Ubuntu as a mediator in coping with multimorbidity treatment burden in a disadvantaged rural and urban setting in South Africa

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ARTICLE INFO

ABSTRACT

Background: People living with multimorbidity in economically precarious circumstances in low- and middle-income countries (LMICs) experience a high workload trying to meet self-management demands. However, in countries such as South Africa, the availability of social networks and support structures may improve patient capacity, especially when networks are governed by cultural patterns linked to the Pan-African philosophy of Ubuntu, which promotes solidarity through humanness and human dignity. We explore the mediating role Ubuntu plays in people's ability to self-manage HIV/NCD multimorbidity in underprivileged settings in urban and rural South Africa.
Methods: We conducted semi-structured interviews with 30 patients living with HIV/NCD multimorbidity between February–April 2022. Patients attended public health clinics in Gugulethu, Cape Town and Bulungula, Eastern Cape. We analysed interviews using framework analysis, using the Cumulative Complexity Model (CuCoM) and Burden of Treatment Theory (BoTT) as frameworks through which to conceptualise the data.
Results: Despite facing economic hardship, people with multimorbidity in South Africa were able to cope with their workload. They actively used and mobilized family relations and external networks that supported them financially, practically, and emotionally, allowing them to better self-manage their chronic conditions. Embedded in their everyday life, patients, often unconsciously, embraced Ubuntu and its core values, including togetherness, solidarity, and receiving Imbeko (respect) from health workers. This enabled participants to share their treatment workload and increase self-management capacity.
Conclusion: Ubuntu is an important mediator for people living with multimorbidity in South Africa, as it allows them to navigate their treatment workload and increase their social capital and structural resilience, which is key to self-management capacity. Incorporating Ubuntu and linked African support theories into current treatment burden models will enable better understandings of patients' collective support and can inform the development of context-specific social health interventions that fit the needs of people living with chronic conditions in African settings.

1. Introduction

Ubuntu, which directly translates to; 'a person is a person through other people,' is a Pan-African philosophy that promotes a communal identity and expresses compassion, reciprocity, dignity, harmony, and humanity (Ewuoso and Hall, 2019; Gade, 2011; Mboti, 2015; Ramose, 2002). A nguni term directly translated as personhood, ubuntu is found in many African languages, but not always under the same name (Kamwangamalu, 1999). Ubuntu explains the connection between individuals and communities and explores how values and beliefs are constructed in these communities, and has its roots in humanist African philosophy (Sambala et al., 2020). Ubuntu and linked core values can provide context on how individuals and communities in Africa develop and live but can also be used to examine how people understand their

own well-being and that of others (Cele et al., 2021; Mugumbate and Chereni, 2020; Sambala et al., 2020). Ubuntu plays a crucial role in how social support and care is structured and managed, as it stipulates how relationships are negotiated, based on cultural norms and values, obligation, and the need to reciprocate (Knight et al., 2016). A well-functioning support network increases patients' social capital – the ability to mobilise and maintain social and material resources – which is inherent to patients' capacity, especially when managing illness.

Historically, the concept of ubuntu was closely linked to kinship, clan ties, heritage, and family bonds, which all contribute to intersubjective belonging and shape the social norms by which individuals understand their relationships and interactions and responsibilities for each other (Gade, 2011). In South Africa, like elsewhere, social networks and caring practices are changing, due to structural and economic change, migration, interpersonal demands, as well as the increasing complexity of illnesses (Knight et al., 2016; Manderson and Block, 2016; Manderson and Warren, 2016; Nkosi and Pretorius, 2019). In this paper, we explore the role that ubuntu as a philosophy plays in shaping social support structures of people living with multimorbidity in low-income settings in South Africa and how this concept mediates their ability to self-manage these conditions.

Evidence shows the valuable role that social support plays in patients' ability to deal with long-term illnesses (Knight and Schatz, 2022; Simbayi et al., 2007). Social networks can offer practical assistance, financial help, or can provide emotional support, often deriving from a moral obligation to help (Harling et al., 2020; Knight et al., 2016; Manderson and Block, 2016). In high-income countries (HICs), social support is largely provided by spouses, offspring, or direct family members, which are defined as the nuclear family (Jaga, 2020; Russell, 2004). In South Africa however, 'family' can also consist of extended kin who live in the same, or other households and can be linked by biological ties, or through financial and care arrangements (Jaga, 2020; Knight et al., 2016). Support that is not only offered by family members, but by extended relationships, form part of patients' larger community of care. This can also include multi-generational households (three or more generations) or friends and neighbours who provide emotional and practical support (Moore and Seekings, 2018). Ubuntu plays a crucial role in how social networks and communities of care are managed, as relationships are constantly negotiated based on cultural values. In South Africa, 32.2% of the population is living in multi-generational households, most commonly out of economic necessity, cultural practice, or care-giving obligations (Moore, 2020). While the literature on African support networks in the context of the HIV/Aids epidemic is well-documented, the role of support networks and ubuntu for people living with multimorbidity is less explored.

1.1. Multimorbidity in South Africa

South Africa is experiencing a rising burden of multimorbidity, defined as the coexistence of two or more chronic conditions, as the epidemics of non-communicable disease (NCD), primarily diabetes, cardiovascular diseases, and hypertension, converge with chronic infectious diseases such as HIV and TB (Asogwa et al., 2022; Levitt et al., 2011). These colliding epidemics are disproportionately affecting people of low socio-economic backgrounds and are increasingly occurring in a younger, working population who should be contributing to the economy (Asogwa et al., 2022). Currently, of those seeking care, the estimated prevalence of multimorbidity is between 22.6 and 48.4% (Lalkhen and Mash, 2015; Oni et al., 2015; Wong et al., 2021).

