Research

The needs, challenges, and burden experienced by informal caregivers in Uganda: a scoping review

A. Komuhangi¹ · C. Jenkins² · F. Nakaggwa¹ · P. Agaba³ · F. Githinji¹ · A. Ewuzie² · J. Apio¹ · A. Kawooya Namwanje¹ · O. Santin² · M. MacDonald² · C. M. McShane² · C. Misinde³ · L. Montgomery² · R. Clarke Nanyonga¹

Received: 18 November 2021 / Accepted: 27 December 2021

Published online: 10 January 2022

© The Author(s) 2022 **OPEN**

Abstract

Background The impact of informal caregiving is increasingly recognised as an important but often particularly neglected area of research in low and middle income countries. It is important to understand not only the effect of care on patient outcomes, but also the impact of caring on caregivers' health and wellbeing.

Methods Guided by the Arksey and O'Malley (Res Methodol 8:19–32, 2005) framework, this scoping review sought to collate and chart existing research on the needs, burdens and challenges experienced by caregivers in Uganda.

Results The results of this review indicate that research focusing on the needs of caregivers for individuals with communicable disease, particularly HIV, has been well developed in Uganda, however, there is a lack of research on caregiving related to non-communicable diseases. Research has been dominated by small qualitative studies that are informative for understanding roles, burdens and contextually-specific aspects of care, but there is a need for larger studies that develop and test interventions designed to support the needs of caregivers.

Conclusions Recurrent themes identified within this review, such as challenges in providing physical support and accessing treatment services, financial costs of care, psychological and mental health impacts and the experience of stigma, should help to inform well targeted and contextually-appropriate future research and interventions.

Keywords Uganda · NCDs · Carers · Ceregiving · Scoping review

Abbreviations

AIDS	Acquired immune deficiency syndrome
HIV	Human immunodeficiency virus
NCDs	Noncommunicable diseases
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QoL	Quality of Life

1 Introduction

Globally, caregivers experience high levels of burden. Challenges often relate to both the activity of care and the impact caring has on their own health [1, 2]. Research, however, remains limited on how care is experienced in Low and Middle Income Countries (LMICs) [3], and no review of research on the needs of caregivers has been undertaken

✉ C. Jenkins, c.jenkins@qub.ac.uk | ¹Clarke International University, Kampala, Uganda. ²Queen's University Belfast, Belfast, UK. ³Makerere University, Kampala, Uganda.

in Uganda. This scoping review sought to collate and chart existing research on the needs, burdens and challenges experienced by caregivers in Uganda and sought to identify common themes and research gaps that could inform future research and interventions in this important area.

The health system in Uganda continues to experience challenges in service delivery, with patients often experiencing multiple barriers to accessing services. These include medication supplies, distance, staff shortages, and costs [4]. An estimated 35% of deaths in Uganda are attributed to non-communicable diseases [5] with this number expected to continue to rise in the future. Given the increased burden of non-communicable diseases (NCDs) [6, 7] and that Uganda is experiencing the beginning of an epidemiological transition, we also discuss whether needs related to caring for someone with an NCD in Uganda differ from those of caring for someone with communicable disease. The findings from this research may also be of relevance to other resource-constrained settings.

2 Methods

The scoping review was conducted according to the five-stage process described by Arskey and O'Malley [8]: identifying a research question; searching for relevant studies; selecting studies; charting the data; and collating, summarizing and presenting the results. To identify relevant studies, we searched the Titles and Abstracts of articles indexed in MEDLINE, Web of Science, PsychInfo, African Journals Online, and Social Policy and Practice using the keywords 'Carers' OR 'Caregivers' AND 'Uganda'. Additional searches for grey literature from NGO (Non-Governmental Organisations) and Government reports and policies, were undertaken. The search was conducted from database inception through to 22 June 2020.

Inclusion criteria included studies and documents related to the needs, challenges and burden of care in Uganda; or interventions, policies and projects to address the needs, challenges and burden of caregivers in Uganda. All health condition types were included in the review. There were no language restrictions applied. Exclusion criteria included studies on needs of Ugandan caregivers who are migrants living in other countries; studies in which outcomes for caregivers were not described, measured or evaluated; and studies in which a specified health condition was not mentioned [9]. Abstracts, poster presentations, study protocols and studies only presenting aggregated data from multi-country studies were excluded. Studies solely on the roles of caregivers without discussion of needs and challenges were excluded [10–12] as were studies on care in the context of HIV but not explicitly caring for someone with HIV [13, 14] (e.g. grandparents caring for children orphaned by HIV), and studies focusing solely on challenges regarding disclosure of HIV status [15].

To select studies for inclusion, two researchers independently screened each Title and Abstract against the eligibility criteria and collaboratively resolved any conflicts with a third member of the research team. Full texts of accepted articles were then screened against the inclusion criteria. Data on study methods, study participants, region, and outcomes of each study were extracted and verified by a second reviewer. Data was charted, based on health condition, region and methods used, before a more detailed examination of key outcomes for caregivers. Screening and data extraction was managed using Covidence software. Thematic categories were inductively identified regarding different challenges and needs and were validated and agreed by the entire research team [16]. This process was guided by Green and Thorogood and involved collaborative familiarization, identification, coding, organising, and validating of all the data extracted from each study [15].

3 Results

A total of 40 articles were included in our review (see Table 1). Of these, 38 were sourced from international databases and 2 from the grey literature (see Fig. 1). Articles disproportionately focused on the needs of caring for someone with HIV ($n = 16$); with other articles exploring care related to cancer ($n = 2$); nodding syndrome ($n = 4$); malaria ($n = 3$); depression ($n = 1$); severe mental illness e.g. schizophrenia ($n = 2$); dementia ($n = 2$); Ebola ($n = 2$); sickle cell disease ($n = 1$); stroke ($n = 1$); spina bifida ($n = 1$); palliative care ($n = 1$); and disability (general) ($n = 1$). Four articles looked at a combination of health conditions; for example, cancer and HIV.

Methodologically, most of the studies completed were either qualitative designs ($n = 26$) or cross-sectional survey designs ($n = 8$). Remaining design types included mixed/multi method designs ($n = 1$); cluster randomised trials ($n = 2$); non-randomised trials ($n = 1$); rapid evaluation design ($n = 1$); and case study design ($n = 1$). Studies were spread evenly

Table 1 Included studies in the review

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Ainamani, Alele, Rukundo, Maling, Wakida, Obua, Tsai	2020	Caregiving burden and mental health problems among family caregivers of people with dementia in rural Uganda	To profile the burden of care and its association with symptoms of depression and anxiety among informal caregivers of people living with dementia in rural southwestern Uganda	Cross-sectional study using structured interviews, assessed using the depression and anxiety subscales of the 42-item Depression Anxiety and Stress Scales (DASS); caregiving burden was assessed using the 22-item Zarit Burden Interview (ZBI) and the Bristol Activities of Daily Living Scale (BADLS) assessed functional impairment	Dementia	Family caregivers	232	Rukiga and Rubanda districts of Southwestern Uganda	47% of caregivers had Zarit Burden Interview scores > 60 indicating severe caregiving burden. A statistically significant positive association was demonstrated between caregiving burden and symptoms of depression [b = 0.42; 95% confidence interval (CI) 0.34–0.49] and anxiety (b = 0.37; 95% CI 0.30–0.45)
Bannink, Idro, van Hove	2016	Parental stress and support of parents of children with spina bifida in Uganda	To explore perceived stress and support of parents of children with spina bifida living in Uganda and examine the factors that influence it	Explorative mixed-study methods. Quantitative instruments included Vineland Adaptive Behaviour Scales (VABS) Daily Living Skills and Parental Stress Index Short Form (PSI/SF) Qualitative methods included semi-structured interviews (with all parents) and focus groups	Spina bifida	Parents	134	Gulu, Kampala, Mbale, Mbarara and Lira	High levels of stress observed across both scales with more than half of the parents (52.7%) scoring above the 90th percentile on total stress. Significant negative correlations with parent stress index outcomes included the child's ability to walk, continence and use of clean intermittent catheterisation and bowel management, receiving rehabilitative care, household income, region of residence and having support from another parent in taking care of the child. In qualitative interviews, incontinence was referenced as a significant and complex factor in managing and caring. Catheterisation was a common practice but was a challenge if e.g. a child attended school and was away from their carer

