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'You can sleep hungry just to buy the medicine': Applying a patient-centred model of cumulative complexity to explore how patients manage the lifelong workload of hypertension care in Kenya

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ABSTRACT

This research applies the Cumulative Complexity model to examine patient experiences of hypertension management following prescription of anti-hypertensive medication in the public health system in Kenya. Set in Kiambu County, central Kenya, it draws on abductive analysis of interviews with patients (n = 24), caregivers (n = 7) and non-participant observation in four purposively selected public facilities conducted between November 2022 and April 2023. Patients undertook three kinds of 'work' to reduce their blood pressure: processing work to accept hypertension diagnosis and its chronic dimension; practical work managing care and medications, and work of managing emotions. Four inter-related domains of patient capacity influenced patients' ability to do this work: individual financial resources; physical functioning; social support and religious faith. Variations in treatment cost and medicine availability increased patient workload. When workload overwhelmed capacity treatment adherence was interrupted. Interruptions in treatment resulted in negative feedback loops further reducing patient capacity. Recognising temporal variability in workload and capacity is key to understand treatment adherence in resource constrained settings. Consideration of adaptive counter-agency can strengthen treatment burden models. We encourage policy makers to prioritise addressing treatment burdens to support treatment adherence and sustained hypertension control.

1. Introduction

'Hypertension' refers to persistently high blood pressure – the physical pressure exerted on artery walls as the heart pumps blood around the body. This pressure puts strain on blood vessels, the heart and other organs, over time leading to stroke, heart failure, heart attack, kidney damage and other health problems (Forouzanfar et al., 2017). Hypertension affects 1 in 3 adults aged 30–79 worldwide, with prevalence increasing over the lifecourse, and greatly increases the risk of serious illness and early death (Cheng et al., 2012; Mills et al., 2020; WHO, 2023). Blood pressure can be reduced through making 'lifestyle' alterations in diet and physical activity and taking daily medication. Physicians support patients to stabilise blood pressure below a specific level (140/90 mmHg) which is described as 'control' of hypertension (WHO, 2018). Regular blood pressure monitoring, maintenance of lifestyle alterations and daily medication use are then expected to continue for the rest of the patients' life.

However, this lifelong endeavour to maintain control of blood

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pressure presents substantial challenges for patients and health systems (Choudhry et al., 2022). Globally, only 21 % of adults (30–79 years) with hypertension are considered to have their hypertension 'controlled' (WHO, 2023) and prevalence of anti-hypertensive medication 'non-adherence' is 27–40 %, (Lee et al., 2022).

In Kenya, 33 % of people aged 30-79 years are estimated to have hypertension (WHO, 2023). The most recent (2015) national survey found that among people who were aware they had hypertension less than a third (29.6 %) were on treatment, of whom half (51.7 %) - less than 15 % of those diagnosed - had achieved blood pressure control (Mohamed et al., 2018). 'Alarmingly low' retention in treatment was identified during a recent initiative to improve hypertension care, with only 12 % of those enrolled in treatment retained in care 12 months later (Mbau et al., 2022). These data are supported by evidence of challenges in treatment adherence (Gala et al., 2023) and blood pressure control (Mbui et al., 2017; Muthuki et al., 2020; Mutua et al., 2014), consistent with findings elsewhere in sub-Saharan Africa (Musicha et al., 2016; Okello et al., 2020). In response to these challenges, regional stakeholders have identified priorities to improve hypertension detection, treatment and control (Dzudie et al., 2018; Olowoyo et al., 2024)., and the Kenvan Non-Communicable Diseases Strategic Plan (MoH Kenva, 2021) aims to increase the proportion of people achieving control of hypertension from 3.4 % in 2015 to 50 % in 2025.

This paper examines the experiences of patients engaged in 'managing' hypertension through medical care in Kenya's national health system, in order to help understand why levels of hypertension control are so low, and inform development and implementation of interventions to support consistent reduction in blood pressure.

1.1. Kenyan national health system context

National hypertension management guidelines (MoH Kenya, 2018) draw on the WHO HEARTS Technical Package. The hypertension care pathway begins with community level prevention and education activities delivered by community health promotors, followed by screening and diagnosis, treatment initiation, regular blood pressure monitoring and treatment review.

The Kenyan health system is organised in six levels spanning community (Level 1) to tertiary care (Level 6). County governments manage Level 1-5 facilities and medication procurement. Diagnosis, treatment initiation for uncomplicated hypertension and follow-up clinics are delivered through primary health care, delivered free of charge at dispensaries and clinics (Level 2) and health centres (Level 3). These services are also provided by secondary and tertiary facilities, in addition to care for complicated cases which are referred upwards as needed to subcounty (Level 4), county (Level 5) and national (Level 6) hospitals. At secondary and tertiary level, patients are charged for consultations, additional services such as laboratory tests, and medications. A limited range of anti-hypertensive medications can be initiated at primary care level, and patients who have been prescribed other medications at secondary/tertiary level can receive prescription refills at primary care facilities (MoH Kenya, 2018). Financial costs, both direct costs charged by the health system and costs of transport, have consistently been reported as a barrier to NCD care in Kenya (Gala et al., 2023; Naanyu et al., 2024). At the time of this study (2022-3) the 'National Health Insurance Fund' (NHIF) aimed to improve equitable access to affordable health care as part of a policy drive toward Universal Health Coverage (MOH, 2020). Patients with active NHIF subscriptions received some services free of charge in some secondary/tertiary level facilities, although services included in NHIF packages varied by facility and were recognised not to consistently meet the needs of non-communicable disease (NCD) patients (Otieno et al., 2023; Oyando et al., 2023). NHIF was replaced in early 2024 by the Social Health Insurance Fund.