Multimorbidity increases the complexity of disease management from both provider and patient perspectives, resulting in higher health care needs and higher costs to the healthcare system (Oni et al., 2015). Additionally, multimorbidity poses a challenge to existing public health services in South Africa, used by more than 80% of the population, which is still largely compartmentalised in terms of care delivery as it is organised and resourced to focus on acute, episodic care and single

conditions rather than multiple chronic conditions (Moffat and Mercer, 2015). Responding to the increased prevalence of NCDs and multimorbidity in South Africa, the National Department of Health has developed the Integrated Chronic Disease Model (ICDM), which is informed by the WHO Innovative Care for Chronic Conditions Framework (ICCC) and is currently being implemented in 42 clinics across three of the nine South African provinces (Ameh, 2020; Ameh et al., 2017; Mahomed et al., 2014). The ICDM aims to integrate communicable and NCD care in primary health clinics by reorganizing facilities and improving operational efficiency, encouraging patients to self-manage conditions at a community-level, and enhancing health knowledge and screening on a population-level (Mahomed et al., 2014). Early evaluation studies have revealed that the ICDM model does not account for the socio-economic factors that complicate patients' ability to seek and adhere to care, and fails to consider the increased illness burden faced by patients living with multimorbidity (Ameh, 2020; Ameh et al., 2017). Although the ICDM model stipulates the need for increased health knowledge for patients and families and proposes community support groups as a possible intervention to improve self-management, it does not acknowledge the positive impact of extended relational networks and the values of integrating and supporting these existing relational networks. Thus, ubuntu in relation to treatment burden remains underexplored.

This study uses two interlinked theoretical frameworks, the Cumulative Complexity Model (CuCoM) and Burden of Treatment Theory (BoTT), to examine the mediating role that the concept of ubuntu and African relational networks play in a patients' ability to self-manage multimorbidity. Both models were developed to clarify patients' ability to cope with self-management in the context of chronic diseases and describe patient complexity as a dynamic state that is impacted by lived experiences, as well as a personal, social and clinical key factor that accumulates over time, leading to complex outcomes (Eton et al., 2012; Shippee et al., 2012). Central to CuCoM is the interaction between *patient workload* as required by the health system and their *capacity* to manage this workload. Capacity includes patients' physical and mental functioning, symptoms, socio-economic resources, educational level or literacy, language, attitudes and beliefs, and ability to mobilise social support (Shippee et al., 2012). BoTT investigates the role of the collective in managing, caring, and supporting the work of being a patient and analyses how patient workload is distributed through and within social networks (Boehmer et al., 2016; May et al., 2014). Both models have been developed and tested in high income settings but research on treatment burden - the impact of the workload of self-management - in LMICs is scarce (Mair & May 2014). The few qualitative studies conducted in developing countries reveal that patients with supportive caring networks have better health outcomes and increased self-management capacity (Chikumbu et al., 2022; Roberti et al., 2022).

Using both CuCoM and the BoTT as a theoretical focus, this paper explores how African-centred values such as ubuntu shape the social networks of people living with multimorbidity in South Africa and allows them to seek care, mobilise resources and build resilience, even when living in constant precarity (Van Pinxteren et al., 2023a). The literature suggests that the concept of ubuntu is most present in traditional, tight knit communities. Therefore, perspectives from our rural site, Bulungula, are presented first and compared to people's lived experiences in urban Gugulethu (Ramose, 2002).

2. Methods

This paper is part of the 'EXploring the TReAtment burden and capacity for self-care among patients with HIV/NCD multimorbidity in South Africa to inform the development of interventions' (EXTRA) study, which examined the relevance and applicability of existing theoretical models of NCD treatment workload-capacity from high income countries to inform future research in the LMIC context of South Africa. The aim of the EXTRA study is to develop an adapted theoretical

model of HIV/NCD workload-capacity and integrate the model into existing initiatives for patient-centred care. This model will form the basis for developing individual, peer group and service level interventions to benefit people living with multimorbidity in South Africa (Van Pinxteren et al., 2023b).

Data was collected from qualitative, semi-structured interviews with 30 people living with HIV/NCD multimorbidity between February and April 2021. The interview schedule consisted of open-ended questions adapted from the BoTT, CuCoM and Treatment Burden Questionnaire (TBQ) (Eton et al., 2012; May et al., 2014; Shippee et al., 2012; Tran et al., 2014). We asked participants about their engagement with health services, their support structures and explored peoples' agency to be resilient when living with multiple chronic illnesses. A description of our methodological approach is published elsewhere (Van Pinxteren et al., 2023b).

2.1. Setting

Data for this study was collected in urban Gugulethu, Cape Town and rural Bulungula, Eastern Cape. Gugulethu is a township 15 km outside of Cape Town, one of several low-income residential areas created for Black people during apartheid (Field, 2001). Gugulethu is home to more than 100,000, predominately isiXhosa speaking people and characterized by high levels of unemployment and low household incomes (Pernegger and Godehart, 2007). Bulungula is situated in a remote coastal area in the Eastern Cape and ruled by traditional chiefs (Porter and Phillips-Howard, 1997). Housing consists of traditional homesteads with sparsely spread amenities such as schools and clinics. Bulungula is among the poorest and most underserved locations in South Africa. Most households rely on government grants and remittances from relatives (Nishimwe-niyimbanira et al., 2021). Health status in the Eastern Cape is poor: an estimated 20% of the population has HIV and hypertension prevalence is 49.8% (National Department of Health S.S.A., 2019). Women in the Eastern Cape also have the highest prevalence of diabetes in the country (18%) (National Department of Health S.S.A., 2019). In the Western Cape, an estimated 18% of the population has HIV and hypertension prevalence is 51.6% (National Department of Health S.S. A., 2019). Men in the Western Cape have the highest prevalence (13%) of diabetes in the country (National Department of Health S.S.A., 2019).

