Caring for caregivers: challenges facing informal palliative caregivers in Western Kenya

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Caring for caregivers: challenges facing informal palliative caregivers in Western Kenya

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Kenya: Urbanization, Health, and Human Rights
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Abstract

Chronic illnesses like cancer, HIV, and other non-communicable disease are increasing globally, especially in developing countries, necessitating development of palliative care and symptom management systems. In Kenya, the burden of care for chronically ill patients often falls to unpaid, informal caregivers like family members or friends. Thirty-five current or past informal caregivers from Kisumu, Kenya were interviewed about their experience, challenges they faced, and interventions they felt would be helpful. Major challenges identified included lack of finances for treatment and other living expenses; inadequate, unaffordable, or interrupted medical care; emotional stress exacerbated by juggling many responsibilities, pressure to emotionally support the patient, and personal sacrifice; and persisting stigma and incorrect beliefs about disease transmission. Suggested interventions include government prioritization to ensure effective and accessible medical care, promotion of collectivized income-generating activities, expanded psychological support resources, and inclusion of caregivers into Kenya’s palliative care policies.
Background

In 2015, 70% of global deaths were due to non-communicable diseases (NCDs), up from 63% in 2008.\(^1,2\) NCDs, including cancer, stroke, epilepsy, chronic obstructive pulmonary disease, cardiovascular diseases, diabetes, and dementia, commonly cause chronic symptoms at the end of life; up to 95% of cancer patients report experiencing moderate to severe pain caused by their illness.\(^3\) In addition to pain, many NCD patients experience fatigue, shortness of breath, loss of appetite, nausea, confusion, insomnia, constipation, and diarrhea, as well as psychological symptoms like depression and anxiety.\(^4\) While HIV is a communicable disease, HIV/AIDS patients experience similar chronic symptoms with up to 80% reporting pain. The global shift from acute illnesses to chronic conditions necessitates increased focus on palliative and hospice care. Palliative care aims to “improve the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering,” and encompasses “physical, psychosocial, and spiritual” care.\(^5\) End of life or hospice care is a form of palliative care; palliative care is intended to reduce suffering and may complement curative care, while hospice care is specifically to maintain comfort, dignity, and quality of life in patients with terminal illnesses.

Access to palliative care services is even more essential in developing countries where a lack of screening, curative care options, or financial access to those options transforms treatable conditions into terminal illnesses. By 2030, the International Agency for Research on Cancer estimates that 70% of cancer cases will occur in developing countries. Four out of five of those cases will progress to an incurable stage before detection, if they are diagnosed at all.\(^6\) High HIV/AIDS prevalence in many of these countries further increases both total mortality and related opportunistic infections, including cancer. The prevalence of other NCDs are also rising in developing countries due to pollution, changes in diet, increased alcohol and tobacco use, and insufficient physical activity.\(^2\)

Access to palliative care is an internationally recognized human right. Article 25 of the Universal Declaration of Human Rights established in 1948 says that “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including… medical care.”\(^7\) The 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR) further elaborates, “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” including “prevention, treatment and control of epidemic, endemic, occupational and other diseases.”\(^8\) While neither document explicitly defines the right to palliative care, human rights literature generally accepts a broad definition of health that includes palliative services: “Health includes the health of people with life-limiting illnesses. The provision of palliative care, where appropriate, is one part of a continuum of health care for all persons. Therefore, an argument can be made that a right to palliative care can be implied from the overall international human right to health.”\(^9\) An addendum to the ICESCR published in 2000 does clarify an obligation to provide “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.”\(^10\) The Cape Town Declaration, a consensus statement drafted during a 2002 conference of African
palliative care professionals, reiterates that palliative care is a human right and emphasizes its importance in sub-Saharan Africa. The right to palliative care implies the right to access the medication necessary to relieve pain. The 1961 Single Convention on Narcotic Drugs, when establishing the original international drug regulations, exempted medical narcotics and opioids because “medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering.” Pain relief drugs, including strong opioids like morphine and codeine, appear on the WHO List of Essential Medicines. The provision of these essential drugs is classified as a core obligation in the 2000 ICESCR comment. A joint letter by the UN Special Rapporteur on torture and the UN Special Rapporteur on health says “the failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel inhuman and degrading treatment.” Including palliative care and medication access in national healthcare policy is therefore essential: in the words of WHO, “a national disease control plan for AIDS, cancer and non-communicable disorders cannot claim to exist unless it has an identifiable palliative care component.”

Despite the extensive human rights legislature, patient access to opioids has historically been low in developing countries; in 2007, North America and Europe accounted for almost 90% of morphine consumption worldwide. Because morphine is an internationally controlled substance, countries must submit annual estimates of need to the International Narcotics Control Board to obtain their supply. Pain management is often excluded from national policy in developing countries, resulting in vast underestimation of need. For example, in 2009, Burkina Faso requested only 50 grams of morphine, enough to manage pain for eight patients out of over 25,000 patients in need. Even if healthcare professionals have access to sufficient opioids, many are hesitant to prescribe because of pervading myths that opioid treatment causes addiction, fear of legal consequences under unnecessarily strict prescription regulations, or cultural beliefs that pain is an unavoidable part of dying. A Nairobi physician stated that “Physicians are afraid of morphine... Doctors are so used to patients dying in pain...they think that this is how you must die. They are suspicious if you don’t die this way – [they feel] that you died prematurely.” Limited supplies and hesitancy to prescribe opioids combine to restrict patients access to pain relief medications in developing countries.

The global trend of increasing chronic disease burden has become evident in Kenya, with half of hospital admissions and over half of hospital deaths now linked to NCDs. In response, the palliative care system in Kenya has undergone massive development in the past fifteen years. Representatives from the few hospice centers in Kenya first gathered to discuss collaboration in 2002. The Kenya Hospice and Palliative Care Association (KEHPCA) was founded in 2005, and their first office established in 2007. The national government began developing national palliative care guidelines in 2011. In 2013, the Ministry of Health addressed limited access to pain relief medications by removing the import tax on morphine and allowing the Kenya Medical Supplies Authority to supply morphine to public hospitals. The Kenya Patients’ Rights Charter, published in 2013, recognizes the right to “promotive, preventative, curative, reproductive,
rehabilitative, and palliative care.”18 As of 2017, the Ministry of Health has begun purchasing, preparing, and distributing oral morphine solution to hospitals nationwide.19 The number of hospice centers has grown from seven in 2010 to more than 70 today, serving 42 of Kenya’s 47 counties.20

