“Why take the patient back home?”: exploring the lived experiences of caregivers of COVID-19 infected individuals in Blantyre, Malawi

Alinane Linda Nyondo-Mipando (lmipando@kuhes.ac.mw)  
Kamuzu University of Health Sciences, School of Global and Public Health, Department of Health Systems and Policy

Deborah Nyirenda  
Malawi-Liverpool-Wellcome Trust Clinical Research Programme

Leticia Suwedi-Kapesa  
Public Health Institute of Malawi

Marumbo Chirwa  
Kamuzu University of Health Sciences, School of Global and Public Health, Department of Health Systems and Policy

Wezzie Nyapigoti  
Malawi-Liverpool-Wellcome Trust Clinical Research Programme

Lusungu Chirambo  
Kamuzu University of Health Sciences, School of Global and Public Health, Department of Health Systems and Policy

Ruth Singini  
Kamuzu University of Health Sciences, School of Global and Public Health, Department of Health Systems and Policy

Victor Mwapasa  
Kamuzu University of Health Sciences, School of Global and Public Health

Research Article

Keywords: Informal Caregiver, COVID-19, preventive measures, Support

Posted Date: October 14th, 2022

DOI: https://doi.org/10.21203/rs.3.rs-2127905/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License. Read Full License
Abstract

Background

Corona Virus disease 2019 (COVID-19) pandemic continues to have serious health and socio-economic consequences. World Health Organisation (WHO) recommends several measures to combat the COVID-19 pandemic. In Malawi, COVID-19 cases are managed at home with hospital admission reserved for severe cases. This study described the lived experiences of caregivers of COVID-19-infected individuals in Blantyre, Malawi.

Methods

This descriptive qualitative study was conducted from January to June 2021 in Blantyre Malawi, among caregivers of confirmed SARS-COV-2 cases enrolled in the SARS-CoV-2 study aimed to explore infections, transmission dynamics, and household impact. We conducted 37 in-depth interviews with caregivers of SARS-COV-2 cases. We captured data using telephonic interviews, digitally recorded, transcribed verbatim, managed using NVivo, and analysed thematically.

Results

The economic status of a family largely influenced the caregiving roles and abilities because it determined the resources that a household could access or not. Caregivers were committed to their role despite being ill-prepared to manage a COVID-19 patient at home in addition to fears about the contagious nature of COVID-19. They prioritised their patients’ health by ensuring that they were present to offer nutritional and medical treatment. The implementation of preventive measures was however challenging because of financial limitations and cultural factors. The increase in death rates and the lack of proper information challenged their expectation of having their patients healed. Caregivers managed their role by sharing responsibilities, getting better at their role with time, and also getting support from religious institutions and social networks.

Conclusion

The economic status of a household determined the experiences of caregivers as they managed their COVID-19 patients at home. Caring for confirmed cases of COVID-19 demanded commitment from the caregivers while ensuring that the transmission of the virus is minimised. There is a need to support households while in isolation with the right information on how to manage their patients and streamline social support for the ultra-poor.

Background

Corona Virus (COVID-19) is a global pandemic caused by the Severe Acute Respiratory Syndrome Corona Virus (SARs-Cov- 2). Most people diagnosed with COVID-19 usually present mild to moderate symptoms requiring home management and nursing. COVID-19 is a highly infectious disease, and the World Health
Organisation (WHO) recommends several measures to prevent the spread of the pandemic. These measures include mandatory wearing of masks, getting vaccinated against the disease, keeping a physical distance of a metre, cleaning hands frequently with soap and water or an alcohol-based hand rub, sneezing into a bent elbow, self-isolation if one has symptoms or tests positive for COVID [1]. Since COVID-19 is a global pandemic, all countries, including Malawi, adopted these preventive measures.

