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Cancer, chemotherapy, and HIV: Living with cancer amidst comorbidity in a South African township

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ABSTRACT

Cancer is on the rise in Sub-Saharan Africa. In South Africa, where cancer detection, intervention, and care are available for many citizens, cancer is poorly detected and understood among politically and economically marginalized communities in rural and urban centers. These trends are reflected in a history of systematic marginalization of such contexts from public resources, including education and health care, stemming from racism and wealth inequity. This article investigates how Black South Africans residing in Soweto, a township of Johannesburg, perceive and experience breast and prostate cancers amidst multiple, concurrent medical conditions. We used convenience sampling to recruit 80 study participants already enrolled in longitudinal studies of breast and prostate cancers at a tertiary hospital in Soweto between June and August 2017. This included 50 women diagnosed with breast cancer and 30 men diagnosed with prostate cancer; three-quarters of the sample had two or more comorbidities, including HIV, hypertension, diabetes, anxiety, and others. Many described sickness in terms of any physical ill-health that affected daily routines, but rarely was it associated exclusively with a specific disease. Men and women described more fear associated with cancer than HIV or hypertension—two of the most common diseases. We found that this may be in part a reflection of how people feared and demonized their cancer diagnoses, calling it “a demon!”, and framing cancer through the trauma of aggressive treatments like chemotherapy (“the red devil!”) and physical disfigurement from mastectomy. In contrast, men's prostate cancer treatments were often hormonal therapy and men associated cancer to a normal side effect of aging. Intervening in how people think about cancer may improve how people live well with the condition amidst other cascading social and health problems they face.

1. Introduction

Cancer is on the rise in sub-Saharan Africa. In South Africa, where cancer detection, intervention, and care are available for many citizens, cancer is poorly detected and understood among low-income communities in rural and urban centers. These trends align with a history of systematic marginalization from public resources, including education and health care, stemming from racism and wealth inequity that fuel disproportionate affliction of multiple conditions, including HIV, among those who have been most politically and economically oppressed (Fassin, 2002, 2007). These inequities are most stark in South Africa's national health indicators that – despite being a middle-income country – reflect the health burdens of a low-income country when considering maternal deaths and undernutrition (Coovadia et al.,

2009). The Black population within South Africa bears the burden of these health inequities—largely due to the social, economic, and environmental conditions cultivated by apartheid. Conditions like overcrowded squatter settlements, migrant labor, and underdeveloped health services for lower income populations reflect the historic racism that fosters a favorable environment for infections, including HIV and tuberculosis (Karim et al., 2009). Although those who identify as Black have the lowest incidence and prevalence of cancers compared to those who identify as White, incidence and prevalence are increasing (Singh et al., 2017) and converging with common chronic conditions, such as HIV, hypertension, and diabetes (Livingston, 2012; Oni et al., 2015).

Nearly one in five people with HIV globally resides in South Africa. The salience of HIV within medical and social settings is in part why HIV has come to define chronic illness in South Africa. Yet, increasingly

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living with HIV and/or chronic illness more broadly cannot be defined by an infectious or non-communicable condition but rather it must be understood through by multiple, convergent ones (Clark et al., 2015; Oni et al., 2015). For instance, Oni et al. (2015) found hypertension, HIV, diabetes, and tuberculosis were the most common conditions for which patients sought medical care at a public clinic in Khayelitsha, a township in Cape Town—22% of these patients had more than one of these conditions. To fully understand how people perceive and experience cancer in this context, then, we must move beyond “acute-chronic distinctions” and recognize how cancer situates itself within complicated life stories that produce “chronicity”—an understanding that people’s identities are fluid and introductions of new sickness requires navigating between self and diagnosis (Estroff, 1993; Manderson and Smith-Morris, 2010). The chronicity of cancer departs from its acute diagnosis in part because 20% of residents in neighborhoods like Soweto are diagnosed with HIV and living on antiretroviral treatment (ART), and many of these individuals face other concurrent conditions like diabetes and hypertension (Levitt et al., 2011).

This article investigates how people perceive and experience breast and prostate cancers amidst multiple, concurrent conditions in Soweto, an urban South African township with a diverse ethnic and linguistic history. In Soweto, many people perceive HIV as the gold standard of chronic treatment-seeking, thereby blurring lines between other chronic conditions (like diabetes) with HIV because of its decades-long treatment programs, extensive prevention messaging, and broad community awareness (Mendenhall and Norris, 2015). Many also perceive chronic conditions like diabetes to be *worse* than HIV because they affect eating patterns, family relationships, and finances, as opposed to HIV treatment in Soweto conveyed as somewhat normalised by taking a pill (Mendenhall and Norris, 2015). Malambo and Erikson (2018) found that in Swaziland, an adjacent country with similar HIV affliction, many people considered cancer diagnosis to be *worse* than HIV in part because of people’s unfamiliarity with the condition and fear of aggressive treatments. They argue that “the recent abundance of clinical space, expertise, money and programing is weaving a new social history of HIV, relative to cancer. HIV, a disease that had once been declared a natural disaster (Daly, 2001) has become normalised, while cancer is increasingly understood as a bigger threat” (Malambo and Erikson, 2018: 4). One goal of this study was to investigate whether our interlocutors in Soweto perceived cancer (like diabetes) to be a ‘worse’ than HIV, and if so, why and in what way?

