Discover Public Health

Research

My husband is my responsibility:" motivations and activities of informal caregiving for patients with chronic diseases in Uganda

Ephraim Kisangala[1] · Margaret Heslin[1] · Edward J. D. Webb[2] · Muhammed Nasir Ayub Khan[3] · Barbara Barrett[1] · Eve Namisango[4] · Godfrey Zari Rukundo[5]

Received: 13 December 2024 / Accepted: 22 April 2025
Published online: 03 May 2025

Abstract

Background Informal care is a vital part of care for many people with chronic diseases in sub-Saharan Africa. Though challenging and demanding, many individuals are involved in the provision of this care. However, it is unclear what motivates people in sub-Saharan Africa to provide informal care. Therefore, this study explored the motivations to becoming informal caregivers of patients with chronic diseases in Uganda.

Methods Focus group discussions (FGDs) were conducted among 33 informal caregivers of patients with chronic diseases at Mbarara Regional Referral Hospital in Uganda. The participants were purposively sampled into one of five FGDs. Discussions were audio-recorded, transcribed verbatim and manually analysed using thematic analysis.

Results The informal caregivers were aged 18 to 67, with 72.7% being females. They were all related to their respective care recipients. Six themes describing the motivations for becoming a caregiver emerged including reciprocity, love, caring as a responsibility, availability to care, desire to improve the patient's health and desire to protect others from burden of care. Also, themes for caregiver activities were: approach to caregiving, activities of daily living, activities that require medical training, activities that motivate the patient and activities that support other informal caregivers.

Conclusion The results indicate that multiple factors motivate people to become informal caregivers and that their activities benefit both the patients and other caregivers. These findings highlight the need for policymakers to design a framework that would enable health workers to collaboratively work with informal caregivers to achieve better experiences and outcomes for both patients and caregivers.

Keywords Informal caregivers · Chronic diseases · Motivations · Caregiving activities

1 Introduction

Africa faces a greater disease burden today than ever before, and it registered a 67% increase in the burden of chronic diseases between 1990 and 2017 (1). Together, the top four chronic diseases, cancers, cardiovascular diseases, chronic obstructive pulmonary disease (COPD) and diabetes are responsible for more than two thirds of the continent's

✉ Ephraim Kisangala, ephraim.1.kisangala@kcl.ac.uk; Margaret Heslin, margaret.heslin@kcl.ac.uk; Edward J. D. Webb, e.j.d.webb@leeds.ac.uk; Muhammed Nasir Ayub Khan, drmnasirayubk@gmail.com; Barbara Barrett, barbara.m.barrett@kcl.ac.uk; Eve Namisango, eve.namisango@africanpalliativecare.org; Godfrey Zari Rukundo, grukundo@must.ac.ug | [1]King's Health Economics, Institute of Psychiatry, Psychology and Neuroscience at King's College London, London, UK. [2]Academic Unit of Health Economics, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK. [3]Department of Health Professions Education, Shifa Tameer e Millat University, Islamabad, Pakistan. [4]African Palliative Care Association, Kampala, Uganda. [5]Department of Psychiatry, Mbarara University of Science and Technology, Mbarara, Uganda.

disease burden, with cardiovascular diseases alone causing 13% of all deaths [1]. Similarly, the burden of chronic diseases has increased in Uganda, contributing half of all deaths in some regions of the country [2]. This in part is attributed to the late diagnosis which places a significant strain on the affected families and the health system [3].

Chronic diseases, commonly known as non-communicable diseases, can be defined as slow progressing diseases that cannot be acquired through person-to-person transmission. The majority of people with chronic conditions will at one point in their lives require medical attention [4]. However, the health systems in sub-Saharan Africa are overwhelmed, with shortages of essential medicines and equipment, insufficient number of trained health workers and high numbers of patients [5, 6]. Given this burden, many families turn to informal caregivers to help address some of these challenges. The informal caregivers are considered a convenient and easy part of the solution because most of them are family members, and this familial relationship puts them in situations where they must do almost anything to keep their patients in good health [7]. Also, in many cultures within sub-Saharan Africa, caring is a duty one must perform to those they love [8]. Therefore, it is quite common seeing patients coming to hospital accompanied by their respective caregivers, who tend to them and perform any assigned tasks throughout their hospital stay [9–11]. The caregivers remain close to their patients even during the nights, by sleeping on the floor next to their hospital beds [12].

Informal caregivers are individuals who provide unpaid support to another person (usually relative or friend) with a disability or chronic disease. These informal caregivers are not formally trained to provide medical care, but provide physical, emotional and economic support to the care recipient [7]. Throughout this paper, these informal caregivers (ICGs) will be referred to as caregivers. In several African countries, including Uganda, caregivers commonly refer to their care recipients as patients [11, 13]. For that reason, the words care recipients and patients will be used interchangeably to refer to people with chronic diseases that are supported with specific tasks due to the nature of their condition. The distinction between caregivers and health workers lies in training and nature of activities. Informal caregivers have a unique attachment to their care recipients which makes their role specifically tailored to the diverse needs and demands of care.

Whilst there is significant literature on caregivers, there is still very little understanding of what motivates people to become caregivers especially in sub-Saharan Africa. Motivation to care refers to those factors that push an individual to assume or continue with caregiving responsibilities. Motivation is an important aspect of caregiving because it affects the effectiveness of a caregiver, the quality of care provided, how long caregivers will be available to provide care and the caregiving outcomes [14, 15]. There is a growing body of literature suggesting that multiple factors including individual factors such as reciprocity and kindness, socio-cultural such as gender and family responsibilities, and economic factors affect one's willingness to provide care [15–17]. There are also people who have had nefarious reasons for becoming caregivers. They use caring as an opportunity to steal wealth or punish the care recipient for previous wrongs [16]. Evidently, there is a link between caregiving activities and motivations to become a caregiver. In their study, Ng et al. [18] found that family caregivers of hospitalised patients in Singapore with intrinsic caregiving motivations performed their tasks with ease, and quickly sought and found solutions to the challenges they experienced during care. In Iran, the caregivers were 'forced' by other family members selectively performed the care tasks [16]. Quite recently, it was also observed that caregivers in Uganda who are overwhelmed with the care activities are less motivated to provide care [19]. Even the Ministry of Health report on Cancer and other Non-Communicable Diseases (NCDs) in Uganda shows that majority of the caregivers are overwhelmed because most people with chronic diseases are diagnosed late [20]. Overall, the motivation to provide informal care and the activities performed are related.

In addition, there are some disease specific studies on motivation to provide informal care in sub-Saharan Africa [21–23]. These studies found that reciprocity, altruism, desire for a peaceful longevity and morality contributed to the decision/motivation to provide care. However, none of the above studies took place in Uganda, and it has been shown that motivation to provide informal care changes over time and varies across different cultures [8, 24]. This explains the need for a study within Uganda with the following objectives: (i) to explore the factors that motivate people to become caregivers of those with chronic diseases and (ii) to describe the activities caregivers perform during care. The results of this study would help in developing tailored programs that support caregivers to provide quality care for people with chronic diseases, and thus improve the caregiving experience.

2 Methods

This cross-sectional study used qualitative methods to explore the informal caregivers' motivation to care for people with chronic diseases in Uganda. Semi-structured interview guide with open-ended questions were used during the face-to-face focus group discussions. The research team was multidisciplinary and consisted of university lecturers (BB, MH, ELM, MNAK, EJDW, GZR), medical doctors (MNAK, EK), a psychiatrist (GZR) and a palliative care specialist (EN). In writing this manuscript, the study team followed the guidance in the Consolidated criteria for reporting qualitative research (COREQ) [25]. The study adopted a relativist ontological approach, which means the experiences of the caregivers were taken as the reality [26]. Each caregiver has a unique experience resulting from supporting patients with different diseases and varying care needs. By using this approach, the research team is able to understand and appreciate the participants' own meanings and interpretations of care activities and motivations. Furthermore, an interpretivist epistemological stance was adopted when extracting meaning from the collected data[26]. In this approach, we considered every caregiver's experience and interpreted data to reflect their realities/perspective. As a benefit, an interpretivist epistemology will enable the research team have an extensive in-depth exploration of the caregivers' unique interpretations of their rich experiences.

2.1 Study setting

This study was conducted within Mbarara Regional Referral Hospital (MRRH) located in Mbarara city, southwestern Uganda from May to June 2023. It is the biggest public hospital for the southwestern region and is 265 km from Kampala (the capital of Uganda). The hospital was established in 1940 and now has a 600-bed capacity. MRRH is the referral facility, providing both in-patient and out-patient services. It has eight main departments: Internal Medicine, Psychiatry, Surgery, Paediatrics and Child Health, Obstetrics and Gynaecology, Accident and Emergency, Intensive Care Unit, and an Outpatient Department with special clinics including Ear, Nose and Throat (ENT), Maternal and Child Health (MCH), and an Adolescent Health and Eye clinic. MRRH is also a teaching hospital for Mbarara University of Science and Technology (MUST) as well as many other medical and nursing schools within the region. It is estimated that MRRH serves a population of about six million people within the more than a dozen districts in western and southwestern Uganda [27]. Refugees from Burundi, Democratic Republic of Congo, South Sudan and Somalia as well as patients from Tanzania and Rwanda are also regular users of MRRH health services [28]. Consequently, many patients and their caregivers must travel long distances to the hospital to access healthcare services, and if admitted, spend lengthy periods away from their families.