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Bass, Opoka, Familiar, Nakasujja, Sikor-ski, Awadu, Givon, Shohet, Murray, Augustinavicius, Mendelson, Bolvin	2017	Randomized controlled trial of caregiver training for HIV-infected child neurode-velopment and caregiver well being	To assess whether a mediational intervention for sensitizing caregivers (MISC) program trained caregivers on fostering daily interactions with young children could enhance neurodevelopment of rural Ugandan HIV-infected children and improve mental health outcomes of their caregivers	Cluster randomised trial	HIV	Women and child dyads	106 children (90%) and 100 caregivers (85%) at follow-up assessment (24 months after baseline)	18 subcounties in Tororo and Busia districts	Carers experienced improved mental health from the MISC intervention. MISC caregivers reported near significant fewer depression symptoms at the maintenance assessment (adjusted mean difference = -0.17, 95% CI 0.34, 0.02), as well as significantly less functional impairment postprogram (adjusted mean difference = -0.15, 95% CI 0.28, 0.01)
Bolvin, Bangirana, Nakasujja, Page, Shohet, Givon, Bass, Opoka, Klein	2013	A year-long caregiver training program improves cognition in preschool Ugandan children with human immunodeficiency virus	To evaluate whether mediational intervention for sensitizing caregivers (MISC) improved the emotional well-being of the caregivers compared with controls	Cluster randomised trial	HIV	Women and child dyads	120 dyads	Kayunga town and surrounding districts, Uganda (80 km northeast of Kampala)	Carers receiving MISC intervention were significantly less depressed irrespective of caregiver category. Differences of 12 months did not reach statistical significance but were still less for caregivers in the intervention group. MISC and Control caregivers did not differ on the HSL-25 anxiety measure at 12 months
Buchmann	2015	These nodding people: Experiences of having a child with nodding syndrome in postconflict Northern Uganda	To examine the impact that nodding syndrome has had on affected children, their families, and communities	Qualitative study consisting of semi-structured interviews, focus groups and participant observations	Nodding syndrome	Family caregivers	33 people were interviewed in the wider study. 10 were informal caregivers (mothers (n = 3), fathers (n = 3), older brothers (n = 2), older sister (n = 1) and an aunt (n = 1))	Pader and Kitgum, Northern Uganda	Themes included isolation of carers and families, reduced economic activities resulting in poverty and food insecurity affecting the whole family, emotional challenges and lack of preparedness for caring. Stigmatisation lead to reduced wider social support. Relationships breakdown, divorce, and child abandonment from stress of caring on other relationships

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Emanuel, Gabrielle A. Emanuel, Eva B. Reitschuler, Anthony J. Lee, Ekira Kikule, Anne Merriman, Linda L Emanuel	2008	Challenges faced by informal caregivers of hospice patients in Uganda	To understand chal- lenges experi- enced by carers at Hospice	Face-to-face survey interviewing	End-of-life care	Caregivers	62	Hospice, Kampala	Frequent needs reported by carers included financial assistance (89%), afford- able medications (77%), opportunities for income (52%), and caregiver training (44%). Caring for a terminally ill family member pressured carers to stop attending school (51%), marry (32%), take embarrassing jobs (47%), If a local day care centre existed, 94% of respond- ents stated they would use it; 80% reported they would consider hiring a caregiver. Barriers to hiring a caregiver included costs (98%) and discomfort with a nonrela- tive caregiver (42%). 96% of participants reported inter- est in becoming a trained and certified caregiver
Gertrude, Kawuma, Nalukenge, Kama- cook, Yperzele, Cras, Ddumba, Newton, Seeley	2019	Caring for a stroke patient: The burden and experiences of primary caregivers in Uganda—A qualitative study	To investigate the burden and experi- ences of caregivers looking after stroke patients in Uganda	Descriptive cross- sectional study. Face-to-face indepth interviews following an open- ended interview guide. STROBE guidelines fol- lowed for report- ing findings	Stroke	Primary caregivers	25	Nsambya Hospital, Kampala	Carers described having to fulfil new responsibilities with increased workload and significant changes to lifestyle. Carers described having to learn new skills and experiencing fatigue and body pain. Carers described loss of income and limited resources. Some borrowed money to pay for treatment and risk of having to abandon treatment. Support networks and spiritual beliefs provided support. Carers described emotional challenges around care, bereavement and grief

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Grant, Brown, Leng, Bettega, Murray	2011	Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies	To describe patient, family and local community perspectives on three palliative care projects	Rapid evaluation using interviews with key informants, observations of clinical encounters and the local health and social care context, and routine data from local reports and statistics	Cancer & HIV	Patients with advanced illness, family carers, staff, volunteers, and community leaders and observed clinical care patients	37 people in total (Ugandan part of study) which includes 8 patients based at home; 7 caregivers; 3 volunteers (community care givers); 6 individual interviews and 10 staff focus groups; 3 community leaders	Masaka	All three programmes struggled to embed palliative care within the community. Community dependence on traditional healers. In Uganda, palliative care demonstrated integration within overall HIV programmes and the health services. Programmes were reported to be successful because they integrated symptom control with practical and emotional care, education, and spiritual care
Hartley, Ojwang, Baguwemu, Ddamulira and Chavuta	2005	How do carers of disabled children cope?: the Ugandan perspective	To assess the beliefs and practices relating to children with disabilities in three districts of Uganda and understand coping strategies of families and carers	A qualitative phenomenological design. Two methods of data collection were used: (1) key informant semi-structured interviews and (2) non-participatory observation schedules	Disability (visual, hearing, physical, mental and multiple)	Parents, siblings and guardian caregivers	51	Mpigi, Iganga and Tororo	Four main themes identified in relation to challenges faced by families: the burden of care (resources, decision making, need for family support, burden falling upon women—mothers and grandmothers), poverty (lack of money for treatment etc.), the impact of the child's disability (stress, isolation, lack of time, fatigue) and communication problems (difficulties communicating with children and understanding their problems). Coping strategies included seeking a cure ('Western' and traditional medicine); seeking social support, beliefs in God's will and acceptance