2.2. Data collection

Data was collected by researchers Myrna van Pinxteren (MvP) and Nonzuzo Mbokazi (NM). Participants in Gugulethu were recruited from Gugulethu Community Health Centre (Gugulethu CHC). In Bulungula, participants were recruited from two villages supported by the Bulungula Incubator (BI), a non-governmental organisation responsible for health programmes in the district. In line with inclusion criteria, all participants were older than 18 and diagnosed with HIV and one or more other chronic conditions. All interviews were conducted in English or IsiXhosa, two of the 11 official languages in South Africa. Interviews lasted between 30 and 90 min and were conducted in a private space in the clinic (Gugulethu) or in participants' homes (Bulungula). Researchers and participants complied with the required COVID-19 regulations, including masking and social distancing (University of Cape Town, 2022). The researchers used an interview guide with open-ended questions focusing on health information, experiences of health services and social support. Before analysis commenced, MvP and NM transcribed and translated all audio-recorded interviews into English.

2.3. Participants characteristics

In total, we conducted interviews with 30 patients with HIV/NCD multimorbidity, 16 in Gugulethu (9 women, 7 men) and 14 in Bulungula (12 women, 2 men). All participants were South African citizens and spoke isiXhosa as their home language. We interviewed 9 participants in English and 21 in isiXhosa. One patient received private health care, 29 attended public health services. The mean age was 56 years in Cape Town and 50 years in Bulungula. Participants' characteristics are shown in Table 1 and Table 2.

2.4. Data analysis

Data was analysed using both inductive and deductive qualitative framework analysis. To guide the interpretative analysis process, we used the following steps: familiarisation, development of coding framework, charting, and further mapping and interpretation (Parkinson et al., 2016; Ritchie et al., 2003). With the aim of exploring which aspects of BoTT and CuCoM were applicable to our context, we developed several categories through an open coding process, which assisted us to organise, summarize and condense data: 1) control conditions and enacting control, 2) structural factors, 3) patient capacity, 4) quality of life and 5) impact of COVID-19. Fieldnotes and narrative memos, which included MvP and NM's personal reflections and interpretations, formed part of the analysis (Van Pinxteren et al., 2023a, 2023b). It was through this iterative analysis process and conversations within the research team that we assessed the patterns and links between the themes and interpreted the philosophy of ubuntu and its linked domains as key-concepts shaping patients' capacity to deal with multimorbidity workload.

2.5. Ethical considerations

This study followed the Principles of Good Clinical Practice and the Declaration of Helsinki (World Medical Association, 2013). The research protocol and informed consent forms were approved by the University of Cape Town's Human Resource Ethics Committee (HREC 232/2020). Permission to recruit participants from Gugulethu CHC was granted by the Western Cape Department of Health and in Bulungula, we received approval from the BI to approach participants who were identified by community health workers (CHWs). Before analysis, we anonymised all identifiable data from participants. As this research was conducted with groups that are considered vulnerable, the research team reflected critically on the objectives, study designs and positionality of the project. Issues of researcher positionality were also addressed. NM is a Black South African woman and MvP is a white European woman, who were both working as post-doctoral researchers in this study. We discussed the potential impact of their experiences and positionality during the data collection phase, the analysis meetings and write up of this paper. We also actively involved the rest of the research team during the analysis process, who gave input based on their own expertise and experience. Further detail of ethical considerations are published elsewhere (Van Pinxteren et al., 2023b).

2.6. Findings

Table 3 outlines the different domains of treatment burden and elaborates how these domains were experienced by our participants. Using these domains, we will describe the experienced workload of people living with multimorbidity and explore the role that social networks and ubuntu play in the capacity of participants to manage their conditions.

2.7. Experienced workload for patients with HIV/NCD's in rural and urban South Africa

For all participants, living with multiple long-term illnesses was considered difficult. Taking various treatment regimes, trying to adhere to a healthy lifestyle and navigating disorganised health services were some of the daily challenges shared by participants. Additionally, many respondents dealt with medication stock-outs in their clinic, impacting their continuity of care.

Table 1
Participants' characteristics in Gugulethu, Cape Town.

Study ID	Sex	Age	Employment	Time HIV+	Co-Morbidity	Carer Present	Main Type of Support
PU001	Female	60	Unemployed	15 Yrs	Diabetes/Asthma/Hypertension, Heart Condition	Yes	Cousin
PU002	Female	62	Unemployed	21 Yrs	Diabetes/HIV	Yes	Son
PU003	Female	53	Retired	14 Yrs	Stroke/Arthritis/Asthma/Depression/Hypertension	Yes	Daughter
PU004	Female	48	Unemployed	17 Yrs	HIV/Hypertension/cellulitis	Yes	Friend
PU005	Female	63	Retired	25 Yrs	HIV/Hypertension/TB in Hip	Yes	Partner
PU006	Female	61	Unemployed	18 Yrs	HIV/Arthritis/Hypertension	Yes	Friend
PU007	Female	48	Unemployed	14 Yrs	Hypertension	No	Husband
PU008	Male	56	Unemployed	19 Yrs	Hypertension	Yes	Friend
PU009	Male	46	Employed	24 Yrs	Diabetes/Hypertension/Depression	No	Wife
PU010	Male	57	Unemployed	19 Yrs	Hypertension	Yes	Partner
PU011	Male	47	Self-employed	5 Yrs	Hypertension	Yes	Partner
PU012	Female	57	Self-employed	18 yrs	Hypertension	No	None
PU013	Female	65	Retired	17 Years	Hypertension/Diabetes/liver failure	Yes	Partner
PU014	Male	72	Retired	7 yrs	Hypertension	No	None
PU015	Male	59	Unemployed	5 Yrs	Hypertension/Diabetes	No	None
PU016	Male	46	Unemployed	26 Yrs	Hypertension/Stroke	No	Brother & sister

Table 2
Participants' characteristics in Bulungula, Eastern Cape.

