collected demographics including age, cancer diagnosis, time since diagnosis, place of residence, and parental status. Symptom and treatment details were not collected as these were not the focus of the study. Moreover, we wanted to protect the privacy of women living in close communities such as very small towns (almost 50 percent of participants).

Analysis

After the story circle and interview data were fully transcribed, we conducted an inductive analysis (Corbin and Strauss 2008). Two authors read the transcripts in their entirety to allow for a general understanding of survivorship experiences (KAD and KLD) and conducted open and

axial coding (Corbin and Strauss 2008). This process allowed us to uncover common themes, compare incidents, and document differences. During axial coding, we (KAD and KLD) worked independently then jointly to identify relationships between categories; we immersed ourselves in the data by reading and re-reading the transcripts (Berg 2009; Corbin and Strauss 2008). NVivo 9.0 was used to manage data and organize emergent and refined coding categories. Subsequently, we met to discuss the initial analysis; disagreements were resolved through discussion and frequent debriefing sessions. The remaining two members of our multiprofessional team (Elmberger et al. 2008) verified consistency of analysis, confirmed emergent themes, revising them as necessary, and audited the claims and illustrative quotes used to support those claims (SPH and AEK).

While the above stated techniques were used to promote trustworthiness and credibility during analysis, a core assumption of this study is that “stories necessarily contain elements of both authenticity and in-authenticity,” making narrative data “always partly trustworthy and partly untrustworthy” (Shapiro 2011, 70). To further strengthen the credibility of our analysis, we provide liberal use of participant quotes to support our claims (Berg 2009), including drawing on participant voices to support analytic arguments (Stevens 1993). Illustrative quotes were edited only to promote clarity and readability; omitted material is indicated by an ellipsis. To further ensure participant confidentiality, we do not provide individual participant identifiers. While the lack of individual identifiers may be a study limitation, our approach allows us to focus on the collective nature of the stories (RCLA 2008) and broader cultural scripting and narratives (e.g., Elmberger et al. 2008; Hutson et al. 2011) revealed in the participants’ illness narratives. Therefore, each illustrative quote is followed by a notation about whether it came from an interview participant (IntP) or story circle participant (SC1, SC2).

Results

Participants

A total of twenty-nine women residing in northeast Tennessee or southwest Virginia across both study phases made up the final sample, representing six different counties and twelve different towns/cities across the TN-VA region of Southern Central Appalachia; four did not report their specific county of residence. Participants’ age ranged from their early twenties to early seventies. Unlike previous studies on mothering and cancer (e.g., Bell and Ristovski-Slijepcevic 2011; Elmberger et al. 2000; 2005), no specific cancer was required for participation in the study. Participants reported a variety of cancer diagnoses with breast cancer accounting for approximately 52 percent. Other reported cancer diagnoses accounted for approximately 31 percent of participants, including: cervical (n=1); colon

(n=1); fibrosarcoma (n=1); melanoma of the lung (n=1); multiple myeloma (n=2); and ovarian (n=3). Approximately 14 percent of participants reported being dual-cancer survivors, including thyroid and breast cancer (n=2); stomach and liver (n=1) and ovarian and breast (n=1). One participant did not report her specific cancer diagnosis. Time since diagnosis ranged from four months to fifty years. Approximately 69 percent (n=20) self-reported as being mothers to either dependent or adult children. Women who did not report being mothers were included in analysis because their illness narratives still reflect broad cultural norms (Coker 2003), strengthening our understanding about mothering-disruption during cancer.

Admittedly, our decision not to collect extensive demographics limited our ability to examine the impact of multiple social identities on individuals' illness and wellness experiences (Kelly 2009). However, our approach enabled us to provide extra layers of protection to participants' confidentiality and offered participants the opportunity to reveal in their illness narratives the social categories they perceived important.

Primary Findings

Two primary themes emerged across age groups, parenting status (i.e., parenting adult or dependent children) and cancer diagnoses. Participants' illness narratives revealed the presence of (1) mothering-disruption, challenging their location in the mothering role; and (2) mothering-connection, with cancer motivating them to relocate to the mothering role and away from the survivor role.

