"It Stays Between Us": Managing Comorbidities and Public/Private Dichotomies in HPTN071 (POPART) Trial Communities

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ABSTRACT
In contexts of scarcity, managing comorbidities is a complex process, shaped by divergent understandings of causes, prognoses, and social meanings of illness. Drawing on research with one young South African woman living with HIV and epilepsy, and 13 other people with comorbidities, we describe how concepts of "public" and "private" shape the management of co-morbid conditions. Despite narratives of HIV "normalization," participants labored to keep their HIV status private, while sharing other illness experiences more publicly. We challenge simple dichotomies between public and private spheres and emphasize the need for more fluid understandings of how people negotiate social space.

On a cool spring day in the Cape Winelands of South Africa, we (LV and HM) huddled in the cramped makeshift bedroom that 23-year-old Elsie Jacobs shared with her partner and another couple. Our knees almost touched as we sat opposite Elsie on the tired mattresses of the neatly made beds. As she had on numerous occasions, Elsie freely recounted her experiences of living with and managing her epilepsy diagnosis. She pointed to the tablets displayed on her bedside table, saying: “I take my medication. I look after my health. I can’t put it behind my back [neglect it].” She explained how her family and small community were essential to managing her symptoms. When we gently probed about her other illness, HIV, she glanced nervously at the doorway, where blankets created an uncertain barrier against the wind and curious neighbors. Looking down, she continued quietly:

I don’t like to put my mind on it. Sometimes I just sit and think, I don’t talk. They [neighbors] like asking questions. I just say that I am thinking about the things I did last night (laughing). Then they won’t know what I am really thinking about.

An estimated 7.9 million people live with HIV (PLHIV) in South Africa (Simbayi et al. 2019), many of whom also manage comorbid conditions. Due to the legacy of apartheid and ongoing socioeconomic inequalities, the burden of disease and the delivery of health services continue to be distributed unevenly (Clark and Worger 2016; Coovadia et al. 2009). Apartheid in South Africa enforced the categorizing, ranking and segregating of persons by race, with privilege and freedom allocated in line with these categories (Clark and Worger 2016). Nonwhite people experienced inferior access to health care and significantly worse health outcomes than whites (Andersson and Marks 1988). Many of these inequalities persist, and black and colored South Africans are disproportionately affected by medical

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Media teaser: People living with comorbid-HIV navigate public/private spaces on multiple levels to manage their health conditions in discreet ways. This article has been republished with minor changes. These changes do not impact the academic content of the article.

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conditions (National Department of Health 2019; Simbayi et al. 2019). For instance, while 16.6% of black South Africans and 5.3% of colored people are living with HIV, only 1.1% of whites are affected (Simbayi et al. 2019).

The South African government rolled out its national antiretroviral treatment (ART) program in 2004 to provide free treatment for the largely poor, marginalized population most affected by the disease. By 2019, 4.7 million people were accessing ART in public sector facilities (Simbayi et al. 2019). These advances in ART access have gone hand in hand with efforts to normalize the highly stigmatized disease, to increase uptake of testing and treatment, and to reconfigure HIV into a chronic, manageable illness (Moyer and Hardon 2014).

While advances in treatment access have been transformative of the experiences of PLHIV, there has been a concomitant rise in chronic conditions as lifespans increase. One study in peri-urban communities in South Africa found that of all clients accessing ART, 19.3% were also accessing treatment for another chronic condition, including hypertension (77%), tuberculosis (TB) (24%) and diabetes (17%) (Oni et al. 2015).

Patients with multiple morbidities often have increased needs for healthcare services, experience greater reductions in quality of life, and have poorer health outcomes in general (van Heerden et al. 2017). Care for chronic illness is further complicated by challenges such as resource constraints, social instability, and high levels of mobility (Hodginott et al. 2018).

HIV illness management is of particular concern for public health specialists because of the transmissibility of the virus and the socio-economic impacts of infection (LeVasseur et al. 2014). The public health attention given to other conditions varies, although there has been an increasing concern with chronic illness in Africa (Oni et al. 2015). Moreover, people’s experiences of comorbidities do not always resonate with the priorities of public health systems or with donor policies (Bosire et al. 2018). People’s illness interpretations and care access are shaped by lived experiences, relationship dynamics, household settings, and community contexts. In addition to the physical burden of living with comorbidities, people with chronic conditions are also often subjected to intersecting stigmas associated with HIV, TB, epilepsy, and other comorbidities, which impact how people access care or disclose their conditions (Elafros et al. 2018; Maughan-Brown et al. 2018).

Further to navigating medical care, people with multiple morbidities negotiate their conditions as “public” – suitable to be publicly shared – or “private” – requiring private containment. This distinction relates to a broader tension between public and private spheres, referred to as one of the “grand dichotomies” in social and political life (Bobbio 1989) and often deployed as a strategy to divide the “social universe in a comprehensive and sharply demarcated way” (Weintraub 1997: 1).

