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## **Caring for people with non-communicable diseases: the views and experiences of health and social care professionals in Uganda**

Montgomery, L., McShane, C., Santin, O., Misinde, C., & Clarke Nanyonga, R. (2024). Caring for people with non-communicable diseases: the views and experiences of health and social care professionals in Uganda. *International Journal of Care and Caring*. Advance online publication. <https://doi.org/10.1332/23978821Y2024D000000050>

**Published in:**  
International Journal of Care and Caring

**Document Version:**  
Publisher's PDF, also known as Version of record

**Queen's University Belfast - Research Portal:**  
[Link to publication record in Queen's University Belfast Research Portal](#)

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## research article

# Caring for people with non-communicable diseases: the views and experiences of health and social care professionals in Uganda

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Resource-limited health systems in sub-Saharan Africa struggle to provide population-wide high-quality primary healthcare, with particular concerns relating to professional workforce issues and the role of family caregivers. This qualitative study design explores the perceptions of ( $n = 19$ ) health and social care professionals of the challenges they face in caring for individuals living with non-communicable diseases in Uganda. Identified challenges resulted from staffing and resource limitations, with wider issues relating to poverty and the burden placed on carers. As non-communicable diseases continue to rise, these empirical findings can inform developments in policy and service delivery in low and middle-income country contexts.

**Keywords** health and social care professionals • family carers • chronic disease • Uganda

To cite this article: Montgomery, L., McShane, C.M., Santin, O., Nakaggwa, F., Agaba, P., Apio, J., Kawooya, A.N., Komuhangi, A., Jenkins, C., MacDonald, M., Githinji, F., Misinde, C. and Nanyonga, R.C. (2024) Caring for people with non-communicable diseases: the views and experiences of health and social care professionals in Uganda, *International Journal of Care and Caring*, XX(XX): 1–20, DOI: 10.1332/23978821Y2024D000000050

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## Introduction

Despite major strides to improve the health of the 42 million Ugandans, their health status remains relatively poor, with high morbidity and mortality from preventable causes (Ministry of Health, 2018). In particular, the incidence and prevalence of chronic non-communicable diseases (NCDs), including cardiovascular diseases, diabetes and cancer, are rising and collectively account for 27 per cent of deaths per year in Uganda (WHO, 2017). The struggle, within resource-limited health systems in sub-Saharan Africa to provide population-wide high-quality primary healthcare has consistently been identified (Soors et al, 2013; Oleribe et al, 2019).

Many sub-Saharan African countries have sought to address the poor health outcomes of their population (WHO, 2013). Core problems in health service delivery in this context have been found to cluster around leadership, governance, professional workforce issues and finances (Roncarolo et al, 2017; Azevedo, 2017; Oleribe et al, 2019). In particular, inadequate human resources, including an inadequate number, skill mix and distribution of healthcare professionals, have been identified as the most significant challenge within the health sector (Oleribe et al, 2019). Thus, for example, sub-Saharan African countries experience a disproportionate global disease burden of 24 per cent but are supported by only 3 per cent of the global health workforce (Oleribe et al, 2019). ‘Brain drainage’ from Africa to North America, Europe and the Middle East exacerbates the problem (Adua et al, 2017). The World Health Organization (WHO, 2017) estimates a projected shortfall of 18 million health workers by 2030, mostly in low- and middle-income countries (LMICs). Key workforce challenges in LMICs directly impact professionals’ ability to deliver optimum care for persons living with chronic illnesses (Oleribe et al, 2019).

Capacity building of healthcare workers is needed to address these challenges. The perceptions and experiences of health and social care professionals (HSCPs), in particular, those working with NCD patients and their carers, can provide insight into the demands, complexities and struggles in the delivery of health and social care. HSCP experiences have been explored in South Africa, with identified barriers to care including inadequate knowledge of NCDs, shortages of medication and shortages of service providers (Maimela et al, 2015). HSCPs have also identified deficiencies in inter-sectoral and inter-professional cooperation, a lack of infrastructure for end-of-life care, and challenges in transferring patients from hospital to home (Heydari et al, 2019). Having to ‘figure things out’, a lack of knowledge and training, a lack of assistive devices and a need for emotional support for providers and carers have also been identified (Scheffler and Mash, 2020). Moreover, the impact of COVID-19 and other public health emergencies has identified significant mental health and well-being issues impacting healthcare workers on a global scale (Søvdal et al, 2021).

This article reports the findings of a study undertaken in 2021, in which the perceptions and experiences of HSCPs working with NCD patients in Uganda were explored. It is part of a wider study exploring family carer experiences in Uganda (Montgomery et al, 2023). Given the centrality of workforce issues in contributing to the poor health outcomes of many LMIC populations (WHO, 2013), such first-hand insights can assist in developing targeted interventions for health and social care providers and family carers.