To help establish the credibility of our findings, we conducted a blended analysis, providing manifest findings to further support our latent findings (Berg 2009). For example, across all story circles and interviews, the word "mother" was mentioned fifty-seven times, "mom" mentioned ninety-seven times, "mommy" mentioned once, and "momma" mentioned twice, totaling 157 mentions. In contrast, "survivor," "survivorship," or "survivors" was mentioned ninety-six times by participants, underscoring that even in a study of cancer survivorship the role of mother dominated the discussion at times without being prompted by the researchers. Repeatedly, participants' illness narratives reflected that the role of mother was the preeminent role for mother-survivors. Moreover, whenever there was oppositional tension between the roles of mother and survivor, participants seemed to locate themselves in the mothering role category, a point to be discussed later. In essence, the women-survivors seemed to transform themselves through a sort of self-decontextualization (Daley et al. 2012) by linguistically relocating away from the survivor role and toward the mothering role. As a result, women-survivors seemingly rejected medicalization of their identities by emphasizing, almost myopically, their mothering responsibilities; yet, though

perhaps a powerful strategy when responding to the disruptive nature of cancer, there may be a reification of the socially and culturally entrenched structures of ideal mothering that are oppressive to women (O'Reilly 2006) regardless of health status.

Emergent Theme One: Mothering-Disruption in Appalachia

In both study phases, participants revealed that cancer adversely impacted mothering, disrupting the ability to meet caregiving demands. In effect, by threatening what mothers can accomplish in their families, cancer can distance women from the mothering role and responsibilities.

Mothering-performance disrupted. Participants' illness narratives featured cancer as interrupting the physical performance of mothering, particularly feeding work. Women who were both mothers and survivors (mother-survivors) described how cancer disrupted their mothering to the point that they "couldn't provide" and prevented them from being a "total and complete mom." (SC1). One breast cancer survivor and mother of a dependent-aged child suggested that her inability to breastfeed her newborn baby post-diagnosis called into question her maternal adequacy: "That's what got me. I had to go through the whole bottle feeding, you know. It was rough." It is as if her inability to feed her infant child with her diseased body threatened to thrust her towards the "bad mother" category. Furthermore, her story highlighted concerns that performing the survivor role (e.g., doing chemotherapy) might result in her getting sick, further impeding her mothering role. In effect, undergoing treatment (favoring the survivor role) would require her to seek help from others and divert her energies away from performing mothering. As the participant explained, "I was afraid that my daughter would think that someone else was her mother" (SC1), her words reflecting the broad cultural assumption that only biological mothers can provide for their children (O'Reilly 2006).

Mothering-disruptions related to foodwork extended to mothers of adult children. Consistent with research indicating that "dinner is a very central social and cultural resource when women talk about themselves and their life" [sic] (Bugge and Almas 2006, 223), and suggesting that this may be no less so for women with cancer, one participant explained:

Holiday dinners are here [at my house]. You know, family functions are here. All of that is here. But for the last year and a half that has been really super hard to do. Because at that time the bulk of it fell on [my husband] and here he is trying to take care of me. And I'm frustrated because it is really challenging to try to keep the family together when you're not together yourself . . . the biggest thing we

tried to do is keep family functions going. You know we didn't back off Christmas, Thanksgiving. We even threw a couple of extras in there. Oh, it's somebody's birthday? Sure. You know just keep them together, keep them going, keep them laughing (IntP).

This participant's description illustrated that the realities of the survivor role made responding to special family events "super hard to do," requiring her to rely on her husband. Yet, as frustrating as maintaining family togetherness and food-centered rituals were, her apparent need to locate herself in the mothering role was so pronounced that she even added "a couple" of extra family functions. This result underscores previous findings that women continue to feel responsible for food provision (Bugge and Almas 2006; Ochs, Shoet, Campos, and Beck 2010; Martinasek et al. 2010; Owen, Metcalfe, Dryden, and Shipton 2010) and that "feeding is one of the primary ways women 'do' gender" (DeVault 1991, 118). In our study, feeding and maintaining family, then, appear to be interchangeable at some level, with food functioning as "a metonym for the family" (Moisio, Arnould, and Price 2004, 362). These practices help participants "do" mothering, perhaps at the expense of "doing" survivorship. Still, while participants' maternal performances may appear as problematic efforts to locate themselves in the mothering role, such performances may serve as "compensatory mothering," communicating to "others" that, even though the body and mind have been disabled by cancer, attempts to strive toward mothering ideals are ongoing (Malacrida 2009, 113).