In South Africa, public/private distinctions are also informed by cultural practices, historical systems, and socio-economic factors. In his critical analysis of privacy and culture in African settings, Makulilo (2016) noted that scholars generally portray “African” cultures as valuing communalism and interdependence as opposed to individualism and independence (see Adams et al. 2012; Eaton and Louw 2000). This dominant view assumes, he explains, “that Africans exist in collectives: family, kinship or other types of groups,” and that “the individual in Africa has no space to claim for privacy as he or she is overburdened by the group’s interests” (Makulilo 2016: 96). However, people’s desires and experiences are more complex than this often-simplistic portrayal of collectivist “culture.” Nonetheless, individuals must negotiate cultural, historic, and contextual factors that shape and constrain their ability to navigate boundaries between public and private spheres while managing their health.

We draw on Ariés (1960), Jacobs (1961), Goffman (1959), and Butt and Langridge (2003) to explore four dimensions of the public/private divide along which people living with comorbidities organize illness, including in social spaces, physical spaces, intersubjective spaces, and the unconscious realm. We engage with these dimensions to understand how people with comorbidities continually negotiate the boundaries between public and private spaces in contexts of fluidity and constraint.

This article is centered on the story of Elsie, a young woman living with HIV and epilepsy. To contextualize her experience, we also draw on data collected with 13 other people living with comorbid
HIV in the Western Cape Province of South Africa. We explore how participants positioned their illnesses as public or private.

Despite public health narratives about “normalizing” HIV as a chronic condition, and a public health mandate that encourages people to disclose their status publicly, participants repeatedly positioned HIV in the private sphere, cementing the imagined position of an HIV diagnosis as private. By presenting the case of Elsie and others, we show how this desired private space was emotionally and practically difficult for many participants to maintain in precarious social and physical spaces. Our findings challenge simple dichotomies between public and private spheres and argue for a more fluid understanding of how people living in contexts of constraint negotiate public and private spaces.

**Methods: collaborative research in community contexts**

For this analysis, we draw on qualitative data collected as part of the social science component of an HIV prevention trial (HPTN 071/PopART) conducted in nine South African and 12 Zambian communities from 2013 to 2018 (see Hayes et al. 2019). The three-arm cluster randomized controlled trial was implemented to determine whether an HIV prevention intervention – regular household HIV testing with immediate access to ART – could reduce community-level HIV incidence. For the social science component of the trial, we recruited 89 households across the South African study communities (all located in Western Cape Province) to explore the varied lives of people and to contextualize trial outcomes over time (Hoddinott et al. 2018).

Using a cohort study design, we purposively sampled households to ensure diversity across trial arms and in age, gender, household structure, and distance to local health facility. At least half of all households included one or more members who self-reported living with HIV.

Data collection involved multiple interactions with households over a period of 18 months between 2016 and 2018 and was informed by the ethnographic approach of “deep hanging out” (Geertz 1998) in the homes and communities of participants. Teams of two researchers were assigned to households, including at least one researcher who was fluent in the household’s home language. Teams conducted participatory research activities framed around six themed modules with each household. Modules focused on the following: household composition; mobility; how people “get by;” love, sex, and romance; experiences of accessing care; and hopes, ambitions and fears (see Hoddinott et al. 2018). While the research was designed to explore life experiences more broadly, discussions of health were often HIV-focused as the data were collected in the context of an HIV prevention trial. To counter this narrow focus, we conducted several discussions to engage with conceptions and experiences of health more generally. Further, the depth and range of topics covered in relation to participants’ lives gave us insight into how they positioned health and illness more generally.

Aside from routine employee turnover, we endeavored to maintain continuity in the researchers assigned to households. Through the team-based approach, we had the benefit of having insight from multiple researchers over time, but it also presented challenges to ensuring consistency and quality of data collected. We addressed this through continuous interactive workshops, standardized discussion guides, and debriefings. The team approach also added new complexities in that participants often revealed information selectively to different team members. By entering their homes for research purposes, different team members imposed new “audiences” (Goffman 1959) for which participants performed and negotiated their own boundaries of what was to be shared or kept private.

Depending on the topic, discussions were conducted either on a one-on-one basis or with groups of household members. We assured participants throughout that information shared on an individual basis would not be shared with other household members. Discussions also took place in a space of the participant’s choosing. All discussions were conducted in local vernacular (Afrikaans, Xhosa, or English) and audio recorded, and researchers compiled detailed field notes and semi-structured reflection notes.