### *Health and social care: Ugandan context*

The health and social care systems in Uganda are a blend of government-run initiatives, private-sector participation and the involvement of non-governmental organizations (NGOs). Uganda faces challenges in healthcare infrastructure, staffing shortages, inadequate medical supplies and geographical disparities, with rural areas often having limited access to quality healthcare. NGOs and private healthcare providers significantly supplement government efforts, particularly in underserved areas. NGOs, for example, often run health programmes, provide training and contribute to healthcare infrastructure. At the community level, community health workers and village health teams serve as vital links between formal healthcare services and the local population, aiding in health education, disease prevention and basic healthcare delivery. Collaboration between the government, NGOs, private sector and community-based initiatives remains crucial for the advancement of healthcare delivery in the country.

In 2001, the Ugandan government introduced Universal Health Coverage (UHC), ending user fees, to improve population-level access to health services (Nannini et al, 2022). Uganda's goal for this scheme is to ensure that by 2030, 65 per cent of the Ugandan population will have access to quality healthcare and financial protection (Nahalamba et al, 2019). However, the country has arguably made limited progress in reaching that goal, with out-of-pocket expenses accounting for 42 per cent of total health expenditure (Kim, 2023). Limited progress has been attributed to underdeveloped insurance schemes, functional inadequacy, the poor quality of health services and the consequences of staff shortages (Nahalamba et al, 2019; Nannini et al, 2022; Kim, 2023).

Despite Uganda's strides in promoting palliative care initiatives, a mere 10 per cent of the 3,400,000 individuals requiring such care can access it (Kamonyo, 2018). In March 2021, all public hospitals were required to establish palliative care units but were not funded to do so, with the integration of palliative care into health systems in Uganda being slow and problematic (Luyirika et al, 2022).

In acknowledging the impact of workforce issues in Uganda, a small number of studies have explored the perceptions of healthcare professionals in relation to their experiences in providing care, including perinatal care (Sarkar et al, 2018), primary care services (Waweru et al, 2019), treatment for patients with cervical cancer (Mwaka et al, 2013) and the delivery of palliative cancer care (Karera et al, 2022). In these studies, professionals' struggles in providing high-quality care with limited resources have been consistently highlighted.

## **Methods**

This cross-sectional explorative study employing qualitative data-collection methods was used to explore the perceptions of HSCPs caring for patients with

NCDs in two purposively selected research sites in Uganda. The primary focus was to explore the perceptions and experiences of health and social care staff and family carers in order to inform service provision through which the quality of patient care could be improved (this article reports the experiences of HSCPs). The research was conducted by an international multidisciplinary research team based in Uganda and the UK, in the following universities: Clarke International University, Kampala, Makerere University, Kampala and Queen's University, Belfast. The team included academics from social work, public health and nursing backgrounds. The ontological paradigm that underpinned the study was constructivist, emphasizing the subjective meanings and interpretations of professionals, based on the assumption that reality needs to be interpreted and understood from the point of view of the individual participants (Bryman, 2016). The gathering and analysis of data were therefore informed by the epistemological approach of interpretivism; the research aims sought to elicit the subjective and socially constructed reality behind HSCP experiences in delivering treatment and care to NCD patients in Uganda. Adopting an ontological paradigm through an interpretive approach was necessary to explore the lived experiences of professionals.

In order to explore the viewpoints of HSCPs in both urban and rural environments, HSCP participants were recruited from Hospice Africa, Uganda (HAU) and Share Uganda, Hampton Health Centre (Hampton HC). These sites could facilitate access to HSCPs working with chronic NCD patients and represented contrasting rural and urban settings. HAU is the main provider of palliative care to patients in Uganda. It runs a unique model of culturally appropriate patient care, training, advocacy and community outreach. Their holistic model incorporates 'total pain control', which includes anxiety management related to end-of-life issues. Although multidisciplinary, the core workforce largely consists of specially trained hospice nurses who can prescribe pain medications and work alongside community health workers providing holistic patient care.<sup>1</sup> Hampton HC is based in the rural setting of Kabira Village, Kyotera District, Western Uganda. Share Uganda is a not-for-profit, community-based healthcare organization providing quality and sustainable health services, supporting the education of local healthcare professionals, and developing collaborative solutions to local healthcare challenges.

In practice, in both settings, patients tend to be diagnosed with NCDs at an advanced stage, receiving acute care in either a regional hospital site, hospice or local community health facility. As noted, to a large extent, palliative care is provided by family carers in both settings, with the majority of longer-term care for all NCDs across both sites provided by family carers at home. Community workers, including nurses, may provide community-level support, for example, through Malaria prevention programmes (Hampton HC) or pain management (HAU).

In each setting, a purposive sampling method was utilized to recruit professionals from both health and social care disciplines, so as to represent the range of staff who engage with NCD patients and their families, and with a range of demographic characteristics based on the following inclusion criteria:

- currently providing medical and/or social care to patients with NCDs;
- working in the capacity of nurse, doctor, social worker, counsellor, psychologist or allied health professional; and
- able to communicate effectively in English or Luganda.

Recruitment was managed by a local staff member in each setting who volunteered to act as a gatekeeper, identifying key HSCPs from staff lists who met the inclusion criteria, informing them of the study and being available to answer interested participants' questions. Interested participants were then invited to contact the research team directly by email. The research team provided a participant information sheet and consent form (made available in English and Luganda), explaining the details of the study and consent procedures. The sample size was contingent upon the HSCPs who demonstrated interest in the study and fulfilled the inclusion criteria. In both settings, the majority of professional staff took part in the study.