Mothering-disrupted: From mothering to being mothered. Participants' illness narratives revealed that mothers are expected to mother others (be a caregiver), not be mothered (be a care-receiver). Even participants who did not have children underscored the mother-caregiver role. For example, one breast cancer survivor, who was close to her mother but not a mother herself, told of becoming physically weak while mowing her lawn (behavior also associated with caregiving of family). She said, "When I saw my mom" she literally started crawling on the ground toward her mother; she explained, "here we are, that Appalachian mother thing, I had to get to her" (SC1). Another breast cancer survivor talked about her own mother, explaining that after chemotherapy "we were having to get [mother] around in a wheelchair and I know how humiliating that was for my mom" (SC2). In talking about their own mothers, these participants illustrate the continued cultural assumption that core to maternal identity is caregiving.

Cancer, then, threatens to simultaneously disrupt caregiving and push participants toward care-receiving. One ovarian cancer survivor told about trying to get back to work: "My goal was getting back to that office as

quickly as possible. I couldn't be a burden to my children. I'm not ready to take their help at this point" (IntP). Another participant, a breast cancer survivor, pointed out that her own mother "fussed" at her for not asking for help while caring for her newborn baby. She noted that "I'm just one of those people that don't ask for a lot of help" (SC1). By and large, participants did not signal that they were concerned about being burdened during their illness experience; rather, they were concerned about their need for care being burdensome to others.

Participants' own mothers, dependent children, and adult children all were implicated as agents of mothering-disruption, apparently working to locate participants in the care-receiving survivor role and away from the caregiving mother role. For example, one colon cancer survivor stated that her adult children treated her like "an invalid."

My kids got on my nerves so bad. . . . When I got sick they didn't want me to get out of the chair and go to the kitchen to get my own drink of water. I told them I wasn't dead yet. (SC1)

This participant's declaration that she "wasn't dead yet" might serve as an acknowledgement that while struggling to survive cancer, she was also struggling to survive her children's expectations that she should become a mothered care-receiver.

Similarly, a breast cancer survivor's story revealed that she had to negotiate with her dependent daughter about how to manage her appearance as a survivor. She explained that she had one remaining patch of hair that she wanted to cut, but her daughter wanted to put it into a braid. "[My daughter] goes, 'No mom. Let me braid it and take pictures. This'd be awesome.' I'm like, 'No. Cut it. . . . Your awesome isn't my awesome.'" Ultimately, the mother-survivor had to talk her daughter into cutting the remaining hair (SC2). This story is especially poignant in that it features participants navigating challenges to identity and body, as well as to authority and agency. When the participant ordered her daughter to "cut it," this declaration seems to linguistically distance her from the less powerful role of survivor and relocate her to the role of mother-caregiver, a role that has traditionally given women cultural authority (e.g., Elmberger et al. 2008), including in Appalachia (Stephens 2005; Welch 2012).

While cancer disrupted survivors' physical lives, it also disrupted mothers' source of agency and authority. Dependence on others is antithetical to standards of contemporary maternal caregiving, particularly in light of supermom ideals (deMarneffe 2004) or sacrificial mothering (O'Reilly 2004) ideologies. Such ideologies suggest that the mother is at the helm of, and

ultimately culpable for, family outcomes, making family members dependent on her, not she on them. Perhaps, then, self de-contextualization becomes a powerful tool to fight against location in the less powerful category of survivor, a topic to be discussed later.

Mothering-disrupted: Family-protector disrupted. Protection of children is at the core of maternal practice (Ruddick 1995). Participants' illness narratives revealed that as the survivor role threatened to overwhelm the mother role, participants reportedly experienced profound guilt.