These cancers are common in Southern Africa, as they are globally (Ferlay et al., 2014). Prostate cancer generally afflicts those with advanced age (Dewar et al., 2018), and thus afflicts many people who have faced (or are managing) multiple medical diagnoses throughout their lives. Many argue that environmental risk factors, such as living in proximity to gold mines (Schonfeld et al., 2014), may play a powerful role in producing prostate cancer (Tindall et al., 2013). Among women, breast cancer is the most common cancer and recent research shows that 20% of those diagnosed with breast cancer in Soweto also have HIV (Cubasch et al., 2013; Cubasch et al., 2017a,b; Singh et al., 2017). Most Black women residing in urban areas, where diagnosis is more likely than in rural areas, are diagnosed when their breast cancer is in the later stages, compared to other racial groups, often making treatment urgent (Joffe et al., 2018; Rayne et al., 2019; Singh et al., 2017). Recent studies found that more than half (56%) of women were diagnosed with breast cancer at stage III and IV in Johannesburg academic hospitals, and that delay in care seeking of greater than three months was significantly associated with advanced stage at diagnosis (Joffe et al., 2018; Rayne et al., 2019).

In this article we focus on how people describe health, sickness, comorbidity, multimorbidity, and the positive and negative experiences of care seeking for multiple diseases, sometimes overlapping and other times quite divergent, conditions. In this way, we investigate how people describe their sickness and health, amidst a cancer diagnosis that is situated within a longer history of chronic illness, from

hypertension to HIV, diabetes, anxiety, and arthritis. Then, we consider how people describe their cancer, by explaining what they think it does, how it should be treated, and the ways in which people perceive it. Finally, we explore the ways in which cancer diagnoses and treatment figure into the complex battery of treatments associated with the often two or more conditions people manage.

2. Methods

2.1. Context and sample

Study participants were from Soweto, a prominent urban township on the southwest side of Johannesburg, South Africa. Johannesburg is the largest city in South Africa, with nearly eight million people and more than one million residents in Soweto. Soweto residents exemplify South Africa’s diversity, representing the country’s various socio-economic, ethnic, and linguistic backgrounds. Many of Soweto’s residents rushed to Johannesburg from rural areas around the country in the early 1900s. At the time, an explosion of industrial opportunities, especially in the gold mining industry, attracted rural workers, increasing urban Black residents nearly ten-fold and transforming the urban demographic landscape. Many who worked in the gold mines resided in Johannesburg, although most were evicted by the British in the early 1900s and relocated to segregated townships (Thompson, 2001). As a form of resistance to state-sanctioned violence by apartheid, Soweto organized the incorporation of six separate townships, now serving as the home of more than 1.2 million residents with diverse ethnic backgrounds, representing multiple histories and language groups, including isiZulu, isiXhosa, Setswana, Sesotho, and Xitsonga. The complex and multiple cultural heritages within Soweto has cultivated its own cultural vitality, with many residents spending most of their lives there and integrating multiple languages and traditions into their everyday life. This ethnic and linguistic diversity was represented by our study participants as well, with most people speaking isiZulu, with English, and many speaking two or more languages, even within the same interview. With its relative wealth and ethnic diversity, Soweto continues to be a major political and organizing centre (Zuern, 2011).

Our study was conducted at the SAMRC Developmental Pathways for Health Research Unit (DPHRU) at the Chris Hani Baragwanath Academic Hospital commonly known as (“Bara”). The world’s third largest hospital and Africa’s largest, Bara is a publicly financed teaching hospital for the University of the Witwatersrand Medical School. One building on Baragwanath Hospital’s vast campus is the headquarters of DPHRU, where residents from Soweto have been engaged in research for nearly three decades. The 80 study participants engaged for this study were recently diagnosed with either breast cancer or prostate cancer and enrolled in other studies at Bara within the past year. Fifty women were recruited from the South Africa Breast Cancer (SABC) study: of which 15 reported an additional hypertension diagnosis and 15 reported HIV. Thirty men were recruited from the Men of African Descent with Carcinoma of the Prostate Consortium (MADCaP) study: of which 13 reported an additional hypertension diagnosis and eight reported HIV. Most sought care at Bara or outlying community clinics (especially for other comorbidities), and only some supplemented this care from private clinics, and fewer from traditional healers. All had received care from the public system for most of their lives.