2.2 Population and sample size

Caregivers of inpatients (admitted) with chronic diseases at MRRH formed the potential sample population. Caregivers were included in the study if they meet the following criteria at the time of the interview: (i) aged at least 18 years old; (ii) identified by the patient as their primary caregiver; (iii) the caregiver's patient has been admitted to hospital with a diagnosis of at least one of the following chronic diseases: type 2 diabetes, chronic pulmonary obstructive disease (COPD), cancer or cardiovascular diseases; and (iv) has provided care (from home or hospital) to the patient for at least one month. The research team excluded participants that were unable to provide consent and those who were actively caring for their patients at the time of the group discussion.

In total, forty potential participants were approached, of which 33 participated in one of five focus group discussions (FGDs) with six to eight participants per FGD, except one group that had only five participants. The number of participants we had in each FGD (5 to 8) is considered ideal for discussions involving sharing experiences because each person will have the opportunity and time to provide an in-depth perspective of their experiences [29]. In addition, Hennick et al. [30] has shown that when more than four FGDs are conducted, the data generated is adequate to provide a good understanding of the topic under discussion. For those that did not take part in the FGDs, their main reason non-participation was having very sick patients on the day of the interview.

2.3 Recruitment process

Patients within the chronic diseases' wards of the hospital were approached by the study team and requested to identify their primary ICG. This was done with guidance and support of hospital staff such as nurses who introduced the study team to the patients and caregivers in the paediatric oncology ward, adult oncology ward, gynaecological oncology

ward, medical ward and emergency ward. Patients with diabetes mellitus, cardiovascular diseases and COPD were in the medical ward and emergency ward while patients with cancer were in the various oncology wards. The caregivers were purposively selected to try to achieve a degree of heterogeneity within the sample. The participants were selected based on their gender, age and patient disease type. Each of the selected participants was approached, given a full oral explanation of the study, and provided with a consent form to sign prior to participation in the FGD. Except for those that preferred documents in English, the consent forms given to participants were in Runyankore-Rukiga language, the dominant language in Mbarara city. The FGDs were conducted in a tutorial room next to the paediatric oncology ward of the hospital. This room chosen because it was considered safe, spacious, well-ventilated and conversations could not be overheard by other people that were not part of ongoing group activity. The room was prebooked to prevent interruptions from other people who could have wanted to use the same space for another activity during the time of the interview.

2.4 Data collection procedure

For this study, data was collected by a female research assistant with a degree in community psychology and more than four years' experience in qualitative data collection. She was a native speaker of Runyankore-Rukiga, a language spoken by most people in the study area and received a two-day training in preparation for this activity. She was recruited because the first author (EK) is not fluent in Runyankore-Rukiga. A translated version of the interview guide that had been developed by the research team was used during the FGDs. Prior to starting the discussion, participants were informed about where they could seek mental health support. They were also encouraged to take breaks particularly whenever they felt distressed during the discussion. EK attended all the FGDs while the research assistant moderated the discussions. A review meeting between EK and the research assistant was held at the end of each FGD meeting. For each FGD, there was a moderator and an observer/notetaker, and the discussions were conducted in Runyankore-Rukiga. These discussions were recorded using an audio-recorder and they lasted between 50 and 75 min.

2.5 Data analysis

To conceal their identity, every participant was given a unique identification which they used during the group discussion. The audio recordings from the FGDs were transcribed verbatim in Runyankore-Rukiga and later translated into English by a translator with two years' experience of working as a translator for various health sciences research projects at Makerere University. The data were manually coded and thematically analysed using the approach suggested by Braun and Clarke [31]. Initially, two authors, EK (a Ugandan) who was an observer in all the focus group discussions and MNAK (a Pakistani) independently read and re-read the same FGD transcript to familiarise themselves with the data and get a deeper understanding of what the participants discussed. Then, each author (EK and MNAK) iteratively read the transcript while identifying, highlighting and assigning codes to segments of the text they considered relevant to the study objectives. They also took note of any ideas and themes that emerged. The two authors (EK and MNAK) then met to compare the codes, and any disagreements were resolved by another author (BB) through discussion and consensus. These steps were repeated for all the transcripts and a long list of codes was generated. Thereafter, the codes with similar underlying meanings were grouped into the same subthemes and similar subthemes were organised under the same theme. Subsequently, the transcripts were carefully read alongside the list of codes resulting into revision of some of the themes and subthemes. Finally, all the authors reviewed the draft document suggesting modification where applicable through discussion and mutual agreement.

2.6 Ethical considerations

Prior to commencing the study, ethical approvals were obtained from these three institutions: (i) King's College London (Reference Number: RESCM-23/24–33,295); (ii) Mbarara University of Science and Technology Research Ethics Committee (Application number: MUST-2023–785); and (iii) Uganda National Council for Science and Technology (Registration number: SS1846ES). Thereafter, the study team received a formal administrative clearance from MRRH. Finally, the relevant MRRH heads of departments and the ward in-charges were informed by the first author about the study prior to the start of the potential participant recruitment. All selected participants provided a written consent after receiving full information about the study, its consequences and being informed of the freedom to withdraw at any stage. The participants were assured of anonymity and confidentiality of their data/information. All personal

identifying information was removed before the collected data was stored on secure servers hosted by KCL. Access to the data was restricted to the research team members only. Importantly, this study was carried out in accordance with guidelines listed in the ethics statements approved by the ethics committees above.

3 Results

3.1 Participants

The Table 1 below presents an overview of the characteristics of the 33 informal caregivers that took part in the FGDs. They were drawn from five different wards and their ages ranged from 18 to 67, with a mean (SD) of 37.1 (12.2) years. Nearly three quarters of the participants were female (72.7%). It is worth noting that all the caregivers were related to their patients, albeit sometimes by marriage. Nearly one third (30.3%) of the caregivers were parents of those they supported. This, followed by being a son/daughter (18.2%) of the patient, were the commonest forms of relationships reported. A total of 36.4% of the people who participated in this study were caregivers of adults with cancers. The rest of the patients had the following diagnoses: 21.2% with diabetes mellitus, 21.2% with cardiovascular diseases, and another 21.2% with childhood cancers.

Table 1 Overview of the social demographic characteristics of the participants

Demographic characteristic	Frequency
Age	
18–27	8 (24.2%)
28–37	7 (21.2%)
38–47	11 (33.3%)
48–57	5 (15.2%)
58–67	2 (6.1%)
Mean (SD)	*37.1 (12.2) years*
Sex	
Male	9 (27.3%)
Female	24 (72.7%)
Relationship of the caregiver to patient	
Spouse	7 (21.2%)
Sibling	5 (15.2%)
Son/Daughter	6 (18.2%)
Parent	10 (30.3%)
Other relatives	5 (15.2%)
Unit where patient is admitted	
Children's cancer ward	7 (21.2%)
Emergency ward	6 (18.2%)
Adult cancer ward	7 (21.2%)
Medical ward	8 (24.2%)
Gynaecological oncology ward	5 (15.2%)
Diagnosis of the patient (care recipient)	
Cancer (in children)	7 (21.2%)
Cancer (in adults)	12 (36.4%)
Diabetes mellitus	7 (21.2%)
Cardiovascular diseases	7 (21.2%)

3.2 Outcomes of the FGDs

After analysis, the results were divided into two distinct categories; motivation to become a caregiver from which six themes emerged, and activities performed by caregivers that had five themes. Each of these categories and their corresponding themes is subsequently described.

1. Motivations for caregiving

Motivations for becoming caregivers refer to those factors that push people to decide to care for those with chronic diseases. During analysis, six themes that provide insight into the motivations for becoming a caregiver emerged. These were: (i) reciprocity, (ii) desire to improve the patient's health, (iii) love/affection, (iv) responsibility, (v) availability to provide care, and (vi) Protecting others from burden of care, and they are described in Table 2 below.

a. Caring as an act of reciprocity

Caring involved the element of reciprocity. Reciprocity can be taken to mean a situation where people feel obliged to perform activities that benefit other individuals that had been or will be helpful to them. It is more of a social practice in which people directly or indirectly return favours to others. Activities aimed at returning past favours are classified as retrospective reciprocity while those aimed at future favours is prospective/expected reciprocity. In this study, the caregivers provided the needed support because of how beneficial their patients had been towards them in the past or would be in the future. They viewed caregiving as a form of payment or reward that they were obliged to offer, therefore could not turn down the opportunity when the need arose. Reciprocity was viewed in two main ways by the participants: (i) retrospective reciprocity and (ii) expected reciprocity.

i. Retrospective reciprocity (Caring as a reward for past good deeds)

For some, becoming a caregiver was a way of rewarding those who had done good things for them in the past. This is especially true for those who were able to remember the past good deeds performed by the care recipients. This is shown in the following narratives.

