Kabale University Interdisciplinary Research Journal (KURJ)

Lived experiences and perceptions of COVID-19 survivors, caregivers and frontline health workers on the COVID 19 disease in Kabale District

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KURJ
ISSN 2790-1394

pp. 178 - 192
Vol 2. Issue 2.
Oct 2023

ABSTRACT

The study's main goal was to understand how COVID 19 victims, their caregivers, and primary healthcare providers in Kabale district experienced and perceived home-based care, in order to help the district taskforce for COVID 19 and the national a task force improve their pandemic response plans. The study was guided by the specific objectives which include; identifying the perceptions of COVID-19 survivors on risks, fears and characteristics of COVID-19 disease, the perceptions of COVID 19 home-based caregivers on COVID 19 disease, the lived experiences of home-based care of COVID-19 survivors, their caregivers and frontline health workers in Kabale district, and the perceptions of frontline health workers on COVID 19 pandemic response in Kabale district. A qualitative study design with a descriptive phenomenological methodology, were adopted to explore the lived experiences of COVID-19 survivors, frontline health workers, caregivers, and home-based caregivers. On the COVID-19's onset, testing, and development, all 59 individuals who participated tested positive for COVID-19; 40 of them were homebased employees at the time of their positive test, while 19 of them were not, but they were still taking precautions like frequently donning masks, frequently washing their hands, avoiding social situations, isolating themselves from others, and drinking clean water. It was found that caregivers had to keep watching and caring for the patients, preparing hot drinks, giving medication at night, paying maximum attention and ensuring the patients took medication, feeding the patient right diet, washing cloths and other chores for the patients, making contacts with the family of the isolated patients. The home-based care givers reported daily practices as ensuring hygiene and clean environment.

Keywords: *COVID-19, Survivors, Caregivers, Health workers*

Introduction

The study's main goal was to understand how COVID 19 victims, their caregivers, and primary healthcare providers in Kabale district experienced and perceived home-based care, in order to help the district taskforce for COVID 19 and the national a task force improve their pandemic response plans. Due to COVID-19 restrictions, classes and outdoor activities had to be suspended. Additionally, during the pandemic and lockdown, some patients' co-morbidities were exacerbated for caregivers, while other patients encountered new problems (Vaitheswaran *et al.*, 2020).

The Chinese city of Wuhan experienced an epidemic of pneumonia cases toward the end of 2019, alarming health authorities around the globe (Lee, 2020). The cause of the rising respiratory infections was quickly identified as a novel coronavirus, a new type of coronavirus that had never before been seen in humans (Fang *et al.*, 2020). The most terrifying pandemic in recent memory, COVID-19, has caused extreme dread throughout the world (Chauhan, 2020). This is due to the fact that there hasn't been an outbreak that has affected as many people globally in earlier decades (Zhang *et al.*, 2020). Even in the most prosperous nations around the globe, SARS-CoV-2 has impacted health systems (Sylaja *et al.*, 2020).

The Kabale district's population was projected by the Uganda Bureau of Statistics (UBOS) to be 248,700 as of 1 July 2020 (UBOS, 2022). The estimated male population of these is 120,000, and the projected female population is 128,700. Between 2014 and 2020, the average yearly population growth rate determined by UBOS was 1.3 percent. In the region, COVID-19 was first announced in April 2020. The region had a total of 2,624 confirmed cases, 1,985 recoveries, 108 COVID-19 deaths, and 128 active cases as of September 30, 2020.

Documenting the experiences of people from various communities will act as a step towards addressing the mental health challenges faced by COVID-19 survivors and caretakers of the affected (Chew et al., 2020). This study aims at understanding the skills of COVID-19 home-grown care by the patients and survivors, caregivers (irrespective of the outcome of the patients), communities, and frontline health workers in Kabale District.