There are no district or regional levels of care in Soweto. Bara provides tertiary (level 3) services. This means that patients are referred directly from primary health facilities to Bara, reducing delays that could have been experienced in the other levels of care (Joffe et al., 2018). As a consequence, up to 50% of patients are detected with late stage cancers at the Bara breast clinic (Cubasch et al., 2013), compared with 70% among patients detected elsewhere in South Africa. Breast cancer treatment usually involves some combination of radiation, chemotherapy, and surgery; 70% of all patients undergo surgery

combined with eight treatments of chemotherapy spaced every three weeks, and for those who receive radiation therapy, a six-week daily treatment course (Cubasch et al., 2013). All patients involved in this study had their breast or prostate cancers identified before it was too severe to treat; those with advanced stage cancer and those with untreatable cancers were excluded from the study in order to respect their privacy and health. In contrast, most prostate cancer patients receive hormonal therapy only, and very few received radiation.

2.2. Data collection

We utilized convenience sampling for this study, inviting those study participants in the parent studies to participate in our extensive life history narrative interview at DPHRU during their routine medical visit in the cancer clinics at Bara. Our interlocutors were already enrolled in SABC or MADCaP and willing to participate; we believe their existing relationships with Bara and the parent studies facilitated our study swiftly and ensured trust and confidence. We conducted 80 extensive life history narrative interviews lasting between two and 3 h between June and August of 2017. These interviews involved multiple sub-sections focused on early life experiences, social dynamics, family life, social stress, resilience, illness and diagnosis, comorbidities, self-care, treatment, and care seeking. For this article we focused on questions such as “What does health mean? What does it mean to be healthy?” and “What do you call your illness?” and “One of the reasons you have been invited here today is because you have previously been diagnosed and treated for cancer. What words do you use to describe cancer?” We also asked “What is cancer?” and “Can you tell me about when you were diagnosed?” We also asked multiple questions about comorbidities, such as: “I am interested in your experiences with hypertension. Do you call it by any other name? What words do you use to describe your hypertension?” Finally, we asked about treatment, care-seeking, and self-care for cancer and other co-occurring conditions; for example, we asked, “Can you tell me how you manage your health? Do you do separate things for different conditions? Can you tell me about self-care?”

Although there are eleven official South African languages, our interlocutors spoke five distinct languages, reflecting the ethnic and linguistic diversity within Soweto. Three women conducted the interviews with women—two of these interviewers conducted interviews in English only (with the assistance at times from a translator). This translator also accompanied nearly every one of the interviews with men, which were conducted by a one male and one female interviewer. Twenty-nine interviews with women were conducted in English (56%), while 13 were conducted in IsiZulu, four in IsiSotho, two in IsiXhosa, and two in Setswana—many involved a combination of two languages (mostly English and one other). Fifteen interviews with men were in IsiSotho (50%), eight in IsiZulu, five in English, and one each in Tswana and Tsonga; many interviews involved a mix of languages. We also conducted the Centre for Epidemiological Studies Depression Scale (CES-D) that has been validated in IsiZulu and IsiXhosa (and we translated into IsiSotho) (Baron et al., 2017). Due to the lengthy interviews, we had a 10-min break in the middle of the interview and provided participants with a cup of tea or coffee and snack. Study participants were compensated 150 ZAR (\$10) for their time and travel. All data collection received clearance by the University of the Witwatersrand Human Ethics Committee (Clearance number M170414), and all participants provided informed consent.

Notably, some might perceive the incredibly long interviews and large research team to be a limitation. Linguistic complexity required that we employ two research assistants to interview or translate those interviews conducted in any of the five local languages spoken (often interchangeably) among our study participants. These two colleagues were a critical part of the research team and in some cases solely conveyed our core questions in multiple ways; there is a possibility that some questions may have been complicated or lost in translation. The

four English-only speaking interviewers may have impeded rapport within interviews, as well, especially when interlocutors did not prefer to speak English. Nevertheless, we find our diverse backgrounds an added strength to the robustness of discussions, reflections, and analysis of data.

2.3. Data analysis

All interviews were audio-recorded and transcribed directly into English by a third-party translation company that deals with complex, multiple-lingual dialogue common in contexts like Soweto because the 80 interviews were conducted in multiple languages (even within the same interview). Immediately following each interview, the research team wrote extensive field notes summarizing major themes and to communicate any non-verbal interactions or dialogue that was not recorded. Several members of the research team (including EM, ENB, AWK) met to generate a code book from the interviews and field notes that involved codes and detailed definitions that were then reviewed and revised codes based on mutual agreement. The second author (EB) carefully applied these codes to the transcripts, which were then reviewed by the first and third authors (EM, AWK) using Dedoose qualitative analysis software (Dedoose 8.1.9). No disagreements in coding were found. For this article, we focus explicitly on codes that described how people perceived and experienced health, sickness, comorbidity, multimorbidity, and care-seeking for cancer and other comorbid conditions in this context; we have published elsewhere on other core themes, such as resilience (Kim et al., 2019; Mendenhall and Kim, 2019).