> *"I am trying so that my old man doesn't die. He looked after me when I was young… Now that life has become better, I am supposed to be rewarding him. That is what made me [care for him]."* (C7, son of a male patient admitted in the adult oncology ward).
>
> *"The patient is my sister. There was a time when I was hurting a lot and she cared for me so when I heard that she was sick, I decided to try and do what she did for me. That is why I'm here."* (C3, younger sister of a patient admitted in the adult oncology ward).
>
> *"She asked for my help [to come and care for her son who was very sick]. I didn't resist since she is my aunt and [she] had been helping me before."* (A2, female cousin of a child admitted in the paediatric oncology ward).

ii. Expected reciprocity (Caring in anticipation for future rewards)

The second way in which the caregivers looked at reciprocity was through anticipation of possible future rewards. They offered to care believing that those receiving the care would support them (caregivers) or do good to other members of the family in the future. These caregivers did not only consider themselves or their immediate families as the would-be beneficiaries, but they were also happy to care for those that would be resourceful to other people within the community. For the caregivers, it was important that the care recipients appreciated, understood and did not forget the good things being done for them now if they are to reciprocate them in future. The following quotes provide expressions from caregivers whose decision to care was hinged on future rewards.

> *"I am the child's father. One day when I'm old and weak, he will be of importance because he will be strong."* (A4, father of a child admitted in the paediatric oncology ward).
>
> *"I care for him so that when he is old, he will be of importance and will appreciate what I did for him. He will also see the need to nurse another person."* (A1, mother of a child admitted in the paediatric oncology ward).
>
> *"What persuades me is that when he gets well, he will see the need to work for me his mother and his younger siblings."* (A5, mother of a child admitted in the paediatric oncology ward).

b. Caring to improve the patient's health

Table 2 Table showing the motivations for caregiving

Theme	Sub-theme	Sample of quotes
Caring as an act of reciprocity	Appreciation/reward for past good deeds	*She asked for my help [to come and care for her son who was very sick]. I didn't resist since she was my aunt, and [she] had been helping me before.* (A2, female cousin of a child admitted in the paediatric oncology ward)
		I am trying so that my old man doesn't die. He looked after me when I was young… Now that life has become better, I am supposed to be rewarding him. That is what made me [care for him]. (C7, son of a male patient admitted in the adult oncology ward)
		The patient is my sister. There was a time when I was hurting a lot and she cared for me so when I heard that she was sick, I decided to try and do what she did for me. That is why I'm here. (C3, younger sister of a patient admitted in the adult oncology ward)
	In anticipation of future rewards	*I am the child's father. One day when I'm old and weak, he will be of importance because he will be strong.* (A4, father of a child admitted in the paediatric oncology ward)
		I care for him so that when he is old, he will be of importance and will appreciate what I did for him. He will also see the need to nurse another person. (A1, mother of a child admitted in the paediatric oncology ward)
		What persuades me is that when he gets well, he will see the need to work for me his mother and his younger siblings. (A5, mother of a child admitted in the paediatric oncology ward)
Caring to improve the patient's health	Improve physical health to be able to fulfill their (patients) responsibilities	*I want him to retain his life and care for his family because he still has young children for example my family is like his. I want him to get his life back and look after his family.* (C6, son of a male patient admitted in the adult oncology ward)
		The main reason as to why I attending to my husband is that I want him to heal so that he can look after our children. That is what hurts me most. That is why I provide for him juice and his medication on time. There is still a lot to do. (B4, wife of a patient admitted in the emergency ward)
	To improve mental health so they (patients) feel better	*Another reason is that I never wanted the kid to see other children healthy at home and he develops depression thinking that he is being segregated or not cared for. We ensure that he doesn't get angry and gets his needs so that he doesn't question his state… My desire is to see him happy all the time.* (A2, female cousin of a child admitted in the paediatric oncology ward)
		This is my fourth-born child and I decided to care for him so that he can know that his life will be okay. He shouldn't see others playing happily when he is not part. I wanted to show him parental love so that he can grow with faith. (A7, mother of a child admitted in the paediatric oncology ward)

Table 2 (continued)

Theme	Sub-theme	Sample of quotes
Caring out of love/Affection	Love expressed because of how valuable the person is	*What motivated me to look after my old woman is that I have no one like her. She's the only person that God gave me. I can get others, but they would not be my biological mother. She is also my friend. That encourages me to care about her when she gets hurt. I work within my capabilities and God also helps where I am unable.* (B6, daughter of a female patient admitted in the emergency ward)
		We still want our old man because of the guidance he gives us especially us who did not go to school. He reads stories for us and tells us what to do. We also make fun with him, laugh and talk [together]. It made me ensure that at such a time, I am nursing him. (C7, son of a male patient admitted in the adult oncology ward)
	Love expressed because of the what the patient is going through (Empathy)	*The sick person is my daughter and what hurts her hurts me as well. That motivated me to come and care for her because she needs me. I prefer to care for her myself.* (E3, mother of a female patient admitted in the gynaecological cancer ward)
		According to me, being with anyone forces me to take of them in hospital because when my people feel pain, I also feel the pain. (E4, adult female caring for husband's mother admitted in the gynaecological cancer ward)

Table 2 (continued)

Theme	Sub-theme	Sample of quotes
Caring as a responsibility	When one feels it is their responsibility to care	*They say that what knocks on the door looks for the family head. I couldn't dodge it as his parent. As I had explained, my wife stayed and I went. I accepted to nurse him because it's my duty.* (A4, father of a child admitted in the paediatric oncology ward)
		There is something that motivates you, for example when it is your mother, and she is suffering from a hectic disease which needs the owner. You need your children and not the daughters-in-law. You need to take responsibility and call your children to nurse you, talk to you so that you are not disturbing other people. (E5, daughter of a female patient admitted in the gynaecological cancer ward)
		I realized that my husband is my responsibility. I should be the one to know how he feels and how his night was. We have children but they don't access him easily. I need to know how he sleeps or eats because I am with him every day. (D1, wife of a patient admitted in the medical ward)
	When the responsibility of care is delegated to the caregiver	*"My in-law is the one who decided to call me to nurse my elder. My elder brother and all his children believe in me and the decisions I make."* (C5, younger brother of a male patient admitted in the emergency ward)
		…my child had younger siblings and I couldn't look after them. I decided that their mother would stay while I nursed him. (A4, father of a child admitted in the paediatric oncology ward)
		I decided with my heart. I saw that the man is the one sending money so he cannot nurse and still make money. So, I decided to come. (C3, younger sister of a patient admitted in the adult oncology ward)

Table 2 (continued)

Theme	Sub-theme	Sample of quotes
Caring because of being available	When you are the only one physically available to care	*The one I have here is my sister and I have no one to leave her with whether behind or in front. I'm her mom and dad and I can't neglect her.* (B1, sister of a patient admitted in the emergency ward)
		I am nursing my sister-in-law. She has no husband, and she also lost her mother. She called me and told me that she was going to hospital, not feeling well and couldn't even stand. I decided to take care of her …. She had just delivered and was weak. (B3, adult male caring for his sister-in-law admitted in the emergency ward)
	When you are only one with capacity/skills to care	*I am here because my other family members had a problem of language barrier. I come from very far and in a place where we specifically speak Lukonzo. A few have the capability of interacting in other languages. That is how I was selected. I ensure that I follow every instruction from the medical instructors.* (D6, grandson of a patient admitted in the medical ward)
		I am the mother of the child. I noticed that nobody else in the family would help me as you may understand that everyone has their problems. I decided with all my heart to attend to the patient under any circumstances. (A1, mother of a child admitted in the paediatric oncology ward)
Caring to protect others from the burden of care		*I want the children to study because they are still young.* (B4, wife of a patient admitted in emergency ward)

Discover Public Health (2025) 22:217 | https://doi.org/10.1186/s12982-025-00616-4

A common motivation for taking up caring role was the desire to see the patients' health improve. These caregivers had had the opportunity of seeing their patients in good health and they could clearly notice the difference between that time and this moment when they are in the hospital. The caregivers longed for the improvement of the patients' health because the chronic disease had disrupted their families' way of life and responsibilities. This motivation was categorized into two as described below.

i. Improve physical health to be able to fulfill their (the patients) responsibilities

The caregivers wanted to see their patients get to better health. They desired to see the patients regain their strength and resume performing the duties they used to do prior to the illness. This motivation was clearly stated by some caregivers through the following quotes:

"I want him to retain his life and care for his family because he still has young children for example my family is like his. I want him to get his life back and look after his family." (C6, son of a male patient admitted in the adult oncology ward).
"The main reason as to why I attending to my husband is that I want him to heal so that he can look after our children. That is what hurts me most. That is why I provide for him juice and his medication on time. There is still a lot to do. I want the children to study because they are still young." (B4, wife of a patient admitted in emergency ward).

ii. To improve mental health so they (patients) feel better

Some caregivers were motivated to tend to their patients because of the desire to protect and safeguard their emotional well-being. The care they provided was meant to give hope, dispel worries and ensure that the person under their care thrives like other people. They hoped the patients would find the care worthwhile, helping to keep them (patients) from negative thoughts.