Kabale district had one of them of the greatest disease transmission rates of COVID-19 infection throughout the second outbreak of Corona virus disease, at 20% (G. B. Turyasingura *et al.*, 2022). On September 8th, 2021, there were 160 active cases in the district, including 51 cases requiring admission and 109 cases requiring home-based treatment. Since March 2020, there have been a total of 2,624 reported infections in the area, and 71% of those (1,860) cases (1,860) were exposed to the virus at the second wave. In Kabale district, 108 individuals died as a result of illness.

Objectives of the study

- To identify the perceptions of COVID-19 survivors on risks, fears and characteristics of COVID-19 disease in Kabale district;
- To find out the perceptions of COVID 19 home-based caregivers on COVID 19 disease in Kabale district;
- To find out the lived experiences of home-based care of COVID-19 survivors, their caregivers and frontline health workers in Kabale district;
- To describe the perceptions of frontline health workers on COVID 19 pandemic response in Kabale district.

Research Methodology of the Study

Study area

The study was done in Kabale District (Christopher, 2021). The district's main office is located in Kabale town. Before the districts of Rukungiri, Kanungu, Kisoro, Rubanda, and Rukiga were carved out to

create separate districts, it was formerly a part of Kigezi District. Kabale is located at the international boundary with Rwanda, about 25 kilometers (16 miles) north of the town of Katuna. There are 56 health institutions in the Kabale district, including 1 regional referral hospital, 2 district general healthcare facilities (PNFPS), 3 health centers 1V, 6 health centers 111, and 44 health centers. Only one regional reference hospital was utilized as a COVID-19 therapy facility out of the remaining 11.

Research Design

A qualitative study design with a descriptive phenomenological methodology (Rahimi et al., 2021), were adopted to explore the lived experiences of COVID-19 survivors (Turyasingura *et al.*, 2022; Turyasingura & Chavula, 2022), frontline health workers, caregivers, and home-based caregivers. A phenomenological approach is one that enables the researcher to explore the lived experiences of individuals as they occur in life. The two main approaches to phenomenology are interpretive and descriptive. This approach was selected because it enables the researcher to effectively describe rather than explain the experiences and perceptions of individual perspectives free from their own hypotheses or perspectives.

Study population

The study had three study populations. The first study population was all people in Kabale district who tested positive to COVID-19 by the national testing facility at UVRI Entebbe who were managed exclusively at their home by both a qualified health worker and an informal caregiver between 21st March 2020 and 30th September 2021 and who recovered from the illness (a list of all home-based care of COVID 19 patients who recovered is available at DHO's office). The second study population was all frontline health workers who managed confirmed positive COVID 19 cases at home and whose case recovered. The third population was all people who provided home-based care for confirmed positive COVID 19 cases and whose cases recovered (list available at DHO's office). The interviewer found respondents at their homes through their contacts (both physical and mobile telephones where available) at DHO's office.

Unit of analysis. There was three units of analysis for this study: The COVID 19 survivor, the frontline health worker and the informal caregiver.

Inclusion criteria

For all the three categories above, all who was available, willing to be interviewed and to provide a written consent.

Exclusion criteria

Survivors found in Kabale district but who were not residents of Kabale districts during the period under study, their health workers and informal caregivers and those who refused to consent. Survivors who were not in Kabale at the time and those who may not be in their right mind at the time of the study.

Sample size determination

The District Health Officer (DHO) patient and care giver contact list was used to conduct the purposive snowball sampling that was used to select the participants. The contacts that the eligible participants had at the DHO's office were used to reach them (Stamm *et al.*, 2021). To achieve the greatest possible variety in recruitment with regard to gender, age, urban, and rural setting, we analyzed interviews concurrently

with subsequent data gathering (Stamm *et al.*, 2021). When data saturation was reached and no codes were found in at least five more interviews, recruitment was halted.

Study variables

The dependent variable was COVID 19 pandemic disease and the independent variables of the study were the perceptions- this variable was explored perceptions of COVID 19 survivors, caregivers and frontline health workers on COVID 19 disease, the experiences variable which was explored experiences of COVID-19 survivors, caregivers and frontline health workers on COVID 19 disease, and the social demographic characteristics (age of participants, sex, educational level), number of people in the household, and health status of participants.