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Kassam, Collins, Sekiwunga	2016	Assets and challenges facing caregivers when managing malaria in young children in rural Uganda	To estimate caregivers' assets and challenges during an acute episode of malaria	Cross-sectional, household survey. 160 questions collected information on the seven educational and environmental factors, household identification, child's disease presentation, demographics/socio-economic status	Malaria	Caregivers	424	Butaleja District, rural eastern Uganda	Caregivers scored highest on knowledge of malaria and correct management of an acute episode (65% and 48%). 56% reported problems in accessing anti-malarial treatment and 74% in accessing medical advice. Caregivers demonstrating greater assets and fewer challenges correlated with children receiving appropriate antimalarial treatment
Kassam, Sekiwunga, MacLeod, Tembe, Liow	2016	Patterns of treatment-seeking behaviors among caregivers of febrile young children: a Ugandan multiple case study	To examine treatment-seeking patterns and to describe experiences of caregivers while managing a fever episode (presumed to be malaria by the caregiver) in their child of 5 years and under	Qualitative exploratory study. Multiple case study methodology consisting of largely unstructured interviews	Malaria	Caregivers	8	Butaleja District-rural eastern Uganda	Caregivers generally took a pluralistic approach to treatment and used multiple different treatment sources including home management. Advice from families and social support circles influenced decision on treatment and treatment sources. Caregivers experienced challenges in seeking care at health facilities including cost of treatment, absentee health staff, lack of available medicines, incivility of healthcare staff. Access to health facilities (on foot) was a significant concern
Katende, Nakimera	2017	Prevalence and correlates of anxiety and depression among family carers of cancer patients in a cancer care and treatment facility in Uganda: a cross sectional study	To determine the prevalence of anxiety and depression and related factors associated with abnormal levels of anxiety and depression among family carers of cancer patients in a cancer care and treatment facility in Uganda	Cross sectional study. Hospital Anxiety and Depression Scale (HADS) standardized tool	Cancer	Family caregivers	119	Uganda Cancer Institute, Kampala	Anxiety and depression is reported as high (45% v. 26%) among carers; Abnormal levels of anxiety (OR 0.27, 95% CI, p=0.01) and depression (OR 0.37, 95% CI, p=0.05) were significantly associated with being a family carer. Male carers reported highest anxiety levels compared to female participants (46.2% v.43.8%). Male carers reported high levels of depression in comparison to female carers (30.8% v. 21.3%)

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Kipp, Tindyebwa, Karamagi, Rubaale	2007	How much should we expect? Family caregiving of AIDS patients in rural Uganda	To describe the care experiences (burden, risks and supports) of family caregivers people living with AIDS	A cross-sectional, exploratory, quantitative study utilising a structured interview-administered questionnaire. The Gubermann, Keefe, Fancey, Nahmias, and Barylak (2001) tool was used to assess family caregiver burden	HIV	Family caregivers	120	Kabarole and Kamwenge Districts (Kaihura, Kibiito, Kahunge, and Kataraka)	Carers highlighted needing support in providing nursing care, support with transport, and requirement financial support. Carers described the need for respite and for social support, as well as for training in how to provide care. 28% described having no support in an emergency situation. 56% described caring as a full time job, and 56% also described medications being unaffordable. Carers described experiencing mental health problems, isolation, depression, and poor physical health. Care was almost exclusively provided by women, with girls being taken out of school to support care
K'ipp, Bajenja, Karamagi, Tindyebwa	2007	AIDS-related stigma: perceptions of family caregivers and health volunteers in western Uganda	To assess challenges for family carers of people living with HIV/AIDS, specifically related to AIDS-related stigma	Qualitative study designed utilising one-to-one interviews and focus groups	HIV	Family caregivers and health volunteers of a home-based care program	16 family caregivers and 18 health volunteers	Four sub-counties in Kabarole and Kamwenge districts	AIDS stigma was reported as still existing, but also in decline. Carers reported a positive change in attitudes towards patients and their families. This was associated with widespread experience of HIV in the community. Stigma still exists in many households and it was reported that this may lead to people avoiding accessing services. Health volunteers revealed fears that HIV positive patients may commit suicide

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Kipp, Tindyebwa, Rubaale, Karamagi, Bajenja	2007	Family caregivers in rural Uganda: the hidden reality	To understand caregiver burden associated with HIV/AIDS care in rural districts in western Uganda and determine which coping strategies are used by family caregivers	Qualitative study design	HIV	Family caregivers	16	Kibito and Kataraka subcounties in the Kabarole district, Kahunge subcounty in the Kamwenge district, and Kaihura subcounty in the Kyenjojo district in Western Uganda	Caregivers reported that their "productivity and income, emotional well-being, and physical health" was impacted by their caring roles. Children were described as having to fulfil more household tasks leading to reduced school participation. Carers reported not having knowledge on skills to provide care and that they had limited support from families, friends, Government of NGOs. Recommendations that men and faith-based organisations could increase their roles in caregiving
Kizza, Mulira	2020	Determinants of quality of life among family caregivers of adult cancer patients in a resource-limited setting	To explore the determinants of QoL among family caregivers of adult cancer patients receiving care from the two main cancer centres in Uganda	Cross-sectional quantitative survey, including the Katz Index of Independence in Activities of Daily Living, the knowledge subscale of Family Pain Questionnaire, the modified Chronic Pain Self-efficacy Scale and the Carer Quality of Life-Index-Cancer. General health was rated on a single item and physical health using the four items of the Caregiver Reaction Assessment scale	Cancer	Family caregivers	284	Uganda Cancer Institute and Hospice Africa Uganda, Kimpala	Caregiver burdens included related to financial concerns, disruption of care. 46.8% of carers reported low Quality of Life. Burden was significantly associated with level of education, impact of care on physical health, time (hours) of caregiving and knowledge about cancer pain management

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Matua, Wal	2015	Living Under the Constant Threat of Ebola: A Phenomenological Study of Survivors and Family Caregivers During an Ebola Outbreak	Describing the lived experiences of survivors and their family caregivers after an Ebola outbreak in Kibale District, Western Uganda	Phenomenological Study Design	Ebola	Adult survivors and their family caregivers	12 (5 survivors and 7 family caregivers)	Kibale, Western Uganda	Both survivors and caregivers described themes of lingering trauma. Participants described fear, ostracism, and stigmatization; an annihilation of actualities and possibilities; and emotions and physical manifestations such as anxiety, worry, shock, loneliness, trembling, shivering, and "heart pain." The Ebola experience was described as inescapable and frightening. Stigma and antisocial behaviour from peers was experienced due to experience of Ebola. Recommendations include developing and supporting resilience within the population groups
Mburu, G. Danielle Oxenham, Ian Hodgson, Alice Nakiyemba, Janet Seeley, and Alvaro Bermejo	2013	Community Systems Strengthening for HIV Care: Experiences From Uganda	To identify community system elements that facilitate care provision in for people living with HIV	A qualitative study design using focus group discussions and interviews	HIV	People living with HIV, family members of people living with HIV, and HIV service delivery stakeholders	65 respondents participated in the study including people living with HIV who were providing palliative care to other people living with HIV (n = 30)	Mbale and Jinja districts of Uganda	Community institutions are important in palliative care, and may offer opportunities to alleviate stresses and burdens on many aspects of palliative care. Community systems may support personal, livelihood, nutritional and bereavement aspects of care

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Mugisha, Scholten, Owilla, Naidoo, Seeley, Chatterji, Kowal, Boerma	2013	Caregiving responsibilities and burden among older people by HIV status and other determinants in Uganda	To assess factors affecting the association of caregiving responsibilities and perceived caregiving burden on the one hand with the health status and well-being of older people, with special attention to HIV status	Interview based-study. Interviews conducted at home using "multi-country Study on global AGEing and adult health (SAGE) standard tools"	HIV	Caregivers	510	Kalungu district, south-western Uganda, and Wakiso district, Entebbe	80% of women and 66% of men were caretaker of at least one person, mostly as the primary caregiver of children. Participants described a lack of energy to fulfil caregiving responsibilities, however 96% also described the role giving them purpose and a sense of accomplishment. Need for focus to provide intensive assistance to poorer, older caregivers who leave in single-adult households. Most of these caregivers will be women with large caregiving responsibilities. Carers who were also HIV positive receive more financial assistance than people who are not HIV positive
Muhwezi, Okello, Neema Musisi	2008	Caregivers' experiences with major depression concealed by physical illness in patients recruited from central Ugandan Primary Health Care Centers	To understand experiences of depression experienced alongside physical illness	Qualitative in-depth interviews	Depression	Caregivers	29	Central Uganda	Caregivers often did not use the description of "depression" but enumerated its features. Depression is stigmatised, which undermined caregiving. Caregivers described the role of providing care as expensive and burdensome

