

Comorbid and Transactional Suffering: Breast Cancer Survivors in South Africa

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Abstract

Cycles of chronic illness are unpredictable, especially when multiple conditions are involved, and that instability can transform “normal” everyday life for individuals and their families. This article employs a theory of “comorbid suffering” to interpret how multiple concurrent diagnoses produce webs of remarkable suffering. We collected 50 life stories from breast cancer survivors enrolled in the South Africa Breast Cancer Study. We present three women’s narratives who grapple with comorbid suffering and illness-related work, which arise interpersonally when comorbid illnesses affects social interactions. We found that women strive to create a balance between living with comorbid suffering and continuously performing routine activities amid treatment. Discrimination and isolation were underpinned by women’s fear of being rejected by their families or how their illnesses created social distance between family members and the wider community. This study therefore illustrates how comorbid suffering requires intensive family commitments amid and beyond illness.

Keywords

breast cancer; comorbid suffering; interpersonal suffering; Soweto; South Africa; qualitative

Introduction

I am always sick, all the time I go to the hospital. My mother feels so sad because of my conditions. She has taken my only child away from me [because] she does not want him to see me this way. I feel so bad too because I want to live with my son.

—Joy (pseudonym), a woman aged 46 to 55 living with breast cancer and HIV in Soweto

Joy’s narrative excerpt introduces how suffering from physical comorbidities is deeply intermingled with other social and family relationships. Despite falling outside the purview of medicine, social scientists have been demonstrating for decades that family dynamics—be they negative or positive—have profound impacts on people’s abilities to cope with the illness, their quality of life, as well as impacts on caregivers (Becker, 1997; Kleinman, 1988; Parsons, 1951; Smith-Morris, 2018). Multiple concurrent diagnoses can produce webs of remarkable suffering that reach into every area of individuals’ and their families’ lives. As Joy’s epigraph explains, the chronicity of her illnesses extends beyond her own well-being to affect her mother as well as her son. Being separated from her son because of those illnesses causes even more agony. Joy’s suffering permeates all aspects of her life and cannot be apportioned to her physical morbidities alone.

Joy’s multiple comorbid experiences exemplify what Weaver (2016) called “comorbid suffering”—or suffering

resulting from overlapping medical conditions in one body—that “arise[s] interpersonally when social interactions are impacted by illness” (p. 3). Comorbid suffering refers to the special complications that arise when a person is managing two or more overlapping medical conditions. As the original article (Weaver, 2016) notes, suffering from multiple conditions often extends beyond the individual to their social networks, just as it did for Joy. The sheer weight and relentlessness of comorbid suffering can, paradoxically, cause concerned others to become desensitized to that suffering more quickly than they might otherwise do, especially as new diagnoses or new symptoms continually arise (as is often the case with comorbid chronic conditions). Because there is no end in sight, comorbid suffering erodes a person’s ability to

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claim a socially sanctioned sick role that affords them extra support and time off regular duties—a role that is, by its nature, intended to be temporary (Parsons, 1951; Weaver, 2016). This ultimately compromises their ability to solicit the support they need, and their caregivers' ability to provide such support.

Scholars have long noted that chronic illnesses force people to work harder to maintain a normal life. Corbin and Strauss (1985), in a classic paper, distinguished between three reciprocally interactive types of work involved in chronic illness management: illness work (which involves taking medications, visiting the clinic, prevention, and diagnostic-related management), everyday life work (which includes domestic chores, office work, marital work, child rearing), and biographical work (defining and maintaining an identity over life course). They argue that any time there is a disruption in one trajectory, there is a corresponding change in the others (also see Manderson & Warren, 2016), and chronic disease is likely to affect all three realms directly. This focus on work provides one way to understand how comorbid suffering creates and sustains life disruptions, and in combination with a comorbid suffering lens, elucidates how those disruptions in life—substantial though they are—can fade into the realm of invisibility as time goes by.