Study ID	Sex	Age	Employment	Time HIV+	Co-Morbidity	Carer Present	Main Type of Support
PR001	Female	61	Unemployed	9 Yrs	Diabetes	Yes	Daughter
PR002	Female	59	Unemployed	18 Yrs	Epilepsy	Yes	Daughter-in-law
PR003	Female	72	Retired	15 Yrs	Hypertension	No	None
PR004	Female	60	Short-term employment	6 Yrs	Heart condition	No	Daughter
PR005	Male	41	Farmer	8 Yrs	Heart disease	No	Wife
PR006	Female	42	Short-term employment	6 Yrs	Hypertension	Yes	Daughter
PR008	Female	40	Unemployed	9 Yrs	Hypertension	No	Mother
PR009	Female	42	Unemployed	6 Yrs	Hypertension	Yes	Sister-in-law
PR010	Female	63	Unemployed	15 Yrs	Hypertension	No	None
PR011	Female	30	Unemployed	7 Yrs	Hypertension	No	Mother
PR012	Female	48	Unemployed	7 Yrs	Hypertension	No	Sister
PR013	Female	50	Unemployed	11 Yrs	Hypertension	No	Sister
PR014	Male	34	Unemployed	6 Yrs	Hypertension/Stomach condition	Yes	Mother
PR015	Female	63	Unemployed	long time	Hypertension/Cancer	Yes	Daughter

"Sometimes you leave the clinic having not gotten what you wanted. I would appreciate it if we got adequate help at the clinic …. It would be good for people to be assisted according to their needs." PR08 [F40] – living with HIV & type 2 diabetes

"Like right now I am out of pills I have asked my friend for pain pills. Mine ran out last week, I will only get more in April." PU002[F62] – Living with HIV & type 2 diabetes

Long waiting times, high staff turnovers, shortage of personnel and lost patient folders were other challenges reported by urban participants.

"The clinic itself is fine, but the administration is horrible, they once lost my file for two months. I went without treatment for two months because they lost my folder." PU010[M57] – Living with HIV & hypertension

Rural settlements in South Africa, and the Eastern Cape in particular, remain underdeveloped. There are few opportunities for work and both quality education and basic services are lacking. This is a direct result of apartheid, when discriminatory policies ensured minimal development in the 'homelands,' which made participants feel like the '*forgotten people*' (PR12 [F48]). Poverty and the impact of precariousness constrained patients' self-management capacity, although most rural participants cultivated food on their land as subsistence farmers. However, they often could not afford other staple foods or travel costs to the closest town to get supplies. This made it hard for participants to oblige to the recommended dietary guidelines.

"Fruit and vegetables are very expensive, I also do not have a fridge to keep some of the food, so buying it does not make sense. But I try when I can afford it. But it is very hard to eat healthy food when you do not have money to eat well. Living in the rural area, you are kind of cut off from a lot because the closest town is quite far and you cannot find work there and commute every day, it is not feasible at all."PR003[F60] – Living with HIV & hypertension

Bulungula respondents also faced challenges when seeking care, but this was largely due to the long distances to clinics, rather than the quality of care received. Health services in rural Eastern Cape are sparse and most participants had to walk for hours over hilly, uneven roads to get to the nearest facility. Time spent picking up medication and receiving routine care contributed significantly to their treatment workload. Rural respondents reported spending much time travelling to the clinic without guarantees of being seen by a doctor or receiving treatment.

"I get up very early in the morning, I bath and get ready and go to the taxi stop to wait for transport, but I come back very late around 5–6 pm because it gets very full at the clinic I go to. Also, it is not like we get to the clinic and the doctor is there waiting for us. He comes from another hospital with our pills. So, we wait until we get our treatment and come back here when it is late." PR009[F40] – Living with HIV & hypertension

Another rural participant had to commute for two days by foot to reach the nearest facility, walking through mountainous terrain, which was a strain for her at the age of 61.

"I walk a very long distance. If I leave today, I must find somewhere to sleep (overnight). I will ask at anyone's house where I can sleep, anyone one who will allow me to sleep at their place. I will then wake up from there, which is closer to the clinic, and walk on to the clinic.

Table 3
Domains of treatment burden experienced by participants in Gugulethu and Bulungula.

Domains of treatment burden (BoTT & CuCoM)	Experiences of participants
Control conditions and enacting control: Including: sense-making (coherence), Practical help (skill-set workability), material and cognitive practices (interactional workability), enacting delegating work (collective action), monitoring (reflexive monitoring)	Learnings about conditions and treatments, how participants undertake self-care and what is required by participants to control conditions (including medication, clinic appointment and seeking health information)
Structural factors: Including: Exploitable resources (contextual integration), social capital (informational and material resources), opportunity (constraints agency), and control over services (structures agency)	Impact of socio-economic factors on the workload for participants, including the organisation of and access to healthcare facilities, relationships with HCPs, living conditions, geography, and culture
Patient Capacity: Including: Building and retaining relational networks (extends agency), agency (general potential), social skill (securing co-operation) and structural resilience (potential to absorb adversity)	Explored participants' social networks, their individual capacity to cope with diagnoses and self-management, including individual agency, resilience, spiritual faith, and strategies to overcoming barriers.
Quality of life: Including: expressing capacity, functional performance (potential to do the work)	Unpacked the impact of multiple chronic conditions on participants' physical, emotional, social, and financial wellbeing.
Impact of COVID-19: Including: control over services, social capital (informational and material resources), mobilizing capacity and opportunity (constraints agency)	Investigated the impact of COVID-19 lockdowns and regulations on participants' access to care and medication, social networks, and available economic resources.