1.2. Critical approaches to models for hypertension management

Across settings, successful implementation of treatment models for hypertension depend on two underpinning factors. Firstly, that necessary health system resources, such as sufficient trained staff, functioning equipment and medicines are consistently available and accessible to patients after diagnosis. Secondly, that patients diagnosed with hypertension actively participate in attending appointments, making lifestyle changes and taking medication to maintain blood pressure control. Sustainment of these inter-related factors over time is challenging in resource-constrained settings. In Kenya, the health system faces funding shortages, financial bottlenecks, understaffing, shortage of equipment and medications (Moses et al., 2021; WHO, 2017). Over one third (38.6 %) of the population live below the national poverty line, and in 2022 74 % had no access to any form of health insurance (KNBS & ICF, 2023). In this context, treatment models may not be consistently underpinned by availability of health system resources and active engagement of patients in maintaining blood pressure control. Internationally, there is increasing recognition that in contrast to the continuous, linear hypertension treatment pathways planned by health care providers, patients frequently experience interrupted, non-linear care, which can be complex and burdensome (Herbst et al., 2021; Mendoza et al., 2022; Perera et al., 2019). A recent review highlighted the need to understand 'the changing barriers to hypertension control along the patient journey' (Brathwaite et al., 2022).

Theoretical approaches to conceptualise patient experiences of managing hypertension and other chronic conditions examine interactions between individual patient level, social, economic and health system factors over time. Mendoza and colleagues (2022) draw on the concept of 'therapeutic itineraries' to examine factors informing patients' care journeys in the Philippines, highlighting how these diverge from clinical pathways and are informed by complex and varied lay understandings and experiences of hypertension. Sociological approaches developed in high-income settings build on concepts of work involved in managing chronic illness (Corbin & Strauss, 1985) and dynamic, temporal patient trajectories of care (Corbin & Strauss, 1988; Pescosolido, 2013, pp. 1770-1777) to examine interactions between patient workload and capacity (Shippee et al., 2012) and 'burdens of treatment' (May et al., 2014). These patient-focused approaches help to reveal the unseen work of patients after medical encounters (Humphris et al., 2020). Their application in resource-constrained settings has illuminated the scale of tasks delegated to patients and their caregivers (Willis et al., 2023), and identified adaptions to better explore patients' experiences in low-income settings, for example through considering cumulative precariousness (van Pinxteren et al., 2023) and the burden of 'lack' of treatment (Chikumbu et al., 2022).

In this paper, we examine the significant workloads embedded in patients' hypertension management trajectories following prescription of hypertensive medication in public facilities in Kenya, to inform development of strategies to improve blood pressure control. Building on recent research about access barriers to NCD medication and patient coping mechanisms in Kenya (Naanyu et al., 2024; Ng et al., 2021; Otieno et al., 2023), we draw on the Cumulative Complexity ('CuCom') Model (Shippee et al., 2012) to examine interactions of factors which contribute to imbalance between patient capacity and workload, influencing adherence to treatment. This model proposes that interaction between **patient workload of demands** and **patient capacity** directly and indirectly influences engagement with health services and self-management, and thus patient outcomes, (Fig. 1). We reflect on limits of this model, which focuses on patient agency, in a context of resource constraint.

In this paper, we propose that temporal variability in both the resources provided by the health system and in patient capacity generates significant additional workloads for patients, and is a key consideration in understanding treatment adherence.



Fig. 1. Workload – Capacity interactions. Adapted from (Shippee et al., 2012).

2. Methods

This research was embedded within the formative phase of a mixed methods study to inform development of a strategy to improve implementation of fixed-dose combination (FDC) therapy for treatment of hypertension in Kenya. Findings regarding acceptability of FDC therapy (Mbuthia et al., 2025) and health system level implementation (Murphy et al., 2025) are reported separately.

2.1. Study setting

A case study approach, setting the study in one county, (Kiambu County, central Kenya) was taken in order to develop a robust understanding of complex, interwoven contextual factors affecting patient's experiences of treatment in a specific context (Greenhalgh & Papoutsi, 2018; May et al., 2016) to inform design of a planned intervention in the region. The majority of the county population (73.8 %) live in urban areas, compared with 38.6 % nationally (KNBS, 2024). Incidence of poverty in the county (2021) was 20.5 % (519,000 individuals), and poverty rates were higher among older people (age 60–69 years: 30.9 %; age 70 + years: 23.4 %) (KNBS, 2023).

2.2. Facility and participant selection and recruitment

In consultation with County stakeholders three government facilities providing care for people with hypertension at Levels 3–5 of the health system were purposively selected to include socio-demographically diverse patient catchment populations from urban and rural settings. Following initial data collection a fourth, rurally located, Level 3 facility was added to increase diversity. Patients aged 18 years/over, ever diagnosed with hypertension and prescribed treatment in the last six months were eligible to participate in the study. With assistance from a triaging nurse at each facility, the second author purposively selected patients with hypertension attending clinic, drawing on patient registers to identify a list of patients from a range of pre-specified categories relevant to experiences of hypertension treatment (age group, sex, comorbidities, caregiver accompaniment) (Table 1). A small number of caregivers, defined as someone in the patients' household or family who supports them in managing their condition, were included to give complementary perspectives. Caregivers aged 18 years/over were eligible to participate if the patient had identified them and given permission for them to be contacted, and were selected purposively by gender, age and relationship to patient to provide diversity in experience (Table 1).