Data collection methods and tools

First, the Kabale district healthcare office provided a list of patients who had been identified with COVID-19 and were on the mend as well as a list of primary care providers who had treated those suffering from COVID-19 at home and were on the mend (Rahimi *et al.*, 2021). The local health office provided the names and phone numbers of informal caregivers who provide care at home. Face-to-face, in-depth interviews that were semi-structured and performed in order encourage participants to talk about their COVID-19 experiences and perceptions. Open-ended interview questions were used to gather data (Benson & Ayiga, 2022), and when additional clarification was required, probes and subsequent queries were added to promote discussion (Rahimi *et al.*, 2021).

Ethical considerations

The National Council of Science and Technology (UNCST) was asked for permission to conduct the research, and the Makerere University School of Public Health ethics review committee did an ethical review. The Kabale District's Chief Administrative Official and District Health Officer provided the necessary authorizations. After explaining the purpose, advantages, risks, and entitlements of the study as well as the rights of the power source participants—whose names shall not be documented in the interview or documented anywhere to ensure their confidentiality—informed consent was sought from the respondents. To ensure their confidentiality, participants' names were never written down or documented anywhere. By keeping the data accessible but under lock and key, privacy was accomplished. The "MAXQDA 10 software was used to accomplish and unify the qualitative data" (Rahimi *et al.*, 2021).

Dissemination of study findings

Study results may be shared with district health and political leaders through quarterly district health stakeholders' workshops at the district level. A research article may be developed and published in a peer reviewed journal.

Results

Biodata

According to the data collected from 59 COVID-19 survivors, 47 of the respondents were aged between 21 and 60 years. 07 were above 60 years of age, and only 05 were below 20 years of age. Males were 28 and females were 31. Bakiiga had 52 respondents, followed by 07 Banyankole and 05 Banyankole.

The remaining two were Banyarwanda and Bafumbira, respectively, staying in different parts of Kabale district.

The respondents had different educational levels; the majority (23) had completed primary, 03 were graduates, 05 had a diploma, 04 had an A-level, and 11 belonged to other categories. 27 were employed in the health and other areas, 26 were unemployed, and 6 were students, with the majority earning between 40,000 and 139,999 Ugandan shillings.

COVID-19's onset, testing, and development

According to the data gathered, all 59 individuals who participated tested positive for COVID-19; 40 of them were homebased employees at the time of their positive test, while 19 of them were not, but they were still taking precautions like frequently donning masks, frequently washing their hands, avoiding social situations, isolating themselves from others, and drinking clean water. Their theory was that they got the virus about social settings like funerals and clubs, from sharing lodging and meals with people who had recovered, from interacting with patients kept in isolation at medical facilities, as well as from other healthcare professionals, relatives, and school visits. Some people, however, were unsure of how they could have picked up the infection.

When they were asked whether other people could have contracted the virus from them, 45 of the respondents did not know whether others had contracted the virus from them, while the other 12 were aware such could have happened. Only two people were not sure whether others contracted the virus from them.

A deeper look at COVID-19 symptoms

During their COVID-19 illness, respondents were questioned about whether they attended a healthcare facility or received clinical care. The 58 participants acknowledged having sought medical attention at a hospital or other clinical care center. During the COVID-19 sickness, 01 was the only patient who chose not to go to the hospital.

The majority of the respondents who were hospitalized spent an average of two weeks; the rest spent either one week or a month depending on their ability to respond to treatment.

The respondents diagnosed with COVID-19 reported having experienced symptoms such as sore throat, body weakness, fever, headache, nasal congestion, dizziness, loss of taste and smell, flu, back pain, loss of appetite, chest pain, difficulty breathing, running nose, sneezing, joint pains, night sweats, fatigue, stomach pain, and vomiting. These symptoms, according to the respondents, come with the fear of death and are psychologically torturous.

The road to Recovery from COVID-19

However, when asked how long they took to fully recover from COVID-19 and associated symptoms, majority believed to have recovered between1-7 weeks and the rest believed to have recovered after 2-5 months.