**Literature Review**

The body of existing palliative and hospice care literature is regionally biased towards developed, Western countries: “evidence of the effectiveness of palliative care... has been almost exclusively generated in high-income settings; few publications have covered the innovations and expertise of African palliative care services.”21 A qualitative review up to 2010 and a scoping review from 2005-16 found 51 and 49 papers respectively for palliative and end-of-life care in sub-Saharan Africa.22,23 Little research from sub-Saharan Africa exacerbates the challenge of designing programs able to function with few resources, compensate for insufficient institutional investment, and incorporate cultural ideas about illness and death. Many papers reiterate the need to ensure that “service provision is effective, appropriate, [and] acceptable,”22 through production of locally-validated evidence: “Where the need for care is greatest and resources most scarce, evidence is even more urgently needed.”21

Both globally and in sub-Saharan Africa, people generally express a preference for end-of-life care to take place at home for a variety of reasons. A quantitative study of terminally ill patients in Kampala, Uganda, found that over 70% of patients preferred care at home because they felt safe, they maintained their privacy, and it was less expensive.24 A street study in Nairobi, Kenya again found over half of people prefer their own home as a first choice place of death.25 Healthcare professionals in Tanzania spoke of cultural and logistical factors, including the duty of family or community to provide care and the cost of transporting a body.26 A study of terminal cancer patients in eastern Kenya found that “surrounded by sickness and unable to see their children or their land and animals, patients felt isolated,” and described superior emotional and spiritual support at home.27

Despite general preferences for home as the end-of-life setting, literature also documents a preference for hospital-based care, often purely for adequate pain management.27 Many studies emphasize that pain is the primary area of concern for end-of-life patients in sub-Saharan Africa.6,24,27–29 A World Health Organization collaboration study of patient and family needs in five sub-Saharan countries consistently identified “relief from pain” as a top priority.29 Because home access to strong opioids is severely restricted, both legally and financially, patients will turn to hospitalization for relief: “Patients at the end of life used hospital resources largely when symptoms became too difficult for caregivers to manage in the home.”30 One study in Tanzania found that while palliative care still offered significant benefits, healthcare workers and patients resented their lack of medication: “You get there and you have nothing with which to help the pain. Sometimes the person needs help, and when you fail to deliver that help, it is as if you have done nothing. They may even wonder why you bothered to visit.”31 Successful home care is
portrayed as an ideal reserved for developed nations, currently inviable in the face of “sheer poverty” and lack of resources.  

Several studies also document the challenges facing informal caregivers, defined as family members, friends, or neighbors that provide care for chronically ill patients outside of the formalized medical system. Past research highlighted financial concerns because of increased expenses for patient care and simultaneous loss of caregiver and patient income, causing “devastating effects of abrupt destitution.”24,28,32,33 The five-country WHO study therefore recommends that palliative care programs include food packages and promotion of income-generating activities as essential pieces of caregiver support.29 Another common challenge was lack of medical knowledge about disease progression and caring techniques, inciting fear and enabling only basic care.27,29,33 A study of HIV/AIDS informal caregivers’ needs in South Africa showed they “wanted support that ‘will make a difference’, including adequate amounts of food, counselling for all members of the household to help them accept the situation, and training to enable optimal caring work.”34

While financial and educational challenges both add to the psychosocial burden of caregiving, stigmatization appears as the largest contributor, especially with HIV/AIDS. Studies from 1999 and 2003 described intense stigma and condemnation of HIV/AIDS patients and their families in eastern Kenya because of fear and perceived self-infliction of the disease.28,30 A 2006 cross-sectional study in the Congo reported 90% of HIV/AIDS informal caretakers experienced stigma and ostracism from friends, neighbors, and relatives and 99% withdrew from normal social activities because of their caretaking role.32 This pressured social withdrawal often results in negative psychosocial outcomes including “loneliness, depression, and isolation.”22 Despite a demonstrated psychological burden, few studies identified support networks or programming for caregivers: “[they] were expected to carry on caring and to suspend their own feelings.”34 One literature review summarizes that the existing research “refute[s] one of the myths about the African caring system, that of the inexhaustible capacity of the extended family to withstand crisis”22

Informal caregivers often go unrecognized and therefore unsupported, both institutionally and in the community. Within the African context, strong ideas about familial duty to the ill result in little attention to caregiver wellbeing, extending as far as national policy. The Kenyan National Palliative Care Guidelines assert that support is essential for patients and their families, but offers only one sentence on informal caregivers: “Carers shall be provided with adequate resources for patient care.”35 A South African study found “respondents wanted their caring work acknowledged by the health authorities and other stakeholders. They felt that this… would have a positive impact on their mental health.”34 It is therefore essential for informal palliative caregivers to be acknowledged and incorporated in national policy to ensure sufficient financial, emotional, and mental support.
Problem Statement

Studies have found that most people prefer end of life care to take place at home because they value comfort, family support, and privacy. However, pain management in home settings is often difficult because of insufficient drug supply and strict prescribing regulations. Therefore, research suggests that patients in developing countries will often prefer hospitalization based solely on chronic symptom management. This contradiction leaves patients with the “unacceptable choice between having symptomatic relief in the hospital and ‘struggling’ at home.”

Kenya has overhauled their palliative care and opioid access policies in the past decade, theoretically alleviating this burden of choice. However, there is not yet literature documenting if and how recent policy changes have affected this dilemma.

Informal caregivers undergo unique challenges through the hospice care process and are often overlooked in palliative care policy. Common psychological effects include “hopelessness, stigmatization, and isolation,” and often result in depression. Terminal illness is characterized as “economically devastating,” because of the loss of income for both patient and caregiver: “Poverty and sickness combined… put families in a critical financial situation.”

Existing literature reviews document the experience of informal caregivers as “an area that tends to be under-researched.” There are only a handful of studies documenting caregiver experiences performed in Sub-Saharan countries over the past decade. This “severe lack of evidence” leads to oversight; caregivers are minimally included in Kenya’s current palliative care guidelines. One literature review clearly articulates the need for additional research: “Understanding the challenges as well as the rewards and functions of caring and how crises are overcome is essential for building appropriate support systems for carers.”

Objectives

- To understand experiences of informal caregivers of patients with a chronic illness within the context of recent developments to Kenya’s national palliative care system.
  - To determine how recent improvements to national palliative care policy translates at the individual level
  - To understand the daily challenges faced by palliative caregivers
  - To investigate emotional, social, and faith support systems utilized by caregivers
  - To relate challenges faced by palliative caregivers to cultural attitudes and stigma about death
Methodology

Setting

The study was conducted in Kisumu, Kenya. Kisumu City is a port city along Lake Victoria in Western Kenya. Home to over 400,000 people, it is the third-largest city in Kenya and the capital of Kisumu County. Kisumu County, with a population of almost one million people, includes Kisumu City and the surrounding area. Kisumu City hosts several informal settlements or “slums,” including Kondele, Manyatta, and Nyalenda. Key industries include agriculture, fishing, and tourism. The predominate ethnic group is the Luo people; commonly spoken languages include Luo, Kiswahili, and English.