Researchers interacted with each household on multiple occasions (at least 10 times) for between one and four hours per visit. Team members also maintained continuous contact with households...
outside of regular field visits by “stopping by” when visiting other households in the vicinity, calling participants, and sending text messages. This approach allowed many meaningful relationships to develop between researchers and participants over time. The intensity of the interactions allowed researchers to observe household members in situ, noting changes in household composition and witnessing exchanges between household members and neighbors (Hoddinott et al. 2018). Participatory research activities (e.g. co-created kinship maps, community maps, illness timelines) also facilitated richer discussions with participants.

Informed consent was practiced as a continuous process, with participants providing written consent at recruitment and reconfirming consent over the course of the study. Additional household members who became known to researchers over time were also invited to participate and subsequently consented. For the analysis on comorbidities presented here, we included data collected with all participants from the cohort who self-disclosed that they were living with HIV and at least one other chronic condition (n = 14). We conducted a narrative analysis (Riessman 2003) of all data (transcripts, field notes, reflection notes). We reviewed available data for each participant and wrote narrative summaries, drawing out themes related to community context, household structure and relationships, illness experiences, and disclosures. We conducted a case-by-case comparison of the participant narratives to identify common and distinct themes across cases. We shared these interpretations with the social science team and expert reviewers as a sense checking mechanism. During cross-case analysis, we identified the narrative of Elsie and the ways in which she managed her comorbidities as resonating with and exemplifying the complexities and tensions experienced by other participants affected by comorbidities. During the in-case analysis, we constructed a detailed timeline of her illness narrative, comparing reflections of the more than 20 hours of engagements we had with the family, exploring our understandings of her health experience against the frame of the public/private dichotomy. In presenting Elsie’s case, we weave together an argument how different individuals negotiate private/public divides in managing illness in contexts of constraint. All names are pseudonyms.

Elsie Jacobs: living out in the open

Our team first came to know of Elsie’s HIV status during a recruitment interview with her mother, Bettie, the matriarch of the Jacobs family. The discussion took place inside the university vehicle parked down the street, a space Bettie suggested as her preferred location for our discussion. It was often difficult to find a quiet space for private conversations in the bustling informal community of Vineridge, a small, densely populated area located in the Cape Winelands region of South Africa. In opting to have the interview in the car, Bettie situated the topic of the discussion in the realm of the private, not to be overheard or shared publicly. Outside the stillness of the vehicle, the noises of the community could be heard and seen – people socializing, cooking on open fires, and recycling glass (a common form of informal labor in the area). In this place, as we came to understand over the course of our fieldwork, everyday activities are often performed in the open. Life is, as Ogden (1996: 169) describes, “both ’domestic’ and intensively public.” Maintaining the boundaries of private and public knowledge often required complex negotiations between residents.

In this first encounter, Bettie casually described her life in Vineridge and her family’s history. When the conversation veered to the topic of health, Bettie began to speak, without prompting, about her daughter Elsie who had contracted HIV from a boyfriend that she “wasn’t open about.” Her voice cracked, but she continued, “I look after her. I keep it [Elsie’s HIV status] to myself. It stays between us, between her father and me. We don’t let her feel that she has the sick [HIV].”

When we (LV and HM) met Elsie for the first time a few weeks later, she easily leapt into discussion about her epilepsy, a condition her mother had not mentioned. She had been diagnosed as a teenager, she told us, and often endured unpredictable seizures publicly. It was another six months before Elsie subtly disclosed her HIV status to us, pointing to the word “HIV” on a household survey we were completing with her and Bettie. After this quiet acknowledgment of her positive status, Elsie continued
to slowly unveil additional details of her HIV diagnosis, although always out of earshot of neighbors and extended household members. During these initial exchanges, we became acutely aware of a tension in the Jacobs’s ordering of daily existence in which certain aspects of their lives and Elsie’s health were selectively positioned as either private – hidden and managed within the close family – or public – openly shared with the collective and wider community.

**The four dimensions of the public/private divide**

As our encounters with the Jacobs family highlight, disclosures about health are not simple, once-off events. Instead, they are layered exchanges in which individuals selectively reveal particular elements of their illness narratives over time (Kleinman 1988). As we will show, for residents in Vineridge and other communities, managing what is revealed and to whom, and deciding who is included in collective processes of care, required intricate and calculated decisions across multiple dimensions of the public/private divide.