Table 1	
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Summary of Participant	Characteristics.
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Participant Charac	teristic	Patients (n) $(total = 24)$	Caregivers (n) $(total = 7)$
Gender*	Female	14	5
	Male	10	2
Age (years)*	<40	2	
	41–50	2	
	51-60	9	
	61–70	6	
	>70	5	
	Mean age	60	41
Education	None	1	0
	Primary	6	3
	Secondary	15	3
	Tertiary	2	1
Condition*	Hypertension	13	2
	Hypertension + Diabetes	11	5
Patient NHIF	Active membership	12	
membership	Lapsed membership	6	
	No membership	6	
Facility Level*	Level 5	6	4
	Level 4	6	1
	Level 3 Urban	7	0
	Level 3 Rural	5	2

* Pre-specified selection category.

Eligible individuals were approached face-to-face (patients) or by telephone (caregivers) and invited to participate. A study information sheet was provided [Swahili/English]. Researchers reviewed the information sheet with each participant, and written consent was obtained for all study participants. Two invited patients declined to participate. Recruitment stopped when participants from the pre-specified range of categories had been included, and no substantial new themes were emerging during interviews.

2.3. Data generation

Fieldwork was conducted between November 2022-April 2023. Non-participant observations were first conducted in each facility by the first and second authors over 1-3 days, structured by an observation checklist. Observations focused on patient flow within the facility and medication dispensing, and informed identification of categories for patient selection and development of interview topic guides. Medical consultations were not observed. In-depth interviews were then conducted using semi-structured topic guides focusing on patients' experiences of engaging in care for hypertension spanning diagnosis, treatment initiation and everyday management over time [Supplementary Information 1]. Interviews were conducted by the second author (n = 28) and a trained colleague (n = 3) in Swahili or English, according to the participant's preference, with the first author present for the first four interviews. Interviews lasted 15-84 min and took place in person in a private room at each facility, with only the researcher(s) and participant present. All were audio recorded with participant's permission. Notes were taken during interviews and regular debriefs were held to discuss emerging and surprising findings and methodological decisions.

2.4. Data management and analysis

Data collected though non-participant observation were used to familiarise researchers with care procedures and compile treatment costs for tracer medications at each facility. Interview audio recordings were transcribed in the source language and translated into English by a professional external transcription/translation team, then translated transcripts were checked against the original version by the interviewer and de-identified. Interview data analysis comprised the following iterative steps: Case summaries produced for each patient, combining patient/caregiver data where both were available, were compared to identify points of overlap and difference in patient and caregiver accounts and in overall trajectories of patient experience. An 'index case' was identified to anchor analysis, a case at the 'edge' of the range of experiences (Timmermans & Tavory, 2022), who was unable to meet their workload of demands consistently despite unusually substantial capacity. An abductive analytical approach was used (Timmermans & Tavory, 2012), identifying initial themes of relevance to the research aim through open coding of patient and caregiver transcripts, then developing questions derived from key constructs of CuCOM to direct focused coding. Supplementary Material 2 illustrates the analysis process. NVivo 12 software was used to support coding (QSR International, 2017). Reflective and analytical memos were created throughout data generation and analysis. Initial findings were shared at a stakeholder workshop in Nairobi in April 2023, with 25 participants including representatives from five health care facilities, Community Health Volunteers, the County Health Department, the NHIF, and the Kenyan Cardiac Society. Participants identified interest in unpacking differences in patients' experiences of care at different levels of care, and in the impacts of locally specific implementation of NHIF, explored here.

2.5. Positionality

The study was a Kenyan/UK collaboration conducted jointly by researchers based in both countries. This combination enabled us to leverage familiarity with local languages and health systems, supporting data quality, while also exploring taken for granted practices, such as the role of caregivers, with an external comparative perspective. A female UK based social scientist with experience of qualitative research in NCD treatment in Kenya and elsewhere supported in-person piloting of tools, participant observation and initial interviews. Interviews were led by a male Kenyan social scientist with experience of conducting qualitative health research in the region. To minimise social desirability bias we emphasised our interest in learning about participants' individual experiences and opinions about their treatment, in order to inform treatment for other patients. Development of the research topic and analysis was led by a UK based researcher and interpretation was discussed regularly with the second author and wider team. We collaborated with a co-developer of treatment burden theories who encouraged their use as thinking tools rather than fixed frameworks, and supported critical reflection on their application in this setting. The wider team included clinicians, health systems researchers and social scientists with experience in implementation research who supported reflection on practical applications of our findings.

2.6. Ethical considerations

The study conformed to the principles embodied in the Declaration of Helsinki. It was approved by Kenya Medical Research Institute's Scientific and Ethics Review Unit (KEMRI/RES/7/3/1), Kenya National Commission of Science and Technology (NACOSTI/P/22/21524) and London School of Hygiene and Tropical Medicine Research Ethics Committee (28062). Permissions were granted by the County Government and each facility before study commencement. Written informed consent was obtained from all participants. Researchers took care to ensure that potential participants understood that participation was optional, and that participation or non-participation in the study would not affect the care they received.