The first case of COVID-19 in Malawi was reported on 2 April 2020 [2]. As of 19th September 2022, there have been 87,981 people who have tested positive for COVID-19 in Malawi, with a case Fatality rate of 3.05% [2]. The second wave, from December 2020 to May 2021 had the highest case of fatality rates among all the COVID-19 waves in Malawi. Malawi has a four-tiered health system that includes the community, primary, secondary and tertiary levels [3]. Testing of COVID-19 infection in Malawi is done in selected primary health care facilities but mostly tested in secondary level facilities. All admissions are at both secondary and tertiary level facilities. Malawi followed a staggered approach in developing sites for testing and admission, with tertiary hospitals championing the services. The mild and moderate cases of COVID-19 are managed at home, with hospital admission reserved for severe cases [4]. These caregivers are usually family members who offer the services voluntarily and may not be adequately prepared for the role [5].

Previous research in other settings showed that caregivers for COVID-19 patients expressed fears of getting infected, perceived their caregiving role as a burden, and compromised due to a lack of support or coping mechanisms to manage the role [6]. The experience of caring for a COVID-19 patient was deemed different from caring for patients with other conditions because COVID-19 was an emerging and unpredictable condition without a clear treatment plan that exhibited fluctuating symptoms unlike other conditions that have an outlined and fixed treatment regimen [7–9]. The care rendered was perceived as compromised because of a lack of information about the disease, lack of health services support, and financial constraints [7, 8]. Caring for a COVID-19 patient resulted in unpleasant physical experiences from the use of disinfectants in the home [7], psychological stress over the illness [7–9], and in other instances, the psychological burden on caregivers [9], and negative social experiences from others [7, 8]. As a coping mechanism, caregivers depended on spirituality [7–9], their relationships [7], maintenance of hope for a positive outcome [8], and adaptation to their role of caregiving [9].

The shift in the management of COVID-19 cases at home and considering the paucity of data on the caregivers’ experiences in managing patients within their homes necessitated the conduct of this study which sought to describe the lived experiences of caregivers of COVID-19 infected individuals in Blantyre, Malawi. This information will inform policymakers on how to draft manuals to assist caregivers in managing their patients at home.

**Methods**

**Study Design**
This was a descriptive qualitative study conducted from January to June 2021 in Blantyre, Malawi, among caregivers of confirmed SARS-COV-2 cases that were enrolled in the SARS-CoV-2 infections, transmission dynamics, and household impact study in Malawi. Our study on the caregiving experiences is part of a larger project, “SARS-CoV-2 infection, transmission dynamics and household Impact in Malawi (SCATHIM)”, a cohort study that aimed at determining the transmission dynamics, determinants, and household socio-economic impact of SARS-CoV-2 infection in Malawian settings. The project had four work packages namely: epidemiology, social science, health economics, virology, and immunology. Our study was in the social science and health economics package. We have reported the study following the COREQ Checklist (Supplementary File 1).

Study Setting

The study was conducted in both urban and rural Blantyre, in southern Malawi. As of 2018, Blantyre had a population of 1.25 million, with 66% of those residing in urban settings [10]. Blantyre is also a commercial city and has varied socio-economic statuses and residential areas. The city is not well planned, with only a minority residing in properly planned low-density, medium-density, and high-density locations that are well serviced with electricity, water, and sanitation amenities. Most of the residents in these areas are formally employed or run formal businesses for their economic sustenance. Most of the population resides in unplanned high-density urban and rural areas with limited water, electricity, and sanitation amenities, including houses in poorly demarcated areas and close to each other. Most residents are informally employed or run small-scale, informal businesses as a source of income. Since the start of the pandemic in Malawi, Blantyre has always been the epicentre of the COVID-19 pandemic. As of 19 September 2022, Blantyre had registered 24,309 cases with a Case Fatality Rate of 2.81.

As alluded to earlier, the study had an epidemiological work package, which used the following demarcations: Blantyre rural, Blantyre Urban Low density, and Blantyre Urban high density and this study followed the same classification. This variation was important for the study because we hypothesised that different settings would accord caregivers varying experiences which will broaden the nuances that caregivers would share in the study. Blantyre has one tertiary hospital and 36 Primary health facilities.