This is because the clinic is far, across the river. It is very hard for me to get there. Another thing is the fact that I have a leg that is not alright. It broke, so walking is very strenuous for me." PR001[F61] – Living with HIV & type 2 diabetes

The cost of transport to access care in Bulungula, especially during emergencies or when seeking specialised care in rural areas, also proved challenging. A trip to a larger hospital meant days of travelling with extra money being spent on food and accommodation:

"I must go look for money for us to go to tomorrow so that we can sleep on that side, and then be able to get up in the early hours of the morning to head to Mthatha [a city in the Eastern Cape] so we get to the hospital in Mthatha early in the morning. I must borrow R100, but that is for transport only, we will not be able to eat." PR14[M34] – Living with HIV, hypertension & a stomach condition

For Bulungula participants, living in a rural homestead without electricity and infrastructure impacted their capacity to make recommended lifestyle changes or seek specialised medical care.

2.8. The support networks used to navigate treatment burden

Whilst navigating the adversity of living in underdeveloped, low-income rural settings in South Africa, many respondents relied heavily on support from family, neighbours, and community members. Without this help, most rural participants would not be able to access care, as they relied on others to share transportation, or to accompany them when walking through unsafe areas.

"You know when you are going to the clinic you need to get up very early and get there and sit and wait for someone else who is also going that way because there is a very big forest you need to walk through. And when you are coming back, you need to wait for people who were behind you in the queue so that you can walk with them. If they take long, then you will take the chance and go in the forest

alone. That is like a huge risk." PR12[F48] – Living with HIV & hypertension

Aside from relying on logistical support, most rural participants would borrow money from their support networks. All but two participants relied on a government grant to sustain themselves. This little income was often shared with partners, children, or other dependents. Without any prospects of formal employment, hand-outs from others were lifesaving.

"You know, when you do not work, you hope that you can receive help from your neighbours and family to be able to live." PR012 [F48] – Living with HIV & hypertension

Sometimes, borrowing money from neighbours was the only way rural participants could access the clinic.

"My wife helps me in a lot of ways. If I do not have money, she is the one who goes to loan money from people in our community who have it for me to get to the clinic; if there is something that I need if she can do something she will." PR005[M40] – Living with HIV & heart condition

2.9. Ubuntu as a mediating factor in managing treatment burden

Aside from practical and monetary assistance, there was also a strong sense of social solidarity in the community of Bulungula, which was less visible in Gugulethu. Where respondents in Gugulethu relied on the support of partners, children, or relatives, rural support networks were more extensive, and caring for others was embedded in participants' everyday life. Although none of the rural participants described this obligation to help others in the community as such, the presence of ubuntu was evident when participants described the support of their family to self-manage their conditions.

"My daughter in-law, daughter, and sister-in-law, they all work together to ensure that I stay well. My daughter in-law is usually the one who does most of the care work for me. My sister wife helps here and there." PR015[F63] – Living with HIV, hypertension & cancer

Many women in Bulungula had to navigate their treatment burden without a partner present, as they had migrated to the urban areas to find work or were deceased. Two participants said that they were in abusive relationships and could not rely on their partners' support. This negatively impacted their capacity for self-management, as income would be spent on alcohol and when their partners were under the influence, they would be more at risk of being verbally and physically abused. To navigate these difficult relationships, these participants would turn to other women for support.

"I speak a lot with my sister-in-law compared to my husband So, my sister-in-law is who I speak to about my health decision-making." PR009[F42] – Living with HIV & hypertension

Other women mentioned being supported by daughters, daughters-in-law, sisters-in-law, mothers, or sisters.

"If I am not feeling well, I will call her [my sister] to come and help me. Maybe she will even accompany me to the clinic. She will help me in the house by cleaning, cooking, and washing my clothes." PR12[F48] – Living with HIV & hypertension

Male participants from Gugulethu who lived alone, missed the presence of a spouse or children to support them practically and emotionally, resulting in loneliness.

"When I am not feeling well, I just sit, and if my niece realises that she has not seen me for 2 or 3 days she comes to check on me. I explain what the matter is, and she assists me in the way she can." PU014[M72] – Living with HIV & hypertension

HIV support groups, offered by clinics or NGO's, were also important support structures for both urban and rural participants. Being linked up with other HIV + patients helped participants to accept their status.

"The support group showed me that there are other people living with HIV and they were fine and that I would be fine too. There is something special about being able to share your challenges with people who are in the same position …. You never understand truly what it means to have HIV. Not unless you have it". PR013[F50] – Living with HIV & Hypertension

Urban respondents, generally with smaller support networks, shared that talking to a counsellor helped them with accepting their diagnosis, disclosing their HIV status to their families, or processing trauma and grief.

"When my husband died, I was really emotional, and someone organised a social worker for me. I was also raped when I was still young and that was the first time I could to talk about that experience. It had been in my heart for a long time and talking about it healed me." PU002[F62] – *Living with HIV & type 2 diabetes*

Aside from practical and emotional support, rural participants relied on their tight-knit community to receive health information. As most respondents did not have radio, television, or electricity at their homes, they received health education and promotion materials from others.

"We have a tight community, we all grew up together and we all have a clear understanding of each other's position and struggle, and we try to assist each other in the ways we can with what we know. Like when we are standing in the line at the clinic, people who have radios will say, I heard this, I heard that, try eating like this or eat that. It is not like we can afford to buy the things they tell us about, but we have that sense of togetherness." PR04[F60], Living with HIV & heart condition

Several Bulungula participants mentioned that the 'sense of togetherness' and being near others was crucial to stay healthy and meet their basic needs. As everyone experienced hardship, asking for help was socially acceptable.