These dimensions included, firstly, the divide between social spaces – or the divide between domesticity and sociability. In this distinction, Ariés (1960) understands the family or the household (as a unit) as part of private life, where care, support and privacy are maintained. By contrast, public life is understood to include others who fall outside of the family unit. Secondly, Jacobs (1961) describes a divide between physical spaces, i.e., public, shared spaces, and spaces limited in terms of allowed audiences. Divides in physical spaces refer, for instance, to the intimacy of household structures, or public communal spaces, such as the spaces where socializing or shared work takes place. Thirdly, Goffman (1959) defines the public/private distinction as between the intersubjective (others) and the individual (self), where some social behaviors take place under the gaze of other people (in public) and other behaviors take place in relative isolation (the private). Lastly, Butt and Langdriddle (2003) expand on a fourth dimension relating to the private sphere, i.e., the realm of the unconscious. In this dimension individuals go through a series of complex processes to reconcile their self-conceptions with their social experiences. In this way, the public (interactions with others) and the private (self-theory) interact, enabling individuals to come to an understanding of “self.”

While these public/private divides are useful for framing illness experiences, we show how the neat dichotomies these theorists propose come apart in the fluidity inherent to people’s daily lives. We describe how individuals living in contexts of constraint negotiate both physical and social boundaries to locate their diagnoses, how these boundaries are tested and renegotiated, and how participants adapt when boundaries are difficult to maintain.

**Sociability and the family space**

When Bettie introduced us to Elsie for the first time, the pair invited us to sit in the narrow space between their front door and their neighbor’s house. We were drawing a floorplan of their home as part of a discussion on household structure when Elsie greeted a young man walking by. Bettie explained that he lived in a makeshift room attached to their house. Assuming that he was part of their family, we suggested they invite him to join the discussion. Both women quickly brushed off this request, explaining that he was not part of the “family,” he “just stayed there.” If we wanted to talk to “the family,” Bettie said, we needed to talk to her or to Elsie. Over time, we came to understand that there was a clear demarcation between those who “just lived” in the home and those who were part of (or allowed to speak on behalf of) the “family.” The Jacobs often added temporary rooms to their home to accommodate friends or extended family in times of need. Extended relatives, unofficial foster children, and acquaintances who lived in these rooms for differing lengths of time were not “family.”

As Ariés (1960) theorized, people actively create boundaries between the public (the community, others, outsiders) and the private (family, us, insiders) in organizing their social world. The complex social arrangements of insiders and outsiders can be seen in the construction of the concept of “family” for Elsie and others in our cohort. Although members of their broader extended household (which
including 10–12 residents at any given time) often shared food and domestic chores, Elsie included only herself, her mother (Bettie), her father (Ben), two brothers, and her boyfriend of the past seven years, Jake, in her family. These six people formed the core of the family. Various other household members shared in selected household knowledge. Only some household members knew that the family sold small quantities of marijuana for extra income, and none of Bettie’s children knew that Ben had previously been incarcerated. Only the core family knew the most private details of the Jacobs’s lives, including that Elsie was living with HIV. For Elsie, the intimate family was the appropriate (private) space for HIV-status disclosure and health support. By contrast, she understood her epilepsy diagnosis to be a more comfortably public matter, which she shared openly with her extended social circle.

On more than one occasion Elsie fetched her epilepsy medication to show it to us. The repeated display emphasized how Elsie viewed epilepsy as part of her accepted public persona – one that she was not afraid to share beyond her intimate family. We came to understand that the distribution of care is not limited by the visibility of the condition but is shaped by the social meanings of illness. Different chronic conditions are experienced differently by those affected and some chronic conditions (often including HIV) are considered to belong in the private sphere. These conditions are often disclosed to and cared for by close family members only. Other conditions are considered more acceptable to publicly reveal, and to ask for and expect support from the wider community.

Fezeka (32), from the Cape Metro area, managed her conditions in ways similar to Elsie. She disclosed her dual diagnoses (HIV and TB) to her siblings and her mother. Although she maintained to us that she did not have a close relationship with them, she emphasized the importance of family and considered this closed group her most trusted form of social support. Fezeka explained that only her family would be able to support her when it came to the intimacies of illness.

In contrast, when Josephine (34) from the Cape Winelands found out she was living with HIV, she told only her grandmother, who kept her secret for five years, until Josephine was ready to share her status with others in her family. Josephine describes herself as involved with “the wrong things,” including drugs and alcohol, which resulted in a strained relationship with her mother, stepfather, and siblings, whom she lived with. The immediate family had long been aware that Josephine had been diagnosed with TB, but not HIV. When Josephine decided it was time to share her HIV status, her boundaries between the public and the private shifted to include her immediate family into her private sphere.