Figure 1: Borders of Kisumu County

Sixteen out of 35 interviews were conducted in partnership with Kisumu Hospice at Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH). Kisumu Hospice was the third hospice center in Kenya, established in 1998 as a single room in the provincial hospital. In 2012, it expanded to an independent building within the JOOTRH complex. Its staff, including two oncologists, serve about 50 patients per month and support integration of palliative care into both Kisumu County Referral Hospital and JOOTRH.
Population

The target population of the study was current or past informal caregivers of people with a chronic illness. Their experience had to be within the past three years. They could not be paid employees of a medical institution or NGO. The patients did not need to be formally diagnosed with a chronic or terminal illness, but those not formally diagnosed must have had symptoms requiring palliative care. To ensure consent, participants had to be at least 18 years old and able to speak either Luo, Kiswahili, or English fluently. Participants were recruited through the Kisumu Hospice outpatient clinic, community health workers in Manyatta, and personal contacts of research assistants.

Methods

The study utilized semi-structured, individual interviews with participants (see Appendix B for interview guides). Interview languages were Luo, Kiswahili, English, or a mix of the three depending on the preferred language of the participant; research assistants provided translation services. Interviews were conducted jointly by the researcher and research assistants and lasted between 15 and 45 minutes. If the participant consented to recording, the interview was recorded and transferred to a computer for reference. If the participant did not consent to recording, the interviewer took written notes during the interview. Interviews took place in the home of the interviewee or a neighbor, in hospice care facilities, or in the SIT office. Participants who traveled to the SIT office received compensation for transport expenses.

In the interviews, participants were asked questions about their experience caring for a patient with a chronic illness. They were asked to speak about related challenges, and who had...
helped them address those challenges. They were also asked to speculate about governmental or non-governmental interventions that they would find helpful.

Interview responses were analyzed thematically, identifying experiences, challenges, means of assistance, or hypothetical interventions repeated in many responses. Common challenges, both explicitly identified by the interviewee or implied by their experience narrative, were organized into a clustered structure illustrated in Figure 8. Participants’ descriptions of current sources of assistance served to identify support mechanisms that worked well and highlight gaps in existing resources. Suggested interventions were used to infer additional challenges and inform recommendations.

Ethics

The study was approved by the SIT Local Review Board. Prior to conducting an interview, consent was obtained. Participants literate in either Luo, Kiswahili, or English were provided with a written consent form in their preferred language (see Appendix A). The consent form explained the purpose of the study and ensured that participants understood their rights. The interviewer guided the participant through the consent form, highlighting the rights and protections outlined in the form. For participants unable to read, a consent form in their preferred language was read aloud and they indicated understanding via a signature or thumbprint in the presence of a witness. Participants could elect to receive an electronic or physical copy of the final report on the consent form.

Because the interview contained questions about sensitive topics like illness and death, the consent form emphasizes participants’ rights to refuse to answer any question or withdraw from the study at any time without providing a reason. The interviewer paused or terminated all interviews where the participant became visibly distressed.

Assuming consent for recording, interviews were recorded on a password-protected phone and transferred to a password-protected computer. Recordings will be destroyed after the conclusion of the study. The interview asked for participant names and demographic information for demographic analysis; this information was kept confidential and only reported in aggregate. In this report, quotes and other individual information are not linked to participant names.

Results

Demographics

A total of 35 caregivers were interviewed about their experiences caring for 29 patients. In some cases, more than one caregiver per patient was interviewed, causing unequal numbers of caregivers and patients. All interviewees lived within an hour’s drive from Kisumu City. Sixteen interviews were conducted in the Kisumu Hospice facility at JOOTRH, eight at the caregiver’s home, six at a neighbor’s home, and the remaining five at the SIT office. All the interviewees identified as Christian, and 31 of 35 were from the Luo tribe.
Figures 3 and 4: Caregiver gender and age distribution.

There were more female participants than male participants (Figure 3). Caregiver age ranged from 23 to 65 years old (Figure 4). Male caregivers tended to be slightly older than female caregivers, with a male median age of 37 years and a female median age of 35 years.

Figure 5: Caregiver education level distributed by gender. Note data do not total 35 as two participants declined to give their education level.
Education level of caregivers ranged from completion of Class 7 to a university degree (Figure 5). Male caregivers tended to be more highly educated than female caregivers; all male participants had at minimum some secondary education. Thirty-one participants had completed primary school, 27 had completed secondary school, and 17 had some higher education; two declined to give their level of education.

![Patient Diagnosis Pie Chart]

**Figure 6**: Diagnosis of patients receiving care. Note diagnoses total more than the 29 patients because some patients had multiple diagnoses.

Only two participants had taken care of patients who had since passed on; all other participants were current caregivers. HIV and cancer were the two most common patient diagnoses (Figure 6). Note that cancer may be over-represented because Kisumu Hospice, one source of participants, works very closely with the JOOTRH oncology department. Several patients had multiple diagnoses; HIV was the most common comorbidity. Two participants did not know the diagnosis of their patient because they were awaiting confirmatory test results.
Most participants, 31 out of 35, were taking care of a relative (Figure 7). Twenty five of those 31 were caring for an immediate family member. Six were caring for a non-immediate relative, such as a cousin, in-law, or stepparent. Only four participants were caring for someone not related to them. Two caregivers met their patient through volunteering for a nongovernmental organization or community health initiative.

**Interviews**

Challenges identified by caregivers were categorized into four primary areas: financial, medical, emotional or psychosocial, and societal or cultural (Figure 8). While interplay between categories is not illustrated in Figure 8, problems in one area often affected problems in other areas. Also, while these issues were repeated across many interviews, a patient’s diagnosis tended to influence the problems emphasized by their caregiver.
Figure 8: Main challenges identified through interviews with caregivers, grouped into four primary areas by color.