In this article, we explore comorbid suffering and illness work among Black South African women residing in Soweto, a township of Johannesburg, who have Stage III and IV breast cancer diagnoses along with other conditions. Our analytic approach is informed by notions of comorbid suffering (Weaver, 2016) and illness work (Corbin & Strauss, 1985) to conceptualize how women and their caregivers manage co-occurring cancer along with chronic disease. These women concurrently juggle chronic care for conditions like hypertension, HIV, and diabetes along with breast cancer treatment. Breast cancer is the most common cancer among South African women, afflicting one in five women with cancer and representing 10% of the entire cancer burden (Statistics South Africa, 2013). Recent studies have revealed that close to 50% of women in South Africa present at the hospital with advanced stage cancer (Stages III and IV), which significantly decreases their chances of a full recovery (Joffe et al., 2018). Concurrently, the prevalence of HIV in the region is high—estimated at 13% of the total population (Statistics South Africa, 2018), while diabetes prevalence is estimated to be 5.2% (International Diabetes Federation, 2017). In addition, approximately 27.4% of men and 26.1% of women in South Africa have hypertension (World Health Organization, 2015), although prevalence of up to 60% has been reported (Gaziano et al., 2017). As such, converging of cancer with common chronic conditions, such as HIV, hypertension, and diabetes is now common in this context (Livingston, 2012; Oni et al.,

2015). This introduces a complexity that requires intensive investment of loved ones, above and beyond their existing care commitments, to support their mothers, sisters, or daughters who face chronic illnesses and breast cancer. Yet, in urban and rural communities in South Africa, the public health sector's reach is limited, breast cancer surveillance (including other chronic comorbidities) is incomplete, and treatment is scarce (Cubasch, Ruff, et al., 2017). This means that a lack of timely treatment for other diseases will increase the burden on cancer patients and ultimately, family members may bear an especially heavy burden of managing comorbid suffering and illness work for their ill loved ones.

This analysis has particular significance for questions of caregiver burnout, when family members experience difficulties in providing care, feel overwhelmed, or sometimes cease to provide the needed support (Figley, 1998, 2002; Hardin, 2019; Yates-Doerr, 2015). This difficulty may even extend further to what Marrow and Luhrmann (2012) have called the “zone of abandonment” (also see Biehl, 2005), when family members disconnect or reject their relationships by disowning those who are sick. The disruption may arise from individuals' inability to perform previously taken-for-granted activities such as “being a mother,” creating caregiving burden to other family members, and negatively affecting their relationships (Thomas et al., 2002; Weaver, 2019).

Our analysis also suggests that in lived experience, the medical distinction between “chronic” and “infectious” diseases has little bearing on the choices people and their families make around care provision. Medical anthropologists have long questioned the overly simplistic distinction between “chronic” and “infectious” diseases (Manderson & Smith-Morris, 2010). Beyond just demonstrating how women negotiate multiple chronic and infectious diseases, these narratives build the important insight that comorbid suffering involves diseases not often labeled as “chronic” but which nevertheless may persist for long periods of time, such as cancer.

Method

This study was conducted in Soweto, an expansive urban neighborhood in Johannesburg, South Africa, that was incorporated in the 1960s, now with a population of close to 3 million people. Unlike other townships with lower income and transient populations, Soweto is known for its socioeconomic variation and largely diverse ethnic communities, including Zulu, Xhosa, Setswana, and others. The complex and multiple cultural heritages within Soweto have cultivated its own cultural vitality, with many residents spending most of their lives there and integrating multiple languages and traditions into their everyday life, such as isiZulu, isiXhosa, Setswana,

Sesotho, and Xitsonga. With its relative wealth and ethnic diversity, Soweto continues to be a major political and organizing center (Zuern, 2011).

This study draws from 2 to 3 hours mixed-methods survey and life history narrative interviews with 50 women living with breast cancer and seeking care at Chris Hani Baragwanath Academic Hospital (or “Bara”). Within Bara, the women were enrolled in the South African Breast Cancer (SABC) Study and invited to participate in our extensive narrative interviews from May to September 2017. Bara is one of the largest hospitals in the world and a public tertiary care institution that serves residents of Soweto and surrounding areas.