3. Findings

Our findings are presented in relation to three concepts derived from CuCom; (1) the **workload of demands** experienced by patients during their trajectory of care; (2) **domains of patient level capacity** which affect patients' ability to interact with and utilise healthcare services for hypertension and (3) **interactions between capacity and workload**. Each is considered in relation to **treatment adherence**.

3.1. Patient workload of demands

The 'patient workload of demands' includes both 'responsibilities of patient-hood', specifically related to management of the patient's condition(s), and 'everyday life demands' related to other responsibilities in daily life (Shippee et al., 2012). Examining workload related to management of hypertension we identify three domains of 'work' generated for participants by the tasks they need to do to reduce their blood pressure and to maintain this reduction; processing work, practical work, and work of managing emotions.

3.1.1. 'Processing' work: accepting hypertension diagnosis and its chronic nature

Acceptance of a hypertension diagnosis is a prerequisite to deciding to undertake treatment. Some patients reported accepting and acting on their diagnosis without question, particularly those who had experienced symptoms and proactively sought care, for example 'you know when you are sick, you accept the disease and also accept taking the drugs' (Patient 18). Others described taking time to process and rationalise their diagnosis and decide to undertake initial treatment. Some described an additional process to then continue treatment or restart after a gap. We group these processes of making sense of information received from different sources and through patients' own bodily experience (or not) of symptoms, and accepting (or resisting) classification as a 'patient' as 'processing' work.

Patients who felt the diagnosis did not make sense for them in relation to their bodily experience reported being reluctant to begin treatment, for example a 30 year-old patient diagnosed when seeking contraception at a child health clinic explained 'I did not believe I had that illness' (Patient 24), and 'initially' did not take medication, then 'made a decision to start taking' This was more common among younger patients and those who were asymptomatic, not seeing or feeling themselves as 'sick'; the unexpected diagnosis a biographical disruption which misfitted their life trajectory (Bury, 1982). The youngest patient interviewed, a 25 year-old female, described questioning why she had hypertension at her age when her peers did not, and experiencing negative feelings following diagnosis: 'I was looking at my age and back home nobody had that problem. So that made me feel bad, I felt bad and hated myself' (Patient 9). Feeling a mismatch between their age and diagnosis was not confined to the youngest patients; a caregiver for a 60 year-old female explained 'she has not accepted that she has pressure', explaining 'she said she is too young to be taking medicine for pressure ... her age hasn't reached the time to be taking medicines every day' (Caregiver 1).

In addition to the processing work of accepting their diagnosis and deciding to engage in initial treatment, we identified subsequent work for some patients in understanding and accepting the chronic nature of hypertension in relation to their own body and therefore the need to sustain treatmentto control their blood pressure, indicating that acceptance is not always stable over time. This does not necessarily reflect an information deficit; patients reported being told that they would need to continue taking medication, but not believing that this would be necessary for them. Some described stabilising their blood pressure through initial treatment and then stopping taking medication, for example: 'I stopped because I thought that I was okay, that I don't have pressure' (Patient 13). A caregiver who was hypertensive described doing 'an experiment with myself', stopping taking her own antihypertensive medication 'to see what would happen' and she realised this made her unwell, stating 'it's something that I have experienced' (Caregiver 3). Restarting was prompted by specific events which caused re-evaluation of information and change in practice such as a return of perceived symptoms, or learning of peers with hypertension experiencing adverse outcomes.

A further element of 'processing' work was identified among participants who reported receiving competing advice about the risks or benefits of long-term medication adherence, for example: 'many people were telling me that if I continued to take medication for my high blood pressure, my blood pressure would only rise further' (Patient 17). This generated work to consider and evaluate contradictory information.

3.1.2. Practical work: making and maintaining practical changes to daily life

All patients reported needing to make practical changes to their daily lives in order to reduce their blood pressure. We identified three main categories of practical changes, each generating specific workloads. Additionally, we found that variability in treatment costs and medication availability within the local health system increased patient's workloads.

Workload of managing diet and exercise

The first category was changes to diet and exercise practices which were widely reported, although we did not assess the extent to which they were implemented. Making dietary changes such as reducing salt, sugar, fats, eating more leafy vegetables and whole grains involved identifying substitutes to normal foods, obtaining substitutes, and adhering to these changes over time. Dietary substitutions could be expensive; one strategy reported to address this was growing leafy vegetables at home to maintain an affordable supply. Participants reported exercising by walking longer distances, undertaking regular farm work, and beginning new activities such as skipping. Conversely, some participants reported reducing their heavier physical activity due to their condition, for example a farm help was employed to reduce a female patient's physical workload: '*we employed someone* ... *I stopped picking the tea leaves. I only do the light jobs like planting vegetables*' (Patient 23). Although these lifestyle changes were discussed by patients as part of their actions taken to manage hypertension, they were not generally described in terms of being challenging or burdensome, with the exception of buying healthier foods, which were sometimes unaffordable.

Workload of managing healthcare. The work of managing healthcare discussed by patients included attending clinics regularly to monitor blood pressure, taking medicines correctly and managing their side effects. Attending clinics involved travel and time committment, with 'lengthy waiting queues' (Patient 17) meaning that clinic visits took several hours. As clinics routinely operated on weekday mornings younger working patients/caregivers needed to regularly request time away from employment or extensions to clinic hours to attend. We observed a younger patient negotiating to be seen because they arrived at the end of the clinic slot, after their paid employment.