**Financial factors**

Financial challenges were the most prominent issue, identified by almost every participant; one caregiver who works as a community health volunteer defined the problems she saw as “only money and always money.” Participants described hospital bills of up to one million Kenya shillings, far beyond their financial means. Chemotherapy ranged from 10,000 KSh per treatment at a public hospital to 35,000 KSh per treatment at a private hospital; a full course includes six to twelve treatments. Radiotherapy costs were several hundred thousand shillings, plus the cost of travel to a facility that offers the treatment. Several patients had to travel to India or Uganda to obtain appropriate treatment. Some caregivers obtained financial assistance through the National Health Insurance Fund (NHIF). According to their website, NHIF “seeks to ensure that every individual and/or family enjoy comprehensive in-patient and out-patient covers to save them from the effects of unpredictable and catastrophic spending on medical bills.” However, other caregivers spoke of their expenses being only partially covered or completely denied by NHIF. Treatment costs were less burdensome for caregivers of HIV
positive patients, because all HIV treatment is free at public health facilities. However, expenses of a chronic illness go beyond just the cost of treatment.

In addition to treatment costs, caregivers described other “hidden” expenses accompanying treatment. Living expenses, like food, rent, and school fees, were neglected when money went to treatment instead. One family had been evicted from their home because of lack of rent. HIV medications must be taken with food; if there is not enough food, patients will default on their drugs. Many chronically-ill patients are prescribed a special, nutritious diet that includes expensive foods like red meat and fruit. Transport to and from the hospital is expensive, especially because families often must hire a car or other special transportation for the patient. Caregivers were unable to afford medical devices, like wheelchairs, causing additional physical difficulties.

Financial strain was further intensified by loss of income, both patient and caregiver, associated with chronic illness. One patient, while recovering from a stroke, was forced to retire because he had been absent from work for too long. This reduction in family income pushed his children to transfer to a less-expensive school. Many people in Kenya work on a causal basis, where not going to work means they earn nothing that day. One husband had begun doing household chores and taking care of their son when his wife became ill. Because he no longer has time to work as a bodaboda (motorcycle) driver, he is not sure if his son will be able to return to school next term. Even unemployed women becoming caregivers can affect household income; one interviewee said she “abandoned her duties” at home to care for her sister, leaving her husband to take on extra domestic chores like cooking, fetching water, or washing clothes and negatively impacting their small business. People unable to hire someone to stay with the patient described leaving work several times a day to check on the patient. Regular hospital visits and unpredictable flare-ups in illness or pain also caused caregivers to skip work, further reducing household income.

To cope with lack of finances, many caregivers turned to fundraising among family and friends. However, these efforts were complicated by widespread poverty and financial need; one participant expressed that “If you go to someone, he also has his own problems. He wants you [to help him], you want him to help you.” Another woman explain that you cannot ask friends for assistance because “everybody is fighting to put something on the table.” Family members were commonly cited as sources of financial assistance, but sometimes fundraising caused tension or guilt. One woman described how she felt abandoned when relatives complained about the cost of treatment, saying her patient’s “illness was burdening them.” Another woman expressed guilt over continually asking her children for money: “I can’t keep on begging, begging, begging my children all the time.” Family and friends were often “also just surviving,” complicating reaching out for financial support. Only one caregiver was able to receive financial assistance from a nongovernmental organization; he was a former employee and had extensive connections within the organization.
Medical factors

Problems also existed with the medical treatment itself. Again, these issues were less pronounced for caregivers of HIV patients because HIV care is widely available. However, in many cancer or stroke cases, caregivers had yet to be able to find a successful treatment for their patients. Specialist services were hard to find and very expensive. One woman, explaining her patient’s recovery from stroke, pointed out that there are no speech therapists in Kisumu. One caregiver had trained herself in physiotherapy techniques because daily visits by a physiotherapist were too expensive. Medical treatment was not often explained fully to patient or caregivers. One caregiver described his frustration with doctors who would not explain diagnoses or treatment “at their level.” Another complained that doctors just prescribed medicine, without giving them any information about its purpose.

Strict restrictions on who can prescribe strong pain relief medication made obtaining appropriate drugs challenging; “morphine is very difficult to get” because it requires a prescription from a registered medical practitioner. Caregivers often coped using drugstore painkillers until they were referred to the Kisumu Hospice and prescribed morphine by the head doctor there. One caregiver described how his patient had to wait for painkillers because the only doctor who could prescribe opioids at the facility they visited was not in that day. Despite delays, patients at Kisumu Hospice were eventually able to obtain oral morphine for pain relief.

The broad categories of “financial challenges” and “medical challenges” do not exist independently; in many cases, problems in one area exacerbated problems in another area. For example, lack of money to fund expensive treatment caused delays or discontinuity in treatment. Patients had to wait weeks or months to obtain treatment until their family could fundraise enough money. One caregiver admitted they were “tempted to skip some of the [chemotherapy] sessions” because of the cost. Other patients had to switch hospitals as many as four times to find affordable treatment. Switching hospitals multiple times often revealed little communication between the facilities; patients would have to wait for test results or treatment records to be sent to the new facility. In contrast, a caregiver that could afford to keep her patient at one hospital spoke very positively about their experience there; she felt the doctors “understood her [patient’s] illness” and were able to provide helpful medical support.

Care was also delayed by medical staff strikes. One caregiver explained that her patient was diagnosed with Stage 3 cancer – advanced but treatable – at the end of 2016, near the beginning of the doctors’ 100-day strike. Their family was financially unable to access treatment at a private facility, so they had to wait for the doctors’ and subsequent nurses’ strikes to end before seeking treatment. By the time the strikes ended, the cancer had progressed to Stage 4 – a terminal diagnosis. Another patient had to wait for months for a diagnosis because of the doctors’ strike; the delayed diagnosis and subsequent surgery left her permanently blind. Several other caregivers had to resort to private facilities, despite additional costs, because of the strikes.

Some caregivers, especially those from outside of Kisumu City, described physical inaccessibility of medical facilities. Local facilities are lacking, so they had to travel long distances for care using poorly-maintained roads. One caregiver from about an hour away from
Kisumu City described how their local medical center misdiagnosed his patient, causing them to wait over a year for the correct diagnosis and treatment. He spoke of a time that his patient became ill in the middle of the night, but they had to wait until morning to visit a health facility because the roads near their home were impassable at night. Outside of the urban center, reaching medical facilities can be physically challenging.

Emotional/psychosocial factors

Many caregivers described the experience of seeing a loved one go through a chronic illness as emotionally burdensome or stressful, especially when resources were insufficient. Several participants spoke about the emotional difficulty of not being able to provide medication, money for hospital visits, or specific foods when their patients wanted them. Other participants described patients who were difficult to care for. One woman spoke about how illness and resulting sexual impotence made her husband suspicious and possessive. Another woman described her patient’s short temper pushing her to leave home for days at a time. Witnessing disease symptoms, such as pain or lack of appetite, was stressful for both the caregiver and the entire family.