The women interviewed for this study resemble the broader population of Soweto: They were ethnically and linguistically diverse, low and middle income, and identified as Black. Many had resided in Soweto for many years and some migrated to Johannesburg from rural areas where they had spent their childhoods. All women were enrolled in the SABC Study, a study focused on understanding women’s experiences with breast cancer and treatment (Cubasch et al., 2013; Cubasch, Joffe, et al., 2017; Cubasch, Ruff, et al., 2017; Joffe et al., 2018), and had been diagnosed with Stage III or IV breast cancer within the previous year. In most cases, it was within the past 6 months; these women had completed treatment, such as chemotherapy, radiation, and/or mastectomy. Many also experienced other conditions—a common experience in Soweto where nearly one in four of the residents are HIV positive.

Each woman enrolled in SABC was invited to participate in a 2- to 3-hour interview with our research team. Just over half felt comfortable conducting the interview in English; the rest preferred their interviews to be in IsiZulu, Sesotho, IsiXhosa, Setswana, and often a mix of these languages with English. The women were between 28 and 76 years of age, with more than three quarters having completed less than secondary school, and more than half unemployed. Most women lived with multiple family members, often including children, siblings, or parents. All participants received 150 ZAR (around US\$10) for transportation back to their homes. Written informed consent was obtained from all women after reading out the content of the information sheet and explaining the purpose of the study. Women’s identities were anonymized and all names used in this article are pseudonyms. All procedures were approved by the University of the Witwatersrand, Human Research Ethics Committee (Clearance number M170414).

All interviews were audio-recorded and transcribed directly into English. The research team wrote extensive field notes following each interview that summarized major themes and provided a jumping off point for the development and definitions for our codebook. Four research team

members proposed codes, provided definitions, then reviewed and revised codes based on mutual agreement. Edna Bosire was the primary coder of the 50 transcripts, and two other coders spot-checked and reviewed these codes (including Emily Mendenhall). Bosire and Mendenhall discussed the codes, emergent themes, and data extensively; from these discussions, the need for more in-depth analysis of the social dynamics among women managing multiple chronic conditions alongside their breast cancer emerged. Thus, we identified women’s narratives that illustrated comorbid suffering and illness work in relation to women’s social, economic, and medical lives.

Results

We use three key informant narrative interviews to unpack these themes. Our first interlocutor, Ntabiseng, was living with breast cancer, HIV, and hypertension and described how her co-occurring medical conditions had a compounding social and emotional effect on her siblings and children, resulting in isolation and discrimination. Lerato conveyed how her breast cancer caused her over-reliance on her partner, which exacerbated physical and emotional abuse from him. Finally, Mpumi was living with breast cancer and hypertension and revealed how her cancer had an enormous social impact on her family, in this case a misfortune to her daughter’s life, although she eventually learned to accept her physical conditions. These cases convey key themes that emerged across the 50 interviews and highlight the range of comorbid suffering that arose (also see other related publications; Kim et al., 2019; Mendenhall et al., 2019).

Social and Economic Dynamics of Family

Ntabiseng’s case. Ntabiseng was a single woman aged 36 to 45, who was born and lived in one of the six adjacent communities of Soweto. Her life had been marked by a remarkable amount of suffering and loss. Ntabiseng’s father died when she was 7 years old, which is why she and her six siblings completed only primary school. Ntabiseng’s mother was a domestic worker and needed her children to help support the household financially. When Ntabiseng was in her mid-20s, her mother died. By that time, she had also lost several siblings; an elder brother died from lung cancer in 1995, one sister and one brother died from HIV, and her youngest brother died from suicide in 2013—he “hanged himself in prison.”

Ntabiseng herself had been diagnosed with a staggering number of illnesses and injuries over the course of her life. She faced a series of car accidents in 1995, 2009, and 2015. “The accidents messed me up,” Ntabiseng explained, “it affected my spine and neck, and smashed my pelvis, and this causes me pain, I also can’t work well because of

this pain.” In 2007, when seeking care for this pain, Ntabiseng was also diagnosed with HIV, and a decade later with breast cancer. Although she had been earning R2,000 (US\$136) a month as a domestic worker, with the onset of more convergent chronic conditions, and especially the buildup of chronic pain associated with the car accidents, her employers lost patience. “The lady [boss] complained that every time you are telling me about the check-ups today, tomorrow [. . .] so they chased me away because of my numerous hospital appointments.” Ntabiseng began relying on a minimal state disability grant worth R600 (US\$40) to buy food, groceries, and all her children’s needs. “Daily needs that I can’t manage, I can’t reach my daily needs and goals . . . I feel this stress will kill me one of these days.” Importantly, she did not blame one diagnosis for her physical disability—but rather, she understood her disability as a result of the combined medical and social stressors that built up over the years.