Sampling And Sample Size

A purposive sample of 37 caregivers was drawn to achieve variation in the characteristics of participants. They were drawn from the enrollment register of the main study. The epidemiology work package had an enrollment register where all patients with SARS-COV-2 were captured, including their primary caregivers’ information and their places of residence. The enrollment log was used to identify the caregivers that the researchers approached for participation in the social science work package. We defined a caregiver as one providing most of the care to the patient. We recruited a caregiver 14 days after the patient was enrolled in the main study to give the caregiver adequate experience to draw their lessons from. The study
was inclusive of caregivers above the age of 18 years, willing to participate, and the primary caregiver of a COVID-19 patient enrolled in the main study. Thirty-seven caregivers were deemed adequate because Guest et.al., [11] argue that by the 12th interview, one would have captured 97% of the required information. In this study, we increased the sample size to maximise the number of rural-based caregivers as they were few, which was also in keeping with the pattern of the pandemic, with the urban areas worst affected than rural settings.

**Data Collection**

We conducted 37 in-depth interviews among caregivers of SARS-COV-2 cases from January to June 2021. Four seasoned qualitative research assistants, three female and one male namely MC, WN, LC, and RS conducted the digitally recorded telephonic interviews. MC and LC are public health specialists while WN and RS are qualitative field workers. At the time of the study, they were working as Research Assistants on the project. We opted for telephonic interviews to minimise the spread of COVID-19. Researchers reviewed the enrollment log of the main study and purposely sampled from the list. The epidemiology work package information leaflet included a clause that primary caregivers may be contacted for participation in the social science work package later. Researchers would make an initial call to introduce themselves and the study, and if a potential participant was willing, the date and time for a telephonic interview would be set. Before the interview, the researcher obtained consent by reading out the consent form to the participant and recording the response from the participant as part of the audio data. After obtaining informed consent, the research assistant proceeded with the interview following an interview guide (Supplementary File 2).

The interview guide was both in English and Chichewa (local language) languages. Before the study, the guide was piloted among caregivers that we did not include in our analysis. The pilot aimed to ascertain the appropriateness and reliability of the questions [12]. Data saturation [13] was realised when there were no more new ideas from the participants, when we got to the 34th interview. However, we conducted three more interviews to confirm saturation and maximise the number of caregivers from the rural areas who were initially few in the study. During the interviews, the researchers compiled field notes that included the process of the interview, the flow, and the participants’ conduct during the interview [14]. There were no repeat interviews. At the end of each week, the team held meetings to discuss the progress of the data collection and resolve any challenges faced during telephonic interviews. Interviews were conducted interviews in English or Chichewa per the participant's preference; in some cases, both languages were used. Of the people that we approached, 13 refused participation because of the following reasons: found the study compensation not enough, not sure of the researchers' identity because of telephonic interviews, concerned with privacy and confidentiality issues because of telephonic interviews, and denial that the patient had COVID-19. The average time of the interviews was 50 minutes.

**Data Management And Analysis**
All audio data were immediately transferred after the interview from the digital recorder and were stored in a password-protected google drive and later transferred to a password-protected computer. We limited access and management to the researchers. Data were managed using NVivo 12 software (QSR International, Melbourne, Australia). Once data collection started, ALNM, MC, LSK, and DN reviewed three transcripts to develop the codebook. Each of them independently reviewed and coded transcripts and later held a meeting where they discussed the codes. Areas of difference were discussed to reach an agreement. All data that were in Chichewa were translated into English by a transcriber who is fluent in both languages. Once the codebook was ready, all data was coded by an independent data coder. The coder held iterative meetings with the researchers to discuss the inclusion of more codes in the codebook or a combination of overlapping codes. Thereafter, the researchers reviewed the data set for patterns including similarities and differences across the codes and grouped all related data under overarching themes. The qualitative data on the lived experiences of the caregivers were analysed and categorised following a thematic approach and guided by the theory of caregiving dynamics [15]. This theory has three constructs as follows: commitment, expectation management, and role negotiation. Commitment entails that a caregiver is dedicated to providing care to the patient irrespective of the risks, challenges, and lack of self-prioritisation that comes with the role. Expectation management states that a caregiver and a patient have expectations such as worsening or a better prognosis of the condition of the patient and also includes the roles that both a caregiver and patient have to fulfill. Expectation management consists of envisioning tomorrow, getting back to normal, taking one day at a time, gauging behavior, and reconciling treatment twists and turns. Role negotiation entails a caregiver pushing and getting grips with the caring responsibility, sharing responsibilities, attending to or listening to the patient’s voice, and vigilant bridging through negotiations with the health system in the care of the patient.