"You know, when you do not work, what can you possibly do, you are the mercy of your neighbours, family, and the government. Hoping that you can receive help, any form of help from them to be able to live. I need this support for my survival as I manage these conditions with no resources." PR012[F48] – Living with HIV & hypertension

The concept of ubuntu was explicitly expressed by community health workers (CHWs) who were employed by the Bulungula Incubator (BI). In several informal conversations, CHWs would describe how community members relied on their neighbours for logistical support, especially in the absence of close family members. Although respondents did not indicate in which instances ubuntu was practiced out of financial necessity, reciprocation, moral obligation, or a combination all three, rural participants felt obliged take care of each other. Therefore, ubuntu was considered key to enhancing perceived patient capacity and improved self-management.

2.10. Health workers' support and attitudes as an essential source of support

Apart from togetherness, solidarity, and humanness, one of the core values of ubuntu is respect, translated from isiZulu or isiXhosa as 'imbeko.' Imbeko also means 'being polite' and taking someone seriously. For rural participants, being treated with imbeko in the health facility was crucial to their well-being.

"Here [in Bulungula], *they treat us with so much imbeko …. that is something that is precious here- the culture of respect. I even observe how they treat elders; it is so respectful. In Mthatha, they did not care whether*

you are young or old, you were just a number. Here, they see us." PR014 [M34] – *Living with HIV, hypertension & stomach condition*

During all 14 interviews in Bulungula, participants mentioned the warm relationship they had with clinic staff, who were considered an essential part of their support structure.

"I feel supported by the [clinic] staff. It is like, they understand the difficulties people in rural areas face, having to wake up at the crack of dawn to get to the clinic. After waiting a long time to just be attended to, they treat us with kindness and care. They make you feel okay about being HIV positive." PR012[F48] – Living with HIV & hypertension

"They treat me very well. They help me with explaining the importance of taking my pills and remind me when my next appointment is for blood work [CD4 test]. They are very pleasant, they work with you as a patient, not against you. They are supportive." PR11[F30] – Living with HIV & hypertension

According to respondents, health staff understood the long distances participants had to travel to the clinic and were sympathetic to their precarious circumstances, offering them chairs to sit on whilst waiting for their appointments, something that was not reported in busy urban clinics.

Community health workers (CHWs), translated to Nomakhaya's in isiXhosa, were also part of rural respondents' social networks. The CHWs employed by the BI would regularly conduct home visits to check up on patients, bring medication, and share health information. Residing in the same village or nearby communities, these CHWs shared similar cultural backgrounds and values, and respected the importance of ubuntu and imbeko. Their work was essential to participants' self-management capacity.

I speak a lot to the CHWs, especially when it comes to taking medication, and not missing dates, they come and check up on me and make sure I am on track with everything that I need to be doing to have my conditions under control. I would say that I am managing quite okay because I have people that I can speak to and who encourage and support me." PR003[F60] – Living with HIV & hypertension

The CHWs also counselled participants after their diagnoses, which helped them to accept their conditions and embrace a healthy, balanced lifestyle.

"When I first found out about my conditions, they [CHWs] *were able to sit me down and take me through what being HIV positive means and how to go about my treatment. It was the same for high blood pressure."* PR008[F40] – *Living with HIV & hypertension*

Being treated with Imbeko in the clinic and keeping warm relationships with CHWs was not shared among participants in urban areas. Overcrowded facilities, long waiting times, high staff turnover and a lack of organisation were among the complaints being raised. Although some of them considered staff to be friendly, one felt he was singled out as an HIV + patient and treated with a lack of Imbeko or respect.

"It feels as if the rude treatment we get is just for us (HIV patients), we are not helped well. We talk amongst ourselves sometimes; we say that maybe the people who help us cannot understand what it's like to live with HIV. It seems as if just because we are HIV positive, they take it as if we are not mentally well. Yes, the treatment is truly bad." PU012[F57] – Living with HIV & hypertension

When prompted, six urban participants also expressed the need for better organised health services and the reinstatement of peer-to-peer support groups to create a sense of ubuntu and offer HIV counselling, which was discontinued during the COVID-19 pandemic. Now, respondents in Gugulethu relied on family members to take over caring duties, which would normally be the responsibility of community

organisations.

> "I rely solely on my son now. There were some carers from Kamva and Red Cross who would come to help people who are sick like me, but they have stopped since COVID." PU002[F62] – Living with HIV & type 2 diabetes

3. Discussion

This paper describes the relevance of two African concepts, *ubuntu* and *imbeko,* in the lives of South African patients who are navigating their multimorbidity workload. Among rural but not urban participants, the philosophy of ubuntu shaped participants' social networks and support structures and enabled them to better navigate the complexities of chronic illness, including securing assistance to monitor conditions, sharing financial resources, and accessing clinics and health information. Ubuntu, as exemplified here, is more than just a sense of community or belonging. It is a social fabric binding people together with shared values, expressed through compassion, reciprocity, and mutual caring, and can be applied to reimagine social support structures in South Africa. Ubuntu was used by rural participants to define and expand networks, but also allowed them to seek both financial and emotional support outside their immediate family structures.