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Murray, Familiar, Nakasujja, Winch, Gallo, Opoka, Caesar, Boivin, Bass	2017	Caregiver mental health and HIV-infected child wellness: perspectives from Ugandan caregivers	To understand caregiver mental health and HIV-infected child wellness and to inform support services for families living with HIV	Semi structured interviews	HIV	Parents and guardians	16	Tororo and Busia district in Eastern Uganda	Participants described emotional effects and stress of providing care. Child sickness placed additional burden on the caregiver and depleted household resources. Care was described as complex, involving multiple health care providers as well as procuring and appropriately administering medicine or home remedies. Financial, logistics and transport challenges were described. Seeking care kept women from earning money and growing food, as "ogoye gima katho malo" (nothing can continue) when a child is sick. Caregivers had to navigate these challenges while dealing with the stress and emotion associated with seeing their child ill, such as crying, kumo (sorrow), pain in the heart
Mutamba, Kohrt, Okello, Nakigudde, Opar, Musisi, Bazeyo, de Jong	2018	Contextualization of psychological treatments for government health systems in low-resource settings: group interpersonal psychotherapy for caregivers of children with nodding syndrome in Uganda	To guide contextualization of psychological treatment in the Uganda public health system for caregivers of children affected by nodding syndrome	A three-step process involved reviewing health services available for nodding syndrome-affected families and current evidence for psychological treatments, qualitative formative research, and analysis and documentation of implementation activities. A qualitative study of caregiver burden for children with NS including focus group discussions (FGD) and in-depth interviews (IDI) was conducted	Nodding syndrome	Members of affected communities, health care workers, therapists, local government leaders, and Ministry of Health officials	73	Pader district, Northern Uganda	Carers described " (1) agony resulting from community stigma and fear; (2) cognitive, emotional, and behavioral disturbances; and (3) physical and financial constraints. "

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Mutamba, Kane, de Jong, Okello, Musisi, Kohrt	2018	Psychological treat- ments delivered by community health workers in low-resource gov- ernment health systems: effective- ness of group interpersonal psychotherapy for caregivers of chil- dren affected by nodding syndrome in Uganda	To evaluate the effec- tiveness of a group interpersonal psy- chotherapy (IPT-G) intervention, when delivered by lay community health workers (LCHWs) in a low-resource government health system in Uganda in order to reduce depression among caregivers of chil- dren with nodding syndrome	A non-randomized trial design was used. Caregivers in the interven- tion villages received 12 weekly 90–120 min IPT-G sessions in addi- tion to usual care for NS	Nodding syndrome	Caregivers	142	Northern Uganda	Caregivers who received IPT-G had a significantly greater reduction in the risk of depression from baseline to 1 month [risk ratio (RR) 0.25, 95% confidence interval (CI) 0.10–0.62] and 6 months (RR 0.33; 95% CI 0.11–0.95) post-intervention com- pared with caregivers who received treatment as- usual. Children of caregivers who received IPT-G had significantly greater reduc- tion in depression scores than children of treatment as usual caregivers at 1 month (Cohen's $d = 0.57$, $p = 0.01$) and 6 months (Cohen's $d = 0.54$, $p = 0.03$). Significant effects were also observed for psychological distress, stigma and social support among caregivers
Nakigudde, Mutamba, Bazeyo, Musisi, James	2016	An exploration of caregiver burden for children with nodding syndrome (luc luc) in North- ern Uganda	To explore chal- lenges in the care giving experiences of caregivers of children with nod- ding syndrome, with a focus on four dimensions (symptom-specific, social, emotional and financial bur- den) of caregiver burden	Qualitative exploratory study consisting of focus groups and in- depth interviews	Nodding syndrome	Caregivers	54	Pader district, Northern Uganda	Key emerging themes included child safety con- cerns (children wandering off at night, and a lack of concern and understand- ing from neighbours), burnout (overwhelmed and without support), social isolation (stigma leading to rejection), and rejection, homicidal ideation (death of the child), emotional and domestic challenges/ abuses (sadness, substance abuse, domestic violence, poor sleep and weight loss) and physical and financial constraints (lack of resources, decisions over resources/treatment)

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Nasuuna, Kigozi, Muwanguzi, Babirye, Kiwala, Muganzi, Sewankambo, Nakanjako	2019	Challenges faced by caregivers of virally non-suppressed children on the intensive adherence counselling program in Uganda: a qualitative study	To understand challenges and support required by caregivers of ART-treated children	Explorative qualitative study	HIV	Caregivers	37	Kampala and Hoima	Themes related to support that caregivers needed included (a) health system reforms (clinic appointments outside school hours, improve ART availability and reduce stock-outs, and improve quality of counselling), (b) psychosocial support (for example, support with disclosure of HIV status to children and their families, and more frequent peer support groups and parenting classes) and (c) economic empowerment (training in vocational skills, school fees support and opportunities to initiate income generating activities). Participants described psychological challenges that included maternal guilt for passing on HIV to the children, life uncertainty for the children, lack of family support and fear of abandonment of the caregiver
Ndikuno, Namutebi, Kuteesa, Mukunya, Olwit	2016	Quality of life of caregivers of patients diagnosed with severe mental illness at the national referral hospitals in Uganda	The aim of the study was to assess the QoL of caregivers for patients diagnosed with severe mental illness attending the National Referral Hospitals in Uganda	Cross-sectional study. Survey based WHOQOL-BREF	Severe Mental Illness including Schizophrenia, Bipolar Affective disorder and Major Depressive disorder	Caregivers	300	Mulago Hospital and Butabika Hospital, Kampala	57.3% of the caregivers had a poor QoL, associated significantly with the environment (Adjusted coefficient = 0.016, 95% CI 0.009–0.023), caregiver satisfaction with their health (Adjusted coefficient = 0.405, 95% CI 0.33–0.487), psychological wellbeing (Adjusted coefficient = 0.007, 95% CI 0.0002–0.013), and education level (Adjusted coefficient = 0.148, 95% CI 0.072–0.225. Quality of Life was impacted by increased burden on responsibilities and occupation of their time, energy and attention, high levels of stress and not having appropriate coping mechanisms

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Olwit, Mugaba, Osinga, Nabye	2018	Existence, triggers, and coping with chronic sorrow: a qualitative study of caretakers of children with sickle cell disease in a National Referral Hospital in Kampala, Uganda	To explore the existence of chronic sorrow, triggers and coping with grief related feelings among caretakers of children with sickle cell disease	Descriptive qualitative study and in-depth interviews	Sickle Cell Disease	Adult caretakers of children diagnosed with SCD	12	Sickle Cell Clinic of Mulago National Referral Hospital, Kampala	75% experienced chronic sorrow. Grief was reported as triggered by health worker related, disease related and support related factors. Healthcare workers should routinely screen for chronic sorrow and assist caregivers in developing effective coping strategies. Caretakers used both external and internal coping strategies. External support was derived from community, family and health facility. Internal coping strategies were behavioural and cognitive
Olwit, Musisi, Leshabari, Sanyu	2015	Chronic sorrow: lived experiences of caregivers of patients diagnosed with schizophrenia in Butabika Mental Hospital, Kampala, Uganda	Understanding the experience of chronic sorrow among caregivers of patients diagnosed with schizophrenia	A descriptive qualitative design using focus groups and in-depth interviews	Schizophrenia	Family Caregivers	22	Butabika National Mental Hospital, Kampala,	Nine of the 10 (90%) participants in the in-depth interviews had experienced chronic sorrow. Caregivers described feelings including sadness, shock, confusion, despair, fear, devastation, pain, anger. Caregivers reported grief-related feelings characteristic of chronic sorrow triggered by many factors. These factors fell into the following categories: unending care giving (lengthy hospitalisation, financial constraints, overwhelming responsibility, loss of independence); patient's change in behaviour (patient's refusing to take medications or go to the hospital and resentment); management of crises; society reaction to the mental illness; and missed companionship. Caretakers wanted healthcare workers to show understanding and flexibility, and strong communication, when dealing with their relatives with schizophrenia. Poor communication involved long waiting