Stigmatization of COVID-19 patients

On the existence of If COVID-19 stigma, only 11 of the interviewees did not experience COVID-19 stigma, compared to 48 who did. Only 10 people were unsure of their encounter with stigma. Those who experienced stigma reported discrimination even after recovering, lack of interaction and visits from friends and relatives and others were neglected by their family. This was based on the way the community, family and friends acted towards them. For instance, according to the respondents, they were not being visited by their friends, family members did not want to sharing things with them, neither touching utensils used by them. That people used to run away from them, and even Local Government Councils at Level One (LC1) publicizing their conditions within the communities. These acts had a big impact to the survivors, some lost their friendships, and other had to close their hotel businesses as clients feared coming close to their facilities.

Experiences of being a COVID-19 patient

When the respondents were asked to narrate their experiences of being a COVID-19 patient, they shared the experiences as stressful, terrible bad, painful, scaring, devastating, stigmatizing, and traumatizing. This led them to a feeling of hopelessness, anxiety and loneliness due to isolation and discrimination. Due to anxiety, worries and the fear of death associated with the virus, some participants developed high blood pressure.

In narrating their overall experiences after the infection, majority lament absolute poverty as a result of no one to attend to their business, some lost their jobs while they were sick, and some stayed home as they could not continue with their daily activities. Even those who expected government support did not get it. In particular one had this to report:

> "After testing positive, I was stopped from work as people feared me."

In regards to emotional trauma, majority developed too much fear, panics attacks and worried about untimely death that led to depression. Some even made verbal wills of their property knowing they would die. The issue of patients being isolated in facilities and others spending 14 days in the hospital was traumatizing to some patients. Some of the patients were abandoned by the family members leaving then lonely and unloved. Although some received counselling they still got fear of any related symptom to be the same especially of high fever, chest pain, constant headache, and fatigue.

The students also had their share of experiences, for instance some missed studies and also missed doing home chores and fun with friend. Others dropped out of schools due to inability of their parents to continue supporting them.

Change in family roles, responsibilities and challenges after infection

A question was asked on how the role of the survivors in the family changed after being infected. Majority of the respondents accepted that their roles had changed, while 20 of the respondents refuted this claim. Those who accepted that their roles changed indicated inability to coordinate work at home and perform daily activities. Those who were productive in digging can no longer engage in such activities, some can no longer provide for the needs of their family as they lost jobs, amidst increased family expenditure. For instance, the single parent claimed that the family's lower salary prevented her from providing for the children. Another person bemoaned his inability to manage the staff. These cleared the path for poverty

to take hold, making it difficult for some people to provide for their families (Laituri *et al.*, 2022). The majority of the students bemoaned their incapacity to focus on their studies following the infection. However, on a positive note, some respondents expressed that the relationship with the family has increased and were glad that everything had returned to normal yet highly prepared and alert for any change.

The respondents were asked on the biggest challenges they faced and their families. According to those who lost loved ones due to the COVID-19 are still grieving the loss of their loved ones, stigma from family and those who recovered from the sickness leave in fear on account that reappearance of symptoms makes them imagine re-occurrence of COVID.

That besides the period being expensive and stressful to manage, poverty came up as the biggest challenge that was attributed to close down of businesses due to lock down. Low farm yields as a result of reduced man power to do some activities. With reductions in income among many families, most respondents reported failure in taking care of their families as required, some were living hand to mouth. That poverty has further stagnated development, increased domestic violence, paved way for child marriages and child labour. For instance, a parent lamented their daughters married at the age 15 after getting pregnant without intervention from authorities. Another parent stated that there was reduced working relationship with the son who didn't return his property that self-had was given to him.