These conceptualizations of the family as part of the private sphere fits with Ariès (1960) understanding of the public/private divide. He positions the family and domesticity as the realm of “the private” while civil society, or sociability, is considered to be “the public.” The private realm is not the realm of isolated individuality, as others have theorized (Goffman 1959), but of intimate collectivity, “constituted by particular ties of attachment, affection, and obligation.” In contrast to the experiences of our participants, Ariès’ conceptualization of the family is tied more closely to the boundary of the household. In our context, the divide between the family and “others” is complex as household composition was fluid and changing, and understandings of “family” and kinship were not universal or fixed. For example, Agnes (45) was being treated for HIV and high blood pressure and did not want her brother to know about her HIV diagnosis. She explained: “He is my brother, my own blood brother, but my family are my children,” indicating a distinction even amongst blood relatives. The fluid and changing nature of families have been described extensively by new kinship studies scholars (Carsten 2004; Reynolds 2015). Carsten (2004: 149), for instance, defines “family” as the broader social unit where “belonging” extends beyond the limits of birth or blood relations, and is rather defined by time and endurance. We found this definition useful in understanding how participants delineated who were “insiders” or part of the private sphere, and who were “outsiders” or part of the public sphere. In our research, we allowed participants to decide who was included in their family. We came to understand “family” as a group of people who are intimately connected, which could include neighbors and close friends. We continually checked with key household members to come to a common understanding of the “family,” and to identify the members of households in our cohort.
**Drawing the line between public and private spaces**

As described in the introductory vignette, it was difficult for Elsie (as for many other participants) to keep her HIV status hidden. In Elsie’s neighborhood, homes stand in close proximity to each other with no more than 1.5 meters between them, and “walls” were rarely more than blankets, corrugated iron, or hardboard sheets. Neighbors were close enough to inadvertently turn intimate conversations into shared knowledge. Individuals needed to be vigilant and manage their physical spaces carefully to establish boundaries between the private (the physical home, the “family,” the self), and the public (shared space, outsiders, or “others”). Life in this context challenges the public/private boundary, as theorized by Jacobs (1961), in that even the physical divide between spaces becomes permeable.

Lack of steady employment, income and resources meant that the Jacobs family and their neighbors from Vineridge have had to make do with repurposed materials to construct homes, while participants from other neighborhoods had access to formalized housing. For many participants, housing structures, even formalized housing, were in close proximity to neighbors and offered little in terms of physical private space. Household structures accommodated several residents and rooms were often shared with multiple others. In addition to the limited privacy within households, the physical layout of housing in resource-constrained communities also lends little privacy between households (Ogden 1996).

Because the boundaries between the public and the private are constantly being constructed, they are neither stable nor impermeable. At any given moment, people make decisions on whether a person should be included as part of their private or public realm. Through these choices, individuals are constantly crafting the boundaries of public and private spheres (Kilian 1998). Yet, the physical layout of households, communities and shared spaces often limits individuals’ ability to conceal elements of life, including health conditions. How people construct the public/private divide is thus determined by both social bounds and physical space (Kilian 1998; Wolfe 1997).

Different housing types presented diverse challenges in managing comorbidities and maintaining privacy. As in the Jacobs’s house, Jasper (34), a former gang member diagnosed with TB and HIV, shared with his father an informal structure without windows, flooring, electricity or running water. While the Jacobs’ house had several add-on rooms, Jasper and his father’s one-room house was nestled in a densely populated corner of their community. There was little protection against the wet, cold Cape Town winters or the scorching heat in the summer months. There was also limited opportunity for Jasper or his father to establish privacy for themselves.

Even with formalized housing, some participants still found it challenging to maintain boundaries between personal and shared spaces. Cynthia and Charlie, both living with HIV, stayed in a two-bedroom government subsidized brick house. To secure an income, the couple compromised their privacy by leasing the second bedroom. They did not disclose their HIV statuses to their tenants, which meant that they often could not discuss their health at home. Similarly, Aviwe, a former police officer, lived in a one room brick house with his wife, son, and daughter. The couple were both living with HIV and did not disclose to their two teenaged children (who Aviwe believed to be HIV negative), explaining that it was a private, adult issue. To create some semblance of boundaries, the family used wall drapes to separate the adult sleeping space from that of the children. Aviwe complained about the lack of physical privacy, as it compromised intimacy with his wife.

The constrictions on private spaces also extended to health settings. When Mark, a Mozambican national living in the Cape Metro, found out that he was living with HIV, he voluntarily disclosed to his live-in girlfriend, Lita, but not to his brother who lived in the same building. When he went to the clinic to access treatment and saw his brother in the queue for ART, both men’s statuses were inadvertently revealed. For Aviwe, Cynthia, Charlie, and others, the public/private divide is complicated by the physical constraints they experience.
The intersubjective and the self