3. Results

Our interlocutors can be classified as two distinct groups by gender and cancer type (Table 1). First, women in our sample were all diagnosed with breast cancer, had an average age of 49 years, and most completed matric and/or pursued post-secondary education. Second, the men had been diagnosed with prostate cancer, were significantly older (average age = 67.6 years) and were unlikely to have higher education or completed matric. The average monthly income was similar for men and women: 2824.80 ZAR (196 USD, 147 GBP). Most participants experienced some form of co-morbidity, and we explicitly recruited some cancer survivors with HIV or hypertension (See Table 1) because we were interested in how people navigated between cancer and these two most common chronic conditions in Soweto.

In what follows, we present the complexities of multi-morbidities found within the sample, highlighting the frequency in which they occurred and with what they overlapped. We also present descriptions of how our study participants perceived, named, and experienced these conditions. Then, we introduce how our interlocutors described sickness and health generally, which is followed by a section describing how people perceived and experienced both cancer diagnosis and

Table 1
Demographics.

	Women (n = 50)	Men (n = 30)	Total (n = 80)
Age (mean ± SD)	49 ± 11	68 ± 7.8	56 ± 13
Education (n,%)			
Completed Primary School or less	6 (12%)	12 (40%)	18 (23%)
Completed or Attended Secondary School	40 (80%)	17 (57%)	57 (71%)
Completed technical or graduate school	4 (8%)	1 (3%)	5 (< 1%)
Income (mean ± SD)	2971 ± 2102	2614 ± 1822	2824.8 ± 1984
Pension (R1,600) or less	13 (26%)	11 (37%)	24 (30%)
More than pension	23 (46%)	14 (47%)	37 (46%)

Table 2
Ever diagnosed morbidities and psychological symptoms (N, %).

	Women (n = 50)	Men (N = 30)	Total (N = 80)
<i>Ever Diagnosed</i>			
Hypertension	20 (40%)	18 (60%)	38 (40%)
HIV	16 (32%)	8 (27%)	24 (30%)
Obesity	1 (< 1%)	1 (< 1%)	1 (1%)
Diabetes (T2)	4 (8%)	4 (13%)	8 (10%)
Tuberculosis	4 (8%)	1 (< 1%)	5 (1%)
Arthritis	3 (6%)	2 (3%)	5 (1%)
Chronic Pain	3 (6%)	1 (< 1%)	7 (9%)
Depression	2 (3%)	1 (< 1%)	3 (4%)
Anxiety	4 (8%)	0	4 (5%)
2 + Comorbidities	36 (72%)	22 (73%)	58 (73%)
Comorbidities (mean)	2.34	2.27	2.31
<i>Symptom Report</i>			
Depression	27 (54%)	23 (76%)	50 (62.5%)
Thinking Too Much	36 (72%)	20 (66%)	56 (70%)
Acceptance	26 (52%)	13 (43%)	39 (49%)

treatment specifically. Finally, we have two sections on how people navigate multiple morbidities by addressing how people differentiate between conditions and how they manage them.

3.1. Complexity of multi-morbidities

All of participants were previously diagnosed with breast or prostate cancer and nearly two thirds were pre-selected to have been diagnosed with hypertension or HIV. However, [Table 2](#) demonstrates the complex multi-morbidities in our participants, with many reporting more than two. The mean number of morbidities was 2.3, and most participants (73%) had two or more diagnosed conditions. Those who had been recruited with an existing comorbidity were likely to have one more. Besides the diagnosed conditions seen in [Table 2](#), participants reported additional complications such as sinus problems, eczema, allergies, asthma, migraines, skin pigmentation disorders, and erectile dysfunction.

The most common comorbidity was hypertension, commonly referred to as “high blood”. Most participants associated high blood with eating unhealthy foods, living a stressful life, or thinking too much. One 62-year old woman described high blood as “when you're always stressed and worried, that's the thing that raises the high blood, because you're constantly worried, and it needs to go down.” Equally, a 70-year old man said when you are thinking too much “you think here I've got nothing today, you think I have got sugar [diabetes], you think about my kid, what is he doing, you think about your wife [...] all those things are building the high blood.” Even though many were pre-selected to have hypertension, 40% of women and 60% of men reported ever having been diagnosed with hypertension. This accounts for an additional five women and three men who had not been previously identified as having this comorbidity during recruitment. HIV was the second most prevalent comorbidity, with 32% of women and 27% of men reporting their diagnosis, accounting for one woman who was not previously identified during recruitment. The two other most common comorbidities included type 2 diabetes and chronic pain (10% and 9%, respectively).