"Another reason is that I never wanted the kid to see other children healthy at home and he develops depression thinking that he is being segregated or not cared for. We ensure that he doesn't get angry and gets his needs so that he doesn't question his state." (A2, female cousin of a child admitted in the paediatric oncology ward).
"This is my fourth-born child and I decided to care for him so that he can know that his life will be okay. He shouldn't see others playing happily when he is not part. I wanted to show him parental love so that he can grow with faith." (A7, mother of a child admitted in the paediatric oncology ward).

c. Caring out of love/affection

Under this theme, the caregivers' motivation to care came from how they felt about the patients. They had a unique attachment or relationship with their patients, and they did not want the disease to affect it. They used words like 'no one like her', 'love', 'only one I have', 'my friend', 'irreplaceable', 'resourceful', and 'what hurts her also hurts me' to describe their love and affection for their patients. Below, we have categorised into two, the caregivers' reasons for expressing this love or affection.

i. Love expressed because of how valuable the person is

Some caregivers stated that the motivation to provide care was the love and affection for the patient. This love/affection often developed out of the value the participants attached to the care recipients, or a relationship that was nurtured over time. They explained that their patients' past good deeds played a role in creating or strengthening the relationship between them. This relationship developed to a level where the patient became valuable and important to the caregiver. The following quotes reflect this theme.

"What motivated me to look after my old woman is that I have no one like her. She's the only person that God gave me. I can get others, but they would not be my biological mother. She is also my friend. That encourages me to care about her when she gets hurt. I work within my capabilities and God also helps where I am unable." (B6, daughter of a female patient admitted in the emergency ward).
"We still want our old man because of the guidance he gives us especially us who did not go to school. He reads stories for us and tells us what to do. We also make fun with him, laugh and talk [together]. It made me ensure that at such a time, I am nursing him." (C7, son of a male patient admitted in the adult oncology ward).

ii. Love expressed because of the what the patient is going through (Empathy)

The caregivers sometimes expressed this love/affection by being empathetic. They used expressions that meant that they would get affected by whatever affects those that were sick, and they had to care so they do not experience the same challenge. A caregiver tending to her daughter explained this well when she said:

"The sick person is my daughter and what hurts her hurts me as well. That motivated me to come and care for her because she needs me. I prefer to care for her myself." (E3, mother of a female patient admitted in the gynaecological cancer ward).

d. Caring as a responsibility

This theme means that the caregivers provided informal care because they considered it their role. This feeling was influenced by socio-cultural factors such as family roles, expectations and directives. In this study, the responsibility to care was assumed in the ways described below.

i. When one feels it is their responsibility to care

Many of the caregivers in this study looked at caring for their loved ones as their responsibility. They considered caring as a familial obligation that they had to fulfill. They considered themselves the most suitable persons to take the caring responsibility for the family member whose condition/disease was severe or required greater care. Some of the statements used indicate that their positions in the family came with certain responsibilities. The quotes below show this.

"They say that what knocks on the door looks for the family head [A saying/proverb in one of the local languages whose meaning may be close to 'a knock on the door seeks the one who holds the key']. I couldn't dodge it as his parent. As I had explained, my wife stayed, and I went. I accepted to nurse him because it's my duty." (A4, father of a child admitted in the paediatric oncology ward).

"There is something that motivates you, for example when it is your mother, and she is suffering from a hectic disease which needs the owner [i.e. emphasizing the need for action from the person with responsibility over the patient]. You need your children and not the daughters-in-law. You need to take responsibility and call your children to nurse you, talk to you so that you are not disturbing other people." (E5, daughter of a female patient admitted in the gynaecological cancer ward).

"I realized that my husband is my responsibility. I should be the one to know how he feels and how his night was. We have children but they don't access him easily. I need to know how he sleeps or eats because I am with him every day." (D1, wife of a patient admitted in the medical ward).

ii. When the responsibility of care is delegated to the caregiver

In other cases, this responsibility of providing care would be delegated by making arrangements so that one or more family members go to support the person in need of care while others with regular activities. Such arrangements would be arrived at through individual or collective decision-making. In situations where the responsibility was self-assigned, the participants either considered themselves better than other family members at doing the job or believed that caring was an activity they were more capable of doing when compared to other activities. In other cases, the caregiver would assume the role because other members of the family have already taken up other roles. However, belief in the participant's ability to perform the caregiving activities was frequently provided as the reason for asking them to become caregivers. The following quotes describe some of these arrangements.

"My in-law is the one who decided to call me to nurse my elder. My elder brother and all his children believe in me and the decisions I make." (C5, younger brother of a male patient admitted in the emergency ward).

"…my child had younger siblings and I couldn't look after them. I decided that their mother would stay while I nursed him." (A4, father of a child admitted in the paediatric oncology ward).

"I am nursing my sister. I decided with my heart. I saw that the man is the one sending money so he cannot nurse and still make money. So, I decided to come." (C3, younger sister of a patient admitted in the adult oncology ward).

e. Caring because of being available

This theme meant that caregivers provided support with care activities because they were the only ones that could do so at that time. They were in situations where no other person could provide care except them. This is because no other person was physically present to provide care or the people around did not possess the essential skills considered vital

for providing care. These people got to understand that it was only them available because no other person offered to care despite the worsening health condition of the patients. These two scenarios are described in the sub-themes below.

i. When you are the only one physically available to care

Some caregivers were in situations where they were the only ones physically available to provide the needed care. They observed that the patients did not have any relative or friend within the vicinity except them. For this reason, they became worried about bad things such as worsening of the health condition and death that could happen to their patients if they did not act. In otherwards, they were left with no other choice but to provide care. Some caregivers were quoted saying:

"The one I have here is my sister and I have no one to leave her with whether behind or in front. I'm her mom and dad and I can't neglect her." (B1, sister of a patient admitted in the emergency ward).

"I am nursing my sister-in-law. She has no husband, and she also lost her mother. She called me and told me that she was going to hospital, not feeling well and couldn't even stand. I decided to take care of her …. She had just delivered and was weak." (B3, adult male caring for his sister-in-law admitted in the emergency ward).

ii. When you are only one with capacity/skills to care

There were also those who became caregivers because they were the only ones with the required characteristics or skills. These individuals were uniquely gifted with skills or resources that were considered essential to providing care. These include ability to communicate with health workers, not having other commitments and being physically healthy to care for another person. For example, the caregiver who was the only one in the family with the ability to communicate in English had this to say,

"I am here because my other family members had a problem of language barrier. I come from very far and in a place where we specifically speak Lukonzo [a language that is not commonly spoken within the area where the hospital is located]. A few have the capability of interacting in other languages. That is how I was selected. I ensure that I follow every instruction from the medical instructors." (D6, grandson of a patient admitted in the medical ward).

Another participant who was from a family where all members had other commitments said, *"I am the mother of the child. I noticed that nobody else in the family would help me as you may understand that everyone has their problems. I decided with all my heart to attend to the patient under any circumstances."* (A1, mother of a child admitted in the paediatric oncology ward).

f. Caring to protect others from the burden of care

Sometimes, the caregivers were concerned about the negative effects caring could have on other members of the family. These caregivers seemed to be cognisant of the how burdensome care can be and how it could interfere with routine or important activities. Therefore, becoming a caregiver was a way of ensuring that the family member's planned activities are not interrupted. This was echoed by a caregiver who did not want her children to be involved in care because of the interruption it could cause to their education.

"I want the children to study because they are still young." (B4, wife of a patient admitted in emergency ward).

2. Activities of caregiving

When one becomes a caregiver, there are activities they are expected to perform while in the role. The activities one performs may vary depending on the care needs and motivation. During analysis, six overarching themes describing the activities performed by informal caregivers were identified and they include: (i) approach to performing the care activities, (ii) activities of daily living, (iii) activities that require medical skills/training (iv) activities that motivate the patient, (v) activities to support other caregivers and (vi) protecting others from the burden of care. These themes are described in Table 3 below.

a. Approach to performing the caregiving activities

The caregivers approached care tasks meticulously and with a joyful spirit. They also understood that the work would take all their time and attention from other activities as described by this twenty-year-old male attending to his sister, *"I make sure that I care for them. People said the patients need an hour, but I think it requires you to be with them all the time. It is not one or two hours. … When you have a patient, you cannot work or do any other thing because you have no time."* (D7, brother of a female patient admitted in medical ward).