Focus group discussions (FGDs) were chosen as the means to examine the ways in which participants collectively understood the issues and to share personal and professional experiences, perceptions and opinions (Bryman, 2016). To guide the FGDs, a structured interview schedule was developed via a scope of the literature and expert feedback within the research team. A scoping review of the literature had been undertaken in preparation for the study and was published by the research team (Komuhangi et al, 2022). The interview schedule was further developed through iterative facilitated discussions between the researchers, drawing on their multidisciplinary expertise (as social workers, nurses and public health experts) and moderated through the cultural lens of local research team members. The interview schedule contained 11 open questions, with prompts to facilitate a comprehensive exploration of expert opinions; the questions focused on HSCP perceptions of the experience of NCD patients and their family carers, the support required by NCD patients and their carers, and the issues and challenges facing HSCPs.

Two female Ugandan research assistants (RAs) conducted the FGDs, along with a third RA who attended solely to take notes. RAs were chosen from the participating institutions based on their interest and prior research expertise. These RAs were integral members of the research team who underwent specialized training in research methodologies (mixed methods) through an intensive three-day seminar (alongside all team members) prior to initiating the study. RAs had no previous relationship with participants. Hampton HC data were collected in February 2021 and HAU data in March 2021. FGDs were conducted in English by the agreement of all participants and took place at each site in a private location to minimize interruptions and ensure confidentiality. Each FGD lasted between one and two hours. Throughout the data-collection process, RAs engaged in reflective practices with research team members, acknowledging personal biases, assumptions and preconceptions. This approach aimed to foster openness to fresh data and to recognize when novel insights ceased to emerge.

Each FGD was audio-recorded, fully transcribed and collaboratively analysed by research team members, and key themes were identified. Six stages of thematic analysis were followed (Braun and Clarke, 2006). The transcribed data were uploaded to a shared online platform that was accessed by all team members; transcripts were checked for discrepancies. Two subgroups of the wider research team, each consisting of Ugandan and UK-based team members, analysed one FGD each up to the point of identifying sub-themes. Collaborative analysis was achieved through establishing a clear approach, regular meetings via Zoom, shared cloud platforms, assigning responsibilities, cross-team training and cultural sensitivity by integrating Ugandan RAs who were familiar with cultural norms. Sub-themes were collated by the RAs and grouped into related themes, with common themes across all data sources then identified and defined. These were agreed upon by the team through iteratively

facilitated discussions. To illustrate the process, [Table 1](#) offers a brief example of a theme, sub-themes and codes.

Data checking to ensure the authenticity of the findings entailed the RAs travelling to each research setting and facilitating a community meeting at which study participants and community leaders were invited to review the findings in a one-day workshop. No changes were made to the data as a result of this process. A second meeting convened key stakeholders from the government, civil society and academia who have a vested interest in and offer services to individuals affected by NCDs in Uganda. The purpose was to disseminate study findings while also generating additional ideas to further this work. Some pivotal takeaways encompassed: the necessity to establish a system for routinely gathering information from carers; the imperative to create clinical directives for carers; and the need to advocate for a multidisciplinary/multi-sectoral strategy to tackle the ramifications of caring on livelihoods.

### *Research rigour*

Research trustworthiness and rigour were promoted as follows. Each FGD implemented a standardized approach using an agreed topic guide. The RAs were Ugandan nationals who were familiar with and adhered to cultural norms, for example, in the use of professional titles. All research team members received training before the study. Data analysis followed a systematic procedure, with preliminary findings critically discussed periodically with the research team. As noted, RAs travelled back to each research site to facilitate data checking. Results are reported following the Consolidated Criteria for Reporting of Qualitative Studies (COREQ) guideline.

### *Ethical approval*

Ethical approval for the study was granted by The Aids Support Organization (TASO) Research Ethics Committee and the Ugandan National Council for Science and Technology (TASOREC/092/2020-UG-REC-009). Participation in the study was voluntary, and each participant signed an informed consent form immediately before the FGD. Ethical concerns focused on ensuring informed consent and voluntary participation, managing potential distress, and managing participant data

**Table 1: Example theme, sub-theme and codes**

Theme	Challenges associated with the structure and delivery of health systems	
Subtheme	Workforce challenges	
Codes: combined	<ul style="list-style-type: none"> <li>• Staffing issues: understaffing, overwork, emotional impact</li> <li>• Inadequate referral systems</li> <li>• Lack of specialist staff</li> </ul>	
Codes	HAU: <ul style="list-style-type: none"> <li>• Referral issues: patients start in private facilities and then go to hospitals and hospices</li> <li>• Not enough staff: brain drain, utilizing students, staff overload, limited resources</li> <li>• Staff burnout: personal well-being, financial burden</li> </ul>	Hampton HC: <ul style="list-style-type: none"> <li>• Limited referral systems: limited resources, low priority of NCDs</li> <li>• Staff challenges: understaffing, lack of specialists</li> <li>• Emotional challenges</li> </ul>

to conform to regulations. RAs provided clear introductions, outlining and agreeing on the boundaries of the FGD, promoting appropriate levels of disclosure, remaining vigilant to possible participant distress or discomfort, and using inclusive language throughout the interviews. The national guidelines for the conduct of research during the COVID-19 pandemic (UNCST, 2020) were adhered to; for example, physical and social distancing was maintained.