Rarely had our participants ever been diagnosed with anxiety or depression, although those who had received a diagnosis from a health professional reported three, four, or five other morbidities. All of these individuals also reported a high number of depressive symptomatology based on scores from the 10-question Centre for Epidemiologic Studies Depression Scale (CES-D). Despite low rates of diagnosis, most women (54%) and men (76%) reported depressive symptoms, and even more women (76%) and men (66%) reported the idiom of distress “thinking too much” (see [Kaiser et al., 2015](#) and [Table 2](#)). Some participants also reported suicidal thoughts and feelings of hopelessness, and chronic fatigue during interviews.

3.2. Defining sickness and health

Most participants described simply being sick rather than describing their specific conditions. When asked about her cancer and hypertension, one 74-year old woman said that they are “the same. When you have it, you have it, and if you care for yourself, you care for yourself.” This may have been in part because, despite most having been diagnosed with two or more comorbidities, half of our study participants expressed having accepted their condition and released this burden.

Many people defined sickness as bodily pains, such as “my body is painful” or “my knees are painful” or “the whole body is painful”. The most common framing was an inability to do what they were capable of in better health. One man described his devastation of losing his dominant social role within his family after becoming sick because he was unable to care for his family—his grief was so intense that he considered taking his own life. As such, many defined sickness as the absence of health or, as one 61-year old woman said, “to have hindrances in life, not able to eat this, not able to do that, not able to reach that.” This was exemplified by a younger woman (43 years) who stated, “Being sick to the point of not being able to get out of bed, that's being really sick. Even if something falls to the floor you have to wait for someone else to pick it up for you because that's how sick you are.”

Some participants perceived sickness only through the guise of physical symptoms. Many connected their sicknesses to how they felt and the symptoms they observed, rather than with their specific diagnosis. It is physical symptoms, not a diagnosis from a health professional, that make someone consider themselves to be “sick.” One 41-year old woman with breast cancer and HIV said, “To tell you the truth, I even forget that I have HIV. Is it because it doesn't make me sick?” Another 52-year old woman with breast cancer and hypertension expressed, “I don't feel that I have hypertension until I don't take my pills. If I take my pills, I feel normal.” This kind of normalcy was also linked with participant's ability to continue functioning in day to day activities both at individual and family levels, despite their illnesses.

However, such normalization did not make them forget that they were sick. When they experienced symptoms, which barred their everyday activities, diseases suddenly took up their attention and reminded them of their own fragility as describe by a 59-year-old woman “I am not able to sleep at night, I don't know which side to sleep with, my body is always painful.” And this drove participants wishing that it would be better if their diseases, and especially cancer would be removed from their bodies. Those who perceived cancer as a removable object had confidence and trust in both doctors and God. One 59-year-old man said “It [cancer] affects me, and eats my muscles, but I trust the doctors to help me live and God, I asked God and the doctors to get rid of this demon [cancer] in front of me.”

In contrast, many did not attribute their disease to sickness, and associated it with aging. This was most common among men in part because the sample was much older than the women. For instance, a 65-year-old man said, “I think when you are old things are coming just like this. When I came back from Bara, I told my wife that I had prostate cancer, [...] I said oh well, its old age.” A woman of the same age said, “HIV, high blood, or cancer, I don't think they have changed my life, it is just old age taking over.” This perception of aging and the clustering of multiple conditions was evident among many interlocutors, including a 60-year-old woman who simply said, “I am not sick when I got cancer, I am not sick. I am just like anybody who takes treatment for high blood, for hypertension, for sugar diabetes.”

Conversely, healthy people were said to be generally younger, able to “work hard” and overall experience a less stressful life. A 42-year-old woman defined health as “[when you are able] to do things like washings, clean your house, cook [...] able to do whatever that you have to,” which was the opposite of being sick, ill, or disabled. One woman described health in terms of survival: “you have to look after yourself.” Many expressed health as something that was visible; this was often juxtaposed to illness: the less visible the disease, the healthier

the person. Others (mostly men) related health to active sex lives, such as a 61-year-old man who said, “because of my health I’m no [longer] able to sleep with my wife.”

3.3. Understanding cancer

When asked what they thought about cancer, most reported that they did not know what caused cancer, such as one woman who said: “I don’t even know the cause of it.” Another woman in her mid-thirties said “They say to me that cancer is the cells inside your body that kills your body, but what causes this problem? I don’t know.” Others used the word “demon” to describe cancer; one man said, “I take it as a demon, I don’t know what I can call it [...] it kills.” On the other hand, a 47-year old woman linked her cancer with stress throughout her life, stating, “they tell me I got cancer, I’m not surprised. Because I was under a lot of stress.”