Table 3 Table showing the activities of caregiving

Theme	Sub-theme	Sample of quotes
Approach to performing the care activities	They joyfully performed the activities	*"I love everything be it giving him water, cleaning him or spending the night with him."* (B4, wife of patient admitted in emergency ward)
		"I look after my husband and get for him whatever he asks for. I bring him food so that he has no desires. I am the one he sees, and I don't want him to crave. … Giving it all my strength encourages me." (B5, wife of a patient admitted in emergency ward)
		"I also make sure that I give my dad what he wants … maybe not 100% but I try to give him weekly what he desires. …I try so much…" (C7, son of a male patient admitted in the adult oncology ward)
	They carefully performed the activities	*"You have to look after your patient and know how much medicine she needs to take at a particular time because you might tell her to take thrice while it is an overdose. Secondly, you need to communicate with the doctors to know what the patient requires."* (D5, sister of a female patient admitted in the medical ward)
		"I came to nurse to my husband. He is suffering from diabetes, kidney and lung failure. I am the one responsible for cooking food with moderate sugar and salt. … Washing him needs an hour because he cannot control his bowels and I have to look for a bucket of water, soap and cloth to clean him. I spend the entire hour cleaning him so that doctors don't reject me." (B4, wife of a patient admitted in emergency ward)
		"…You cannot rush them. They need to be helped carefully and slowly. You wait for them to wake up, [and] take them to the shower…" (E4, adult female caring for husband's mother admitted in the gynaecological cancer ward)
Activities of daily living	Basic activities of daily living	*"…She's been having trouble controlling her bowels at night. She had lost her side to worms. I would dress her in Pampers and clean her… She has also been using a wheelchair because she could stand and felt dizzy."* (B2, husband of a patient admitted in the medical ward)
		I wake up at 6am and…brush her teeth and then I lay the bed. … I care for her, give her food, … and make sure that I keep her body clean. I take her to the bathroom and bath her." (E2, mother of a patient admitted in the gynaecological cancer ward)
	Instrumental activities of daily living	*"Washing for the child, … and at times I get [buy] for him his medicine and take him to hospital when sick… I love playing with him because he doesn't walk or play. I bought him toy cars and balls. He plays until he is tired, and I take him so that he can have some rest."* (A3, mother of a child admitted in the paediatric oncology ward)
		"I learned how to be creative and cooperate with others. You could work together with your man to nurse [him] and look for money." (A6, mother of a child admitted in the paediatric oncology ward)
Activities that require medical skills/training		*"My patient suffers from diabetes, and he injects himself every day. I found myself injecting him with penicillin, yet I never got training. I also remove his cannula."* (B6, daughter of a female patient admitted in the emergency ward)
		"There is a lot to do. My patient has kidney failure, and her [blood] pressure and blood glucose were high. Sometimes she is on oxygen. I monitor her drip, examine the pressure, medication. I give her food and wash her. Everything concerns me. The doctors only treat her but I also buy the medicine. I counsel and guide her to strengthen her heart so that the disease doesn't take her quickly." (B2, husband of a patient admitted in the medical ward)

Table 3 (continued)

Theme	Sub-theme	Sample of quotes
Activities to motivate the patient		*"I give him any other form of care. I ask, talk to him and tell him what he wants to hear so that he gets peace. … I pray for my husband and comfort him saying father of twins, you will recover. I stay where he is and tell him that his suffering will pass."* (B4, wife of patient admitted in emergency ward)
		"The child asks whether he is going to die and I distract him. I also distract him when he can't eat. We laugh a lot which helps me build his patience." (A4, father of a child admitted in the paediatric oncology ward)
		"*I try to be hard working so that I provide all he needs on time. I also guide and counsel him so that he doesn't lose hope. I try to correct him, share experiences of those who got healed. I also pray for him and dedicate him so that he is relieved of stress. I also connect with neighbours so that they come in when I'm overloaded."* (D6, grandson of a patient admitted in the medical ward)
Activities to support other caregivers		*"I also connect with neighbours* [caregivers of other patients] *so that they come in when I'm overloaded."* (D6, grandson of a patient admitted in the medical ward)
		"First, I love correcting others and showing them what to do as a consultant. I was here from April and I have seen patients like mine. Sometimes they lack money and I'm called to counsel them and tell them my experience. I also love getting advice from doctors and I also correct others. I ensure that the patient takes medicine, eats and drinks." (B2, husband of a patient admitted in the medical ward)
		"Nursing [caregiving] *is important because you get to help each other in terms of money and working together."* (A1, mother of a child admitted in the paediatric oncology ward)

The participants in this study approached care in ways described below.

i. They joyfully performed the tasks

The caregivers enjoyed assisting their patients with various care activities. They (caregivers) talked about how they loved what they were doing and expressed their utmost commitment to doing all they could to satisfy the needs of those under their care. Upon assuming the caregiving role, these caregivers joyfully did everything within their abilities to meet patients' needs. This is evident in the expressions below:

"I love everything be it giving him water, cleaning him or spending the night with him." (B4, wife of a patient admitted in emergency ward).
"I look after my husband and get for him whatever he asks for. I bring him food so that he has no desires. I am the one he sees, and I don't want him to crave. … Giving it all my strength encourages me." (B5, wife of a patient admitted in emergency ward).
"I also make sure that I give my dad what he wants … maybe not 100% but I try to give him weekly what he desires. …I try so much…" (C7, son of a male patient admitted in the adult oncology ward).

ii. They carefully performed the tasks

The caregivers paid great attention to the details involved in successfully performing the required care tasks. They knew they had to be efficient in their role as informal caregivers. So, they endeavoured to learn what to do by observing fellow caregivers perform care tasks and by attentively listening to the health workers' instructions. This level of carefulness and detail could be seen in the way they prepared meals, bathed the patient and communicated with the health workers. To them, the benefit of being efficient in the provision of care was threefold: First, they would avoid mistakes like inappropriate dosages which could negatively affect their patients' health; Secondly, it would incentivise the health workers into providing better treatment and support to their patients; and thirdly, it would facilitate the development of a good relationship with the health workers. The accounts below offer valuable insight into how caregivers' learnt skills and meticulously approached care.

"You have to look after your patient and know how much medicine she needs to take at a particular time because you might tell her to take thrice while it is an overdose. Secondly, you need to communicate with the doctors to know what the patient requires." (D5, sister of a female patient admitted in the medical ward).
"I have learnt how people behave because I have been with many people and learnt how to treat my patient. For example, you can see someone with a wound or internal cancer and learn how to nurse yours." (C2, mother of a female patient admitted in the adult oncology ward).

The caregivers believed that having a good relationship with the health workers was particularly important because it would give them the platform to easily and confidently share their worries (about themselves or their patients) and receive the required support. Generally, caregivers are strongly desirous of opportunities to discuss their worries/concerns with health workers, and they feel better when their thoughts are taken seriously (32). However, the desire to meet expectations and have a good relationship with the health workers occasionally put some kind of pressure on the caregivers causing them to hurriedly perform tasks or make significant adjustments to their routine. This was echoed by these caregivers.

"I came to nurse to my husband. He is suffering from diabetes, kidney and lung failure. I am the one responsible for cooking food with moderate sugar and salt. … Washing him needs an hour because he cannot control his bowels and I have to look for a bucket of water, soap and cloth to clean him. I spend the entire hour cleaning him so that doctors don't reject me." (B4, wife of patient admitted in the emergency ward).
"When you give the doctors what they asked for, they help you." (B5, wife of a patient admitted in the emergency ward).

The quote below is from a caregiver who had to wake up earlier than usual to hurriedly get the patient ready for treatment. It is possible that such pressures may affect the quality of the care provided.

"When he is to get treatment at 7am, I wake up at 6am go the bathrooms, clean up and then change … and provide breakfast depending on the instructions of the doctor." (D5, sister of a female patient admitted in the medical ward).

b. Activities of daily living

i. Basic activities of daily living

In some cases, caregivers discussed their experience performing basic activities of daily living to their patients. These are activities that are important for one's everyday life and are meant to meet one's physical basic needs. The basic activities of living that the participants performed include feeding the patient, assisting with personal hygiene, ambulation, dressing and toileting.

These two caregivers were quoted giving an account of the activities they regularly performed:

"…She's been having trouble controlling her bowels at night. She had lost her side to worms. I would dress her in pampers and clean her… She has also been using a wheelchair because she could stand and felt dizzy." (B2, husband of a patient admitted in the medical ward).