Guilt seemed especially pronounced for at least one mother-survivor who perceived that she had "passed" her cancer on to her adult daughter. A dual cancer survivor (breast and thyroid), this participant explained that her daughter had been diagnosed with "breast and thyroid, just like her momma. Except she had it four times." She added, "I gave my oldest daughter all the bad stuff," explaining, "you just feel so guilty. . . . What have I done to this child?" (SC1). In this instance, the participant seems to self de-contextualize, linguistically, and negatively, locating herself in a bad mother role because her cancer disrupted her ability to protect her child. Her daughter, a participant in the same story circle, echoed that her mother "felt guilty," adding, "you know it's that trying to protect your children and your husband and your family. You're always the woman . . . the one that's strong" (SC1).

Previous research on mother-survivors (Bell and Ristovshi-Slijepcevic 2011) identified a "hierarchy of suffering." That is, the suffering by mothers with dependent children was viewed as more significant than other survivors' suffering. In our study, though, participants generally did not reveal a "hierarchy of suffering." Participants of all ages, including those who parented both dependent aged and adult children, described cancer's negative impact on parenting and associated negative emotional states with having illness interrupt their child-protector responsibilities. One participant told of feeling bad that she couldn't protect her young adult daughter from the impact of her cancer, saying:

When I was waking up from the mastectomy and I looked at [my daughter] and she was wringing her hands. And I thought she's twenty-five, but she's still young.

Even though in her illness narrative she described her daughter as supportive and involved, this participant chose to continue chemotherapy alone, perhaps signaling her determination to emotionally protect her adult daughter: "Chemo I wanted to do on my own" (SC1). She seems to suggest that a balancing of the mother and survivor roles is impossible, so when the survivor role did require attention, she shifted to the lone-survivor rather than a mother-survivor.

Although there was not an expressed “hierarchy of suffering,” a small number of participants’ stories revealed additional challenges to the child-protector responsibilities when parenting children whose dependency was more pronounced (e.g., because of age, physical health impairments, cognitive impairments). As one participant explained:

When I was diagnosed, my youngest was a sophomore in college and I was glad that I wasn’t diverted with the daily grind and I didn’t have to take care of everybody else. I really couldn’t take care of them. And I was a really dedicated mother and it would have been really hard for me to divide myself if they had been home” (SC2).

This excerpt seems to capture the tension between being a “good mother” (Elmberger et al. 2005) and being a “good survivor,” suggesting that for these participants at least, the mother-survivors do not perceive balance as possible. Movement toward the mothering role seems to offer some solution to the dilemma, though it may be, as we argue later, a solution that can reify idealized motherhood structures.

Emergent Theme Two: Mothering-Connection in Appalachia

Participants’ illness narratives revealed a second primary theme. While cancer disrupted mothering, it seemed to simultaneously serve as a connector, motivating mother-survivors to relocate to the mothering role, especially after physical debilitation had temporarily forced them to attend to survivor responsibilities.

Mothering-connected: Role relocation. Participants rarely communicated that the survivor role was a priority, supporting previous mothering-disruption research (Vallido et al. 2010). What emerged was that some participants adopted a goal-driven approach to help them relocate closer to the mothering role—and farther from the survivor role. For example, one participant described in her illness narrative why she delayed having her mammogram even prior to her breast cancer diagnosis:

I just thought there was something going on. I cannot tell you that I felt anything. [My breast] just looked different to me. . . . So my son was graduating from college the next Friday and I said, “I’m not missing graduation” (SC1).

After receiving a cancer diagnosis, some participants signaled the presence of this goal-driven approach:

I've got a son. . . . My goal was, when I was diagnosed—he was a freshman in high school, and I'm like, "If I can just see him graduate, that's all I want. After that, it's whatever . . . if I can get to that goal, I'm fine." Well, I seen him graduate and [. . .] I said, "Okay, I'm still here and we've got him graduated" (SC2).