Many people perceived cancer as fatal. A 44-year old woman said cancer is “a disease that cannot be cured. When you have cancer, you die.” Similarly, a woman in her early thirties grieved that cancer “eats” away at you, such that it normally “comes back after five years, so you can’t say you’re cured when you have cancer.” A 50-year-old woman explained that in IsiZulu, the word for cancer is *umdlavuzza*, meaning “something that bites aggressively.” Many participants stated that they feared their cancer would return five or ten years later even if fully cured. People expressed distress over not knowing where cancer would strike next. One 41-year old woman described her cancer as “eating” her, having first taken her breast, and feared that “next time it will eat your hair, or the other side.”

Other patients commonly singled out cancer as different from their other comorbidities due to its unique treatment. When asked which of the diseases was better, most participants ranked cancer as worse than others. A 54-year-old woman said “I think if I had just high blood my life would be better than now with cancer.” Others used statements such as “cancer is the worst”. While comorbidities such as hypertension and HIV were commonly treated with oral medications, which were seen as mostly an inconvenience, cancer was differentiated because its treatment frequently required combined surgery and chemotherapy. One 42-year old woman with breast cancer and HIV compared the difference in treatment intensity as such: “Because HIV, you just take the pills and then done. Cancer, it’s got so many things. So many things.” The difference in treatment intensity was seen as drastic, such that a person with only HIV and/or hypertension could still go about their daily lives without much interruption. One 30-year old woman bemoaned that, “before cancer, I had a normal life, I struggled and worked and did not depend on anyone ... [now] I am limited.”

Chemotherapy was a source of major concern, it was commonly referred to as “the red devil” or “a poison that attacks the cancer” and was believed to not only attack the cancer but also damage the whole body, making patients sicker. This led to some patients going so far as to say they would rather get a mastectomy than undergo chemotherapy, describing the pain from the operation as “much better” than the pain from chemotherapy as exemplified by a 56-year-old woman “the operation is better, even those ladies from Joburg Gen [Hospital] would say to me, ‘operation is better than chemo’. Yes, chemo is bad, you don’t have a taste for food, you vomit, you can’t eat, your skin goes black, hair falls out, finger nails change color, your feet are sore.” One other 42-year-old woman cited a family friend as having “her breast amputated so she didn’t have to go through chemo.” Many people found chemotherapy so painful that the treatment itself could actually kill you, with one 44-year-old woman saying, “if you are weak, [you say] cancer killed you, only to find out it is the treatment that killed you.” Some patients thought of chemotherapy as a separate sickness from cancer; a 42-year old woman differentiated the two when she said, “cancer is much better than chemo. Chemo is a modern cancer in your body. You’re sick with modern cancer which makes you miserable.”

Because both surgery and chemotherapy are more intensive and

more visible markers of sickness, a great deal of participants cited cancer as the least favorable condition to have out of their other comorbidities. Many compared cancer negatively to HIV, such that HIV is less detectable and still allows one to live a normal life. One 44-year old woman noted that “HIV people carry on with their lives as long as they take their treatment ... a person tells you that you know I’m HIV [positive] but you don’t see anything wrong with him.” Yet, cancer was described through by how treatment transformed the physical self. One 62-year-old woman spoke of her experience with chemotherapy as having “really messed me up. It changed the way I looked. I lost weight. I became much darker. I really fell ill that time.” Distress over hair loss, skin pigmentation changes, darkening of nail beds, and weight fluctuation was common. In many ways, women rejected these changes, as woman in her early forties said with chemotherapy “your hair will be gone, your nails will be dark, everything [...] I was so ugly.”

Some women that had undergone mastectomies stated that they felt disfigured. One 33-year old woman remarked that after “they took out my breast, [it made me feel kind of] like I’m uncomfortable with myself, my body.” Another 52-year old woman also spoke of feeling desexualized after her mastectomy: “They cut my breast. And you know a woman’s pride is her breast. So now I do not feel a woman. So that’s why every time men approach me, I don’t want them to get closer, because I’m ashamed, because I only have one breast.” One 30-year old woman said, “I am forced to always have [an artificial breast] on in order to hide the fact that I have one breast, because people look at me in a funny way. They don’t accept me the way I am.” On the other hand, some women described a process of normalization of their post-operative self: a 40-year-old woman spoke of interactions with her neighbors after her mastectomy: “Neighbors, they don’t even believe. They be like, sure you have [had a mastectomy]-can I see? Can I see? I don’t believe, it’s like you are normal to me. And I’m like can’t I act normal? I just don’t have a breast.”

3.4. Differentiating between conditions

Most participants described co-existing conditions to be “the same” or identified cancer as the condition most concerning. Some said cancer was “like HIV. You can treat it.” But it was also common for people to differentiate conditions by the intensity of treatment and risk for fatality, as exemplified by a 61-year old man who stated that all his conditions seem “the same because they all kill if they aren’t taken care of.” Many associated cancers with death, such as a 44-year-old woman who said, “People with HIV live and people with cancer don’t live.”