Patients prescribed multiple medications, particularly those with comorbidities, undertook administrative work of medicine organisation to take correct doses at different times of day. For example a patient with hypertension and diabetes taking six to eight medications daily described a two stage system; first arranging medications into morning/ evening doses, then decanting these daily into cups: *'when I get home my work is to arrange them'* (Patient 21).

Managing or accommodating side-effects of anti-hypertensive medications also generated work for patients. While some discussed side effects with their doctors and had prescriptions altered, others reported ongoing side-effects including changes in sexual function (males), which they found problematic in intimate relationships, and frequency of urination when taking diuretics. The latter could cause awkwardness in social situations and disturb other family members sleeping at night. A patient explained '*it has forced me to build a toilet inside my room*' to avoid waking others. Participants expressed feelings of embarrassment about these issues and may have found them difficult to raise with health care providers.

Workload of accessing treatment. Tasks which participants presented as most burdensome and difficult to maintain were related to enabling access to treatment, particularly locating and obtaining a continuous supply of medication. This workload was impossible for most participants to consistently fulfil. Patients reported constant tasks of 'looking for money' to pay for clinic-related costs, including transport, and medication. Patient's individual financial status varied, but consistent financial security was rare. Patients in both casual and stable employment reported allocating substantial proportions of their earnings to medication costs, which involved frequently assessing and prioritising competing demands for resources. When participants did not have money to pay for medications, they reported asking family members or friends for financial loans or gifts, for example 'I don't have money for those medicines prescribed to me, so I tell them to lend me some cash so I can buy a few ... ' (Patient 18).

When free of charge or lower cost medications were not available at the public facility patients needed to visit private pharmacies to look for them: 'the problem is there the days these drugs are not available ... It's going around looking' (Patient 20). This was more time-consuming and costly for patients in rural locations. Where patients needed to purchase medications with limited financial resources they reported buying smaller volumes of medications than their full prescription, for example: 'because of our income, we buy medicines daily, we cannot buy medicines that will last a long time' (Caregiver for Patient 10). This often meant purchasing from private pharmacies, at higher prices, because patients did not live close to the facility to visit frequently, or public facilities did not sell small amounts. While this strategy enabled patients to better maintain continuity, it involved more frequent trips to purchase medications at higher overall cost.

In addition to workloads related to financial costs, obtaining prescribed medicines in public facilities involved several stages requiring time and physical effort, including visiting multiple offices, navigating making online payment, and queuing for long durations. This was more difficult for patients who were older, less physically mobile, or less familiar with Swahili, and was supported for some by accompanying caregivers.

Health system variabilities increase patient workload. An unexpected finding was that variability in two aspects of the local health system increased patient's workloads of managing healthcare and accessing medications. Variability in treatment costs between health system levels meant that the same service delivered at different government facilities cost different amounts to the patient depending on the facility level, the patient's health insurance status and facility policy on insurance coverage. The cost to obtain a months' supply of the lowest priced, commonly prescribed medication (diuretic Hydrochlorothiazide 12.5 mg) ranged from no charge in primary care facilities to 656 KSH (\$US 5.25) for an uninsured patient in a Level 5 secondary care facility (including registration, clinic visit and medication). Anti-hypertensive medication costs were covered for insured patients at the Level 4 but not the Level 5 facility: 'It is not being given, [without charge] even though I have the NHIF card. It is to buy. They don't give blood pressure medication' [Patient 14]. This variability in fixed costs created differential affordability for patients seeking the same services at different government facilities. In response some patients undertook additional work of navigating services to minimise financial cost, sometimes in ways contrary to expected patient pathways, such as downwards self-referral of patients with more complex conditions and treatment regimens from secondary to primary care facilities to access free services.

Variability in availability of anti-hypertensive medication also affected patient's workloads. Changing availability in the public system meant that patients could not reliably plan where they would obtain their medication from, at what cost, generating substantial increased workload in finding medication and re-planning monthly budgets. At the urban primary care facility (where medication was free-of-charge) medications were regularly out-of-stock. Medications were more frequently available at higher level facilities, but not continuously so. When medications were unavailable, patients were directed to purchase from private pharmacies: 'the ones that are missing, they put a star, they tell you to go and look for it at the chemist' (Patient 16). Costs at private pharmacies were substantially higher, e.g. angiotensin receptor blocker losartan cost 225-930 KSH/month from private pharmacies, 140-200 KSH/month from secondary care facilities and was free of charge at primary care facilities when available. At the rural primary care facility medications were rarely available through the government supply chain. To address this a patient-led group pooled funds and arranged bulk purchase of medications from a private wholesale pharmacy, reportedly resulting in more reliable availability.

3.1.3. Work of managing emotions

A third aspect of patient's workload was generated by avoiding feelings of stress and anger. Patients reported that experiencing these feelings had direct physiological impacts on their blood pressure, for example 'it [blood pressure] rises when you have stress, when you have too many thoughts. When you are also angry it will rise' (Patient 18). Specific practical strategies to avoid experiencing these feelings included deliberately avoiding 'thinking a lot' about subjects that generated negative emotions, or removing themselves from specific situations to control their blood pressure: 'I avoid commotions, when I see someone will make me angry, I avoid it a lot and I will leave' (Patient 21). This careful management of emotions, together with other aspects of managing their condition, could be a significant effort: 'I have to control everything, even my emotions, and try to maintain balance. It's like a routine I have to stick to, and sometimes I miss out on things because of it' (Patient 19). Where patients were not able to maintain this control of their emotional wellbeing, physiological impacts of 'thinking too much' and feeling stress were perceived to directly impact blood pressure control.