In addition to the divide between the family (as a private unit) and those outside of the family (the public), the public/private divide is reinforced through a distinction between intersubjective “others” as the public sphere and the “self” as the private sphere. Goffman’s (1959) use of the dramaturgical metaphor is useful in this regard. Public encounters, as “staged performances” are “rarely natural or spontaneous” (Wolfe 1997: 184). Instead, it is in the private space of individuals’ own minds, or “backstage,” where people retreat to their “true selves” in anticipation of future public performances. Participants’ public performances, such as when Elsie spoke of her diagnoses, are used to gauge the reaction of audiences and to assess what is acceptable to make public. Throughout our interactions, Elsie and her mother were set on presenting a specific appropriate image when we were with them. In a few instances in which slippages in appearance (or performance) occurred, such as swearing or expressing anger at community members, Elsie and her mother were quick to correct themselves. These corrections seemed to be about more than composure, but about the maintenance of the family’s ordentlikheid (Afrikaans for decency/respectability) in front of outsiders like us. Afrikaans-speaking members of our cohort often raised the concept of ordentlikheid in their descriptions of expected and proper behavior and social interactions, including sex. In her explanation of ordentlikheid, Teppo (2015: 287) describes it as intertwined with concepts of morality, social and spatial boundaries, and forms of belonging. To be ordentlik, people are expected to adhere to, or appear to adhere to, abstract and unwritten normative practices in how they act and speak, or perform, in public spaces. However, ordentlikheid is more than just good manners; it is understood to be part of individual and collective identity, and to powerfully shape how individuals portray themselves to select audiences. For example, Elsie referred to a “socially acceptable” or ordentlike narrative of how she contracted the virus. In this version, she became HIV positive through cuts on her hands (from recycling) while helping an elderly, sickly neighbor (an often-repeated narrative).

Other cultural groups in South Africa have similar, often gendered, notions of respectability. In Xhosa- and Zulu-speaking communities, the concept of ukhlonipha similarly creates clear “proscriptions in terms of action, space and language” (Herbert 1990: 457). The rules of ukhlonipha also dictate the use of appropriate language in social circumstances (Ogden 1996). Both ordentlikheid and ukhlonipha imply preconceived notions of appropriate public performance or persona. These personae can be “compromised” by the diagnosis of a chronic condition. Treichler (2002: 261) pointed out that chronic illnesses, including HIV, are conditions of signification: in addition to the weight of mortality that is still associated with a positive diagnosis, HIV is a “nexus where multiple meanings, stories, and discourses intersect and overlap, reinforce, and subvert one another” and that beyond the biomedical implications of the illness, it is “an epidemic of signification.” Illnesses can have social meanings which relate (negatively) to respectability (Bond 2010). However, all conditions are not “equal” as beliefs about the public/private status of health conditions are also informed by the moral interpretations of illness acquisition, their prognoses, and the possibility of disease transmission (Bosire et al. 2018). Participants actively decide which conditions should be kept within the private domain and which conditions are “appropriately” within the public domain. These decisions are based in part on reinforced social experiences. Simmel’s (1906: 441) description of secrecy illustrates how the shift between public and private spheres can happen. He explained that “in all relationships ... there develops ... intensity and shading in the degree in which each unit reveals himself to the other through word and deed.”

In asserting if a condition should be shared, participants “tested” the potential consequences of disclosing. Lesley, an openly gender fluid woman from the Cape Winelands, revealed that she did not disclose her HIV status openly as this would confirm community preconceptions that someone who is gay, transgender, and a former drug user is likely to be HIV positive. She explained that when people at work had “open conversations about HIV” she might give her opinion and correct them, but would not “give too much” so that they think, “why are you so well read in this topic?.” This strategy of
engaging in the topic of HIV, testing the reactions of their audience but without “letting on” that they knew more than others, was employed by many other participants, including Elsie.

Lesley also engaged in subtle, partial disclosures. She purposefully left her HIV medication open. When her mother enquired about the pills, Lesley explained that they were “nothing, they’re just for my back.” While she went through extraordinary steps to hide her HIV treatment from other household members (removing pill container labels, carefully emptying the pills onto her bed to avoid noise), Lesley chose not to hide her tablets from her mother. This limited disclosure created an unspoken “don’t ask, don’t tell” agreement between Lesley and her mother, in which neither of them explicitly acknowledged Lesley’s HIV status but which allowed Lesley to gauge what her mother’s reaction would be if Lesley were to openly disclose. Despite high levels of reported stigma associated with the disease (Murray et al. 2013), her TB diagnosis was openly shared and Lesley involved her wider social networks for support.

Partial disclosures also extended to the researchers. Across our cohort, many participants shared details about their health, including their HIV status, with us, even during initial recruitment visits. Others took time, or “tested the waters,” to determine reactions to selective disclosures before allowing us into their private sphere, where they felt comfortable to disclose health concerns.

**The public/private, the affective and the unconscious**

The house was unusually quiet when we met for one of our final discussions with Elsie, as most of the household members were out and Bettie had gone to visit her sister. In contrast to her usually upbeat demeanor, Elsie somberly described her shock upon being diagnosed with HIV and how she had considered suicide. After a moment of silence, she explained with renewed vigor, “actually, I don’t put my attention on the HIV … My thoughts are more on the epilepsy because it doesn’t feel like I really have it [HIV].” Despite these words, she often alluded to spending time thinking about HIV.