## Results

A total of 19 HSCPs participated in the study (see Tables 2 and 3), with 8–11 members in each FGD. Participants included doctors, nurses, social workers, counsellors, psychologists and allied health professionals.

Thematic analysis demonstrated two overarching themes: HSCP perceptions of challenges within the structure and delivery of the health system; and personal and professional challenges faced by HSCPs. Themes and associated sub-themes are presented in Table 4, with discussion supported by selected participant quotations.

### *Theme 1: Challenges associated with the structure and delivery of health systems*

Frustrations caused by limitations within the wider Ugandan healthcare system were evident in the narratives in both FGDs. Participants described the current healthcare systems within Uganda as inadequate, making it difficult to provide appropriate and optimal care for patients.

#### *Workforce challenges*

A central narrative in each FGD focused on perceived difficulties in fulfilling professional responsibilities, which impacted the delivery of health and social care to patients. This was

**Table 2: Participant details: Hampton HC**

Gender	Professional occupation	Years of experience
Female	Senior nursing office	6
Male	Clinician in charge	4
Female	Nursing officer	2
Male	Clinical officer	N/K
Female	Retired nurse/midwife	50
Male	NCD sedentary worker	10
Male	Retired principal district health inspector	35
Male	Data manager	2
Female	Counsellor	N/K
Female	Nurse	N/K
Female	Medical health officer	N/K

Note: N/K = not known.



**Table 3: Participant details: HAU**

Gender	Professional occupation	Years of experience
Male	Psychologist	3
Female	Palliative care nurse	11
Female	Palliative care nurse	6
Female	Palliative care nurse	10
Female	Social worker	4
Female	Palliative care nurse	15
Female	Medical doctor	12
Female	Palliative care nurse	3

**Table 4: Overview of themes and sub-themes**

Overarching themes	Sub-theme	Combined codes
Challenges within the structure and delivery of health systems	Workforce challenges	<ul style="list-style-type: none"> <li>Staffing issues: understaffing, overwork, emotional impact</li> <li>Inadequate referral systems</li> <li>Lack of specialist staff</li> </ul>
	Practical challenges impacting patients and carers	<ul style="list-style-type: none"> <li>Challenges in obtaining medication</li> <li>Challenges in securing necessary equipment</li> </ul>
	Challenges associated with the wider determinants of health	<ul style="list-style-type: none"> <li>The impact of poverty</li> <li>Inaccessible health facilities</li> <li>Transport problems</li> <li>Home visit feasibility</li> </ul>
	Caregiver burden	<ul style="list-style-type: none"> <li>Impact of caregiving</li> <li>Need for respite</li> <li>Carer support and educational needs</li> <li>Multiple roles of carers</li> </ul>
HSCP personal and professional challenges in fulfilling their role	Professional responsibility: personal cost	<ul style="list-style-type: none"> <li>The physical and emotional strain on HSCPs</li> <li>Patient attachment and loss</li> </ul>
	Limits in professionals' knowledge base	<ul style="list-style-type: none"> <li>Limits in HSCP knowledge of traditional medicines</li> </ul>

attributed to logistical challenges and resource limitations, including facility understaffing and overworked staff. The majority of participants across both settings described facing excessive professional demands, limiting their capacity to deliver treatment and care. For example, HSCPs in Hampton HC reported that one member of staff would typically have a responsibility to assess and care for over 100 patients daily, which led to HSCP fatigue and reduced care for patients. Similar concerns were identified by HSCPs in both settings: 'Most of these facilities are understaffed. For example, at [X hospital], you find only one healthcare worker clerking almost 200. By the time they reach or clerk 100 people, they are also tired... You come from home and find a very long line, you may just return home!' (HSCP Hampton HC 4). Similarly, within HAU, the perception of work overload was noted, as, for example, with the practice of staff making themselves available to patients at all times: 'So, there is 24-hour availability with the clinicians; however, when you see a very sick patient who insists on talking to you again, we do

give them our personal numbers, like, whether you have an emergency phone, you are on call throughout' (HSCP HAU 1).