Even while they were struggling emotionally, caregivers felt pressure to “be strong” and encourage the patient. One woman chose not to disclose her patient’s cancer diagnosis to the patient or her family because she thought it would be discouraging. Several participants spoke of hiding their emotions: “I used to wait for [the patient] to go to bed and I’d sit and cry when the lights were off. But I don’t anymore, because I realized he’s looking up to me. He’s depending on me, so I can’t be weak. I just have to be strong.” Two participants who take care of children emphasized wanting the child to “not think there’s any uniqueness about [them].” Maintaining an optimistic attitude around the patient within a sobering reality sometimes felt like deception; one woman described how “towards the last days, personally, I knew she would die... but I could just encourage her, tell her to be strong, she’ll make it... I just lied to her. I lied to her that she could make it.”

Another source of stress was juggling additional responsibilities beyond taking care of the patient, including holding a job, taking care of children, or, when the patient was not an immediate family member, caring for their own family. One woman described an overwhelming day trying to care alone for the patient, her two young children, and her elderly grandmother. Several participants were splitting their time and finances between their own family and the relative they were caring for. One woman spent most of her time in her rural home caring for the patient, visiting her own husband and children in the city one week a month. Another man explained “your own kids can’t even get your time.” Caretaking demands scarce time and resources, causing participants to give up time with their family.

Stories of personal sacrifice – giving up time with family, but also stopping projects they were planning to pursue, quitting jobs, losing sleep, missing work, and even skipping meals – were common. Many described the feeling of putting their own life on hold to prioritize the patient: “I don’t have a life... There’s nothing I can do for myself. From when I wake up in the
morning, there’s no time. You want to do something, but something will hold you down.” Another said “You have your own things to do, but you have to take care of her. You don’t have an option.” A participant described caregiving as “a 24-hour thing… if you're leaving, you have to make sure somebody is there for him.” Patient well-being was more important than financial security or food security, worth incurring debt or missing meals. When a family could not afford medication, they would “go and borrow from someone so that they could buy medicine.” One woman explained that because her family was ill, she “better stay hungry, but for them, they get something.” Most caregivers described some level of personal sacrifice.

Friends and family were important support structures in dealing with the emotional burden of caregiving. In addition to financial support, family members would come visit and offer advice. While friends were not necessarily supportive financially, they visited; the importance of social connections, like “someone just calling you” or “that visit only,” was emphasized. A few participants expressed it was difficult for them to confide in friends, saying their friends had been hesitant to ask about their experience or that, “Not many people will understand… They don’t feel what you’re really going through. They haven’t been there.” However, strong friendships were highly valued by caregivers with strained family relationships. Church members also visited patients and prayed for healing. A few participants spoke about relying on God or their faith for emotional support, citing prayer and reading the Bible as sources of strength.

Cultural/societal factors

Stigma and lack of information contributed to emotional challenges, especially for caregivers of HIV positive patients. Many caregivers had witnessed others gossiping and speaking negatively about people living with HIV, even their own family members. Participants often chose not to disclose the cause of their patient’s illness because of the belief that caregivers of HIV positive people cannot avoid contracting HIV themselves. One woman said she receives no help from her community because they think “if they come to care for [the patient], they might contract the disease.” Another participant began caring for a friend after her family refused to provide anything beyond basic care. Lack of information about what causes disease extends beyond HIV; one woman explained that her husband’s family blamed her for his stroke and said it happened because the couple did not follow their marriage traditions. Stigma and other societal challenges both increased stress and impaired caregivers’ ability to build a support system.

The theme of familial duty in caregiving was repeated extensively throughout the interview responses. Duty was not limited to within the immediate family; people caring for a distant relative would often explain how that person’s immediate family was somehow incapacitated and thus the responsibility passed to them. Over and over, participants expressed how the responsibility to care for family took precedent over financial or emotional challenges: “You cannot neglect your parents, saying that you don’t have money. You try your best, even if it means borrowing.” One woman spoke of returning after her mother’s temper had caused her to temporarily leave home, saying, “I always get angry but I do say that after all, she’s my mom, so
I have to go back and I must take care of her because I’m the eldest daughter.” Duty may carry a negative connotation, but several participants spun it more as an act of compassion. One woman said, “someday it might be me, it might be my children, and hopefully someone would step in and help.” Another framed caregiving as helping someone while they’re alive, in contrast with the Luo tradition of elaborate funerals. A community health volunteer explained “I can’t just see somebody suffering and come back here and sit.” Ultimately, willing or not, families were responsible for ensuring the patient’s well-being.

**Interventions**

Suggested interventions were mostly focused on obtaining financial security through direct provision of money or food or through promoting caregiver income-generating activities with grants or loans. As one participant phrased it, “With money, you can manage everything.” Several participants referenced an existing program designed to provide elderly people with a monthly allowance and proposed expanding it to chronically-ill people. Government prioritization of oncology, like there has been for HIV, was proposed as an essential step in developing effective, affordable treatment options for cancer. Several participants suggested training on how best to care for someone with a chronic illness, but this suggestion was mostly made on behalf of others; participants with some health education would recommend others receive the same information. A few requested counselling for themselves and their patients, with one participant suggesting combined training and support group for caregivers.

**Discussion**

The demographics of this study differed from most existing literature. Past studies have found most informal caregivers to be woman with little formal education. While this study did include more women than men, it was not an overwhelming majority, and half of the participants had some higher education. However, primarily family relationships between patient and caregiver is consistent with past research in sub-Saharan Africa.

When asked about the challenges they were facing and hypothetical interventions that could alleviate them, so many caregivers responded by describing problems facing the patient and solutions for those problems. Consequently, many of the challenges described in this report are shared by the patient, especially lack of effective, affordable medical care. Seeing the patient in distress without the resources to remedy their situation had a negative psychological impact on caregivers. However, while financial and medical insufficiencies exacerbated stress levels, participants described other stressful aspects independent from lack of treatment or money, such as “being strong” for the patient and putting their own life on hold. Even participants with the means to obtain treatment experienced emotional challenges inherent to caring for a chronically ill person.

The main problem seemed not to be actually caring for the patient, as most participants were strongly motivated to do so by compassion or a sense of responsibility. The issues were
obtaining the resources necessary to maintain their standard of living and provide adequate care, as well as coping with the inherent emotional challenges of caregiving. Therefore, assistance must be threefold: effective medical care must exist, caregivers must be able to obtain it for their patients, and caregivers must have appropriate support structures to deal with the psychological burden of caring for a chronically-ill person.