There were other important parallels between cancer and HIV. Many spoke of a new form of stigma that has emerged around cancer, much like before observed for HIV. One participant stated, “They hid HIV before. But now they talk about it. Now, they hide cancer. People, they are very negative about cancer.” HIV remains highly stigmatized, as several patients noted, although, such stigma does not seem to be associated with death (as cancers do). Although nearly one-third stated that they would not talk openly about their cancers, many people describing unburdening their cancer diagnosis only to close family members, despite fears that it would cause their loved ones’ distress. A 43-year-old woman exclaimed, “I don’t want to see them [my family] crying, the suffering. I know they are going to cry.”

Many modeled their understanding of cancer and other comorbidities around people who they know had experienced these conditions. For instance, a 61-year-old man diagnosed with prostate cancer said, “I think I’m gonna die and that gives me stress, because in the last two weeks I buried my brother-in-law who died of prostate cancer.” Similarly, a 49-year-old woman receiving treatment for breast cancer said she overheard “one of [my neighbor’s] daughters was talking to my son saying, ‘wow, cancer is spreading in our community, because my mother died of cancer and another neighbor died of cancer. Now it will be your mother’”.

This fatalism, defined by a perceived inevitability of cancer, may be

why many people described suicidal ideation. This is exemplified by statements by the following older man: “I was thinking of killing myself, committing suicide.” A younger woman with HIV, cancer, and hypertension relayed similar feelings: “There was a lot of stress on my mind, I couldn't handle it and I wanted to die.”

3.5. Managing multiple conditions

Study participants who had undergone treatments for cancer and HIV revealed the most arduous experiences managing their multiple conditions. Many participants reported that their white blood cell count dropped dangerously low during chemotherapy, and that their HIV required closer care during their chemotherapy treatments. One 49-year old woman said outright, “chemo really almost killed me. It was the cause of my white blood cells dying, [the doctors] told me that my CD4 cells are down.” In addition, some participants felt that cancer and HIV were the most difficult diseases to manage because they distorted their bodies and affected their personal identities. A 65-year-old woman said “I think I am not a person anymore because I have two illnesses and they are both strong. Cancer and HIV, which means that my body is fucked up, I don't think I have anything anymore.”

However, because many participants thought of their co-existing conditions as “the same,” many people thought that having additional chronic diseases did not impact their lives more than having just one. One 57-year old man, upon being asked if his life would be different if he just had condition, replied, “I don't think so. I would still be suffering from that disease and I would still be taking daily medications. So nothing changes there.” Another 62-year-old woman, with cancer and hypertension, stated, “I would say they're almost the same because they're both diseases, I have to take care of both of them, and not put one aside in favor of focusing on the other.” This may be due to similarity in treatment for those who only had to take oral medication. Yet, one man stated, it was “a burden to him” to “carry my tablets with me all the time,” and expressed frustration at not being able to travel and spend the night elsewhere because he left his medication at home.

Another woman spoke about the complexity of multiple co-occurring conditions, indicating that she was at her tipping point. She said, “Right now I have these three [diseases] but it is still ok, but if I have another one and make it four, I will not be right [...] there are those that live with about five diseases and when they talk, you can see that they have given up.” This depicts a fear of getting overwhelmed by additional diseases (in terms of management)—revealing that they had accepted their current situation but could not face a more arduous challenge.

4. Discussion

To the best of our knowledge, this study is the first to critically examine how people perceive and experience breast and prostate cancers amidst other concurrent and chronic conditions in Soweto. We found that many feared and demonized their cancer diagnoses, framing it like a trauma that had an invasive effect on their bodies through the aggressive treatments often employed. This was particularly salient among women because their treatment was more aggressive than men's treatments, which were often a hormonal therapy, with some incurring less invasive surgery. This distinction may be why most men and some women connected their cancer to aging. Many perceived physical disfigurement, such as mastectomy, as severe and threatening to living good, healthy lives, and more severe than other, “ordinary” (Das, 2006) conditions like HIV. Thus, through their cancer diagnosis and treatment, many women were forced to renegotiate their sense of self amidst surgery and physical disfigurement linked to the breast, while men found their minimally invasive treatment for prostate cancer to align with other existing conditions and to reflect a natural aging process.

Despite the fact that some people had one or more existing diagnoses in addition to cancer, most perceived their conditions to be “the same”

and defined sickness in terms of feeling bad. Many people associated stress with their hypertension or diabetes, and between half to three-quarters of the sample reported symptoms of depression and/or the idiom of distress thinking too much. This may be in part because there is a strong association between depression and increasing physical morbidity in Soweto (see Mendenhall et al., 2013). However, the most common grievance associated with being sick was not being able to engage in normal routines, including work, caring for loved ones, or engaging in sexual intimacy (also see Livingston, 2012). Being healthy for many was living a normal life and appearing healthy to others.