All these themes were reviewed against the audios and transcripts to ensure that they were correctly represented. All themes that had no data supporting them were dropped while those with similar data were combined.

Results

Characteristics of participants

The median age of the participants was 41 with an Interquartile range of 32–51 years. Twenty of the caregivers were males and 27 of them were married. Twenty-seven had college-level education. Twenty-four caregivers were employed and 15 resided in low-density urban areas of Blantyre, respectively (Table 1)
Table 1
Characteristics of Caregivers (N = 37)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Median 41; IQR 32–51</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>20</td>
</tr>
<tr>
<td>Male</td>
<td>17</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>27</td>
</tr>
<tr>
<td>Widow</td>
<td>9</td>
</tr>
<tr>
<td>Single</td>
<td>9</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>College</td>
<td>27</td>
</tr>
<tr>
<td>Secondary</td>
<td>8</td>
</tr>
<tr>
<td>Primary</td>
<td>1</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>24</td>
</tr>
<tr>
<td>Business</td>
<td>8</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
</tr>
<tr>
<td>Area of Residence</td>
<td></td>
</tr>
<tr>
<td>Low density urban</td>
<td>15</td>
</tr>
<tr>
<td>High density urban</td>
<td>12</td>
</tr>
<tr>
<td>Rural</td>
<td>10</td>
</tr>
</tbody>
</table>

Economic Influence On The Management Of A Covid-19 Patient At Home

In this study, the overall and commonly stated factor that largely influenced the lived experiences of caregivers was economic resources. The economic resources determined the adoption of preventive measures within households, access to relevant treatment, and provision of adequate care to the patient.
Participants who regarded themselves as poor stated that they were economically challenged to care for COVID-19 patients at home while those who did not regard themselves as poor were able to offer necessary support to the patient. As such, the results of our study are underpinned by the economic status of a family. Figure 1 below illustrates the interconnection of the factors with economic factors as the platform of the caregiving experience.

Economic challenges were more pronounced among families whose members were not formally employed but depended on small-scale businesses. The economic hardships that caregivers and their patients faced were exacerbated by the demands of isolation as a measure of preventing COVID-19. Such economic challenges were compounded in circumstances where a breadwinner was the index patient or when the primary caregiver was also the breadwinner and needed to isolate. The aspects of their livelihoods that were affected included nutrition supplies, rental obligations, and in some instances, families went into debt to meet their financial demands.

“Our daily welfare wasn’t good at all, we were affected so much because our only source of money was him (the patient), and we were living in hell, and it was difficult for us to find food. We could find food through some of our relatives who were sending us some money, which was used to take care of us here. So, sometimes we could just go out and buy some pumpkin leaves and eat, and sometimes we could reach the point of sleeping without eating anything…” Participant 1041 Blantyre Rural Caregiver

“The major challenge was on the financial part; we were forced to improve our diet because from our understanding one has to have a good immune system to be able to fight the virus. So it is like compromising a lot of things ranging from financial obligations to borrowing money from others, just to make sure that our daily diet was good to boost our immunity.” Participant 1079 High-Density Urban Caregiver

On the other hand, financially stable caregivers stated that managing a COVID-19 patient at home, enabled them to save because they never spent money on transportation.