"I wake up at 6am and…brush her teeth and then I lay the bed. … I care for her, give her food, … and make sure that I keep her body clean. I take her to the bathroom and bath her." (E2, mother of a patient admitted in the gynaecological cancer ward).

ii. Instrumental activities of daily living

Most caregivers supported patients with instrumental activities of daily living. These are activities must be done for one to live independently in the community, and they require a certain level of organizational skills. Some of the activities they performed include preparing meals, laundering clothes, administering medication, transporting the patient to hospital, providing companionship, covering medical expenses and communicating with the health workers. The selected quotes below outlines some of the instrumental activities of caregiving.

One caregiver narrated, *"I love cleaning for him, washing for him and answering his questions. … At times I get [buy] for him his medicine and take him to hospital when sick. … I love playing with him because he doesn't walk or play. I bought him toy cars and balls. He plays until he is tired, and I take him so that he can have some rest."* (A3, mother of a child admitted in the paediatric oncology ward).

And another also added, *"I learned how to be creative and cooperate with others. You could work together with your man to nurse [him] and look for money."* (A6, mother of a child admitted in the paediatric oncology ward).

c. Activities that require medical skills/training

The caregivers also performed some activities that would ideally have required a particular medical skill or prior training in healthcare. Some of these activities include administrating injectable medicine, cannula removal, counselling, monitoring administration of intravenous fluids and taking/measuring blood pressure. They learnt to perform these activities from health workers and fellow caregivers The following quotes show some of these activities.

"My patient suffers from diabetes, and he injects himself every day. I found myself injecting him with penicillin, yet I never got training. I also remove his cannula." (B6, daughter of a female patient admitted in the emergency ward).

"There is a lot to do. My patient has kidney failure, and her [blood] pressure and blood glucose were high. Sometimes she is on oxygen. I monitor her drip, examine the pressure, medication. I give her food and wash her. Everything concerns me. The doctors only treat her but I also buy the medicine. I counsel and guide her to strengthen her heart so that the disease doesn't take her quickly." (B2, husband of a patient admitted in the medical ward).

d. Activities that motivate the patient

Most caregivers were also involved in doing activities they thought would give hope and motivate those under their care. They used statements such as *"[so] his strength is regained," "build his patience," "so that he can be hopeful" and "so that he is not depressed" to describe what they wanted to achieve from these activities. These activities include joyfully answering the patient's questions, "leading him [the patient] in prayer"* [A4, father of a child admitted in the paediatric oncology ward], reading the bible, encouragement, laughing together, diverting the patient's attention, promising to meet the patient's needs/desires, regularly talking nicely to the patient, counselling, and always being near the patient. They used the following quotes to describe some of these activities.

"I give him any other form of care. I ask, talk to him and tell him what he wants to hear so that he gets peace. … I pray for my husband and comfort him saying father of twins, you will recover. I stay where he is and tell him that his suffering will pass." (B4, wife of a patient admitted in the emergency ward).

"The child asks whether he is going to die and I distract him. I also distract him when he can't eat. We laugh a lot which helps me build his patience." (A4, father of a child admitted in the paediatric oncology ward).
"I try to be hard working so that I provide all he needs on time. I also guide and counsel him so that he doesn't lose hope. I try to correct him, share experiences of those who got healed. I also pray for him and dedicate him so that he is relieved of stress. I also connect with neighbours so that they come in when I'm overloaded." (D6, grandson of a patient admitted in the medical ward).

e. Activities to support other caregivers

These caregivers also had time to support other caregivers with work. While in the hospital, they forged a social relationship with other caregivers which they found important throughout their time in hospital. Theys acknowledged that caring was sometimes overwhelming, necessitating them to seek support from caregivers of other patients. The support came in various forms including gifts, sharing, and loans. From their explanations, caregivers with more experience, time and resources supported those with less to learn new skills and to gain confidence and hope. This was clearly supported by these participant statements below.

"I also connect with neighbours [caregivers of other patients in the same ward] so that they come in when I'm overloaded." (D6, grandson of a patient admitted in the medical ward).

A participant whose patient had been re-admitted in the hospital had this to say: *"First, I love correcting others and showing them what to do as a consultant. I was here from April and I have seen patients like mine. Sometimes they lack money and I'm called to counsel them and tell them my experience. I also love getting advice from doctors and I also correct others. I ensure that the patient takes medicine, eats and drinks."* (B2, husband of a patient admitted in the medical ward).

"Nursing [caregiving] is important because you get to help each other in terms of money and working together." (A1, mother of a child admitted in the paediatric oncology ward).

4 Discussion

This study investigates the motivational elements that drive caregiving for people with chronic health issues. Our analysis identified six themes describing the caregivers' motivations to providing care including reciprocity, love, responsibility, availability, desire to improve the patient's health and desire to protect others from burden of care. Similarly, five themes describing caregivers' activities emerged and they are: approach to caregiving, activities of daily living, activities that require medical training, activities that motivate the patient and activities that support other informal caregivers. These findings highlight numerous critical elements Ugandan caregivers face with making a decision to care, such as reciprocity, love and affection, responsibility, and availability. These topics demonstrate the intricate interaction of personal values, past experiences, and current circumstances that influence caring behaviour. This study delves into these elements in depth, providing a deeper view of the caregiver experience. Informal caregivers' disclosure of the numerous activities they engage in while caring for their patients in the hospital gives a clearer picture of their unique approaches to daily living activities, as well as their role in inspiring and supporting both patients and other caregivers.

The participants in this study were predominantly immediate family members of the care recipients with a mean age of 37.1, a finding consistent with participant characteristics in other studies in SSA [11]. This study found that parents constituted a substantial proportion of caregivers, comprising nearly one-third (30.3%) of participants. While this figure exceeds the prevalence reported in many studies of caregivers [11, 13, 19, 33], it falls significantly below findings from research specifically focusing on caregivers of children with chronic illnesses [9, 34, 35]. This disparity arises from our study's inclusion of caregivers for both children and adults in the various focus group discussions. In Uganda, the responsibility of caring for sick children is primarily on their parents [36]. However, when parents are unable to fulfil this role due to factors such as illness, exhaustion resulting from extended periods of long-term care, poverty, family breakdown, employment demands, or death, caregiving responsibilities typically shift to other extended family members [36–38]. This informal arrangement, whether temporary or long-term, commonly occurs within the home setting and involves individuals known to the child or their parents [36]. This contextual understanding explains the presence of non-parental caregivers for some children in our study. Although it is important to understand the specific factors that differentiate the motivations of those caring for children from those caring for adults, such an exploration was beyond the scope of our study.

A common motivation that emerged from this study was related to rewards for past or future good deeds, a concept known as reciprocity. The participants in this study were strongly moved to care because of how good the care recipient had been to them in the past or how helpful they would be in the future. This finding is consistent with those from multiple studies from other countries as shown in a recent review that summarized evidence on reasons why people provided informal care [17]. A key challenge with expected reciprocity as a motivation for care is the fact that the caregiver does not have much control of it. First, the caregiver cannot determine how the patient will value the care being provided. For example, it is possible that an ICG may, in the near future become disappointed with the later actions of a patient who does see much value in the care being provided. Secondly, they cannot control unfortunate future events such as economic hardships and natural disasters that may disrupt their wishes and dreams. In this study however, the caregivers were not too specific and seemed to have wider view of the possible direct beneficiaries of the anticipated reciprocity. These beneficiaries included not only immediate family members, but also other members of the community who may not be known to them. This could be described as a form of altruism where an individual feels the responsibility to do good for the benefit of others. Just like in this study, altruism is an important characteristic found in people that spend a longer time providing care since it is associated with resilience and better caring experience [39, 40]. Certainly, caregiving can be complex, often having to deal with the delicate balance between hopeful expectations and the challenging realities. However, it should be noted that caregivers regularly reassess their expectations, understanding that caregiving can be unpredictable and often thankless. It may not be the patient to reciprocate the care in the future. It is a realization that human beings need one another, one meeting a need today may be the one in need tomorrow.

This study found responsibility a key motivating factor for caregiving. In particular, the participants were convinced that it was their responsibility to look after close family members. They also felt more suited for the role when the care recipient's condition was severe and in need of greater care or support. Perhaps, the rationale stems from a considerably long-standing good relationship amongst the family members putting them in a better position of understanding the patient's life and needs. These participants considered it their moral and filial duty to care for specific members of the family, a finding consistent with the outcomes of two previous studies that investigated motivation in different contexts. One of these studies was conducted among Iranian caregivers of people with dementia [16] and the other was among older caregivers of elderly Nigerians [22]. Similarly, some women in this study cared for their husbands and children because it was culturally expected of them to do so. Across many societies in sub-Saharan Africa, there is sharing of household responsibilities, with women playing a central caregiving role for the sick children and spouses [41]. Another aspect of responsibility found in this study was the delegation, as caregiving was either self-assigned or suggested by others. The caregivers had to adjust their routine roles to incorporate the additional responsibility. The assignment to the caregiving role, whether in a self-delegated situation or when delegated by others, was based on caregiver's availability, capability and preference as well as the trust other family members had in the caregiver.