But cancer was very different for most study participants. Cancer was called a “demon” or “bites aggressively” and for many was perceived to be fatal. This was not unlike how Linda Hunt (1998) described cancer in Mexico two decades ago, as detection and diagnosis escalated, to hold moral tones and fears, where people described cancer as “invoking images of purity and danger, propriety and misconduct, goodness and evil” (298-9). For those comparing their co-morbidities, many described cancer as “worse” than hypertension and HIV because of the serious interventions associated with it—not unlike what was found in Swaziland. For instance, one interlocutor in Swaziland described: “Cancer kills. Diabetes kills. HIV is better, at least you continue, you just live as a whole person” (Malambo and Erikson, 2018: 7). Many said that they forgot about having hypertension or HIV at times because treatment was only taking a daily tablet—in this way, other conditions did not consume them. In contrast, chemotherapy was considered “poisonous” and “the red devil” because it not only attacked the cancer cells but also destroyed other body cells ultimately weakening the immune system. In addition, mastectomy caused extraordinary disfigurement, which many feared and lamented. In this way, cancer fear was associated with treatment. This may be in part because 80% of breast cancer patients received complete mastectomies as opposed to partial or targeted ones (a lumpectomy) and most receive chemotherapy (Cubasch et al., 2017a,b); this study validates the argument of these authors who, in their own clinic in Soweto have advocated for less physically invasive interventions.

Moreover, our findings align with other studies that show type and severity of conditions, as opposed to simply the number of comorbidities, influence how patients prioritize conditions (Kerr et al., 2007) and how a patient conceives of the seriousness of one condition compared to another (Beverly et al., 2014). People's familiarity with a disease, such as HIV, compared to less familiar conditions, like cancer, then influence how people prioritize such conditions in their minds and organize their care. This cultivates a cognitive dissonance between biomedically prioritized conditions and those conditions that are physically more aggressive (be it immediate, or prolonged) (Rifkin et al., 2010).

The stress of living with multiple conditions concurrently was often described in relation to disruption to daily life, much like Gay Becker (1997) described in her work among people who confront a new and unfamiliar condition that transformed how they perceived the self and their lifeworld. The introduction of cancer, then, amidst a complicated slate of other conditions, produces a melding of what illness is and how it moves through the body because it cannot be dissociated from other, existing conditions. Cancer becomes woven into a cacophony of conditions as an added layer of stress, such as having to remember to carry along sufficient medication when away from home. The chronicity of illness, then, is not distinguishable between chronic and acute conditions because few people have one or the other, but instead they have uniquely situated and overlapping conditions that transform what it means to have “cancer” or “hypertension” or “HIV”. Instead, “chronicity is a process through which almost any patient may pass, regardless of the diagnostic label they carry” and “healing comes not from the biological cure, or even from therapy *per se*, but from identity change and restabilization in response to each disruption” (Manderson and Smith-Morris, 2010: 25). This may be why many described that they reached their maximum capacity, meaning that they have learned to live and identify with what they currently have but an additional load

may push them too far.

The increasing needs of patients in communities like Soweto underscore the need for integrated medical care that is person-focused. There is increasing social recognition and political momentum to take seriously the provision of person-centered care for multiple morbidities (Hurst et al., 2018) and the recognition that social and political factors drive these clustered conditions, often known as syndemics (Singer et al., 2017). Particularly, the current health care system is siloed and less integrated. This work contributes to the evidence for the need to greater realize support for cancer patients so that they can effectively manage cancer within the context of challenging social circumstances and multiple mental and physical morbidities. This provides an opportunity to better understand how the health system could be strengthened to be more integrated but also provide much needed support.

These findings have important relevance beyond urban South Africa, as person-centered care and/or an integrated continuum of care often is lauded as the ideal but continues to be sidelined within profit-oriented health systems and difficult to implement in underfunded public systems in high-income and low-income countries alike (Thornicroft et al., 2019). Taking stock of how people perceive cancer amidst complicated medical histories is particularly relevant among historically marginalized populations that tend to carry the burden of multiple, overlapping diseases. Although an ideal person centered, multidisciplinary model of care (see Loonen et al., 2018) may be difficult to implement within resource-constrained settings, recognizing local institutional capabilities to become more integrated and person-centered is imperative to fully realize good health for patients.

In closing, our study reveals the powerful role of breast cancer treatment in the lives of the women in this study, and how effective, less invasive treatments for breast cancer may improve not only individual experiences but also social messaging and emotional experiences around cancer diagnosis. In contrast, few men had invasive treatments and rarely focused on interventions as a major stress related to their diagnosis. Moreover, recognizing that many whose conditions were well-managed did not feel “sick”; instead, it was the experience of feeling bad that people deemed disabling. In this way, intervening in how people think about cancer may be an opportunity to improve how people *live well* with the condition amidst other cascading social and health problems they face. When we think about health and illness in terms of these multiplicative, interactive conditions in people's lives and communities, we can truly understand the complexities through which people interpret, experience, and embody the world around us.

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