This participant's declaration, "I'm still here," is potentially of significance. By linguistically relocating her goal away from fighting cancer and toward watching her son graduate, the claim "I'm still here" signals an attempt to gain agency over cancer via mothering practices. Further, the phrase "I am here" is at the center of one's sense of home and family (Noddings 2002, 19, 227); thus, mothers facing cancer's disruption may still be compelled to be present as mothers.

Mothering-connected: Disrupted performance as prompt. Similar to other mothers facing "bodily challenges" (Malacrida 2009, 110), participants in our study faced barriers to physically doing mothering. Physical deterioration appeared to serve as a role-relocation prompt, triggering surges in resolve to meet the demands of parenting. One breast cancer survivor with two dependent children, including an infant, said, "I can't get sick. . . . I can't get run down. I have children," adding:

You know, [other people] can do the housework and stuff but when it come to me and my daughter. . . . I had my arm in a sling and couldn't use it. . . . I got real good about picking that baby up with one arm. . . . And when I did get diagnosed it was like, "Okay, I have to do. I have to do this, I have to do that" (SC1).

The reason we use role-relocation here is that especially at times of pronounced physical vulnerability, weakness, and depletion, participants seem to move towards the role of survivor, maybe out of necessity. Yet, such moments also seemed to be when participants harnessed the physical manifestations of their cancer to re-connect to the mothering role and responsibilities:

At one point, I wanted to give up because I was so sick. And my middle child said, "Mother, you've got to do it for us." And that was the end of it. . . . I never gave up again. So, dealing with [cancer] with the children was really hard (SC1).

For this participant, parenting her children was "hard" in the context

of dealing with being a survivor. Nevertheless, in the midst of being “so sick” she seemingly rallied, mindfully relocating back to her mothering role.

Notably, across story circles and interviews, there was only one communicated exception to the mothering role-relocation. Like many of her fellow participants, one woman’s story revealed the oppositional tension between the mother and survivor roles. Diagnosed with lymphoma over two decades ago, she explained that her daughter had a brain injury from an automobile accident. “And so, I used every ounce of energy I had to survive for her, more so than surviving for myself . . . I’m just surviving for her. . . . You know I kept thinking, “No, you know, I can’t do this. I have to live for her”” (SC2).

Unique among our participants, though, this woman’s illness narrative also revealed her mindful attempts to relocate to the survivor role, distancing herself from her mothering role. She explained, “You have to play mind games” to survive:

There were times when I was so sick that . . . I had to pretend that [my daughter] didn’t exist because I needed all that energy, every ounce of energy I had for myself to heal. And [I couldn’t have] if I had been worrying or stressed (SC2).

This participant apparently had to get “so sick” before she was willing or able to relocate herself toward the survivor role. Additionally, the participant apparently had to consciously adopt delusional thinking, playing “mind games” and pretending that she had no daughter. In this case, self de-contextualization appeared to enable the participant to temporarily distance herself from the mothering role (via trickery) and move towards the survivor role (out of necessity). Noticeably absent, though, were other participants revealing similar strategies that aided a movement toward the survivor role.

Discussion

In this article, we explored what the illness narratives of women-survivors living in Southern Central Appalachia reveal about mothering-disruption during the cancer experience. Specifically, we found: (1) cancer disrupted mothering, impeding motherhood performances and challenging caregiving and child-protection; and (2) cancer emerged as a motivating force, pushing women closer to the mothering role and its responsibilities.

Implications of Mothering-Disruption and Mothering-Connection

A mother, her body, and her children are deeply connected (Kinser

2008). Thus, when cancer interferes with a mother's body, it also has the potential to interfere with that connection, robbing her of the feeling that she is "here" (Nodding 2002) for her child. During treatments, her bodily needs might call her to seek solitude or render her cognitively absent even when she is physically present. Moreover, cancer might disrupt a mother's efforts to strive for those impossible but seductive mothering ideals.