Moreover, some participants found themselves in specific situations that made them uniquely suited to provide care. In all the cases, these caregivers were the only ones within the patient's network with the characteristics that propelled them to provide care. Through this study, it was evident that being the only available relative of the patient, ability to speak multiple languages including that used by health workers and having fewer commitments compared to other family members were the key factors triggering caregivers into care. To these participants, caring was inevitable, and it involved a degree of responsibility/duty to care. This finding agrees with those from Ezulike and colleagues' study [22] on motivation among older caregivers in Nigeria, in spite of the difference in the health condition of care recipients. That is chronic disease in our study, and old age in Ezulike et al.'s study [22]. Their study pointed out being more financially stable, being closer to the care recipient and having better caregiving skills as circumstances that motivated people to become caregivers. This contrast in the findings might be related to the difference in the ages and health condition of care recipients as the study in Nigeria was among older caregivers of elderly people. That is, older caregivers might have had more opportunities to provide care, thereby gaining caring skills and experience. Also, older caregivers have had more years and chances to build wealth compared to the caregivers in our study, whose average age is 37.1 years.

The caregivers enjoyed caring, enabling them to give their best while in the role. Their tasks ranged from supporting their patients with emotional and physical activities to supporting fellow caregivers with their activities. These activities were very demanding, necessitating caregivers to be more creative and flexible, for example by adjusting their sleep pattern and increasing the speed of performing the care tasks. This adjustment sometimes resulted from the pressure to meet health workers' expectations. These results are consistent with a study conducted in southwestern Uganda which also found that caregivers of people with stroke routinely woke up early and quickly performed care tasks prior to scheduled medical activities [19]. One surprising result distinct from other studies is that support included encouragement, loans, physical help and gifts that caregivers received from each other. A possible explanation for this might

be an outcome of the hospital arrangement where multiple patients with their corresponding caregivers are admitted to the same ward, thereby sharing the same room and facilities for a considerable period. When caregivers are within the same space, they interact, and their bonds of friendship grow as they share experiences and realise that some of the challenges, they face are similar. Such a connection could put caregivers in a situation where they are happy to seek and provide support to each other in various ways. This study brings out multiple benefits caregivers gained from associating with other caregivers within the same setting, including financial and emotional support as well as reduced care burden.

Another finding that is worth noting are the complex activities performed by caregivers that require some level of training and knowledge in health care. It is not uncommon to find studies with caregivers in SSA performing such tasks [42, 43]. It is already known that these caregivers find themselves in situations where they have got to quickly learn these skills while already in the role, helping fill the gap caused by the shortage of health workers in the hospital [42]. In the study to understand experiences of caregivers of cancer patients in hospice facilities in South Africa, it was found that the caregivers learnt how to perform some of these activities through trial and error [44]. However, this study provides additional dimensions on how the caregivers were able to perform these activities, particularly learning from the more experienced caregivers and through observing the way the health care workers also did similar tasks.

4.1 Strengths and limitations of the study

The strengths of this study were: First, purposive sampling which was used in this study resulted in the selection of participants with diverse characteristics such as age, disease condition and background. With discussions lasting between 50 to 75 min, the participants had reasonable time to share their unique experiences. Secondly, there were discussions among the authors throughout the stages of the study making the study more reliable because of the collaborative brainstorming and regular checks for personal biases, assumptions and interpretations. Also, the FGDs were conducted by a research assistant with experience in qualitative research in the presence of the first author. The credibility of the study was further strengthened by the fact that the first author held a review meeting with the research assistant at the end of each FGD.

On the other hand, this study had several limitations. First, the findings of this study were drawn from a relatively small number of participants drawn from the same setting sharing their personal experiences. More than half of the participants cared for people with a form of cancer. Participants for this study were drawn from MRRH, a hospital serving the population in greater southwestern region of Uganda. This would negatively affect the transferability of the findings. However, this was mitigated by selecting a hospital that serves not only the western region of Uganda, but also people from other countries neighbouring Uganda. Also, the participants were a diverse group of individuals that included caregivers of both young and older people with various chronic diseases. In addition, some selected participants could not participate in the study because they were required to be with their care recipient at the time of the interview. This means that important views that could potentially change picture of the findings were not captured by this study. Instead, the focus groups discussions were conducted to saturation, a point at which no new information is generated by additional FGD. This meant the research team collected as much information as possible from the those that participated in the study.

5 Conclusions

This study contributes additional literature to the understanding of informal caregivers in sub-Saharan Africa. The results indicate that multiple factors, both intrinsic and extrinsic, motivate people to become caregivers. In addition, this study did not find any negative reasons for becoming a caregiver. The consequences of having caregivers who are negatively motivated to provide care include provision of poor-quality care services and dissatisfaction. These findings will be of particular interest to policy makers and health workers who regularly interact with caregivers in the following ways. First, policy makers and health workers need to have a good understanding of each caregiver's motivation to care so that the patient treatment plan is developed without inadvertently including factors that discourage their (caregivers) efforts and willingness to care. Secondly, it is important to develop a framework that enables the hospital staff (health workers) to collaboratively work with caregivers. Such frameworks should include specific support to enable caregivers perform their activities better. Lastly, the Ugandan government needs to consider covering the full treatment cost of people with chronic diseases to reduce the financial burden on caregivers.

Acknowledgements We duly acknowledge the support of Ms. Mbivnjo Etheldreda Leinyuy throughout the writing of this manuscript. We also acknowledge the support of patients and their caregivers and staff of Mbarara Regional Referral Hospital in Uganda during the data collection. We also want to thank the research assistants that supported with data collection and translation of the interviews.

Author contributions The authors made substantial contributions to the manuscript in the following ways: EK, BB, MH, EJDW conceptualized and designed the study. EK collected the data, made the first draft, and all authors contributed to the interpretation of the data, as well as the revision of the manuscript. BB, MH, EJDW, EN and GZR supervised the study. EK and MNAK conducted and analysed the interviews. All authors reviewed and approved the manuscript.

Funding This qualitative study is one of the key outputs from the first author's PhD research/studies funded by the Centre for Doctoral Studies, King's College London. The sponsors or funders did not play any role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Data availability The data that support the findings of this study are not openly available but may be provided by the corresponding author upon reasonable request. All data that was collected was stored on secure servers hosted by King's College London.

Code availability Not applicable.

Declarations

Ethics approval and consent to participate This study received ethical approvals obtained from these three institutions: (i) King's College London (Reference Number: RESCM-23/24–33,295); (ii) Mbarara University of Science and Technology Research Ethics Committee (Application number: MUST-2023–785); and (iii) Uganda National Council for Science and Technology (Registration number: SS1846ES). In addition, the study team received a formal administrative clearance from Mbarara Regional Referral Hospital (MRRH). The study was carried out in accordance with guidelines listed in the ethics statements approved by the above ethics committees. Informed consent was obtained from all subjects to participate in the study. This was done after each caregiver had been given full information about the study, and being informed of the freedom to withdraw at any stage. In addition, the caregivers were assured of anonymity and confidentiality of their data/information, and no person identifiable information was included in the manuscript.

Competing interests The authors have no competing interests to declare that are relevant to the content of this article.

References

1. Gouda HN, Charlson F, Sorsdahl K, Ahmadzada S, Ferrari AJ, Erskine H, et al. Burden of non-communicable diseases in sub-Saharan Africa, 1990–2017: results from the Global Burden of Disease Study 2017. Lancet Glob Health. 2019;7(10):e1375–87. https://doi.org/10.1016/S2214-109X(19)30374-2.
2. Natukwatsa D, Wosu AC, Ndyomugyenyi DB, Waibi M, Kajungu D. An assessment of non-communicable disease mortality among adults in Eastern Uganda, 2010–2016, vol. 16. PLoS ONE: Public Library of Science; 2021.
3. Bunani N, Nakanwagi Kisakye A, Ssennyonjo A, Nuwaha F. Late diagnosis among patients with prostate cancer at the Uganda Cancer Institute: a retrospective cohort study. Afr Health Sci. 2024;24(3):147–55.
4. WHO. Noncommunicable diseases. 2018. https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases. (Accessed 31 Aug 2020)
5. Gupta N, Coates MM, Bekele A, Dupuy R, Fénelon DL, Gage AD, et al. Availability of equipment and medications for non-communicable diseases and injuries at public first-referral level hospitals: a cross-sectional analysis of service provision assessments in eight low-income countries. BMJ Open. 2020;10(10): e038842. https://doi.org/10.1136/bmjopen-2020-038842.
6. WHO. Assessing national capacity for the prevention and control of noncommunicable diseases: Report of the 2019 global survey. Geneva; 2020. https://iris.who.int/bitstream/handle/10665/331452/9789240002319-eng.pdf?sequence=1
7. Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: a reappraisal from population-based studies. Gerontologist. 2015;55(2):309–19.
8. Zarzycki M, Seddon D, Bei E, Dekel R, Morrison V. How culture shapes informal caregiver motivations: a meta-ethnographic review. Vol. 32, qualitative health research. SAGE Publications Inc.; 2022. p. 1574–89.
9. Dawson CP, Aryeetey GC, Agyemang SA, Mensah K, Addo R, Nonvignon J. Costs, burden and quality of life associated with informal caregiving for children with Lymphoma attending a tertiary hospital in Ghana. Int J Care Coord. 2020;23(4):165–72. https://doi.org/10.1177/2053434520981357.