HSCPs in both FGDs also raised concerns regarding inadequate referral pathways, with a limited range and availability of specialist staff and services to refer patients to. Participants expressed frustration that when problems were identified that required more than general medical treatment, there were often no avenues for specialist care. This resulted in patients attending hospital and not being treated by specialist staff or, in some cases, receiving incorrect care. Moreover, due to the lack of formal communication mechanisms between services, it was challenging for professionals to share vital information and ensure that patients received appropriate and coordinated care. This is exemplified by one participant in Hampton HC:

We don't have any clear referral networks. Actually, on very many occasions, I am saddened when I refer someone, for example, for review by a physician. For example, you tell them, 'Go to [X hospital], there will be a physician', and when the person comes back, he has been mismanaged. (HSCP Hampton HC 2)

### *Practical challenges impacting patients and carers*

Continuing the theme around wider healthcare limitations, participants identified the limited availability of medication, with medications often unavailable or costly, resulting in patients not receiving prescribed treatment. Problems with access to medication at government facilities due to gaps in funding were consistently highlighted within both FGDs. Uganda's limited progress in the provision of UHC (Nannini et al, 2022) meant that there was limited compulsory insurance and few alternative mechanisms to obtain medication. This resulted in some patients purchasing necessary medications at pharmacies at a huge expense:

There are so many drugs which are being prescribed for these clients and they can't get them at the government facility. They are not there. That means that they have to buy the drugs in the pharmacy, of which it is very expensive. (HSCP Hampton HC 1)

When they go to [X Hospital], sometimes they come back after they have confirmed their NCD illness, they come back home after taking or swallowing the drugs, they come back to you to tell you, 'The drugs are over, and I do not have the transport to take me back'. (HSCP Hampton HC 11)

In addition to medications, a lack of equipment that was fit for purpose contributed to poor patient outcomes; for example, the lack of suitable wheelchairs proved a challenge in daily life, adding to patient and carer stress: 'Wheelchairs are not designed for the homes in our setting ... the wheelchair does not pass through or fit' (HSCP Hampton HC 2).

### *Challenges associated with wider determinants of health*

HSCPs in both settings identified wider structural challenges faced by patients and carers due to which the demands of obtaining treatment were often experienced as

overwhelming in the context of families that were already living with the impact of poverty. This was compounded by health system resource limitations. Within the Hampton HC FGD, many participants expressed frustrations around inaccessible health facilities and inadequate patient transport systems. Problems were identified when patients were required to attend appointments and did not have the financial means or the available transport to access treatment. One participant suggested: 'The greatest challenge faced by caretakers is transport' (HSCP Hampton HC 2). This discussion was expanded by a second participant, who highlighted the impact of inadequate transport: 'Then, the distances they travel are long from the homes to the clinic. By the time they come for consultation, you find them even sleeping because they are tired from walking the long distance' (HSCP Hampton HC 3).

Moreover, patients and carers could often not afford to travel to medical appointments together due to the multiple responsibilities of the carers and prohibitive travel costs. Consequently, HSCPs were unable to gather information from the carer and patient together or offer advice and education to the family unit:

You ask a patient whom she stays with; she tells you, 'With my son, so if I come, my son stays to keep the home'. So, you always get one person at a time – if the caretaker comes, the patient doesn't come – and yet there is information you need from both of them. (HSCP Hampton HC 2)

HSCPs in both settings identified the potential value of visiting patients at home. This was seen as a solution to transport and access difficulties, facilitating joint access to the patient and carer. However, while the value of home visits was discussed, resource limitations that rendered home visits unfeasible were noted in both FGDs:

We may need to visit their homes as health workers and observe the conditions under which they care for these patients.... You might find that the patient stays with her one son and yet she is a lady; she feels like for her son to change her, she would rather die! (HSCP Hampton HC 2)

There is a need for home visits; we are not able to do home visiting because of lack of transport. (HSCP Hampton HC 5)

Poverty-related issues were highlighted in both settings. Within the HAU FGD, the impact of poverty was seen to be compounded by the specific stresses of urban living.

I am also looking at the nature of patients.... They are very poor and have found themselves in urban centres where a patient is renting, and they eventually fail to pay rent, and they are sent out of the house; they become homeless. It is so traumatizing to both the caregivers like the hospice and even the patients themselves. (HSCP HAU 1)

### *Caregiver burden*

During each FGD, HSCPs identified family carers as having a pivotal role in supporting patients. However, caring was presented as having a far-reaching and largely negative impact on carers, which in turn adversely impacted patient care. In each setting, HSCPs

reported that the level of carers' stress contributed to difficulties in delivering appropriate and optimal patient care. As explained by HAU-based participants, the demand for carers to meet the needs of patients was often overwhelming: 'The carers have a long-term impact after they have cared for these patients ... most of them are drained. You find they have physical, social, psychological [impacts]' (HSCP HAU 2). Carers' stress was compounded by the multiple roles and responsibilities required of carers:

[If] the patient has been the breadwinner, you find that this carer is so much worried of the future and the maintenance of the home or the family altogether. (HSCP HAU 1)

You find that these children are on top of taking care of their mother who has cancer; they are worried about what will happen next when mother goes: 'Our property, what about school fees?'. Some are at the university; at the end of the day, they run back to us, and they are, like, 'What can we do? Our relatives are not supportive, aren't we going to lose our home? Aren't we going to drop out of school?'. (HSCP Hampton HC 3)

The suggested need for respite care was presented as a response to the burden of care experienced by family carers. Respite care was provided within HAU but was not available in Hampton HC: 'They get tired caring for these patients .... so that is why as a hospice, we try to give them the opportunity to have respite care' (HSCP HAU 8).