Finally, the COVID-19 survivors were asked on how they think their experience would impact their future life and that of their family. Some of the respondents were optimistic that they would not suffer again from COVID-19 in the future, that they were now better equipped to respond to other diseases, learnt to take precautions seriously especially strict adherence to SOPs, and visiting hospitals before conditions worsen. They also reported of working together as family that has led to increased food production. However, the 15 of the respondents felt that the experience did not have impact in the future. Those who were affected negatively in one way or the other reported fear of damaged internal organs caused by COVID-19 and Post COVID complications [shortening lifespan] as the negative impacts to their lives. That this paved way for other infections and high blood pressure.

Some further lamented of recurring debts and persistent poverty as the biggest impact to them and their families. This was attributed to loss of jobs, financial loss, unemployment, low rate of family development, selling off property such as land, recurring debts, and dependence on loans, reduced energy to work and carry out usual activities, and inability to be productive as before. One parent had this to report:

> "I have lost hopes of educating my children after one daughter marrying off and another abandoning school."

Frontline health workers and home-based caregivers

Data was collected from both home-based care givers and frontline health workers. The front-line health workers included medical officers (MO), senior clinical officers (SCO) and nursing officers (NO).

Please describe your caring experience of a patient with coronavirus disease in as much detail as possible. Experience in caring for patients with COVID-19

The front-line health professionals and home-based caregivers were questioned about their experiences caring patients with COVID-19. The home-based caregivers described their experiences as being extremely stressful, stigmatizing, traumatic, and exhausting. The majority of them were anxious and afraid of contracting the disease because of the character of the illness.

Accordingly, caregivers had to keep watching and caring for the patients, preparing hot drinks, giving medication at night, paying maximum attention and ensuring the patients took medication, feeding the patient right diet, washing cloths and other chores for the patients, making contacts with the family of the isolated patients. This was coupled with their other activities of daily recording of recovery rates and taking temperatures of the patient in the morning and evening and reporting to the health center. One respondent reported thus:

> "Over working and being old, as I take care of patient resulted into other health complications [sic]"

Although the home-based care givers were given guidelines and encouraged to observe standard operating procedures, some of them could forget to observe SOPs. Others found the guidelines hard to follow. And those patients they encouraged to put on a mask and observe social distance, would sometimes forget. This resulted in some of their children contracting the virus too from the following statement.

> "There was too much trauma because my children also got infected."

As a result of contacts with the patients, and the nature of the disease, some of the home-based care givers had to use some vitamin tablets and other drugs that were expensive and costly. Some were isolated from their families while others had limited time for their families and businesses. This they reported to have costed them a lot of money coupled with the high expenditures in food and transport costs due to limited movement from one place to another.

However, according to them, some patients were cooperative and supportive. One particular patient could do house chores by herself and made sure she took her treatment at the right time.

According to the front-line health workers, the experience they had in caring for COVID-19 patients were somehow related home-based care givers. From their experiences, they described the situation as being tiresome, stressful with little rest and fear of contracting the virus. Some reported of fearing to go home so as not to infect their families. They also reported compromised mental health which was more related to anxiety, fear, grief, depression, and stress.

That although some lacked personal protective equipment [PPE], those who had got skin damages due to long hours in the PPE. They complained of increased workload, Lack of experience and confrontations with ethical dilemmas, uncertainty and helplessness attributed to the need to adhere to new requirements at the facility as some of the negative experiences. Furthermore, the negative attitude of the patients towards the disease made then to take on additional role of comforting, health education, palliative care to patients, super counselling, both physically, health-wise and emotional after the patients testing positive to the virus. One MO stated:

> "One patient was very much stressed when she knew that she was COVID-19 positive, I established a good relationship but it was risky."

The patients who had a positive outlook followed the precautions, they were cooperative and adhered to treatment and preventive measures.

For instance, One Medical Officer stated:

> ". It was a fearful situation for both workers and patients...."
> "It was Scary, horrible and stigmatizing with fear of death..." reported another.
> "I experienced negative impact on my physical health like sleeping disorders due to sleepless nights spent at the facility. "indicated another.

However, the front-line health workers also reported positive impacts they acquired such as resilience, problem solving, sense of self-motivation, pride, sense of purpose, meaningfulness and personal growth due to increased positive feedback from patients.