Ntabiseng’s family was supportive, but only up to a point. She and her children had lived with her two surviving siblings in harmony even after her HIV diagnosis. But her breast cancer diagnosis drove her into a deep depression—and she leaned heavily upon her siblings for support and care. Ntabiseng narrated how her siblings complained about her psychological suffering, which became too burdensome for them, as they each had their own children to care for along with her three children. It was as if they had had enough, and they finally forced her and her children out of the family house.

My siblings are isolating me because of my illnesses [. . .] Even if I had my line for washing, they don’t want to hang their clothes where I hang mine. Everything they do is to isolate me.

This isolation was not only social but also physical—after the family kicked her out of the house, she and her children had to build a shack behind the family home to live in. She explained, “They have also discriminated against my children, they forced all of us to leave the house.” One of her sons was HIV positive, and being kicked out of the house made his situation worse. “He is very sick these days because the shack where we live is not good [to help him care for his disease].”

This physical and social dislocation from the family home cut deeply into Ntabiseng’s psyche, as well as her children’s well-being. In 2010, she explains that she asked, “What am I living for? I decided to stop taking the anti-retroviral treatment (ARVs) so that I could die. It is so painful, I’m always crying. They’re not supporting me, they’re always calling me funny names.” She even offered to purchase enough poison not only for her own suicide but also for her children. Yet, God intervened,

Ntabiseng explained, so she went to the hospital for counseling. This was when she was diagnosed with depression. After repeated counseling sessions, Ntabiseng explains, “I no longer feel this way. I am better now.”

Despite the alleviation of her suicidal ideation, Ntabiseng remained troubled by her family’s treatment. It was the shame her siblings felt about her multiple diseases that bothered her the most: “They tell me to hide inside the house because they are ashamed of me and don’t want people to talk about our family.” Ntabiseng’s narration depicts how her siblings took on her suffering as their own, apparently through the perception that her illness conferred stigma to them and their larger family reputation. Her experiences clearly reflect what Goffman (1986) described as “courtesy stigma,” where an individual’s stigmatized identity is transferred to their family and social network. Elsewhere, researchers have also described the experience of patients being or feeling stigmatized by family member as “Kinship Stigma” (see Dibley et al., 2019).

Ntabiseng expressed how she felt that her family was concerned about courtesy stigma, but their withdrawal from Ntabiseng also seemed to be related to a process of burnout accrued over the years during which they had been taking care of her. As Weaver (2016) noted, an important factor shaping whether an individual’s comorbid suffering does or does not “rub off” on their social contacts is the question of disability, as it is the ill person’s inability to fulfill everyday life work that often generates excessive burden for others. Figley’s (1995, 2002) work among mental health professionals was the first to demonstrate how counselors can experience what is known as “secondary trauma” when helping trauma patients. Over time, this secondary trauma can lead to compassion fatigue and eventual burnout that makes it virtually impossible for caregivers to continue to extend sympathy to their care recipients. The psychological and social impact of caring for Ntabiseng may have simply become too much for her siblings to bear.

But there is something even deeper going on here. This intra-familial suffering illuminates the legacy of disease and death on a family over many years, and how the enduring disability of a remaining loved one may perpetuate pain and fear among healthy survivors. Ntabiseng had experienced such severe and accruing misfortune that her identity completely transformed in her family’s eyes. No longer was she a family member to whom some unfortunate things had happened; now, time had proven her to be a harbinger of bad news herself. There was thus no end to the suffering they expected her to attract, and they seemed to feel compelled to remove her—both physically and socially—from their presence, lest the misfortune further affect their own lives (also see, Markle

et al., 2015). In so doing, they pushed Ntabiseng into the zone of social abandonment (Biehl, 2005; Marrow & Luhrmann, 2012). With an ever-receding horizon promising no end to suffering, it is little wonder that Ntabiseng's family had lost the ability to be empathetic. Again, in this case, it was not a specific illness, but the social stigma and fear associated with sickness itself (and the threat of future sickness) that caused the most duress—arguably for both Ntabiseng herself and for her extended family.