10. Mthembu TG, Brown Z, Cupido A, Razack G, Wassung D. Family caregivers' perceptions and experiences regarding caring for older adults with chronic diseases. South Afr J Occupat Therapy. 2016;46(1):83–8.
11. Adejoh SO, Boele F, Akeju D, Dandadzi A, Nabirye E, Namisango E, et al. The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: a multi-country qualitative study. Palliat Med. 2021;35(3):552–62. https://doi.org/10.1177/0269216320974925.
12. Sadigh M, Nawagi F, Sadigh M. The economic and social impact of informal caregivers at Mulago national referral hospital. Ann Glob Health. 2016;82(5):866–74. https://doi.org/10.1016/j.aogh.2016.06.005.
13. Najjuka SM, Iradukunda A, Kaggwa MM, Sebbowa AN, Mirembe J, Ndyamuhaki K, et al. The caring experiences of family caregivers for patients with advanced cancer in Uganda: a qualitative study. PLoS ONE. 2023;18(10): e0293109.
14. Quinn C, Clare L, Woods RT. Balancing needs: the role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. Dementia. 2015;14(2):220–37.
15. Zarzycki M, Seddon D, Morrison V. Informal caregiver motivations, values, challenges and gains: a photovoice and interpretative phenomenological analysis of interrelationships. J Health Psychol. 2023;28(6):568–82.
16. Zahed S, Emami M, Bazargan-Hejazi S, Eslami AA, Barekatain M, Zamani-Alavijeh F. What motivates informal caregivers of people with dementia (PWD): a qualitative study. BMC Palliat Care. 2019;18(1):105.
17. Zarzycki M, Seddon D, Bei E, Morrison V. Why do they care? A qualitative systematic review and meta-synthesis of personal and relational motivations for providing informal care. Health Psychol Rev. 2023;17(2):344–76. https://doi.org/10.1080/17437199.2022.2058581.
18. Ng HY, Griva K, Lim HA, Tan JYS, Mahendran R. The burden of filial piety: a qualitative study on caregiving motivations amongst family caregivers of patients with cancer in Singapore. Psychol Health. 2016;31(11):1293–310. https://doi.org/10.1080/08870446.2016.1204450.
19. Eriksson GM, Kamwesiga JT, Guidetti S. The everyday life situation of caregivers to family members who have had a stroke and received the rehabilitation intervention F@ce in Uganda. Archiv Public Health. 2021;79(1):100. https://doi.org/10.1186/s13690-021-00618-z.
20. Shalom K, Annabel O. Ministry of Health, Uganda. 2024. Ministry calls for collective effort to bridge the care gap in handling Cancer and other Non-Communicable Diseases. https://www.health.go.ug/2024/02/12/ministry-calls-for-collective-effort-to-bridge-the-care-gap-in-handling-cancer-and-other-non-communicable-diseases-2/. (Accessed 19 Nov 2024)
21. Kusi G, Mensah ABB, Mensah KB, Dzomeku VM, Apiribu F, Duodu PA. Caregiving motivations and experiences among family caregivers of patients living with advanced breast cancer in Ghana. PLoS ONE. 2020;15(3):e0229683.
22. Ezulike JCD, Lu S, Chiu MYL. Aging and caring: exploring older adults' motivation for informal caregiving to other aging individuals in Nigeria. Innov Aging. 2024;8(4):igad140.
23. Lekganyane R. Motivational factors for caring for people living with HIV in South Africa: home-based caregivers' experiences. Soc Work. 2020;56(4):478–93.
24. Ferraris G, Zarzycki M, Gérain P, Elayan S, Morrison V, Sanderman R, et al. Does willingness to care fluctuate over time? A weekly diary study among informal caregivers. Psychol Health. 2023. https://doi.org/10.1080/08870446.2023.2249538.
25. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57. https://doi.org/10.1093/intqhc/mzm042.
26. Denzin NK, Lincoln YS. The Sage handbook of qualitative research. Sage; 2011.
27. Kajabwangu R, Bajunirwe F, Izudi J, Bazira J, Farjardo Y, Ssedyabane F, et al. Magnitude and trends in cervical cancer at Mbarara regional referral hospital in South Western Uganda: retrospective analysis of data from 2017–2022 Peters ES, editor. PLOS Global Public Health. 2024;4(1):e0002848. https://doi.org/10.1371/journal.pgph.0002848.
28. Nabulo H, Gottfredsdottir H, Joseph N, Kaye DK. Experiences of referral with an obstetric emergency: voices of women admitted at Mbarara regional referral hospital, South Western Uganda. BMC Pregn Childbirth. 2023;23(1):498. https://doi.org/10.1186/s12884-023-05795-z.
29. Krueger RA, Casey MA. Participants in a Focus Group. In: focus groups: a practical guide for applied research. 5th edition. Thousand Oaks, California: SAGE; 2014. p. 198–9.
30. Hennink MM, Kaiser BN, Weber MB. What influences saturation? Estimating sample sizes in focus group research. Qual Health Res. 2019;29(10):1483–96.
31. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101. https://doi.org/10.1191/1478088706qp063oa.
32. Strang S, Fährn J, Strang P, Ronstad A, Danielsson L. Support to informal caregivers of patients with severe chronic obstructive pulmonary disease: a qualitative study of caregivers' and professionals' experiences in Swedish hospitals. BMJ Open. 2019;9(8): e028720. https://doi.org/10.1136/bmjopen-2018-028720.
33. Bessa Y, Moore A, Amey F. Caring for a loved one with cancer: it is my job. J Psychosoc Oncol. 2012;30(2):217–38. https://doi.org/10.1080/07347332.2011.644397.
34. Dhada B, Blackbeard D. Caregivers of children with diabetes mellitus: challenges of caring for and perceptions of consultations in a South African public sector context. South Afr Family Pract. 2019;61(4):117–35. https://doi.org/10.1080/20786190.2019.1606491.
35. Duru CO, Okpokowuruk FS, Adesina AD, Worgu GO, Adeniji FO, Chinawa JM, et al. Caring for children with congenital heart diseases: economic burden of pre-surgical management on nigerian families. West Afr J Med. 2021;38(2):144–51.
36. Simone D, Jenny P, Amiya B, Rehema N, Joan Ritar K, Brian Junior M, et al. Young people's experiences of informal kinship care in Luwero Uganda. Child Youth Serv Rev. 2024;159:107527.
37. Owino GE, Yigezu M. The role of fathers and care-giving arrangements in informal settlements in Kenya and Ethiopia. Front Public Health. 2023;11:1099568.
38. Bakaraki MP, Dourbois T, Kosiva A. Attachment theory across cultures: an examination of cross-cultural perspectives and alloparenting practices (Mini-Review). Brazilian J Sci. 2024;3(8):36–42.
39. Hussain M, Usman A, Tariq J, Ahmed Lak T, Seemi Malik A, Nadeem MA. Spirituality, altruism, and resilience of older patient's informal caregivers: investigating the moderating effect of the context of care in Pakistan. J Relig Spiritual Aging. 2023. https://doi.org/10.1080/15528030.2023.2251916.

40. Brown RM, Brown SL. Informal caregiving: a reappraisal of effects on caregivers. Soc Issues Policy Rev. 2014;8(1):74–102. https://doi.org/10.1111/sipr.12002.
41. Githaiga JN. Culture, role conflict and caregiver stress: the lived experiences of family cancer caregivers in Nairobi. J Health Psychol. 2017;22(12):1591–602. https://doi.org/10.1177/1359105316631199.
42. Gertrude N, Kawuma R, Nalukenge W, Kamacooko O, Yperzeele L, Cras P, et al. Caring for a stroke patient: the burden and experiences of primary caregivers in Uganda–a qualitative study. Nurs Open. 2019;6(4):1551–8. https://doi.org/10.1002/nop2.356.
43. Kisangala E, Mbivnjo EL, Webb EJD, Barrett B, Rukundo GZ, Namisango E, et al. Health and economic impact of caregiving on informal caregivers of people with chronic diseases in sub-Saharan Africa: a systematic review. Batura N, editor. PLOS Global Public Health. 2024;4(12):e0004061. https://doi.org/10.1371/journal.pgph.0004061.
44. Ketlogetswe TS, Jansen Van Rensburg JJ, Maree JE. The experiences of caregivers of patients living with cancer admitted to a hospice in South Africa. Int J Palliat Nurs. 2022;28(4):164–71. https://doi.org/10.12968/ijpn.2022.28.4.164.