Participants in both FGDs also focused on limitations in the health literacy of carers. HSCPs reported that patients and carers experienced difficulties in navigating the medical journey and understanding the signs, symptoms and treatment pathways of the conditions. Information and education support was needed to guide carers in day-to-day activities. Health literacy problems were compounded by public health information that participants in each setting described as not always well understood: 'So, we also have another problem of conflicting health education messages.... Our health education messages have messages really which cannot be understood by people in our local settings' (HSCP Hampton HC 2). Conflicting health messages were also attributed to the often-confusing advice offered by family and friends: 'Some people get advice from visitors, and, unfortunately, the more visitors, the more confusion' (HSCP Hampton HC 4). Health literacy discussions also included reference to a variety of belief systems held by patients and carers, as identified by two participants in the HAU FGD:

And other patients' and carers' beliefs are really different. Despite going to hospital and being diagnosed with the disease, they think it's witchcraft; they think it's a punishment from God for what they did or what their parents did. Despite all that, when they come here, we give them information about the disease and how it comes about, possible treatment, and care, but then they come back and also tell you another story. (HSCP HAU 1)

What type of sickness? That [the patient says] 'I feel something moving inside me', thinking that they are bewitching him.... To get him out of that mentality of 'I am being bewitched', we first discovered that it's cancer. (HSCP HAU 2)

## *Theme 2: HSCP personal and professional challenges in fulfilling their role*

The second key theme related to participants' well-being, which impacted their ability to carry out their roles.

### *Professional responsibility: personal cost*

A central discussion within both FGDs was the personal cost staff felt in carrying out their professional responsibilities. HSCPs discussed the ways in which their jobs had a negative impact on their own health and well-being. A lack of resources, a busy working environment and unmanageable workloads contributed to physical and emotional strain on professionals. Feeling exhausted and lacking energy were commonly experienced, making it challenging to provide adequate care and support to the high volume of patients seen daily. Caring for patients living with NCDs was described as emotionally challenging, particularly as patient death was common, leading to HSCPs experiencing a sense of loss and distress. This was discussed in similar ways in both FGDs:

There is distress to the healthcare workers. Those people always come early in the morning. So, the healthcare workers may come when the patients are so many already.... So, you, as the healthcare workers, you are also tired; then, you do not help as expected because you are also tired. (HSCP Hampton HC 10)

Psychologically, it's very distressing; like my friends have said, it's fulfilling, yes, but it can get distressing if the patient has so many problems, and then you are thinking, 'How do I support them through this?'... [It] is very challenging. (HSCP HAU 4)

HSCPs in both settings also emphasized their personal attachments to patients:

It has created that attachment with the patient ... I mean, to be very much attached that you can't leave the patient to do without you, but then you realize that every time you relate to the situation of the patient, you are spending a lot of time on the patient, and you are forgetting your own social life. (HSCP HAU 4)

Discussion in both settings focused on the strong sense of sadness shared by participants when patients died. In this context, HSCPs discussed the need for self-care due to the emotional and physically exhausting nature of their work:

Every patient that dies, I am told about them, that they died, so it stays on your heart.... They tell you, 'That patient friend of yours who used to sit in that corner died'. It leaves you drained and grieved. That is what we talk about in the clinic: 'We look after these patients, but for us, who cares for us?'. (HSCP Hampton HC 2)

HSCPs also appear to identify with the patients, as when they describe a personal fear of illness: 'We also have a lot of issues, and, actually, you find that those NCDs

can affect anyone, including us, the healthcare workers. You say to yourself, “I am also going to get sick and be like these, my patients” (HSCP Hampton HC 5).

### *Limits in professionals' knowledge base*

Participants in both FGDs also identified some vulnerability in relation to their own knowledge base. In particular, this related to uncertainty in offering professionally informed responses to patients and carers who presented with a diversity of beliefs around the causes of illness and range of treatments. In this context, the use of herbal medicine was identified as a common alternative treatment for patients; however, HSCPs acknowledged limitations in their knowledge and understanding of these alternative treatments: ‘We don’t know whether we have any accurate information on the effectiveness of herbs, and yet people, however much you tell them that we are not having any adequate information on these herbs, they are using them, actually more than the drugs you give them’ (HSCP Hampton HC 2).

## **Discussion**

The *Global Action Plan for the Prevention and Control of Noncommunicable Diseases (2013–2020)* (WHO, 2013) sought to reduce the preventable and avoidable burden of NCDs and to support populations to reach the highest attainable standards of health and productivity. Concerns relating to professional workforce issues and the sustainability of the role played by family carers have been highlighted as barriers to achieving these goals (Agyepong et al, 2017; Ewen et al, 2017; Oleribe et al, 2019; Waweru et al, 2019). In this context, HSCPs are a critical group for identifying health system limitations and areas for development and improvement to meet these goals. This study has presented the voice of HSCPs, conveying at first hand the multiple demands, complexities and struggles in the professional task of delivering health and social care within resource-constrained conditions. The key findings are discussed according to two major themes – challenges within the health systems and personal and professional challenges – with recommendations made in relation to each identified theme.