Ntabiseng's experience was, unfortunately, not unique among our study participants. Family members were often a source of pain, rather than support. This was also the case for our second key informant, Lerato.

Lerato's case. Lerato, aged 36 to 45, had been diagnosed with breast cancer on top of her preexisting hypertension and HIV. Like Ntabiseng, Lerato lost her job, which left her entirely dependent on her abusive husband to support her and their daughter. Lerato was concerned about her health, but her spouse's disregard for her needs troubled her just as much. She said he "never bothers to ask what I am doing or how I am feeling." She explained,

My partner is stressing me every day, he says that I should stay in the house because I am sick. Whenever I step out to the shop to buy something, he will always accuse me that I was looking for other men.

Lerato fought tears as she described her personal insecurity within her home. "He beats me up almost every day for no reason," she said, describing numerous examples of sexual and physical abuse. This violent behavior did not diminish with her breast cancer diagnosis, and in some senses intensified. "Two days after my operation, he demanded sex, and when I said I was feeling unwell, he said that he must have sex with me because only the upper part was sick." Lerato grieved, "I have no one else to help me. I don't have a family around and I must stay with him because he pays rent and buys food." Yet, when the violence peaked, she explained, "I always run to my neighbors for refuge. But they [neighbors] can't do anything to him, they are afraid of him." Such violence was reported by more than half of our study participants at some point in their lives, a finding that is similar to early reports by the South African Comparative Risk Assessment, which showed that acts of family and community violence were the second leading cause of healthy life-years lost across South Africa (Norman et al., 2010).

The two cases provided above portray transference of personal suffering from individual women to their children and siblings and husbands, producing a dependency that these social others often rejected through disowning or violent behavior toward the sick person (also see Thomas et al., 2002; Whyte, 2015). In addition, for

some women stuck in this cycle, their own children became abusers. This is exemplified by a woman aged 26 to 35 with breast cancer and HIV who narrated her case as follows:

P: I'm scared of my son. [. . .] I feel like . . . I'm stressing him because of my diseases. Because I can see now, he got like [. . .] I don't know what I'm doing to him.

I: What do you mean?

P: How can I explain that? He's always been angry when he came back. When I talk to him, he must hit me with something, hit me with anything.

This woman read her son's abuse as an expression of his unspoken stress about his mother's illnesses. Remarkably, it seemed that his imputed stress was more of a concern to her than the fact that he was beating her. Yet, even when they were supportive, children or other family members could be a source of strain for women. This was typified in our study by a woman aged 56 to 65 with breast cancer and hypertension:

My daughter always says, "Mama, don't be stressed, because you're going to kill yourself, it will end up being a stroke [. . .] and I will feel bad." She was always with me during chemotherapy. Sometimes my daughter will not go to work. Even if I ask her to go to work, she wouldn't. She follows me all the time, her behavior is stressing me too.

In each of these cases, comorbid medical, social, and financial problems were significant contributors to women's illness burdens. Importantly, as these cases show, the presence of family members may very well be a negative factor influencing a sick person's life—not a uniformly positive one, as some studies have suggested (Dumrongpanapakorn & Liamputtong, 2017; Hobbs et al., 2015). Weaver (2016) noted the same in her work among women with diabetes in India, where a woman with diabetes, hypertension, and sleep apnea was blamed by her daughter for her lack of diabetes control, leading to feelings of guilt and resentment. Beyond the many burdens of comorbid diseases, social ostracization and critique from social others deeply affected these women's quality of life (Biehl, 2005; Marrow & Luhrmann, 2012). And as Das (1997) and Kleinman et al. (1997) have noted, this social suffering is most often multi-directional, transferring not only from the patient to their family, but also back from the family to the patient. This, as Ntabiseng's story demonstrated, can distort and even diminish one's personhood, such that the suffering individual becomes an agent of misfortune rather than a person deserving of empathy. This brings us to our third and final case of a woman named Mpumi, for whom social,

economic, and environmental stressors produced a different kind of diminished personhood when they intersected with her breast cancer and hypertension.