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Osafo, Knizek, Mugisha, Kinyanda	2017	The experiences of caregivers of children living with HIV and AIDS in Uganda: a qualitative study	To understand the experiences of caregivers that provide home-based care for HIV patients and their survival strategies	Qualitative study	HIV	Caregivers of children born with HIV	18	Children and adolescent HIV clinics and one psychiatric hospital in Kampala (x2) and Masaka (x2)	Major themes emerging from the study included a Labour of caregiving (insecure employment, provision of food, time, transport and logistics) and Survivalism (organising, managing and sharing of limited resources, support networks). Struggles centre on material scarcity, home-based care offers opportunities but also comes with challenges that should not be shouldered by caregivers
Owokuhaisa, Rukundo, Wakida, et al	2020	Community perceptions about dementia in southwestern Uganda	To identify community perceptions about people with dementia in southwestern Uganda	Cross-sectional qualitative study using focus groups and in-depth interviews	Dementia	Traditional healers; local council, religious and community leaders/elders; community development officers	59	Southwestern Uganda: Nyakabungo in Kabale, KASHARIRA in Ntungamo, and Nyakakoni in Mbarara districts	Community members in southwestern Uganda largely identified dementia as a problem that comes with older age, and can identify key features of dementia presentation.. Themes emerging were 'labelling of illness' (dementia as part of old age/mad/mentally disturbed, forgetfulness); 'causation as biological' (attributing forgetfulness to syphilis, cancer, allergy, taking certain medications); 'causation as ageing: causation as psychological (stress, trauma, anger, domestic challenges e.g. violence); causation as nutrition deficiency and substance abuse, poverty, causation as traditional beliefs (spirits), Impact (inability to provide care; mistreatment; elder abuse); Need for emotional support, socio-economic support services and sensitisation (creating awareness)

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Park, Akello	2017	The oughtness of care: Fear, stress, and caregiving during the 2000–2001 Ebola outbreak in Gulu, Uganda	How care was experienced in the Ebola outbreak od 2000–2001	Retrospective study FGDs and IDIs—presentation of case studies	Ebola	Carers and Health-care Workers	198	Gulu	"Caring constitutes a fundamental moral experience of the vulnerabilities of social life, and men and women might go about it differently. Who offers care and help in times of Ebola? Who shuts his doors and dies in isolation? Who leaves others alone? These are crucial questions to be examined in order to grasp local understandings and practices of care. Such an examination is, however, foreclosed when we narrowly explain caregiving among family members at the household level through a cultural model of Ebola that is set apart from the biomedical model. These models do not capture how the need to care, as well as fear, turn caregiving into a moral uncertainty. Nor does it reveal the practical nuances in people's responses to and reasoning about caring in situations of radical insecurity."

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Rahimi, Kassam, Dangi, Sekiwunga	2019	Challenges with accessing health care for young children presumed to have malaria in the rural district of Butaleja, Uganda: a qualitative study	Understanding perceptions and challenges caregiv- ers face when seeking care for their very young children with fever presumed to be malaria	Qualitative study using focus groups	Malaria	Caregivers of children with pre- sumed malaria	61	Butaleja, Eastern Uganda	Major challenges identified during the study include: (1) logistics challenges in getting to public health facilities due to long geo- graphical distances and lack of affordable transporta- tion; (2) poor service once at a public health facility, including denial of care, delay in treatment, and negative experiences with the staff; (3) difficulties with managing the child's illness at home, including challenges with keeping home-stock medicines and administering medicines as prescribed; and (4) constrained to use private outlets despite their short- comings
Rutakumwa, Zal- wango, Richards, Seeley	2015	Exploring the care relationship between grand- parents/older carers and children infected with HIV in south-western Uganda: implica- tions for care for both the children and their older carers	To understand the needs and responsibilities of both the HIV positive child and older carer and the nature of the relationship, and to assess the implica- tions for care for the children and the older carers	Qualitative study	HIV	Children-caregivers dyads	40 dyads	Kalungu, South Western Uganda	Major themes included reciprocal relationships between children and older carers. HIV positive children required support for basic and health needs. Carers take household tasks. Older carers often experienced significant challenges in their caregiving role, includ- ing poor physical health and psychosocial wellbe- ing, poverty, reliance on cultivation livelihoods, and inadequate wider social and family support

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Sadigh, Nawagi, Sadigh	2016	The Economic and Social Impact of Informal Caregivers at Mulago National Referral Hospital, Kampala, Uganda	To holistically study the emotional and economic burden of informal caregivers in the hospital setting, with recommendations from caregivers themselves	Face-to-face interviews with informal caregivers using a 39-question survey tool	HIV (21%); hypertension (8%); diabetes mellitus (8%); congestive heart failure (7%); anaemia (6%); stroke (6%); the remaining 44% included a variety of diagnoses	Informal caregivers	100	Mulago Hospital, Kampala	Challenges include emotional burden and wellbeing, lack of sanitation, accommodation, finances, and recognition, as well as difficult conditions in the hospital (heat, lack of bedding, seating etc., proximity of care with other patients/carers, lack of toilet sanitation and facilities). Lack of funds to purchase medications. On average, 150,840 UG Shillings (\$52.19 USD) were spent on patient-related out-of-pocket expenses and 97,330 UG Shillings (\$26.79 USD) on personal out-of-pocket expenses. Unable to earn money when caregiving. Recommendations that carers are affording the same recognition as other hospital employees
Seeley, Kajura, Bachengana, Okongo, Wagner, Mulder	1993	The extended family and support for people with AIDS in a rural population in south west Uganda: a safety net with holes?	To examine the assumption that the extended family provides a safety net for individuals in times of need in rural Uganda	Observations, informal interviews and case of death reports from carers, relatives and neighbours	HIV	HIV-positive patients	30	Masaka	27 of the 30 carers described limited care by carers to patients. Lack of food, finance, poverty. Carers described childcare, work responsibilities, caring for others, physical poor health as contributing to difficulties in providing care. Limited assistance from wider social networks and family. Descriptions of stigma. Incremental nature of caring for someone with HIV places heavy burden on family, family resources. Need for practical, moral and material support (encouragement, reassurance, advice)

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Ssengonzi	2009	The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda	To understand changes in the household structure and living arrangements of older persons (50 years and above) after they take on caregiving responsibilities for persons suffering from AIDS-related illnesses and orphans and vulnerable children (OVC) affected by HIV/AIDS	Qualitative study—in-depth interviews	HIV	Elderly caregivers	27	10 rural and urban communities within Luwero and Kamuli	No urban/rural differences reported. Participants reported significant responsibilities that differed based on characteristics such as age and marital status. Travel, changed living arrangement, prolonged absence from home and prolonged travel were all reported, as was increases in household size due to caregiving responsibilities. This has implications on health of elderly caregivers (wellbeing, productivity, physical health)
Ssengonzi	2007	The plight of older persons as caregivers to people infected/affected by HIV/AIDS: evidence from Uganda	To understand challenges faced by elderly persons (50 years and above) providing care to people living with HIV/AIDS	Qualitative study using focus groups and in-depth interviews	HIV	Elderly caregivers	47	10 rural and urban communities within Luwero and Kamuli	Challenges of caring for the people with HIV/AIDS is compounded by the responsibility to care for the children affected by HIV/AIDS—impacting on economic, emotional, physical, and nutritional wellbeing. Responsibility for daily care falls primarily on elderly females, who reported a higher rate of physical ailments than male respondents. Participants reported feeling anxiety about their future health and well-being, and that challenges exacerbated the aging process of the affecting health and well-being of caregivers already affected by the poor resource base and weak health infrastructure