As underscored in our findings, women-survivors who are mothers retain a sense of responsibility when it comes to organizing and feeding family. Illness aside, family foodwork is "an emotionally fraught" (Anving and Sellerberg 2010, 205) and demanding practice, providing opportunities for household members to unite but requiring that someone—usually the mother—organize the social event (DeVault 1991). Participants' illness narratives indicated that bringing together and feeding family went beyond a social demand: Foodwork became both carework and identity work (Bugge and Almas 2006), helping women-survivors bolster their care-giver identity and minimize their care-receiver identity, thereby partially disrupting cancer's disruptive effects on valued maternal practices and interactions.

Mothering-disruption research. Our findings extend the mothering-disruption framework (Elmberger et al. 2005, 2008; Vallido et al. 2010) in two ways in particular. First, we were able to deepen our understanding of how participants managed the oppositional tension between mothering and survivor roles. Feminist scholarship has concerned itself in part with how dominant narrators strip patients of their complex social identities and reduce them to oversimplistic oppositional categories (e.g., Coker 2003; Daley et al. 2012). We also found that when participants were the dominant narrators of their own illness narratives, they de-contextualized their experiences. Mothers who are survivors may be challenged by pain, uncertainty, and ambivalence, but we contend that participants' linguistic role-relocation reflected a larger strategy of disrupting cancer's disruptive nature, thereby allowing women-survivors to regain agency during mothering-disruption.

Self de-contextualization might be seen as a rejection of medicalization (Daley et al. 2012) whereby participants resist being reduced to cancer and its symptoms, causes, and treatments. Potentially problematic, however, is that for survivors who are mothers, medicalizing may be replaced by motherizing. To relocate the problem(s) of cancer firmly within the territory of mothering roles and responsibilities could perpetuate mothering ideals and "good mothering" prescriptions. Of course, role-relocation may be advantageous, motivating mother-survivors to live and care for their children, but striving to meet impossible mothering norms may also result in them continuing to care-give beyond their physical, cognitive, and emotional limits. Ultimately, the role-relocation (from survivor to mother) present in participants' illness narratives may result in additional silencing

of intricate maternal narratives and the rehashing of old, familiar “good mothering” narratives.

Of course, our intent here is not to fault women surviving cancer for not being able to cast off idealized motherhood prescriptions any more than any other group of women can. Instead, we hope to illuminate: (1) the potentially dangerous impact that the cultural institution of motherhood (Rich 1976) and the good mother/bad mother dichotomy (Caplan 1998) have on women surviving cancer; (2) the difficulty these women may experience in reconciling their survivor role with their mother role in light of that impact; and (3) the necessity of reconfiguring ideologies of sacrificial mothering (O’Reilly 2006) such that women surviving cancer can continue to find motivation through their mother role for surviving, but not be derailed by the inability to achieve the impossible ideals of motherhood in that effort.

In addition to health researchers and feminist scholars, our finding about role-relocation is relevant to health professionals, including providers, educators, and interventionists. A report from the Center for Disease Control and Prevention (CDC) stated that “to better address the needs of cancer survivors, we must have an understanding of the types and magnitude of issues faced by them as a result of cancer diagnosis and treatment” (Fairley, Pollack, Moore, and Smith 2009, 1526). Our study’s examination of role-relocation contributes to an improved understanding called for by the CDC. The role of mother might be unwittingly overlooked by health professionals, including providers, for example, who tend to emphasize disease-related information while inadequately addressing the complex support needs of their patients who are also parents (Elmberger et al. 2008). Mother-survivors may be skeptical about, even dismissive of, health professionals’ survivor-centric messages (e.g., “Make yourself a priority;” “Stay active!;” “Take care of yourself”), especially if their multiple identities, goals, and obligations are not accounted for in provider-patient interactions or public health campaigns targeting cancer survivors. In the end, health professionals working with mother-survivors in Appalachia would be wise to acknowledge the parenting role and responsibilities of their patients.

Second, by exploring mothering-disruption in a previously unexplored population, we also broaden our understanding of how mothering ideals are disrupted and mothering realities are managed during the cancer experience. Overall, our study participants shared similar mothering-disruption experiences with Canadian mothers (e.g., Bell and Ristovshi-Slijepcevic 2011; Malacida 2009) and Swedish mothers (e.g., Elmberger et al. 2005, 2008). There was one potential difference that emerged in our findings: Our participants’ illness narratives generally did not reveal the presence of a “hierarchy of suffering” (Bell and Ristovshi-Slijepcevic 2011).