Continued efforts to increase the standard of care for chronic illnesses, particularly cancer, is necessary but not by itself sufficient. The current treatments are not accessible to many people, either physically or financially. In June 2017, the Kenyan Ministry of Health released a National Cancer Control Strategy that seeks to improve cancer treatment and expand the number of cancer treatment centers. While this document evidences government prioritization of cancer and should make treatment physically accessible to more people, the cost of treatment must also be reduced. NHIF was a hit-or-miss resource for participants; some caregivers submitted all their expenses, while others had their claims completely denied. Strengthening NHIF and increasing its coverage area would increase financial access to expensive, extended treatment and protect families from sudden destitution. When strikes interrupt public treatment options, government partnership with private hospitals could make time-critical treatment consistently accessible for patients.

Even if treatment is affordable, caregivers also identified a need for living expenses like food, school fees, and transport costs. The high financial burden of caregiving beyond treatment echoes previous research in sub-Saharan Africa. While many caregivers suggested direct support, like food deliveries or a monthly stipend, these interventions are temporary stop-gaps for a chronic problem. Instead, promoting sustainable, income-generating activities will support caregivers both with living expenses and treatment costs. Because many caregivers have unpredictable schedules and little free time, cooperative business ventures by groups of caregivers would be ideal. Many existing small-business support organizations target entrepreneurial projects by women, people with disabilities, youth, or other specific demographics. A similar program explicitly targeting caregivers, via governmental or non-governmental routes, could provide start-up capital and institutional support for cooperative income-generating activities. Existing community health volunteers are aware of caregivers in their community and could assist in forming both connections between caregivers and linking a group with a financial backer. Additionally, organizing into a group of people with similar experiences could provide a valuable network of emotional support.

Ensuring that caregivers have access to professional counselling and personal support systems is essential. One such support network could be connecting with other caregivers on an income-generating venture, but reducing stigma would also guarantee caregivers could rely on their family, friends, churches, and communities without fear of being ostracized. Continuing to support community health programs that educate the public on disease transmission, prevention, and treatment is essential in reducing stigma, especially of HIV. As mentioned earlier, improving treatment for chronically-ill people and ensuring caregivers have adequate resources will also help the psychological burden of caregiving.
Recent developments in the Kenya palliative care system seem to have made pain relief medication more accessible. Once participants linked with the Kisumu Hospice, they could obtain affordable morphine to control pain at home. However, relaxing regulations on prescription of strong pain relief medication could further increase access, as patients would no longer have to wait for a prescription from a doctor. In 2015, the Nursing Council of Kenya and Ministry of Health began conversations about letting registered nurses prescribe opioids. The 2017 National Cancer Control Strategy also supports a move towards relaxed prescription regulations, an encouraging step towards pain relief availability.

**Limitations and Future Suggestions**

Because participants were primarily recruited through outpatient hospice services, participation was biased towards those who have sought medical care. As previously stated, many Kenyans are unable or unwilling to utilize medical services because of financial, geographic, or cultural reasons. Soliciting references from community health volunteers and interviewees helped to identify possible participants that have chosen not to utilize hospice care services.

The primary researcher was not fluent in Kiswahili or Luo. Therefore, language barriers limited the ability of the researcher to capture the subtleties of participant opinions, especially unfamiliar cultural concepts. To address this limitation, research assistants from Kisumu with fluency in both local languages and English were present at interviews with participants who are not comfortable expressing themselves in English. They facilitated both translation during the interview and explanation of location- or culture-specific concepts.

The limited geographic scope affects results. Because most people in Kisumu are from the Luo tribe, results are confined to a Luo cultural context. Additionally, most of the patients lived in or around Kisumu City. Results are therefore biased towards challenges specific to an urban setting. Finally, most of the patients in the study were diagnosed with HIV or cancer, so the results do not represent the full spectrum of chronic conditions. Future expansion of the study to include participants from a variety of tribes, from both rural and urban locations, and who care for patients with other chronic conditions like renal failure, diabetes, cardiovascular diseases, or dementia may reveal additional challenges or possible support mechanisms.

**Conclusion and Recommendations**

Contrary to most Western hospice care systems, professional palliative caregivers and nursing homes are not necessary pieces of a successful continuum of care for chronically ill people in Kenya. Informal caregivers, primarily family members, express a strong sense of duty and compassion to care for their loved ones. The medical sector and nongovernmental health organizations therefore have a responsibility to enable them to do so.

Prioritizing chronic illnesses means guaranteeing access to effective, affordable, uninterrupted treatment close to home. The 2017 National Cancer Control Strategy steps in this
direction, but requires measures that reduce the impact of strikes on time-critical care, such as partnerships with private facilities. Expansion of NHIF to cover more treatments would also help secure financial accessibility for those unable to pay the high cost of treatment. Additional programs that address costs beyond treatment by promoting sustainable, cooperative income-generating activities would assist caregivers in obtaining financial and food security. Improvements to standards of care and a reliable source of income would help reduce the emotional burden of caregiving. However, caregiving with sufficient resources is still stressful. Professional counselling and a strong support system uninhibited by stigma are necessary to protect caregivers’ psychological well-being.

In the past ten years, Kenya’s palliative care system has dramatically improved, especially in providing adequate pain relief, and new policies show encouraging new medical developments for chronically ill patients. However, their caregivers continue to face many financial, medical, emotional, and societal challenges and remain absent from those policies. Within Kenya, informal caregivers are part of the palliative care team, taking on the largest care burden for chronically ill patients. In order to guarantee counselling services and financial support, they must be explicitly included in the Kenyan National Palliative Care Strategy. The well-being of the caregiver and patient are entangled; one directly affects the other. As the chronic disease burden continues to increase, providing adequate financial and emotional support to caregivers will be an essential piece of successful policy.
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Appendices
Appendix A: Consent Forms

PARTICIPANT CONSENT FORM

1. Purpose of the Study
The purpose of this study is to understand the challenges and experiences of informal end-of-life caregivers in Kisumu, Kenya. An end-of-life caregiver is someone who provides care to person with a life-limiting illness, like cancer or late-stage AIDS. Informal caregivers are not paid and do not work for a hospital or healthcare provider. They are often family members, friends, or neighbors. Often, support for these people is not included in government policy about end-of-life care. This study aims to gather experiences of informal caregivers to inform and improve future policy.