Characterized by a shared culture through kinship, clan ties and heritage, ubuntu is an unspoken rule of engagement in much of rural South Africa (Ewuoso and Hall, 2019; Gade, 2011). Ubuntu philosophy and kindship solidarity governs, often unconsciously, how people shape their support structures, not out of obligation or expectation to be reciprocated, but through respecting linked values (Hailey, 2008; Knight et al., 2016; Mboti, 2015; Mugumbate and Chereni, 2020; Ramose, 2002). For rural respondents, this support is essential to their well-being, as they had to rely on others for basic needs such as food or shelter, but also to self-manage conditions or navigate health emergencies. Asking for help is socially accepted and sharing of resources is seen as a communal responsibility. Even though support structures were smaller in urban areas and not defined by close kinship or clan ties, participants who could rely on friends and family, felt more in control of their conditions as they could share their treatment burden. In both Gugulethu and Bulungula, most carers were women and female participants relied largely on the support of other women, either by choice or out of necessity. This gendered obligation to care is in line with the feminist literature, which emphasises that women's contribution to the care economy is disproportionally larger than men's, due to the burden of unpaid health work conducted by women in African contexts (Allman, 1997; Gumede, 2021; Hunter, 2010; Mikell, 1984).

This paper reports findings about the role of social networks in the context of multimorbidity treatment burden through the lens of ubuntu. Similarities can be found with outcomes from Manderson and Block (2016), who argue that providing care and support is an enacted achievement of human connectedness and compassion, even when provided outside of the family context (Manderson and Block, 2016). Findings are also in line with observations form Cele et al. (2021), who explored how *ukuphumelela*, flourishing, assisted chronically ill patients to pursue good health in South Africa's Soweto (Cele et al., 2021). Their findings illuminated that both caring and uplifting community members or being cared for and helped in return for is essential to patients' ability to flourish (Cele et al., 2021). In turn, the absence of relational ties can reduce 'good health' (Cele et al., 2021). This is equally reported in HIV literature, where patients with insufficient support report decreased engagement in care (Knight and Schatz, 2022; Zanoni et al., 2019). Treatment burden studies conducted in Malawi, Argentina and Ghana have also reported that chronically ill patients in low-income settings with strong support structures expressed more capacity to self-manage their conditions and had better health outcomes compared to patients without support (Chikumbu et al., 2022; Morgan et al., 2019; Roberti et al., 2022).

Results in this paper exemplify how Ubuntu cultivates resilience, as it draws on cultural and collective resources and meanings, creating a shared identity (Kim et al., 2019). For participants in this study, the concept of ubuntu was applied as an unwritten cultural script allowing respondents to positively cope with chronic conditions despite experiencing hardship, and strategically use local support systems (Kim et al., 2019; Van Pinxteren et al., 2023b). In the context of self-management, resilience was expressed as 'just going on with life' and recognising that through Ubuntu, 'you are not alone,' but you are supported by a larger community (Jin et al., 2023; Kim et al., 2019). Key to patients' capacity to be resilient is '*ukwamukela*', translated as acceptance from isiZulu and isiXhosa. Introduced by Kim et al. (2019) as one of the idioms of resilience, acceptance of illness diagnoses was key to participants' ability to positively cope with their conditions, especially when well informed about illness prognoses (Kim et al., 2019).

In Bulungula, engagement with CHWs was key to participants' resilience, leading to positive coping skills and increased self-management capacity. The approach to care given by CHWs was also understood as ubuntu, as CHWs felt an intrinsic responsibility to look after community members, with whom they shared a history, clan ties or familial bonds. Importantly, CHWs treated their patients with respect and dignity, in their terms, Imbeko, which was central to the provider – patient relationship. CHWs provided biomedical and social care, health information and lifestyle advice, but it was the 'culture of respect' that appeared invaluable. This ongoing support from CHWs resulted in rural respondents' positive perceptions of both the quality and continuity of care. These sentiments were not shared by urban respondents, who spoke about disorganised health services. CHWs' acknowledgement of patients' socio-economic challenges was particularly appreciated, as well as their understanding that despite hardships, patients tried to attend clinic appointments and live a healthy lifestyle. Both the sense of togetherness through ubuntu and respect through imbeko cultivated positive patient engagement with healthcare services which was noted as absent in urban clinics. This differs from literature on health care experiences in South Africa, where patients report, high staff turnover and bad staff attitudes, which negatively impacted their perceptions of received care, which in turn, decreased their self-management capacity (Maphumulo and Bhengu, 2019).

Using BoTT and CuCoM enabled us to explore the role of African-centric communities of care, as both treatment burden models emphasise the important role that support networks play in patients' ability to engage with material and informational tasks as required by the health system (*cognitive sense-making*). Similar to May et al. (2014), we found that most participants in Gugulethu and Bulungula have some form of supportive relationships, but the size and complexity of these networks may change over time due to the practical and emotional demands of the workload as well as the illness trajectory (May et al., 2014). As recognised in BoTT, our study also illustrated that health workers are understood to be an essential part of patients' support network, especially in rural Bulungula. Notably, however, was that in the rural South African setting, social networks are organised according to ubuntu's culturally constructed norms, creating an obligation to assist family or extended kin, and in turn, creating a social insurance through reciprocal support to maintain a community of mutual caring (Cele et al., 2021; Knight et al., 2016; Knight and Schatz, 2022). The absence of ubuntu, as experienced by urban respondents, resulted in smaller networks and increased treatment burden, especially among male participants. Ubuntu also ties support networks through kinship and shared identities, which extend beyond nuclear family structures and include extended kin or wider social relationships (Knight et al., 2016; Knight and Schatz, 2022). These networks do not only provide emotional or practical assistance but offer financial and informational support. Additionally, the values of ubuntu are governed by culturally constructed norms, whereby support networks are morally obliged to assist family or kin, creating a social insurance through reciprocal support to maintain a community of mutual caring (Cele et al., 2021; Knight and Schatz,

2022). Lastly, the use of BoTT and CuCoM enabled us to make the concept of ubuntu, often hidden in patients' everyday lives and actions, visible as a powerful cultural philosophy that needs to be better recognised when aiming to improve self-management models of care.