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Streid, Harding, Agupio, Dinat, Downing, Gwyther, Ikin, B.; Mashao, Mmoledi, Moll, Sebuyira, Higginson, Selman	2014	Stressors and resources of caregivers of patients with incurable progressive illness in sub-Saharan Africa	Investigation of burden experienced by carers	Qualitative in-depth interviews analysed using a Stress Process Model	Incurable illness with HIV and Cancer explicitly analysed	Caregivers	37	Uganda and South Africa	Stresses reported relate to daily provision of care, emotional stressors, financial stresses, family responsibility, and social isolation. Inability to provide care created feelings of failure, hopelessness. Caregivers reported providing care as effective adoptive parents, providing single parent roles and providing care for children in the community. Caregivers reported feeling pressure from family to provide quality care, and fear of consequences and blame should a patient die. Family was described as a stressor rather than a resource by many participants
Taylor, Seeley, Kajura	1996	Informal care for illness in rural south-west Uganda: the central role that women play	Understanding the ability of female informal carers to cope with illness episodes in the home	Qualitative using focus groups	All with a focus on HIV	Female caregivers	54	Masaka District	Participants described not having the financial resources necessary to meet the caring roles expected of them. While social networks of friends and family were seen as a useful resource, many did not have adequate resources to offer financial assistance. Women provide main caring roles in the household. Male involvement centred around the purchasing of tablets and food supplies, provision of water, transport for the sick person to the clinic and paying for any medical expenses. Women's income generating activities such as agricultural work often interrupted by caregiving. Women's resources—economic and social—are not adequate for burden of caregiving associated with HIV

Table 1 (continued)

Author	Article date	Article title	Research objective/ Question	Study design	Health condition	Study population	Participants	Region/Loca- tion	Key carer outcomes
Too, Watson, Harding, Seymour	2015	Living with AIDS in Uganda: a qualitative study of patients' and families' experiences following referral to hospice	To understand what motivates patients and their families to seek formal healthcare, barriers existing to help-seeking behaviour, and to understand help and support provided by Hospice Africa Uganda	Cross sectional Qualitative Study	HIV	Patients with AIDS and their relatives (family caregivers)	22 patients (10 women and 12 men) and 20 family caregivers	Hospice Africa, Kampala	Themes included strains of providing care, care and poverty, carers providing care while also managing their own illness (11 caregivers also were HIV positive), stigma around HIV status. Hospice provided pain management, reduced loneliness and helped encourage rehabilitation

across Uganda, with most taking place in hospital-based facilities in Kampala ($n=9$). Seven studies compared different areas (normally rural/urban comparisons). Half the studies ($n=20$) were conducted between 2016 and 2020; with ten conducted between 2011 and 2015; eight between 2006 and 2010; and two prior to 2005. Most studies reviewed the roles, needs and challenges of women as caregivers, although a small number of other studies focused on the roles of men, children and the elderly.

All identified studies focused on the needs of informal caregivers (those not in professional employment). Five themes identified from the reviewed articles included: the extensive and essential roles provided by caregivers, and the burden of care (including economic burden, practical daily challenges, providing support for treatment with limited knowledge of the patient's health condition). The papers in our review described the impact of care on caregivers' quality of life, mental health, and the extended family. In addition, caregivers reported experiencing stigma and discrimination, relationship challenges, and receiving variable levels of support. Additional themes identified included the prevalence of reciprocal care relationships and the importance of coping mechanisms and peer support.

3.1 The extensive and essential role of caregivers

Roles of caregivers in Uganda are described as both extensive and essential in supporting the health of individuals they care for. In broad terms, these roles include counselling, administering medication, supporting logistics around hospital appointments; doing day-to-day household tasks like cooking, washing clothes, shopping; and providing social support and companionship [17]. Caregiving is described as an act of caring, helping, welcoming, nurturing and attending to the needs of others [18]. Studies in our review highlight specific roles in supporting palliative care regarding providing economic support, nutrition and food, and bereavement support [12], and that often such roles are supported by wide community networks and systems.

Care is often provided by family members, with studies indicating that care was often provided by women, spouses, grandparents and children. Women play more active caring roles than men in many of the studies we reviewed [19–21] with some participants describing caring as a full-time job [22]. In one study on malaria, male involvement in caring was described as centering on the purchasing of medication and food supplies, provision of water, and transport for the sick person to the clinic and paying for medical expenses, while care provided by women often involved household tasks and emotional support [23].

Family and community networks were described as essential in a number of studies on how care is conceptualised and undertaken. Streid et al. [24] in their study among HIV and cancer caregivers describe care as being provided to children in the community particularly when there were multiple cases of HIV infection in the same family. In a rural sub-county in Masaka District, however, Seeley et al. [25] challenged the assumption that the extended family provides a safety net for individuals in times of need. This theme was echoed by Nakigudde et al. [26] and Matua & Van der Wal [27] and appears to be a specific sub theme related to stigmatised illnesses, for example nodding syndrome and epileptic conditions.

Care, particularly related to HIV, was described as reciprocal between grandparents and children, with children with HIV depending on grandparents for material support, basic and health needs; and grandparents relying on children to do household tasks [28]. Most of the studies in this review were focused on care at home, and/or care in the community, highlighting the lack of institutional support for caregiving outside of Kampala-based and specialised health centres. Additional common themes present across the reviewed studies were marginalisation and isolation of caregivers, and a lack of specific recognition from the formal health system [29–31].

3.2 The economic burden of care

Lack of economic resources and the financial burden of care were consistently highlighted themes within studies. Caregivers across studies described struggling to afford medicine, transport, and costs associated with staying with people admitted to hospital. Caregivers in Districts with older populations in southwestern Uganda (Nyakabungo in Kabale, KASHARIRA in Ntungamo, and Nyakakoni in Mbarara) described financial stress related to the need for food, medication, and transport costs to the clinic or hospital. Sadigh et al. [32] for example, found that informal caregivers in Mulago Hospital's internal medicine wards were economically burdened by having insufficient funds to buy prescriptions.

Financial stress was compounded by the inability to work due to increasing caregiver requirements in the home [32, 33]. Providing care was described by participants in one study as all-encompassing, stating that "ogoye gima kathyo malo" (nothing can continue) when a child is sick [34]. Similar themes were described by caregivers of children with nodding

syndrome in Hoima and Kampala who reported that in the absence of healthcare services or support groups, full-time caregiving was done at the expense of other activities that could help support the home such as finding paid work [35]. Across different health conditions, caregivers were described as having to make the challenging decisions on whether to prioritise the needs of the healthy children over those of their sick child [26, 36].

3.3 Practical daily challenges

Across the reviewed studies caregivers expressed a variety of challenges in providing daily care and supporting treatment of family members. For caregivers providing care in an in-patient setting, challenges were described as a lack of sanitation, lack of mosquito nets, infection control, and heat. Lack of bedding and seating were reported as pressing difficulties. Lack of toilet sanitation was voiced as a crucial concern, as well as the close proximity of toilet facilities to beds. The large number of beds packed close together without curtains for partition was described as inhibiting privacy and infection control, which was compounded by the admission of patients with a variety of conditions to the same wards. Providing care within this environment was described as challenging [28, 32].

Studies also highlighted numerous challenges in providing care in the home and community. In one study on caring for a child with mental ill health and HIV, caring was described as a complex process that included taking children to multiple providers, procuring and appropriately administering medicine or home remedies, and continually monitoring [37]. In another study girls were taken out of school if help with care was needed, demonstrating the disruptive nature of providing care on other areas of life such as education.