### *Challenges within the structure and delivery of health systems: recommendations and responses*

HSCPs perceived Ugandan health and social care systems as inadequate, making it difficult to provide appropriate and optimal care for patients. Notably, there were very few differences in the findings between rural and urban settings in terms of health system challenges. Concurring with findings in other LMICs (Heydari et al, 2019; Rawal et al, 2021), in both settings, health facilities were understaffed, systems lacked a comprehensive structured referral system for NCD patients and necessary medication and equipment were often unavailable or limited (Scheffler and Mash, 2020). Challenges associated with the wider determinants of health were also evident in both settings, concurring with other studies (Martinsen et al, 2015; Pindus et al, 2018; Waweru et al, 2019). HSCPs in this study identified a variety of ways in which help-seeking behaviour and adherence to treatment regimens were strongly impacted

by such practical issues as poverty, a lack of medication, inaccessible health facilities and transport limitations. Difficulties for patients accessing health facilities were identified as a significant persistent challenge in Uganda and are widely reported within LMICs (Tsolekile et al, 2014). Although not widely available in Uganda, facilitating professionals to conduct home visits was identified as a strategy to help address access issues and has been provided in other settings (Tsolekile et al, 2014).

As noted, the Ugandan UHC scheme has made limited progress. The impact of these limitations was clearly felt by Ugandan HSCPs and has been noted in other studies (Nahalamba et al, 2019; WHO, 2017). Arguably, however, the government strategy to accelerate progress towards UHC and to integrate palliative care within all public hospitals (Luyirika et al, 2022) has the potential to address many of the challenges identified in this study. Recommendations include a multi-sectoral approach to increase public investment in the prevention and treatment of NCDs, an expansion of geographical cover for NCD service delivery from centralized to locally available services, and strategies to ensure that all health facilities have stocks of essential medicines (Nahalamba et al, 2019).

Within the context of inadequate healthcare provision compounded by poverty and poor infrastructure, the role of family carers in shaping responses to illness and treatment was highlighted. Findings were similar to the identified roles and experiences of family carers in other African countries (de-Graft Aikins et al, 2010; Maimela et al, 2015; Nakigudde et al, 2016). HSCPs identified both the pivotal role played by family carers in providing long-term patient care in their own homes and the impact on carers, which was extensive and perceived to be largely negative. Demands on carers were often overwhelming, with family carers experiencing difficulties in understanding the patient's condition and navigating the medical journey. Understood within the framework of caregiver stress theory (Pearlin et al, 1990), caregiving requires carers to adopt new roles and responsibilities, often in the context of increasing dependencies and the reorganization of family life (Aneshensel et al, 1995). In the Ugandan context, in both settings, many of the multiple roles and responsibilities that family carers adopted were compounded by the impact of poverty, with family carers struggling to care for patients, transport them to healthcare facilities or secure necessary medication or equipment. The reorganization of family life was particularly pertinent when the patient had been the breadwinner, with fears expressed about the sustainability of the family as a unit. The significant impact on family carers' emotional and physical well-being was highlighted. In a similar socio-economic context, Awuviry-Newton et al (2022) applied an ethics-of-care framework to understand the motivation and vulnerabilities of family carers in Ghana, with similar findings reported in Nigeria (Faronbi et al, 2019). Core ethics-of-care principles, such as valuing interdependence and mutuality, were found to underpin the commitment of family carers. In this study, while caring obligations, interdependence and commitment were evident, limited support and poor infrastructure meant that the capacity for family carers to continue in this role was challenged.

Carer stress can be mitigated to some degree by enhancing carers' coping strategies and resilience, enabling carers to continue in the caring role (Roberto and Teaster, 2017). In keeping with recent global initiatives, the needs of family carers in sub-Saharan Africa should be an overarching objective of policy development and service delivery in combating preventable NCD mortality and carers' stress (WHO, 2017; Mugehera and Parkes, 2020). While Uganda has developed a robust policy framework

to improve the quality of care for all citizens, especially those suffering from NCDs, and has signed and integrated the Sustainable Development Goals (SDG) into its National Development Framework, the protection and support of family carers is yet to be integrated into policy. The findings from this study suggest not only the need for health systems investment but also the need for development and investment in carer policies, services and infrastructure in family-, community-, institutional- and national-level programming (National Planning Authority, 2020). This requires an understanding of the pressures associated with caring, carers' stress and challenges, and the economic impact of chronic illnesses on families, health systems and communities from multiple perspectives, including those of the providers of care. Developments in research, policy and practice in relation to family caring should be prioritized to maintain the stability of the healthcare system (Komuhangi et al, 2022).

### *Personal and professional challenges*

In the second key theme, HSCPs identified personal and professional challenges in fulfilling their roles; in both settings, they identified barriers to their ability to provide high-quality services for NCD patients and their carers. As recognized internationally (Maimela et al, 2015), HSCPs in this study also identified logistical and staffing-level difficulties, through which they experienced a heavy and sometimes overwhelming workload.