Meaning, Metaphor, and the Distorted Body

Mpumi's case. Mpumi came from one of the largest provinces in South Africa, where she lived for nearly 30 years before she moved to Soweto. Having lived more than 19 years in Soweto, Mpumi cared for her daughter and granddaughter while her son lived in a rural province in South Africa. Mpumi was recently diagnosed with breast cancer, but was diagnosed with hypertension in 1999, nearly two decades before the interview. She explained how she became accustomed to managing her hypertension, and only faced difficulty when she could not get to the hospital and ran out of medication.

[If] I don't have pills, I don't take medication. My chest becomes tighter and I can't breathe, I become tired as if I'm going to pass out. [. . .] Sometimes, my pills get finished and I don't have transport to get to the hospital where I can collect them.

These systemic barriers were the only impediments to self-care that she associated with her hypertension.

Mpumi felt differently about her cancer, however. She called the disease a "curse" and the "devil" because it was associated, in her mind, with an extraordinary misfortune in her family's life: While Mpumi was hospitalized from intense stress migraines soon after the cancer diagnosis, three men broke into her home when her son and daughter were alone there. Her son had been watching television, and her daughter had just arrived home from church. The men carried guns, took their phones, and raped her daughter. Mpumi's daughter was so emotionally distressed that she dropped out of school, and Mpumi blamed herself for this because she was away from her children at the time. However, Mpumi's need for treatment was immediate and intense—They found a lump in her breast, which required mastectomy. Mpumi said, "Everything that happened was because of this cancer. I was not there for [my daughter] and you know where I live it's very unsafe." Mpumi went on, "I get worried all the time that it can happen again. Anytime I go to the hospital, I get worried." After the attack, Mpumi reveals that her daughter had some post-traumatic stress, felt jittery and scared, and worried every time her mother left the house. She worried aloud, "Why can't God look after me?" and at one point stated, "Why then should I be alive?"

Now Mpumi didn't feel sick, but her relationship to her body had fundamentally changed both in a physical and a metaphorical sense in the wake of this family tragedy. First, during treatment, she described that her body's basic

physiological functions changed. "Chemo is so painful. You can't do anything. You sleep the whole week. Your body can't function. You feel hungry, but you don't have appetite. You can't even walk." When asked what constitutes "health" for her, Mpumi replied that it meant to "feel strong, I feel like I can do anything." She compared this with not feeling healthy, using words like "miserable" and "always tired." She went on to explain sickness as follows: "You don't feel anything in your heart, you just sleep. You're always in pain in your body." Mpumi's understanding of what it felt like to be healthy was a holistic one, involving her heart, body, and mind—and this account underscored how far she had deviated from that state of health herself.

In addition to these physiological changes, Mpumi described metaphorical changes to her body as well (see also Mendenhall et al., 2019). She used the metaphors "curse" and "devil" when describing how her cancer had disrupted her life and that of her family, reasoning that if it were not for her cancer, her daughter would not have been raped. She also used the word "devil" to signify that cancer was there to destroy her body and health. Mpumi also felt stress about not feeling "woman enough" after her mastectomy; she said, "What makes me stressed is that they cut my breast. And you know a woman's pride is her breast. So now I do not feel a woman." Studies have shown that metaphors structure meaning (Fernandez, 1991), and as Becker (1997) and Sontag (2001) argued, individuals recount experiences of illness disruption metaphorically, drawing on important cultural themes to help them reestablish order and continuity in their lives. For Mpumi, cancer was ultimately evil—a source of bodily destruction that exacted retribution on innocent family members, too—leaving her body "less than" what it once had been. These metaphors reveal a connection between Mpumi's and Ntabiseng's narratives because both women conveyed their suffering as being transferred to their children. The sets of children acted differently in response to their mother's illnesses—while Ntabiseng's appear to be resentful or unhelpful, Mpumi's were supportive.

Mpumi had a strong support system—including her children, older brother, and a close friend from church. These people were fundamental supporters in her treatment, medication, and food preparation, essentially helping her manage the physiological transformations she underwent with her illnesses (see Pesantes et al., 2018; Thomas et al., 2002). Unlike Ntabiseng, these family members constituted a very positive force in Mpumi's life, which may reflect a preexisting filial strength or one built through their collective trauma. Despite their help with the physiological challenges, they could not mitigate the metaphorical transformations Mpumi experienced around her body through illness. These kept her somewhat socially isolated, unable to feel comfortable starting

new romantic relationships. “So that’s why every time men approach me, I don’t want them to get closer,” she explained. “Because I’m ashamed, because I only have one breast.” Our findings parallels what Ginter and Braun (2017) reported about women with breast cancer having negative experiences with dating post-diagnosis.