2. Possible Risks and Right to Withdraw
To gather that information, I am interviewing current or past informal end-of-life caretakers. During the interview, I will be asking questions about your experiences caring for your sick loved one. We will also talk about cultural ideas regarding illness and dying. I know that these topics are potentially very difficult and emotional to talk about. If a question makes you uncomfortable, you can ask to skip that question. If at any point you wish to take a break or stop the interview completely, you may do so. You do not have to give a reason for skipping a question or terminating the interview.

3. Confidentiality and Future Publication
At the beginning of the interview, I will ask you for your name. This information is only for my records and will not be published in the final report. In the report, the information you provide will be identified by an anonymous number that is not associated with your name. It is possible that the final report may be published and accessible online. By signing below, you indicate your consent for quotes or information you provide to appear in this report.
I want to be able to focus on our conversation, so I plan to record our interview using an audio recorder on my phone. The audio recording will be transferred from my phone to my computer. Both are password-protected, and no one except the researchers will have access to the recording. If you are uncomfortable being recorded, we still can conduct the interview, but I will record your responses in written notes instead. Please initial the appropriate line below:

____ I understand that this interview will be audio recorded and I consent to the recording.
OR
____ I consent to the interview, but not to being audio recorded. I understand that the interviewer will record my responses in written notes instead.
4. Rights Notice

In an endeavor to uphold the ethical standards of all SIT ISP proposals, this study has been reviewed and approved by a Local Review Board or SIT Institutional Review Board. If at any time, you feel that you are at risk or exposed to unreasonable harm, you may terminate and stop the interview. Please take some time to carefully read the statements provided below.

a. Privacy - all information you present in this interview will be recorded and safeguarded. If you do not wish to be recorded and prefer the information recorded in written notes instead, indicate this preference by initialing the appropriate line above.

b. Anonymity - all names in this study will be kept anonymous.

c. Confidentiality - all names will remain completely confidential and fully protected by the interviewer. By signing below, you give the interviewer full responsibility to uphold this contract and its contents. The interviewer will also sign a copy of this contract and give it to the participant.

If you would like to receive a copy of the final report, please provide an email address or mailing address below:

___________________________________
___________________________________

Please ask any questions you may have before signing the consent form.

___________________________________  __________________________________
Participant name printed                      Participant signature or thumbprint and date

___________________________________  __________________________________
Interviewer name printed                     Interviewer signature and date

if participant is illiterate:

___________________________________  __________________________________
Witness name printed                          Witness signature and date
FOMU YA IDHINI YA MHUSIKA (MHOJIWA)

1. Lengo la uchunguzi huu


2. Athari na haki za kujiondoa


3. Usiri na uchapishaji wa badaye


Ninataka kuwa, maelezo haya itahamisha kutoka kwa simu yako. Kama hupendi kurekodiwa bado tunaweza kufanya maojiano, lakini nitaandika majibu yako tu badala yake. Tafadhali andika kwa herufi za kwanza yako kwenye mstari hapa: 

--- Ninaelewa kwamba haya maojiano yatarekodiwa kwa simu na nitapeana idhini yangu.
AU
--- Ninakubali kufanya maojiano lakini nisirekodiwe. Ninaelewa kwamba maojiano haya majibu yangu yataandikwa badala ya kurekodiwa.
4. **Haki za ilani**

Katika juhudi za kutekeleza viwang'o vya maadili ya uchunguzi wa SIT, huyu uchunguzi umekaguliwa na kупитишва na kamati au taasisi ya SIT. Kama wakati wowote ule una hisi kwamba uko hatarini unaweza kujiondoa katika mahojiano haya na kusimamisha mahojiano. Tafadhali chukua wakati wako kwa makini, soma maelezo hapo chini.

   **a. Faragha** – maelezo yote utakayotoa katika mohojiano haya yanaweza kurekodiwa na kuhifadhiwa. Kama hutaki maelezo haya kurekodiwa na kupendekeza majibu yako kuandikwa badala ya kurekodiwa, hakikisha umewandika hapa juu.

   **b. Kutojulikana** - majina yote katika huu uchunguzi hayatajulikana.

   **c. Usiri** – majina yote yatabaki kuwa siri kabisa na kulindwa kabisa ya mwenye kukuhoji.

Kwa kutia sahihi hapa chini, unampa mwenye kukuhoji jukumu kamili ya kutekeleza huu mkataba na yaliyomo. Mwenye kukuhoji atatia sahihi kwenye hii nakala ya mkataba huu na kumkabidi mhusika/mhojiwa.

Kama ungependa kupokea nakala (kopi) ya ripoti ya mwisho, tafadhali peana anwani ya barua pepe (email) au sanduku la posta hapo chini:

_____________________________________________________________
_____________________________________________________________

Tafadhali uliza swali lolote ambalo una kabla ya kutia sahihi katika fomu hii ya idhini.

_____________                         ________________
Jina la mhusika                          Sahihi au kidole cha mhusika na tarehe

_____________                         ________________
Jina la mwenye kuhoji                    Sahihi ya mwenye kuhoji na tarehe

Kama mhusika hajui kusoma na kuandika:

_____________                         ________________
Jina la shahidi                          Sahihi ya shahidi na tarehe
1. Gimo miyo watimo nonro.

2. Inyalo yie kata tamori donjo enonro to ok ochuni.
   Mondo mi ayud weche duto, abiro penjo jarit jatuo weche moko kaluwore gi kaka ose bedo kode. Wabiro penjo kuom weche mag kweche maluwore kod tuoni. Bende abiro penjo kuom lony ma in go kuom rito jotuo. Wa ngeyo ni weche gi tek to yie mondo wayad adiera mantie kaluwore kod kweche moteno gi. Ka wach moro ok inyal duoko to inyalo wacho mondo wakal kanyo. Bende ka idwaro weyo to oyieni.

3. Ratiro mantie kod kaka wabito lando wache gi.
   Abiro chako kod ngeyo nyingi to ma konyo mana an kende, ok abi lando nyingi kamoro amora. Weche gi biro konyo joma biro neno kata winjo mondo orang kaka inyalo konyo joma rito jotuo. Ok abi tiyo kod nyingi kuom weche ma iwacho. Abiro kwayo mondo iketna sei ni iyie wuoyo koda enonroni. Akwayo ni iyie amak duondi mondo obi okonya e repot. Atimwe kuom simo kod computer.

   ___ Ka iyie mondo wamaki to waketo Y ka idagi to waketo N.

4. Ratiro mantie.
   Weche gi oritig gi chike mag skul ma antie ma iluongo ni SIT man e piny ngima. Ipuodhe gi buche mag skundni. Ka idwaro weyo to oyieni sa asaya.
   a. Rit makende - Wechegi omi rit makende ma onge ngato manyalo donjo ma somgi. Bende inyalo wacho mondo kik wa mak duondi to wa ti mana gi ndiko.
   b. Ok wati kod nying madieri - Wabiro tiyo kod nukta kar nying.
   c. Rit makende - Nying dudo wamiyo rit makende ma onge ngama nyalongi ngeyo.