Daily experiences in caring for patients with COVID-19

The home-based care givers reported daily practices as ensuring hygiene and clean environment as they were in constant contact with patients; providing good meals daily and regularly; assessing and administering medication to the patients; observing strict standard operating procedures (SOPs); ensuring strict isolation rules; comforting the sick who would be worried; washing clothes of the patient; isolation of the patients; visiting patients to record some improvements; putting on the masks when assisting the patients and ensuring the patients adhered to the instructions of wearing masks. However, on the issue of masks this is what one had to say

> "...I could wear mask every day which is uncomfortable...

These experiences were amidst scarcity of finances for purchasing food and drugs, restricted movements, failure to get time for family more especially the children. And daily fears of getting in contact with asymptomatic patients, transmitting the virus to their family members. That this came with stigmization, anxiety, stress and tiredness.

From the perspective of the NO, their daily activities included isolating the patients who presented fever, caught, sore throat, running nose and difficulty in breathing from other members although these patients who were isolated would sneak back and interact with the rest. They also assessed the patients with vital diseases.

The SCO reported their daily experiences as taking vital measurements for the patients every morning, giving treatment, monitoring those with severe side effects and sometimes referring those with severe conditions even when they did not have PPE.

The MO ensured the patients were isolated from the relatives, carrying out daily home visits, taking temperature measurements and ensuring the patients were taking their drugs as prescribed, counseling and feeding, reassuring the patients that they would get better. This was done in fear of contracting the virus due to lack of PPE. Although the MO reported suffering from loneliness, were not knowledgeable, and did not have experience in treating the patients, had concerns of health deterioration of patients, and taking care of those neglected and abandoned by family members due to fear of disease; some achieved satisfaction of treating patients to recover and as thus gained experience and knowledge.

Knowledge of treating individuals with various COVID-19 variants:
Front-line healthcare employees and those who provide care at home were asked to describe their encounters with patients who had various COVID-19 variants. The home-based care givers responded that although patients presented different signs and symptoms, they did not get information about COVID-19 variants. Some of them were not even aware about the variants. That this was on the account that the tests did not indicate COVID-19 variants. Even the patients that tested positive were not informed of the variants they had. This made it difficult to identify the variants in the patients.

According to the front-line health workers, there was no information about which COVID-19 variant a patient had. Some reported of not being sure of different variants. All they were trained to diagnose patients by use of signs and symptoms. This is backed up by the following statements by MO

> "…. We were trained to diagnose a patient by use side effects which helped us suspect the patients and carry out a lab test…"

That although it was reported that the first variant killed many people compared to other variants, that some variants spread faster than others such as Omicron that spread more easily than the original [first] and delta variant.

> "…. Caring for COVID-19 patients caused panic and fear, but the other variants came when I had gained confidence, and even had PPE and other equipment's to use…" reported one frontline health worker.

That although most variants became resistant to treatment, Omicron had less severe effects and people who were vaccinated got a break through from sickness.
Perception of Home-based care givers and front-line heath care workers on different COVID-19 variants

The home-based care givers and front-line health workers were asked to explain their perceptions about different COVID-19 variants. The home-based care givers perceived all the variants to be the same except for the fact that the symptoms and signs were different. That this was on account that the variants had mutant genes. That there was a likelihood of a patient contracting all the variants of COVID-19 which were dangerous and life threatening with so much pain. Those who perceived that the variants were different reported that COVID-19 variants had different severity and affected the body differently, that the variants showed different symptoms and spread differently. For instance, some believed that Delta had a high transmission rate and caused a lot of mortality, while others said COVID-19 was more severe than other variants and that it was hard and complicated to manage. That although other variants can't affect those who have had COVID-19 before, 2nd and 3rd variants were the worst.