Just like Mpumi, others in the study discussed how cancer disease and treatment disrupted their self-perceptions of both their metaphorical, social bodies, as well as their physical bodies. Reconciling these changes is what Corbin and Strauss (1985) referred to as the “biographical work” of chronic illness management. Biographical work was especially acute among those who had undergone mastectomy. Breasts signified a woman who could breast-feed or attract men. Loss of one or both breasts meant that their bodies were physically distorted and their social roles within the private and public spheres were transformed (see Everson, 2009; Piot-Ziegler et al., 2010). For example, a woman aged 46 to 55 said, “They cut off my breast, I feel empty because I lost my womanhood.” These findings were similar to what Linda Hunt (1998) found women describe in Mexico two decades previously: “When they talked about the causes of female cancer, they frequently reached back into their personal histories, searching for a thread, an antecedent that might explain why this illness had come into their lives” (p. 311). In this context, women described their cancers in relation to other problematic events within their biographies, such as spousal abuse or traumatic birthing experiences. Although most women we spoke to were beyond reproductive age, they nevertheless linked a loss of womanhood to the physical removal of their breast (also see Kocan & Gursoy, 2016). Furthermore, chemotherapy treatment led to loss of women’s hair and blackened their nails and skin—a physical transformation that they further linked to loss of femininity. This was exemplified by a woman aged 36 to 45 who said, “I think cancer is the worst one. I’m scared of chemo[. . .]. It changed my skin colour, I am darker, and my hair was out, my nails used to be black.”

Becker (1997) maintained that to understand the disruption caused by illnesses, we must also understand cultural definitions of normalcy. She questions what is normal for a family, for health, for womanhood and manhood, and for growing older. Now two decades with hypertension, Mpumi said, “I don’t feel that I have hypertension until I don’t take my pills. If I take my pills, I feel normal, like other people who don’t have it.” In addition, her description of health as “feeling strong” or “I can do anything” illuminated how she related her physical health to social and emotional well-being. She often minimized her pain in reference to others, such as by stating, “You can heal—despite your pain—but others have it worse.” In this way, Mpumi normalized her personal suffering and thus managed to minimize the disruption of her

illnesses in her life to some extent (see Kim et al., 2019). Yet her body had fundamentally changed, and she, like Ntabiseng, remained troubled by the transference of her suffering onto family members (through the rape of her daughter).

Although their experiences were quite different in many ways, both Ntabiseng and Mpumi had undergone processes of transformation to their personhood as a result of their illnesses. Ntabiseng’s transformation was social, and it was externally imposed: Her siblings shifted from viewing her as a sick person needing support to a stigmatized individual who could only bring misfortune to them. Mpumi’s transformation, on the contrary, was mostly located in her body as an internal process. Reckoning her illness as part of the body, and something physical—as opposed to social—may reflect a process of acceptance (reflecting a culturally scripted form of resilience) through which Mpumi was able to accept her situation despite feeling grieved by the physical pain (see Kim et al., 2019). By accepting the idea that her suffering was not as bad as some people’s, and focusing on her health in terms of how she physically felt, she moved beyond her personal suffering to focus more on the collective affliction of those who “have it worse.” These varied kinds of transformation reflected very different social experiences for each woman: Ntabiseng was socially ostracized, while Mpumi was strongly supported by her family and social networks.