3.4 Impact of care on emotions, mental health and Quality of Life

A number of studies indicated significant mental health challenges and impact on QoL related to caregiving roles [38]. These challenges were similar in nature across disease type, and largely stemmed from the emotional impact of caregiving. In one study on the health of caregivers caring for someone with severe mental illness such as schizophrenia, bipolar

Fig. 1 PRISMA diagram

affective disorder and major depressive disorder at the National Referral Hospitals of Uganda, 49% reported being very dissatisfied with their state of health. Of the 300 caregivers that participated in the study, 172 (57.30%) had a poor QoL. QoL decreased with increasing age of the participants; while it increased with physical health, psychological well-being, environment, and social relationships [39]. For caregivers of someone with cancer, Kizza and Muliira [37] reported low Quality of Life (QoL) in the domains of burden (50.7%), disruptiveness (53.5%), and support (56.7%), while family caregivers of patients with dementia in the Rukiga and Rubanda districts of southwestern Uganda reported not having enough time for themselves [40].

Other studies described the challenges of coping with the stress and emotion associated with seeing their child ill, such as crying, *kumo* (sorrow), pain in the heart, and most predominantly, worry or *ka paro teki teki* (over thinking) [34]. Anxiety and depression were commonly reported, particularly in male caregivers in studies on people caring for someone with a cancer diagnosis [41], while helplessness, desperation, isolation, fear and sadness were reported by caregivers of people who had contracted Ebola [27]. Chronic sorrow, grief-related feelings, sadness, shock, confusion, despair, fear, devastation, pain, anger, were all described by caregivers of people with schizophrenia [42].

3.5 Experiences of stigma and discrimination

Caregivers of particular conditions described experiencing stigmatization, discrimination and social isolation within both communities and families. This was described by caregivers caring for someone with poor mental health [34], schizophrenia [42], Ebola [27], nodding syndrome [26] and HIV [22, 43]. Experiences of stigmatization led to caregivers reporting similar themes of living in fear, ostracism, and social isolation. Isolation often compounded challenges of providing care by reducing support from the community and family members.

Positive changes were noted with some conditions such as HIV, in which stigmatization was reported by some study participants as having reduced over time. Caregivers associated this change with the spread of the epidemic and that many families have been affected by HIV/AIDS, and therefore it was no longer new within the community. Others reported stigma is still prevalent among many households making it difficult for people to disclose their HIV/AIDS diagnosis and for caregivers to provide care and avail of support from the wider community [22].

4 Discussion

The majority of studies examined within this review focused on the needs of caregivers providing care for someone living with HIV/AIDS. Given the scale of the impact of the HIV pandemic on Ugandan communities this may be expected. However, as Uganda undergoes the beginnings of an epidemiological transition with the increasing burden of NCDs [7] and as caring for the needs of people with other long-term, chronic conditions becomes more common, more research will be required to understand the specific challenges that arise from the management of e.g. cancer, diabetes and stroke. Most of the literature returned by this review indicated that research on NCDs has largely been located in specialised centres in Kampala. Needs of caregivers in the community and in rural areas are less well understood. This is a significant research gap, not just regarding the health of caregivers, but also for patient outcomes given the fundamental role informal caregivers play [2].

Literature from other contexts suggests that long-term care is expensive and requires technical skills and knowledge creating specific burdens on caregivers [3]. While literature on HIV in Uganda likely provides insights into themes around long-term care and stigma, specific and targeted research on other conditions would be beneficial in informing the design of future policies, interventions and services. Unlike HIV, programmatic support for caregivers of people suffering other ill health are likely less developed, as demonstrated by our analysis within this review. This likely deepens all challenges associated with life-long care. Research that has focused on NCDs suggests that care is demanding across all domains of daily life, finances, and emotional and mental health. The long-term nature of care for many NCDs often has life-shaping consequences for caregivers, particularly for women given the often gendered nature of care. Given that this scoping review has suggested that the burden of care in Uganda often falls on women, and that girls may be taken out of school to support caregiving thus exacerbating existing gender inequalities, further research within the area is essential.

The incidence of NCDs are rising yet there is limited understanding of its impact on families in low middle income countries. The development, testing, and evaluation of services designed to support caregivers should be considered

an urgent priority. While in resource-constrained contexts it is understandable that funding priorities are often directed towards patients given their immediate needs, international research has demonstrated the importance of caregivers in the health and wellbeing of patients [1]. Other studies have demonstrated the importance of culturally tailoring interventions for caregivers, given the specific ways that care is conceptualized in different contexts [44].

Other research gaps also exist. This review has indicated that there is a relatively large amount of qualitative data related to informal caregiving in Uganda. Only a small number of large-scale surveys, and an even smaller number of trials have been undertaken. Larger datasets that quantify the scale of this challenge, and studies exploring the economic impact of care would be hugely valuable, given that one avenue for supporting caregivers may be providing financial assistance.

This scoping review has provided an insight into common themes and challenges experienced by caregivers in Uganda. A strength of this review is that data was analyzed by a diverse and multidisciplinary team with expertise across cancer, social care and different methodologies. Grey literature and a wider number of databases were additionally searched, thus providing a fuller picture of all available data. Limitations included that studies were not quality checked, as is the norm with scoping reviews. As a result, caution and further research is required when interpreting these results.

5 Conclusion

Irrespective of age, gender, and type of illness, caregivers of individuals with chronic conditions in Uganda face similar challenges. Caregivers are not only challenged to support daily care and treatment of unwell family members, but also experience distress and financial hardship. Time and effort is invested in caring and in turn caregivers' quality of life and economic livelihoods are often affected and disrupted, with caregivers also often experiencing stigma and discrimination. Interventions, programmes and policies addressing the needs of caregivers of individuals with chronic illnesses should be further developed, with clear strategies on how to improve support to caregivers given their crucial and often invisible role.

Authors' contributions AK and CJ lead the analyzing of data and writing of the paper; AK, CJ, PA, FG, FN, AE, CMcS, and LM supporting screening of articles; AK, CJ, FN, PA, FG, AE, JA, AKN, OS, MM, McS, CM, LM and RCN analysed data collaboratively; and RCN, LM, and CM supervised and managed the study. All authors read and approved the final manuscript.

Funding Department for the Economy (DfE)—Global Challenge Research Fund (GCRF) Awards, 2020/21 Round.

Data availability All data generated or analysed during this study are included in this published article [and its supplementary information files].

Declarations

Competing interests The authors declare no competing interests.

Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>.

References

1. Northouse LL, Katapodi MC, Schafenacker AM, Weiss D. The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Oncol Fam Caregiv*. 2012;28(4):236–45.
2. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology*. 2010;19(10):1013–25.
3. Treanor CJ, Santin O, Prue G, Coleman H, Cardwell CR, O'Halloran P, et al. Psychosocial interventions for informal caregivers of people living with cancer. *Cochrane Database Syst Rev*. 2019;6(6):CD009912.
4. Koutsoumpa M, Ododo R, Banda A, Meurs M, Hinlopen C, Kramer K, et al. Health workforce financing in Uganda: challenges and opportunities. *Eur J Public Health*. 2020;30(5):ckaa165-525.