The front-line health workers had different perceptions about COVID-19 variants. Some reported to have had a myth about the variants. According to them, COVID 19 was deadlier than the variants on account that COVID-19 had complicated symptoms as compared to delta and Omicron that were not severe. That in as much as Omicron spread much faster all of them can could kill if not treated early. And that with full immunization, the disease can easily disappear. In their own words:

> ".....COVID-19 variants [delta and Omicron affected both vaccinated and unvaccinated but taking booster dose offered protection against OMICRON…." reported a Medical Officer
>
> ".....variants constantly changed through mutation and sometimes change into other viruses" … said a Nursing Officer

> ".....Some variations allow the virus to spread more easily or make it resistant to treatment or vaccines...." lamented a Senior Clinical Officer.

How the Home-based care givers and Front-line health workers were treated after caring for COVID-19
In response to the question posed on the treatment of the family after caring for COVID-19 infected patients, the home-based care givers respondent that some were treated normally at home, their family understood their sacrifice for others and treated them well. This according to them increased the love their families showed them. However, some went through stigmatization due to the fears associated with the disease.

Some of the frontline health workers experienced stigmatization, rejection, neglect and they were feared by their family. However, with constant assurance, and understandings about the situation and their line of duty, they were accepted by their families. Hitherto, only a few reported getting support from their families after understanding the situation.

Change on family responsibilities and relationships among the home-based care givers and frontline health workers

The changes reported by the home-based care givers encompass around individuals and their family as a whole. According to them, the challenges that emerged included, poverty due to increased expenditure, and reduced income, stigma, reduced concentration on family and other activities. From the positive side, family relationships have been strengthening, sanitation and hygiene observation has been maintained, and growth in their faith.

The frontline health workers reported improved spiritual commitment to God, resilience, personal growth, and problem-solving attitude as a family. Some responded that they started family meetings that included care for patients and the sharing of advice on control measures and observance of SOPs. Negatively, most of the frontline health care providers lamented disassociation from their children and felt isolated; some did not have family time due to spending more time away from family.

Impact of the COVID-19 experience on future life and family of the home-based care givers and frontline workers

When the home-based care givers and frontline health workers were asked about the impact of the COVID-19 experience in the future, the home-based care givers responded that they had acquired enough experience to manage complications related to infectious diseases. And their families will be able to handle infectious diseases like COVID-19 in the future using different treatments such as local herbs and home remedies. Some also reported having learned teamwork in a family, knowledge about right health practices, and have been equipped to be better caregivers in the future. From the perspective of others, the bond between self and family had reduced; that would take time to come back, and poverty would take time to reduce. One talked of being suspicious of every disease that would come.

While the frontline health workers reported spiritual growth in their families, continued observance of SOPs, improved knowledge on how to deal with infectious diseases, early preparation for any eventualities, and awareness of control measures for diseases in families, Individually, they reported meaningfulness to society and family, future life enlightened, and that they got a sense of purpose from the past experiences, making them more comfortable in their profession.

However, the negative impacts cannot be left out. According to them, stress and trauma caused by the pandemic, social and economic constraints, and a feeling of being cheated will continue to be among them. Although they anticipated being able to overcome these through support and assistance from one another.

Comments and insights about COVID-19 experience

The home-based care givers, when asked about comments and insight with COVID 19, had this to say: Although there is a lot of misinformation about COVID 19, from all over the world, we are optimistic that COVID will not come back.

They also gave insights that all SOPs and MOH guidelines should not be taken for granted, that people should always go for testing early before conditions worsen, that the government should enforce strict measures early to curb down the spreading of diseases, that vaccination should be enhanced to reduce the spread and rate of COVID-19, that regular sensitization of communities should be conducted in case of any outbreak, that personal health should always be taken as a priority, that clear information should always be given to the public, that the government should provide adequate PPE to the workers, and that people should protect themselves from the disease.

The frontline health workers proposed safety precautions to be observed even after the COVID pandemic, continuous health education about COVID to continue, vaccination for all should be encouraged, good nutrition should be emphasized among the population as key to prevention of COVID, continued observance of SOPs.

They commented that in getting more experience in conducting disease surveillance, health workers should get fresher trainings in case of a new disease and work together to fight the COVID-19 stigma. From their observations, it appears that funding facilitation for the epidemic was very low, there was no adequate allowance, and the relatives who were empowered to care for patients did not get formal treatment.