Conclusion

This study explored how comorbid suffering influences women’s breast cancer experiences, and how those experiences can transform fundamental personhood by generating new kinds of illness work in people’s and their families’ lives. Our narratives showed that women experienced disruptions or disabilities as a result of their illnesses—some social, some physical. In each case, women felt themselves transformed. These disruptions alienated women from their routine activities (both in public and private spheres), while altering their identities (see also Pritlove et al., 2018). Importantly, this was not only a personal experience; it also became interpersonal (when shared) or transpersonal (when stress was passed along) with other family members. This transference of suffering was most common when sufferers depended upon family members for care or financial assistance. Earlier studies have argued that living with chronic illness can disrupt people’s identities (Becker, 1997; Capps & Ochs, 1997; Kleinman, 1988; Mattingly, 1998; Mendenhall, 2012; Whyte, 2015) and that comorbidity may cause a greater negative impact on patient–family relationships due to additive care needs (Nichter, 2016; Weaver, 2016). In this study, everyone had experienced serious, potentially life-threatening disease. But the women who

struggled the most were those whose social worlds had eroded along with their illnesses, such as Ntabiseng. We found that a culturally defined notion of resilience—in this case, acceptance of one's conditions—may function as a critical mediator of interpersonal suffering between an individual and their family, as was the case for Mpumi (also see Kim et al., 2019).

Women's comorbid suffering was transformed through their social worlds, when stigma or fear of judgment from neighbors caused caregivers to treat breast cancer survivors in ways that inevitably had an impact on their well-being (also see Bell, 2014; Markle et al., 2015). For instance, Ntabiseng reported how her siblings deterred her from walking on the streets so that their neighbors would not shun them (which mirrored the case of Lerato as well). Living with chronic conditions was challenging not only for patients but also for their families. Although studies have shown how families or partners discriminate against cancer patients due to their diseases (Lobchuk et al., 2008; Marlow et al., 2015), we found discrimination and isolation were often underpinned by the threat that women with cancer posed to family social relationships: women's fear of being rejected by their families, denial, or social distance created between the family members and the wider community. Ntabiseng's story illustrated how the presence of social others is not always a benefit to people with illnesses; rather, it may be a significant source of burden (see Pesantes et al., 2018).

Recognizing the complex relationships among people living with acute and chronic illness and their family members is critical for thinking about the illness experience. In many ways, health services can intervene to identify those who struggle to achieve optimum health according to clinical standards. But this is probably not enough to help women like those in our study; other socially mediated interventions that mobilize the social and emotional resources around the patient would also be necessary. Moreover, our findings provide a deeper understanding of informal care systems (e.g., home context) that are often overlooked in policy and practices which seek to shift care from hospitals to community. Thus, it is imperative to recognize how family members and caregivers face challenges specific to their caregiving activities that can negatively affect their mental health (Maes, 2017; Thomas et al., 2002). These narratives reveal the complex social worlds surrounding comorbid suffering and the impact of illness work on the lives of ill people and their social contacts. Health care providers must take seriously how patients make calculated decisions about their health while they work to balance symptoms, social roles, positive identities, and daily life.

This study has implications not only for health care practitioners, but also educators, health advocates, caregivers, and family members who are involved directly or

indirectly in caring for patients with chronic illnesses. The public health sector in South Africa is limited to provide care for patients with chronic comorbidities, including breast cancer (Cubasch, Ruff, et al., 2017). There is need for training and equipping health care professionals (especially in medical schools) with both cultural and structural competence skills that can help them better understand and manage patients with chronic medical and social issues. Good and thorough communication between the patient and health care provider is also of utmost importance. Shifting care from hospitals to community and patient's homes requires intensive family commitment. There is need to strengthen informal care systems through equipping caregivers with skills on chronic care management and also providing them with strategies for coping with caregiving burden. This may help reduce some of the stress experienced by caregivers and also to take care of self and balance the caregiving burden.

A limitation for this study is that it only focused on women with breast cancer and comorbidities. These findings may not reflect men who are patients with cancer and comorbid experiences, given the differences in gender roles, which may influence transference of suffering from the patient to other family members. Another limitation is that all study participants lived in Soweto, which is a low-income setting in South Africa and our findings may not reflect women from higher income settings. Moreover, we did not speak to caregivers or family members of the women who participated in this study; instead, women's narratives powerfully conveyed the significance of these social dynamics in their experiences with cancer and comorbidity. As such, their interpretations and perceptions might be different from that of their caregivers. More studies are needed that use both qualitative and quantitative methods, and also from high-income settings to confirm our findings or shed more light on comorbid suffering for individuals with multiple chronic illnesses. It is paramount for future researchers to explore caregivers' experiences on caring for women with breast cancer and comorbidities.

Authors' Note

E.N.B. and E.M. contributed equally to this article.

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