3.2. Patient capacity to interact with and utilise healthcare services

We identified four main domains of patient capacity, described in the CuCom Model as 'abilities, resources, or readiness to address demands' (Shippee et al., 2012) which affected patients' ability to do the 'work' needed to interact with and utilise healthcare services for hypertension. Participants' accounts highlighted the extent to which capacity can change over time. The long-term nature of hypertension meant that finite resources supporting capacity can be exhausted, for example: 'some people have sold their properties and the disease has not gone away, they have no-one to help them' (Patient 22). In parallel requirements of patients to draw on different domains of capacity could also vary as workloads fluctuated.

3.2.1. Financial resources domain

Individual financial resources directly affect ability to pay costs to access health services, including transport costs, NHIF subscriptions, charges at secondary care facilities and medication costs where these are not covered by insurance/in stock at government facilities. Most patient participants had insecure individual financial status, i.e. were in informal work without regular income or retired, their financial resources fluctuated over time and did not reliably cover their healthcare needs. The most widely reported impact of financial resources was on determining ability to purchase medications. In their financial prioritisation, patients emphasised the importance of budgeting for medications, for example aligned with basic food needs: 'At this time, I don't have a job, but there're places I can go for two hours and earn my 300 shillings ... I spend 200 shillings on food, and 100 shillings on my medication' (Patient 17). Some prioritized medications above food, for example: 'medicine is more than food. You can say I will not eat today, I will eat tomorrow, but that's not the same case with drugs' (Patient 14). Financial resources also affected ability to adhere to dietary guidance as recommended foods cost more: 'it gives you a challenge ... you want to eat different kinds of food and you don't have enough money' (Patient 10).

3.2.2. Physical functioning domain

The second capacity domain was physical functioning, which varied substantially across participants. A minority reported experiencing no effect of hypertension on their physical functioning, for example 'I don't have body malaise and those signs and symptoms, however when I come and get tested I am told I have pressure' (Patient 2). Others reported feeling dizzy, fatigued, or having strong headaches. Good physical functioning was reported as conditional on medication adherence for many patients, for example after running out of medication 'you will then feel you are not comfortable and you have a headache' (Patient 24). Patients who had experienced complications of hypertension or comorbid conditions reported more restricted physical function, for example being unable to move around independently. Where physical function was very restricted, travelling to health facilities to attend monitoring clinics was difficult, entailing higher costs when patients could not use communal transport or motorcycle taxis due to their physical condition. Physical function also affected patients' ability to work and therefore financial resources, for example a female amputee explained 'it's challenging because ... now I don't have a leg, so what I do now is begging' (Patient 2).

3.2.3. Social support domain

The most widely reported source of social support was the patient's family, who provided different types of support which enabled patients to do various kinds of 'work' needed to utilise services. Financial support helped to supplement individual financial resources to enable purchase of medicines and services. This was both offered: 'when they hear I don't have medicine, they send money so that I can buy medicines' (Patient 4) and sought: 'when you find that the medicine is expensive, I call my children for help' (Patient 12). Financial assistance was sometimes combined with administrative support: 'I was looking for a way to go to hospital and there was not enough money and I did not have an NHIF card. So my niece went and got me one and paid for three months' (Patient 8). Patients also reported practical support with treatment adherence, including dietary adjustments 'my wife cooks for me these vegetables and foods that don't have sugars' (Patient 4), encouragement and reminders to take medication. Neighbours and colleagues were also reported as sources of social support by some. Conversely, others reported having no social support, and one patient explained he preferred not to involve others: 'I don't want anyone to remind me to take my medication because I have to take responsibility for my health' (Patient 17).

3.2.4. Religious faith domain

We identified religious faith as a fourth domain of patient capacity. Some patients described drawing on prayer to support their day-to-day work sustaining long-term treatment, particularly on relation to managing emotions, and hope of being 'healed' through God's intervention was expressed, for example that '*I will get healed one day and I will leave all this medication*' (Patient 7). Although a hope that hypertension could be 'over completely' (Patient 24) may not appear to support acceptance of a chronic diagnosis it was not positioned by participants as contrary to treatment adherence. Religious faith was instead discussed as mutually reinforcing medical treatment, for example 'you use the prescribed medication adhering to the doctor's instructions. When you do that, also believe you will get better, we know the doctor cures but God heals' (Patient 22).

3.4. Interactions between workload and capacity

Patient workload generated by the tasks they need to do to manage their condition, other responsibilities of daily life, and patient capacity were inter-related through multiple interactions. Overall, we found that the substantial workload of accessing treatment and patients' constrained financial capacity contributed most significantly to a consistent imbalance between workload and capacity, although other factors were also important.

Fig. 2 illustrates the domains of patient workload to manage hypertension and patient capacity to manage this work identified in this study.