Based on Hoschschild's (1983) path-breaking work, healthcare professionals' experiences can be understood as 'emotional labour', in which emotions are managed (induced or suppressed) in order to sustain the outward countenance that enables others to feel cared for. Although the factors impacting emotional labour have been contested (Grandey, 2000), Henderson (2001) claims that emotional labour is a choice that individuals make between emotional engagement and detachment. Within a sub-Saharan African context, Metz (2010) suggests that the moral imperative of 'I am because we are' applies to healthcare professionals, with reciprocal obligations to emotional engagement with patients, in which mutual responsibilities and duties exist between healthcare professionals and their patients.

In keeping with other studies (Koren et al, 2018; Scheffler and Mash, 2020), HSCPs in this study appear to identify a strong moral obligation to their patients, for example, describing an 'attachment with the patient' in which 'you can't leave the patient to do without you'. HSCPs identified the personal impact of their work, including emotional and physical exhaustion, which they attributed in large part to their significant personal investment in their role and their strong sense of responsibility. Feelings of distress and helplessness were reported, particularly in situations where professionals were unable to offer optimum care to their patients.

While the provision of quality care in this context is difficult, the obligation is on the patient and family carer to comply with treatment, follow preventive measures and support daily lives, with a duty also on organizations to provide the infrastructure to enable this to happen. A study among healthcare professionals in Ghana (Lartey et al, 2019) identified perceived organizational support as an important factor in moderating professionals' emotional dissonance and promoting emotional regulation. Organizational support was found to have a direct impact on the quality of service provision (McQueen, 2004).



In this study, HSCPs identified a concern about who cares for the carers. In enhancing reciprocal obligations at an organizational level, HSCPs' well-being should be included in capacity-building initiatives in Uganda and beyond. Evidence-based interventions are needed to determine organizational and systemic measures that would enhance the well-being of HSCPs. Health system improvement is said to be achieved through attracting and retaining health professionals (including specialists) through continuous salary improvement, improved working conditions, housing and other motivational aspects (Nahalamba et al, 2019; Nannini et al, 2022; Kim, 2023). Research should further explore ways to promote HSCP self-care, along with steps to reduce stigma for HSCPs seeking help for psychological distress (Sovold et al, 2021).

### *Study limitations*

A qualitative study with a purposive sampling method and the inclusion of 19 professionals in two districts is limited by its small numbers and specific geographical focus and may not necessarily represent the views of the broader Ugandan population. However, this qualitative study does present the voices of HSCPs, identifying their perceptions of the demands, complexities and struggles in the delivery of health and social care. Future studies should consider HSCP training, a more detailed review of the broader policy context and an exploration of the impact of specific interventions or policies that have been suggested in this study to address the identified challenges.

### **Conclusion**

This study has highlighted the perceptions of HSCPs working in either an urban hospice or rural health centre setting, identifying the challenges they face in caring for individuals living with NCDs in Uganda. Challenges were attributed to staffing issues, poor infrastructure and resource limitations within the healthcare system, with wider issues relating to patient poverty and the burden placed on family carers. The emotional cost of this work on both professionals and family carers was emphasized.

The study is timely, as despite major strides to improve the health of the Ugandan population over the last 15 years, there remains high morbidity and mortality from preventable causes (Ministry of Health, 2018), including a growing burden of NCDs. Health systems in Uganda are ill-prepared to manage not only the current burden but also any increasing prevalence of disease (Nahalamba et al, 2019). As noted, the WHO (2017) estimates a projected shortfall of 18 million health workers by 2030, mostly in LMICs. In strengthening health systems to address the prevention and control of NCDs within LMICs (Pindus et al, 2018; Waweru et al, 2019; Rawal et al, 2021), there is a need to consider investment in NCD human resource structures, including prioritizing the needs of both HSCPs and family carers. As NCDs continue to rise, the findings from this study will add to the body of literature used to inform developments in policy and service delivery in Uganda and are applicable in other LMIC contexts.

### **Note**

<sup>1</sup> See: [www.hospice-africa.org/where-we-started](http://www.hospice-africa.org/where-we-started).

## Funding

This work was supported by a grant from the Northern Ireland Department for the Economy (DfE) Global Challenges Research Fund (GCRF) (2020–21). Research training for researchers Florence Githinji, Angela Namwanje Kawooya, Florence Nakaggwa, Alimah Komuhangi, Judith Apio and Rose Clarke Nanyonga for research reported in this study was supported in part by the Fogarty International Center of the National Institutes of Health, US Department of State's Office of the US Global AIDS Coordinator and Health Diplomacy (S/GAC), as well as the President's Emergency Plan for AIDS Relief (PEPFAR) under Award Number 1R25TW011213. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

## Acknowledgements

The project team wishes to express their gratitude to the range of professionals who took the time to engage with us in the research process. Special thanks should go to Dominic Mukwaya, SHARE Uganda, Ms Nashiba Nabunje from Hampton Health Centre, Kyotera, and Ms Harriet Nakiganda Muganga from Hospice Africa, Uganda.

## Conflict of interest

The authors declare that there is no conflict of interest.

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