5. Ministry of Health, Uganda. Non-Communicable Disease Risk Factor Baseline Survey: Uganda 2014 Report. Ministry of Health Uganda; 2014.
6. Meghani A, Ssemugabo C, Pariyo G, Hyder AA, Rutebemberwa E, Gibson DG. Curbing the rise of noncommunicable diseases in Uganda: perspectives of policy actors. *Glob Health Sci Pract*. 2021;9(1):149–59.
7. Schwartz JI, Guwatudde D, Nugent R, Kiiza CM. Looking at non-communicable diseases in Uganda through a local lens: an analysis using locally derived data. *Glob Health*. 2014;10(1):77.
8. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005;8(1):19–32.
9. Matovu SN, Wallhagen MI. Perceived caregiver stress, coping, and quality of life of older Ugandan grandparent-caregivers. *J Cross-Cult Gerontol*. 2020;35(3):311–28.
10. Nankinga PN, Maling S, Chemali Z, Wakida EK, Obua C, Okello ES. Informal support for people with Alzheimer's disease and related dementias in rural Uganda: a qualitative study. *Int J Ment Health Syst*. 2020;14(1):33.
11. Ntozi JPM. AIDS morbidity and the role of the family in patient care in Uganda. *Health Transit Rev*. 1997;7:1–22.
12. Mburu G, Oxenham D, Hodgson I, Nakiyemba A, Seeley J, Bermejo A. Community systems strengthening for HIV care: experiences from Uganda. *J Soc Work End-Life Palliat Care*. 2013;9(4):343–68.
13. Nabunya P, Ssewamala FM, Ilic V. Family economic strengthening and parenting stress among caregivers of AIDS-orphaned children: results from a cluster randomized clinical trial in Uganda. *Child Youth Serv Rev*. 2014;44:417–21.
14. Matovu S, Rankin S, Wallhagen M. Ugandan Jajjas: antecedents and rewards of caring for grandchildren in the context of HIV. *Int J Older People Nurs*. 2020;15:e12304.
15. Kiwanuka J, Mulogo E, Haberer JE. Caregiver perceptions and motivation for disclosing or concealing the diagnosis of HIV infection to children receiving HIV care in Mbarara, Uganda: a qualitative study. *PLoS ONE*. 2014;9(3): e93276
16. Green J, Thorogood N. Qualitative methods for health research. 4th ed. New York: Sage Publications; 2018.
17. Muhwezi WW, Okello ES, Neema S, Musisi S. Caregivers' experiences with major depression concealed by physical illness in patients recruited from central Ugandan primary health care centers. *Qual Health Res*. 2008;18(8):1096–114.
18. Kizza IB, Maritz J. Family caregivers for adult cancer patients: knowledge and self-efficacy for pain management in a resource-limited setting. *Support Care Cancer*. 2019;27(6):2265–74.
19. Hartley S, Ojwang P, Baguwemu A, Ddamulira M, Chavuta A. How do carers of disabled children cope? The Ugandan perspective. *Child Care Health Dev*. 2005;31(2):167–80.
20. Osafo J, Knizek BL, Mugisha J, Kinyanda E. The experiences of caregivers of children living with HIV and AIDS in Uganda: a qualitative study. *Glob Health*. 2017;13(1):72–72.
21. Mugisha JO, Schatz E, Seeley J, Kowal P. Gender perspectives in care provision and care receipt among older people infected and affected by HIV in Uganda. *Afr J AIDS Res*. 2015;14(2):159–67.
22. Kipp W, Tindyebeba D, Rubaale T, Karamagi E, Bajenja E. Family caregivers in rural Uganda: the hidden reality. *Health Care Women Int*. 2007;28(10):856–71.
23. Taylor L, Seeley J, Kajura E. Informal care for illness in rural southwest Uganda: the central role that women play. *Health Transit Rev*. 1996;6:49–56.
24. Streid J, Harding R, Agupio G, Dinat N, Downing J, Gwyther L, et al. Stressors and resources of caregivers of patients with incurable progressive illness in Sub-Saharan Africa. *Qual Health Res*. 2014;24(3):317–28.
25. Seeley J, Kajura E, Bachengana C, Okongo M, Wagner U, Mulder D. The extended family and support for people with AIDS in a rural population in south west Uganda: a safety net with holes? *AIDS Care*. 1993;5(1):117–22.
26. Nakigudde J, Mutamba BB, Bazeyo W, Musisi S, James O. An exploration of caregiver burden for children with nodding syndrome (lucluc) in Northern Uganda. *BMC Psychiatry*. 2016;16(1):255.
27. Matua GA, Wal DMVD. Living under the constant threat of ebola: a phenomenological study of survivors and family caregivers during an ebola outbreak. *J Nurs Res*. 2015;23(3):217–24.
28. Rutakumwa R, Zalwango F, Richards E, Seeley J. Exploring the care relationship between grandparents/older carers and children infected with HIV in south-western Uganda: implications for care for both the children and their older carers. *Int J Environ Res Public Health*. 2015;12(2):2120–34.
29. Buchmann K. "These nodding people": experiences of having a child with nodding syndrome in postconflict Northern Uganda. *Epilepsy Behav*. 2015;42:71–7.
30. Kassam R, Sekiwunga R, MacLeod D, Tembe J, Liow E. Patterns of treatment-seeking behaviors among caregivers of febrile young children: a Ugandan multiple case study. *BMC Public Health*. 2016;16:160–160.
31. Park S-J, Akello G. The oughtness of care: fear, stress, and caregiving during the 2000–2001 Ebola outbreak in Gulu. *Uganda Soc Sci Med*. 2017;194:60–6.
32. Sadigh M, Nawagi F, Sadigh M. The economic and social impact of informal caregivers at Mulago National Referral Hospital, Kampala, Uganda. *Curr Top Glob Health*. 2016;82(5):866–74.
33. Owokuhaisa J, Rukundo GZ, Wakida E, Obua C, Buss SS. Community perceptions about dementia in southwestern Uganda. *BMC Geriatr*. 2020;20(1):135–135.
34. Murray SM, Familiar I, Nakasujja N, Winch PJ, Gallo JJ, Opoka R, et al. Caregiver mental health and HIV-infected child wellness: perspectives from Ugandan caregivers. *AIDS Care*. 2017;29(6):793–9.
35. Nasuuna E, Kigozi J, Muwanguzi PA, Babirye J, Kiwala L, Muganzi A, et al. Challenges faced by caregivers of virally non-suppressed children on the intensive adherence counselling program in Uganda: a qualitative study. *BMC Health Serv Res*. 2019;19(1):150–150.
36. Grant L, Brown J, Leng M, Bettega N, Murray SA. Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies. *BMC Palliat Care*. 2011;10(1):8.
37. Kizza IB, Muliira JK. Determinants of quality of life among family caregivers of adult cancer patients in a resource-limited setting. *Support Care Cancer*. 2020;28(3):1295–304.
38. Wadhwa D, Burman D, Swami N, Rodin G, Lo C, Zimmermann C. Quality of life and mental health in caregivers of outpatients with advanced cancer. *Psychooncology*. 2013;22(2):403–10.

39. Ndikuno C, Namutebi M, Kuteesa J, Mukunya D, Olwit C. Quality of life of caregivers of patients diagnosed with severe mental illness at the national referral hospitals in Uganda. *BMC Psychiatry*. 2016;16(1):400.
40. Ainamani HE, Alele PE, Rukundo GZ, Maling S, Wakida EK, Obua C, et al. Caring for people with dementia in rural Uganda: qualitative study of caregiving burden experienced by informal and formal caregivers. *J Glob Health Rep*. 2020;4:e2020038.
41. Katende G, Nakimera L. Prevalence and correlates of anxiety and depression among family carers of cancer patients in a cancer care and treatment facility in Uganda: a cross-sectional study. *Afr Health Sci*. 2017;17(3):863–76.
42. Olwit C, Musisi S, Leshabari S, Sanyu I. Chronic sorrow: lived experiences of caregivers of patients diagnosed with Schizophrenia in Butabika Mental Hospital, Kampala, Uganda. *Arch Psychiatr Nurs*. 2015;29(1):43–8.
43. Rispel LC, Cloete A, Metcalf CA. “We keep her status to ourselves”: experiences of stigma and discrimination among HIV-discordant couples in South Africa, Tanzania and Ukraine. *SAHARA J*. 2015;12(1):10–7.
44. Santin O, Jenkins C, Nghiem HLP, Prue G, Reid J, Lohfeld L, et al. The development of a web-based resource to provide information and psychosocial support to informal cancer carers in hospitals in Vietnam. *Psychooncology*. 2020;29(5):920–6.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.