Temporal variability characterised interactions between workload and capacity. This was primarily due to fluctuating medication availability generating a changing workload, and to a lesser extent to changing patient capacity (unstable financial capacity and day-to-day prioritisation of resources for treatment). In itself, the fluctuating nature of this relation generates a heavier workload because work cannot be routinised when the parameters change, for example where patients have changing daily incomes and are uncertain whether they will be able to buy subsidised medication or need to purchase privately at higher costs, vs allocating a fixed amount of a fixed budget to monthly medication costs. The vastly differing costs of medications from one month to the next were particularly difficult for patients on low and/or precarious incomes to accommodate. Some were only able to obtain medication when it was in stock free-of-charge at primary care facilities.

Workloads associated with other everyday life demands varied by individual circumstances, such as presence of comorbid conditions and family responsibilities. Where patients had multiple responsibilities and limited capacity, they described tensions between meeting their hypertension-related workload to sustain treatment and fulfilling other responsibilities. For example a female with dependent children explained *'when you are buying this medicine and you have no money and you have other duties to do it becomes a challenge'* (Patient 7). Where capacity was constrained, some patients acted to reduce their hypertension related workload, such as by moving from secondary to primary care facilities to access free services, even where the services offered there did not meet their needs.

As well as direct interactions between distinct elements of capacity and workload there were also more complex, cumulative interactions and feedback loops impacting treatment adherence. For patients whose hypertension-related symptoms interfered with physical functioning, this affected their ability to work, and individual financial status, thus ability to buy medications and to fulfil other financial responsibilities such as supporting dependents. Reduced ability to buy medications then reinforced reduction in physical functioning. This feedback loop is illustrated in Fig. 3 (red), illustrating the experience of a father with



Fig. 2. Patient capacity and workload of demands for hypertension management identified in this study.



Fig. 3. Interaction between capacity, workload of demands and outcomes. Adapted from (Shippee et al., 2012).

hypertension and diabetes who discussed the impact of missing medication on his ability to fulfil parental responsibilities. His starting point was treatment adherence: '*if you don't take medication, your blood pressure will go up, your sugars will go up and as a result you won't manage doing your work'* [Patient 4]. His ability to work and earn money then impacted his ability to both support his child and to purchase medications 'as a father I need to look after her. If I fail to go where I normally go for work, this life is going to be difficult. And also if I fail to go where I normally go for work, I won't manage to get money to buy the drugs.'

3.5. Treatment adherence

Where workload exceeded capacity, consistent utilisation of health services and self-care practices became difficult for patients to maintain, impacting treatment adherence. Impacts included: (1) stopping medication after initially stabilising blood pressure; (2) taking medication daily but not as prescribed, e.g. a partial dose, one or some of several medications prescribed, (3) frequently having gaps in taking one or all medications, but with the intention to continue as far as possible; and (4) taking historically prescribed medication without attending monitoring appointments to optimise treatment. Each of these specific situations may be masked in a medical consultation by a patient expressing an acceptance of their diagnosis and willingness to adhere to treatment.

4. Discussion

In this study of patients seeking care for hypertension at four government health facilities in central Kenya we identified a substantial workload of condition-related demands, generated by the tasks patients needed to do to control their blood pressure. Over time, workload was frequently reported to exceed patients' capacity to meet these demands, resulting in disruptions to blood pressure management. This aligns with findings of a study in Western Kenya reporting a high treatment burden among people with diabetes and/or hypertension (Koros et al., 2023). Temporal variability in both workloads and capacity was an important novel finding of our study. We reflect on findings in light of investment in hypertension care in the region (Olowoyo et al., 2024), and propose approaches to support a sustainable balance of workload and capacity for patients attending government health facilities.

Three domains of work were identified; processing work, practical work, and work of managing emotions. Significantly, processing work was a pre-requisite for treatment initiation and adherence among those whose self-perception did not fit with a patient role, generating a substantial workload. Work of this nature has been widely identified for patients diagnosed with non-communicable chronic conditions in high-income settings (Bury, 1982; Corbin & Strauss, 1985) and with HIV (Russell & Seeley, 2010; Wells et al., 2023). This work can be supported by outreach activities to raise awareness and understanding of hypertension among all age groups, including information about diagnosis across the life-course to reposition age-related conceptions of risk. Awareness of the significance and variability of processing work may help clinicians identify and support patients likely to encounter challenges.

Within the domain of practical work the workload of accessing medication, underpinned by financial precarity, created the heaviest demands. Patients adopt a range of coping strategies for costs of chronic disease care, which can be difficult to sustain over time and have adverse wider effects (Murphy et al., 2019). To reduce this workload, affordable medications need to be consistently available in government health facilities, so that patients and their caregivers can reliably plan where and when to obtain them, at what cost, to avoid structurally induced non-adherence (May et al., 2009). Our findings resonate with research about multimorbidity and chronic conditions in Malawi which identified a burden of 'lack of treatment', contradicting 'an implicit assumption that medications and therapies are available' (Chikumbu et al., 2022). For patients with limited financial resources who cannot afford to purchase a full month's medication supply, allowing purchase of small quantities of medication in the public sector may sustain access to medication, supporting adherence. Wider implementation of fixed-dose combinations, combing two or more medications in one pill, could reduce medication-related workloads. Standardisation of costs for routine services across facility levels would remove unintended incentives to self-refer to free primary care facilities.