Ka idwaro yudo kaka nonro odhi to wanyalo oroni e email kata e adress mari:

________________________________________________________________________

________________________________________________________________________
Inyalo penjo kapok iketo sei.

_________________________                         ___________
Nyingi                                         Sei

_________________________                         ___________
Nying jatim nonro                                Sei

Ka ok inyal ndiko:

_________________________                         ___________
Nying mar ngama in go                             Sei mar ngama in go.
Appendix B: Interview Guides

English:
First, I want to know a little bit about you.

♦ What is your name?
♦ How old are you?
♦ What tribe do you come from?
♦ What is your education level?
♦ What is your religion?

Now I want to talk about the sick person that you take/took care of.

♦ Who do/did you care for?
♦ How are/were you related to this person?
♦ Do/did you know their diagnosis?
  o if yes: What is/was their diagnosis? Where did you get the diagnosis?
  o if no: Do you have an idea of what their diagnosis might be/have been? What are/were their symptoms? Why do/did they require care?
♦ How long have you been caring/did you care for this person?
♦ What does/did caring for this person usually involve? What does/did your usual day look like?
♦ Do/did you get help from any doctors, nurses, healthcare professionals from a public or private hospital? What do/did they do for you?
♦ Do/did you get help from any NGOs? What do/did they do for you?
♦ Where did you care for this person? Have they ever been admitted to the hospital? Why were they admitted?

I want to talk about how caring makes/made you feel, what made it easier or harder.

♦ What are/were your feelings about caring for this person?
♦ Can you talk about a time that felt really hard? Why was it hard?
♦ Can you talk about a time that felt rewarding? Why was it rewarding?
♦ How did starting to care for this person change your life?
♦ if they mention money:
  o Did you have a job before you began caring for this person? Did they have a job before they became ill?
  o How did this person's illness affect your household income?
♦ if they mention stigma:
  o How did friends and family react to this person's illness? Is it related to their diagnosis (like AIDS)?
  o How have you changed your social patterns since you began caring for this person?
♦ if they mention seeing person in pain:
Have you been able to obtain medicines that treat pain and other symptoms? Which medicines? Where do you obtain them? How much do they cost?

Could you make a list of a few things that are most challenging for you?

I want to talk more about the people who helped you (not the patient) cope with your role as a caregiver.

Where have you found comfort/support?

How has your family helped you?

How have your friends helped you?

depending on religion:

How has your church/place of faith helped you?

How has your faith helped you?

How have doctors/nurses/community health workers helped you?

How have NGOs helped you?

What would be most helpful for you as a caregiver?

If you could talk to the government or doctors about your experience, what would you say?

Kiswahili:

Kwanza, ninataka kukujua.

Jina lako ni nani?

Unatoka wapi?

Unakaa wapi? (for interviews outside of home)

Unakaa na nani nyumbani?


Ulizaliwa wapi? Una miaka mingapi?

Wewe ni wa kabila gani?

Ulisoma mpaka wapi? (secondary, university, college, primary)

Wewe ni wa dini gani? Dhehebu gani? (mkristo, mwislamu)

Sasa, ninataka kuzungumza kuhusu mgonjwa ambaye unauguza.

Unauguza nani? Anaitwa nani?

Mna uhusiano gani?

Unajua anauguza nini? Ana shida gani?

ikiwa ndio: Ulijuaje? Nani alikuambia?

ikiwa hapana: Unabahatisha? Ana dalili gani? Kwa nini anahitaji kuuguzwa?

Umemeuguza kwa muda gani? / tangu lini?

Unamfanyia nini kila siku? Unafanya nini kila siku?

Unapata usaidizi kutoka kwa mtu yeyote?

Unapata usaidizi kutoka kwa familia yako? Wanakufanyia nini? Wanakusaidiaje?

Unapata usaidizi kutoka kwa jamii yako? Walikufanyia nini? Wanakusaidiaje?
o Unapata usaidizi kutoka kwa madaktari, wauguizi, watu ambao wanafanya kazi hospitalini? Wanakufanyia nini? Wanakusaidiaje?

♦️ Unamuguzia wapi? Amewahi kulazwa hospitalini? Kwa muda gani? Kwa nini?

Ninataka kuzungumza kuhusu vile unasikia kuhusu kuuguza, na ni nini inasababisha kuwa rahisi au ngumu.

♦️ Unasikiaje kuhusu kuuguza huyu mtu?
♦️ Unaweza kuzungumza kuhusu siku moja ambayo ilikuwa ngumu. Kwa nini?
♦️ Na pia siku moja ambayo ilikuwa rahisi. Kwa nini?
♦️ Kuuguza mgonjwa kulikubadialisha vipi? Na pia, kulibadialisha vipi shughuli zako?
♦️ Unaweza kusema vitu vichache ambavyo ni changamoto/ngumu?

ikiwa unasema pesa:
  o Kabla ya kuuguza huyu mgonjwa, ulikuwa na kazi? Alikuwa na kazi?
  o Imepunguza mapato yako?

♦️ ikiwa unasema usumbufu
  o Watu marafiki, jamii, family, wanafikiri nini kuhusu huyu mgonjwa?
  o Ni mgonjwa gani ambayo yanaleta usumbufu? (AIDS, cancer, hypertension, etc)
  o Hii imebadilisha vipi uhusiano wako na watu? Na pia vitu ambavyo unafanya?

♦️ ikiwa unasema maumivu:
  o Unaweza kupata dawa kwa kutibu uchungu na dalili zingine? Dawa gani?
  Unazipata wapi? Zinagarimu pesa ngapi?

Ninataka kuzungumza kuhusu watu ambao wanakusaidia au wamekusaidia na kuuguza mgonjwa.

♦️ Nani amekufariji? Nani amekusaidia?
  o Famili yako imekusaidia vipi?
  o Marafiki zako wamekusaidia vipi?
  o Kanisa lako limekusaidia vipi?
  o Imani yako imekusaidia vipi?
  o Madaktari au wauguizi au wafanya kazi wa afya ya jamii wamekusaidia vipi?
  o NGOs imekusaidia vipi?

♦️ Ni nini inaweza kukusaidia zaidi kama mtu ambaye anaguza mgonjwa?
♦️ Kama utawezeka kuumbia serikali au madaktari kuhusu hii, utasema nini?