Over time, Elsie, with Bettie’s help, found ways to distance herself from her HIV status by downplaying the severity of her own illness. She distanced herself from others who were living with HIV by emphasizing her difference from them because she did not have “deep” HIV. Elsie explained that her doctors had agreed that she likely did not contract HIV through sex, and this was why her HIV was not as severe. Robins (2006) and others have described an HIV diagnosis as a transformative event, inducting individuals into a new collective and shifting their sense of self. In her narrative, Elsie avoided claiming any identification with this broader collective and resisted what she found to be negative associations linked to her HIV status. There was a clear disjuncture between the image that Elsie held of a person with HIV — someone who is sexually promiscuous and not “proper” — and her self-image as an ordentlike woman from a good family. This sentiment was most obvious when Elsie reflected on her onbeskafdigheid (rudeness), as she described it, when she was younger — consuming too much alcohol and engaging in fights. In one discussion, she considered out loud whether her HIV might be the (moral) consequence of her “bad” behavior in her youth.

Bond’s research with PLHIV in Zambia revealed that while a lack of disclosure “can be dangerous and even tragically fatal, it also allows individuals living with HIV room for maneuver and the possibility of defining their identity separate from their disease” (2010: 6). Although Elsie shared her status with a few individuals in her private sphere, she still (partly) disavowed her HIV diagnosis in her interactions with others and at the level of her own unconscious. Even to the small group of people aware of her status, Elsie was able to shape the image of her condition and her identity by presenting herself as proper and different to other PLHIV.

Across our cohort, people diagnosed with multiple conditions described the various iterations they go through in their daily lives to reconcile their conditions with their identity, and to assert what should be kept private or made public. However, beyond simply “keeping it secret” (in the realm of the unconscious), individuals go through complex processes to reconcile their self-conceptions (or self-theory) with their diagnoses. The dimension of the unconscious, conventionally excluded from
theoretical understandings of the public/private, contributes to a more nuanced understanding of the ordering of social life.

In exploring expressions of sexuality, Butt and Langdridge (2003: 479–480) describe how “the public reaches into the private sphere, producing a self-theory, and how (perhaps unconscious) self-deception is practiced in order to maintain this theory.” They theorize that individuals go through a process of acting (pre-reflective) in the world, and retreat to reflect on their acts. From previous interactions, and with the aid of internalized language acquired from previous social interactions, individuals either reconcile their pre-reflective engagements with their (morally informed) self-theory, or disavow their acts if they did not resonate with their self-theory. In this way, public interactions impact the most intimate conceptualization of the private sphere. This production of self-theory resonated with the experiences of participants in coming to terms with their dual diagnoses.

Over time, participants in our cohort compared the impact of different morbidities on their lives. Perhaps surprisingly, many presented their other chronic conditions (TB, diabetes, high blood pressure) as “worse” than HIV, with a more profound impact on their lives in terms of pain, anxiety, or discomfort. By contrast, HIV was often superficially presented as an unwelcome aside to their everyday experiences. In the quiet moments during intimate discussions, however, participants hinted that HIV had a significant presence in their most private of spheres.

While several participants downplayed the visibility and the impact of HIV in their lives, concerns about their diagnoses remained (mostly) unspoken but ubiquitous. In reflecting on their HIV diagnoses, participants reconciled or disavowed (through suppressing thoughts of) their HIV diagnoses in efforts to confirm their self-theories – their sense of what characterizes them (Butt and Langdridge 2003). As an example, Cynthia, who described herself as an alcoholic, was diagnosed with HIV and TB and lived with her partner Charlie, also diagnosed with HIV. We often left Cynthia’s house without having had any discussions with her because she was unwilling or unable to participate. When we did talk, she made no secret that her life with Charlie was less than desirable; she described it as a “shit life.” In these already difficult circumstances, Cynthia revealed that she tries to keep her thoughts away from HIV: “I take it as it is, I don’t focus on the illness [HIV]. I try to shift my thoughts to other things.” In dealing with her diagnosis, she preferred to keep her thoughts private: “I keep it all to myself. I just want to be alone. I lock my door and put the music on loud.”

Jasper, a former gang member introduced earlier, expressed thoughts on his HIV and TB diagnoses that contradicted what he revealed in moments when he vented more freely. He had endured long periods of TB-related hospitalization. During one visit, we found him to be extremely frail, so much so that we feared that he might pass away soon. After another four-day stay in hospital, he explained that he was angry over his TB diagnosis and had stopped caring about himself. His concerned family phoned the ambulance. He continued to explain that “TB took over his body” and that “HIV wasn’t that bad.” In a later sullen moment, however, he reflected: “I skel [shout/admonish] often. I don’t want to blame the disease [HIV] the entire time, but to me it just feels like everything is just fucked up. My life is fucked up . . . I don’t want anyone around me.” Elaborating, he added: “They can tell you that you can live normal, but you can never be normal.” While Jasper would describe TB as consuming his entire body, he believed his HIV diagnosis separated him from those who are “normal.” Dealing with the anguish of his diagnosis was an intensely private affair that Jasper did not readily share with others.