Satisfaction of Homebased care givers and Frontline health workers in management of COVID-19

The home-based health care providers and front-line health workers were asked whether they were satisfied about remuneration for the work done. The home-based care givers were not satisfied on account that they got little allowances that were not commensurate to the work they did. Many lamented that they never got what they were promised. Accordingly, even the PPE were not enough.

However, some of the front-line health workers were satisfied in terms of remuneration, such as allowances, transport facilitation, increased PPE, and privileges given to them as health workers. They agreed that the remuneration was fair since it was a disaster that they had prepared for. Others were not satisfied with the remunerations. That the incentives were not enough to support the health workers, there was little PPE, allowances were delayed, and the remuneration was too small, yet they would hear a lot of funding coming to the district.

Discussion

Lived experiences in caring for patients with COVID-19

The home-based care givers and front-line health workers were asked about their daily experiences in caring for patients with COVID-19 disease at home. The home-based care givers reported daily practices as ensuring hygiene and clean environment as they were in constant contact with patients; providing good meals daily and regularly; assessing and administering medication to the patients; observing strict standard operating procedures (SOPs); ensuring strict isolation rules; comforting the sick who would be worried; washing clothes of the patient; isolation of the patients; visiting patients to record some improvements; putting on the masks when assisting the patients and ensuring the patients adhered to the instructions of wearing masks. A Malaysian-based study based on the lived experiences of older adults in aged care homes indicated that older adults have a higher risk of contracting COVID-19 and that old age with multimorbidity increased the risk of dying from COVID-19 (Mutya *et al.*, 2021). The current findings are in line with Matovu et al. (2021) who notes that individuals' health status and access to healthcare were worsened by socio-economic disruptions, an inability to meet basic needs, and engaging in unhealthy behaviors such as sedentary lifestyles and alcohol consumption. Violent re-enforcement of public health restrictions was mentioned as another hindrance to seeking healthcare (Giebel *et al.*, 2022).

Study findings have shown that COVID-19 caused a number of socio-economic problems with access to health services, availability of medical supplies, and affordability of health care (Mok *et al.*, 2005). Research studies indicate that COVID-19 brought both direct and indirect challenges. Direct in the form of causing fear and anxiety, persistent health problems and complications, economic issues, i.e., collapsing of businesses, and reduced quality of health. Indirect challenges like a change in life style and a decrease in social and family relations (Hui *et al.*, 2020).

Lived experiences of COVID-19 caregivers

According to a study on the caregivers' actual experiences when the COVID-19 pandemic (Suzuki *et al.*, 2020), caregivers were worried about preserving good hand hygiene, wearing a face mask, and avoiding social contact. When instructed, patients would not comply and become agitated. (Bauza *et al.*, 2021). In the same research, caregivers stated that if their patients were hospitalized due to COVID, neither they nor a stranger would be able to care for them (Abila *et al.*, 2020). In addition to managing changes in their patients' daily routine activities, caregivers also had to deal with outdoor games and piano lessons that had to cease due to restrictions imposed by COVID-19. Additionally, caretakers noticed that patients' already-existing issues were getting worse (Vaitheswaran *et al.*, 2020).

Recommendations

To the policy makers: There is need to keep monitoring the community members who survived from COVID-19 to avoid any other outbreak of diseases unknowingly.
To the ministry of health-Uganda: There is also a need for mass education on the effects of COVID-19 and community outreach to comfort those survivors. This improves people's perceptions on the pandemic.
To the government: The government should put in place a strong committee on education to provide a new learning programs that enhance awareness on COVID-19.

Declaration of competing interest

None

Acknowledgement

Research reported in this publication was supported by the Forgarty International Center of the National Institutes of Health, the US Global AIDS Coordinator and Health Diplomacy (SIGAC), and the President's Emergency Plan for AIDS Relief (PEPFAR) under Award Number IR25TW011213. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Health.

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