An additional area of patient work involved managing emotions to

avoid experiencing negative feelings seen to exacerbate blood pressure. While this did not directly impact treatment adherence, it was widely reported as an aspect of condition management requiring specific strategies and effort to sustain, contributing to the overall burden faced by patients. Integration of strategies to support mental health with hypertension care (Stein et al., 2019), as for HIV (Chuah et al., 2017; UNAIDS & WHO, 2022) could support this workload by equipping patients with additional tools to manage emotions.

A significant volume of patient workload was generated by variability in care delivery in the local health system, requiring changing resource input from patients and their social support networks. Simultaneously, patient's capacity fluctuated over time, particularly for those in precarious financial situations. Together, these changing parameters undermine patients' ability to consistently embed monitoring and treatment routines in their everyday lives and sustain treatment adherence. Research in South Africa highlighted that precarity reduced capacity and increased treatment burden for patients with multimorbidity in low-income settings (van Pinxteren et al., 2023). While the varied nature of patients' trajectories is increasingly recognised (Brathwaite et al., 2022), and recent research on hypertension care cascades in the region identify steep drops between diagnosis, treatment and control (Jobe et al., 2023; Osetinsky et al., 2022) variability in service provision and it's significant impact in inflating patient workloads is less visible. Levesque et al. (2013) describe the 'dynamic interface' between health systems and the populations they provide care for as underlying access to health care services, highlighting variability of access from both supply (health system) and demand (patient) sides. We suggest that recognising perpetual temporal fluctuations in workloads and patient capacity, together with burdens of 'lack of treatment' (Chikumbu et al., 2022) is key to understanding treatment adherence for both hypertension and other chronic conditions in resource-constrained settings. This highlights a limitation of the Cumulative Complexity Model in this setting; consistent with its development in a stable, high-income health system, it does not anticipate or accommodate fluctuations in healthcare provision, nor counter-agency of actors within the system adapting their practices under conditions of constraint.

Social support networks were a key domain of capacity, interacting with others, particularly financial resources as reported elsewhere in Kenya (Ng et al., 2021). Family support is reported to encourage hypertension treatment adherence in a range of resource-constrained settings (Chacko & Jeemon, 2020; Seguin et al., 2022). A recent study of people living with multimorbidity in South Africa found that social networks influenced by the philosophy of Ubuntu, which promotes solidarity, togetherness and respect, improved patient capacity and enabled patients to cope with their workloads, despite facing economic hardship (Mbokazi et al., 2023). In contrast in this context social support did not enable patients to cope with their workloads sufficiently to adhere consistently to treatment. Religious faith was identified as a separate capacity domain, recurring tacitly embedded across patient's and caregiver's accounts, and understood to mutually reinforce medical treatment. We suggest the role of faith in supporting patient capacity at the individual level merits further exploration, complementing recent research on the role of faith -based institutions in hypertension health promotion (Sanusi et al., 2023). This resonates with calls for researchers and health system actors implementing public health interventions to pay attention to the ways in which 'people's locally situated sense of themselves in terms of spirituality, gender, kinship and generationality' can shape behavioural norms (Mbali & Rucell, 2022).

Finally, we suggest that while social support did not enable patients to overcome substantial structurally induced challenges to treatment adherence in this context, social norms play a significant role in mediating interactions between personal agency and structurally induced counter agency. This should be considered both in adaptation of theoretical models of burdens of treatment for resource-constrained settings, and in planning expansion of hypertension care.

4.1. Limitations

The scope of this study is limited to patients attending government health facilities therefore those who are not seeking care, including those who may experience the greatest workload/capacity imbalance, are excluded. This analysis was prompted by observation of complex and substantial workloads described by patients in a study about acceptability of FDC therapy. While the study was designed to explore the wider context of treatment, interviews were not structured to investigate topics less typically associated with biomedical models of care such as social support and religious faith, limiting fuller exploration of these domains in analysis. Depth and robustness of analysis of available data was maximised through iterative comparisons within and between cases, and these domains could be developed in future research designed collaboratively with patients and care-givers.

5. Conclusions

Overall, we found there was substantial commitment to adhere to treatment among study participants, despite the workloads involved in doing so. We suggest that an important core consideration is to encourage policy makers to reflect on how far the health system enables patients to do the things it advises to manage hypertension, and prioritise addressing patient related burdens to make the tasks being asked of patients realistic for them to manage. This is relevant in both the national Kenyan context and more widely in resource-constrained contexts in low- and high-income settings. While intervening to support patient capacity is beyond the remit of the health system, recognition of these domains and the crucial ways in which they accommodate patients' more and less visible workload of hypertension enables better understanding of treatment adherence. To support sustainable blood pressure control, initiatives to expand services should aim to reduce patient workloads and consider differential capacity and workload among patients. More broadly, this paper makes a positive case for analysis of treatment-related patient workload as part of the development of clinical interventions and of the implementation of existing interventions in new settings.

CRediT authorship contribution statement

Ruth Willis: Writing – review & editing, Writing – original draft, Visualization, Supervision, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. Daniel Mbuthia: Writing – review & editing, Resources, Project administration, Investigation, Formal analysis, Data curation. Mary Gichagua: Writing – review & editing, Supervision. Jacinta Nzinga: Writing – review & editing, Supervision. Carl May: Writing – review & editing, Supervision. Peter Mugo: Conceptualization, Supervision, Methodology, Project administration. Adrianna Murphy: Writing – review & editing, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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