In fact, mothers of all ages and who parented both dependent-aged and adult children detailed suffering triggered by mothering-disruption.

This finding in particular may indicate the influence of the culture in which our participants live, work, and mother. Possibly, mother-survivors living in Appalachia continue to actively engage as mothers even after their children are no longer age-dependent. Reviews of literature continue to describe modern Appalachia as family-centered (Bush and Lash 2006; Stephens 2005; Welch 2012) and indicate that the kinship social structure is still in place, especially in smaller rural areas (Keefe 2005; Stewart Burns, Scott, and Thompson 2006). This is not to suggest that women in other communities and cultures simply “vanquish” the mothering role once their children become adults. Our point is that mothers and children in Appalachian communities may remain geographically closer; therefore, mothers in this region may maintain a more active parenting role and feel morally, personally, and culturally compelled to continue being a routine caregiver, even to their adult children.

Of course, we must be cautious when advancing any claim about “Appalachian distinctiveness” as such a claim mischaracterizes the region as having a homogeneous population (Swank, Fahs, and Haywood 2012, 126). When it comes to discussing cancer in Appalachia, even well-meaning discussions can fuel long-held stereotypes and reliance on reductionistic frameworks to explain a complicated phenomenon (Dorgan et al. 2009; Drew and Schoenberg 2011). The findings of our study should be used to guide further investigations. For example, a cross-cultural comparison examining mothering-disruption, including the possible “hierarchy of suffering,” would help promote our understanding of the intricacies of the cancer experience across multiple cultures, including in the historically rich and diverse region of Appalachia.

Methodological Considerations

Although our study provides insight into mothering-disruption brought on by cancer, it is not without its limitations. First, participants of this study were recruited through use of oncology nurses, local cancer centers, and snowball sampling; therefore, the study only represents a subset of self-selected women living in Southern Central Appalachia. Second, all participants were cancer survivors by means of self-report; no medical records were collected to verify cancer diagnosis. After analyzing data collected from the cervical cancer survivor, doubts emerged as to whether the participant had been diagnosed with cervical cancer or cervical dysplasia, often referred to as cervical pre-cancer (Palefsky and Handley, 2002). Due to the participant perceiving herself as a cervical cancer survivor, though, her story was not removed from the data, given that all narratives contain accuracies and

inaccuracies (Shapiro 2011). Third, our decision to not collect extensive demographics limited our ability to follow a feminist intersectionality approach (Kelly 2009). Because of our lack of demographic data, we were not able to sufficiently compare within and across-group differences. Such within-group stories are necessary to more fully understand how multifaceted identities might impact the mothering-disruption experience.

Conclusion

The contributions of our study should not be minimized, however, even given its limitations. Participants' illness narratives revealed the presence of: (1) mothering-disruption and (2) mothering-connection when parenting during the cancer experience, with these findings yielding far-reaching implications. First, we advanced scholarship focused on gender roles in Appalachia, but we sought to do so by offering complex characterizations and being mindful of overgeneralizations (Swank et al. 2012). Second, we provided insight into the seemingly opposing roles of mother and survivor, encouraging health professionals to consider the tension faced by and needs of patients who are both mothers and survivors. Third, we extended the important, but still limited research about the impact of illness on mothering (Elmberger et al., 2000, 2005, 2008). Fourth, we confirmed that women who parent during physically and/or mentally incapacitating events find ways of empowering themselves (Malacrida 2009; Elmberger et al., 2008), even while one of their primary sources of traditional empowerment is threatened (i.e., being a care-giving mother). These last two points are particularly important in that participants' illness narratives captured something remarkable: During an illness event that triggers feelings of vulnerability and challenges traditional sources of power, participants revealed efforts to regain agency and continue performing as mothers. Perhaps by doing so, familiar mothering ideologies were upheld. Yet, the women-survivors featured here were able to survive cancer in their own ways.

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