When using treatment burden theories in low-income settings in Africa, we believe that ubuntu is a crucial part of patients' social capital, as they receive practical, emotional, and financial support through common heritage, kinship, and shared values, even if the concept is understood and practiced differently in urban and rural areas. As illustrated in Fig. 1, relational networks, amplified by imbeko and ubuntu are central components increasing patients' capacity in rural settings, as they produce structural resilience on which [individual] functional performance depends. Indicated by examples from both urban and rural South Africa, when functional performance is hampered by socio-economic forces (colonisation, migration, urbanisation), then structural resilience is diminished and capacity for functional performance is reduced (May et al., 2014). Being developed and tested in high-income settings, we believe that by proposing to integrate ubuntu and linked values as core principles in BoTT, the new framework will be more appropriate and applicable for studies exploring patient workload and capacity in African settings, even when used in varying contexts, such as Gugulethu and Bulungula. Whilst recognising that LMICs differ from each other, using the adapted BoTT can be an entry point to further explore the social, family and care context in which care activities are managed, providing rich and context-specific data that can inform research agendas and intervention studies (Skou et al., 2022). This is important, as loneliness, social isolation and poor family mechanisms translate into higher treatment burden and chronic illnesses occurring at earlier ages (Chikumbu et al., 2022; Skou et al., 2022).

Unpacking the crucial role that the concepts of ubuntu and imbeko play in patient self-management can also inform patient-centred health care initiatives in South Africa. Firstly, Ubuntu can be readily incorporated into the ICDM, as the model aims to strengthen social support systems inside and outside the facility through leveraging existing community structures (Mahomed et al., 2014). Ubuntu-based values can also revive peer-to-peer support groups and community structures, as many existing support groups were discontinued during COVID-19 (Jardim et al., 2022). Secondly, ubuntu, and more strongly, imbeko, can facilitate a stronger patient-provider relationship, improve staff attitudes, and strengthen organisational management in the clinic. Thirdly, findings affirm the invaluable role of CHWs in patient self-management, as they actively link communities to clinics and are considered to be the cornerstone of South Africa's primary health services, providing continuity of care (Schneider et al., 2015).

3.1. Strengths and limitations

This study has several limitations. We intended to recruit an equal sample of men and women in both field-sites, but were only able to recruit two male participants in our rural sample, due to ongoing migration and high rates of violence and premature death due to undiagnosed ill-health (Cornell et al., 2017). Furthermore, while this study included people with HIV and a variety of other chronic conditions, all NCDs, a broader sample of less common illnesses would have been desirable, especially in the rural field-site. Lastly, all respondents were living with HIV/NCD multimorbidity, which means we cannot report on experiences of patients who are HIV negative. Therefore, additional work with patients with other patterns of multimorbidity is worth exploring in future research. A key strength is the comparative nature of the study, allowing us to explore the variation within a common experience, as participants' experiences differed based on their culture, background, and social meanings. Another strength is the prolonged engagement with the study sites, as we travelled regularly to Gugulethu CHC and stayed in Bulungula for two weeks and were able to collect rich insights on people's perceived treatment burden and capacity and reached data saturation in both settings (Van Pinxteren et al., 2023b).

4. Conclusion

This paper contributes to a growing body of literature on experiences of multimorbidity in low-income settings. Using CuCoM and BoTT as conceptual toolkits, this paper demonstrates that the concept of ubuntu shapes social relations, increases social capital and provides a much-needed support system for people living with multimorbidity in low-income settings in South Africa. Ubuntu improves patients' capacity to self-manage their conditions and engage with health services and builds structural resilience, even when living in precarious circumstances. We further highlight how a lack of Ubuntu, experienced by urban patients, results in isolation from social networks, feeling less in control and reduced reported self-management capacity. By incorporating ubuntu, imbeko and other African social support theories into existing treatment burden models, we decolonise individual illness behaviour theory developed in HICs and move towards acknowledging culturally embedded patterns of support and collaboration. Future interventions need to recognise the invaluable role that ubuntu plays for people living with multimorbidity in South Africa and consider how existing social networks can be strengthened to enhance self-management capacity, especially in a changing health care landscape where patients are expected to take more responsibility for their own health.

Author contributions

Myrna van Pinxteren: Conceptualisation, Data Curation, Writing-Original draft preparation Nonzuzo Mbokazi: Conceptualisation, Data Curation, Writing-Original draft preparation Katherine Murphy: Supervision, Writing-Review & Editing Frances S. Mair: Funding acquisition,
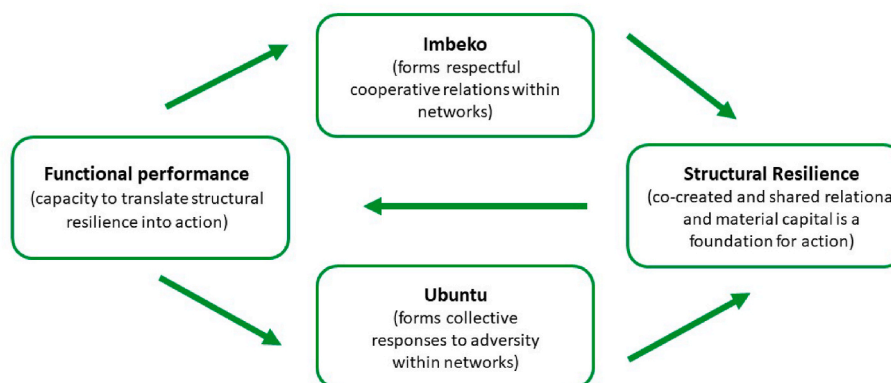

Fig. 1. Incorporating ubuntu and imbeko into burden of treatment theory.

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