Some participants, however, embraced their HIV-positive status as part of their identity. When Nceba (48), a Xhosa woman from the Cape Metro, found out that she was living with HIV, she disclosed her status widely and joined the Treatment Action Campaign (an activist group instrumental in making treatment available for PLHIV in South Africa) (Friedman and Mottiari 2005). She believed that her diagnosis should be widely and publicly revealed to facilitate access to care and cement her place in the community as a care provider to newly diagnosed patients.

Elsie’s and others’ choice not to dwell on their HIV diagnoses represented a form of disavowal and a decision to avoid any self-examination (see Butt and Langdridge 2003: 487). Participants created a moralistic self-image of themselves that allowed them to retain a sense of self-respect and virtue. As
much as participants positioned HIV as “not as important” as their other conditions, it was an unavoidable unconscious presence. Bond noted that HIV is hard to conceptualize as “a ‘manageable’ chronic illness because it is weighted by such extraordinary baggage” (2010: 9). Because of this moral “baggage,” HIV is experienced as different from other chronic illnesses. To manage this, PLHIV often position their diagnosis as private – even from themselves.

Elsie’s (and others’) challenge in coming to terms with the diagnosis and the conviction that HIV should be private is in part informed by her interpretation of what an HIV-positive status signifies. To Elsie and others, HIV is still considered a disease of promiscuity and moral transgressions (Leibowich 1985: 5). The implication is that when people reveal that they are living with HIV, they are also potentially revealing other aspects of the “self.” This public engagement in the world informs how individuals reflect on and make meaning of comorbidities, including the repeated positioning of HIV as a condition that should be kept private.

**Conclusion**

Across the four dimensions, the public sphere has been understood to be an “outside” or “other” domain – as shared spaces, sociable “others,” outside the intimate family, or outside of the unconscious “self.” The private sphere, by contrast, is understood to be part of the “intimate” domain – personal spaces, the individual, the limited family, and understandings of “self.” We have shown how people living with chronic illnesses in precarious social contexts and constrained physical spaces often find it challenging to maintain boundaries between these spheres. When managing their health conditions, Elsie and other participants repeatedly attempted to position HIV as a condition that should be private, reinforcing the idea that HIV is a private affliction. Faced with the potential risk of the collapse of the boundary between private and public spaces, participants continuously had to (re)draw and negotiate the line between these spheres, across domains. For instance, although participants often made a distinction between family “insiders” and other “outsiders” whom they entrusted with illness support, the boundary of the “family” was porous and shifting, forcing participants to renegotiate who was privy to their multiple diagnoses. Participants also described their challenges maintaining privacy in physical spaces where homes were temporary or flimsy and shared spaces encroached on areas that people would prefer to keep private. In addition, performances of health and illness in intersubjective spaces and unconscious understandings of illness were complicated when both physical and social spaces were constrained.

In a public healthcare system that is resource-constrained, there is little space to negotiate around people’s private lives or personal boundaries. Physical space at public health facilities in South Africa, as elsewhere, is not designed to facilitate the desired private boundaries and health providers are often not attuned to the complexities of how different people manage their illnesses. The recent national shift toward integrated care, where HIV care and treatment are aligned with other care options at public health facilities (Njuguna et al. 2018), is aimed at decreasing stigma and making care more accessible and cost effective. Grouping conditions together for public healthcare, however, does not resolve the tensions that individuals living with comorbidities experience in managing the different social implications of their illnesses.

The repeated challenges in maintaining preferred boundaries between public and private spaces powerfully illustrate the lack of control that people experience over the boundaries between these spheres. Our analysis illustrates that they must reconcile themselves with an increasingly constrained private sphere. Perhaps, one might suggest, the private sphere is a space of privilege that a limited few can claim for themselves or maintain.

**Notes**

1. A condensed version of Elsie’s story is described elsewhere (Viljoen et al. 2020).
2. South Africa has done away with racial classification for the purpose of legislated discrimination for people of color. However, commonly used categories – white (for European), black African (for African decent), and
colored (a complex category used for people of mixed racial descent or with ancestry from Indonesia or Khoisan) are still used in official and everyday language (Posel 2001).

3. While authors LV and HM were involved in data collection for Afrikaans-speaking participants, we relied on Xhosa-speaking researchers for collection with Xhosa-speaking participants.

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