“On my part, I saved on fuel because I am not that mobile, I am not going to any drinking joint, so the money that I would use on drinks, on a Friday and Saturday, means I am home and I am not using that one… I cannot say that it impacted me negatively but it did on my savings, so my savings were huge.” Participant 1007 High-Density Urban Caregiver

The Commitment Of The Caregiver

According to the theory of caregiving dynamics, commitment has four dimensions that were deduced as sub-thematic areas for this study. These dimensions include enduring responsibility, prioritizing the patient, supportive presence, and self-care. There was an overlap between prioritizing the patient and offering a supportive presence and these have been combined in our results
Enduring responsibility in the absence of information and anxiety to managing “highly contagious” patients at home

Most caregivers were committed to caring for their patients at home despite some concerns about caring for patients with a 'highly contagious disease' at home instead of the hospital. Despite these concerns and lack of information on how to care for the patients at home, they were committed to caring for them. The lack of information on how to care for the patient at home perpetuated the caregivers' anxiety.

“At first, we thought that anybody who is positive for COVID-19 is supposed to be admitted to the hospital, so after telling us that we should be going home, we were very anxious to say: why take the patient back home and how will we be able to take care of her back home? Hence being anxious in the process...”
Participant 1012, Blantyre Rural Caregiver

“So our only worry comes in because we do not know how we are supposed to be taking care of COVID-19 patients and wish the hospital staff were able to come and teach us how to do it...I have never seen anywhere where the procedures of how people can be taking care of their patients are stated, so I believe that if they were able to do that, things would have been better because those caregivers will be greatly assisted. So maybe we were lucky because he didn’t reach a very critical stage.” Participant 1023 Blantyre High-Density Urban Caregiver

Making The Patient A Priority And Offering A Supportive Presence

Caregivers stated that the nature of the condition and the demands that ensued upon the family necessitated the prioritization of the patient's needs, over everyone else in aspects concerning nutrition, medications, and comfortability. Caregivers prioritised the family's health over other financial demands like bills and rentals and ensured that they had finances to cater to their medical-related bills.

“I think we just prioritised what was just necessary then, which was first buying the medication and then the food ... On the businesses, I had to put on a standstill” Participant 1009 Blantyre High-Density Urban Caregiver

“I just reduced some of the things that I was doing on other projects which I was working on, and instead concentrated much on our nutrition for us to remain healthy like buying some fruits, and vegetables ... rushing to the hospital whenever we felt sick, and even buying some fuel to take us to the hospital and sanitisers.” Participant 1032 Blantyre Rural Caregiver

Some caregivers said that despite being positive for COVID-19 as well, they prioritised the care of the index patient over their illness because of the severity of the illness of their patient. In such instances, caregivers continued to provide care and attention to the patient even though they were infected themselves.

“Again, I was supposed to prepare food, and buy the food, but since we were both in isolation; we were not supposed to go out... I was supposed to take care of them, whilst I was also a patient and the rest of
the people in the house were also waiting for my services.” Participant 1026 Blantyre High-Density Urban Caregiver

As an extension of prioritising the patient, caregivers provided a “Supportive Presence” to their patients. For caregivers to do this, they had to relinquish other responsibilities like business, work commitments, social responsibilities, and others sent away their house-help to prevent spreading the disease. The unfamiliarity and the rise in the COVID-19-related deaths that occurred at the time of the study influenced the presence of the caregiver and the level of prioritisation that was accorded to the patients.

“Again, since you always wait for her to give you a sign, so if she says that she has a headache or stomachache, or even having diarrhea, this stresses you because of how people were dying at that time.” Participant 1029 Blantyre High-Density Urban Caregiver

“For starters, like at church, I am also privileged to be a treasure of one of the fundraising committees, so, what I did when my wife was found positive, I met one of the members in the committee and I told them that “this is the case, my wife is positive, so, I am handing over my things to you for I think, for the next 2 or 3 weeks. I will not be seen around even at church or at home cells, weekly meetings at church I won’t be around until I have or the family has been confirmed negative” Participant 1009 Blantyre High-Density Urban Caregiver

**Implementation Of Preventive Measures- “self-care”**

**Use of Face Masks and Sanitisers**

Participants mentioned that in some cases the implementation of some preventive measures was challenging because they feared that it would be construed as discriminatory and stigmatising. While some caregivers indicated that they wore face masks to prevent contracting the disease, other caregivers indicated that they did not wear a face mask because they perceived it as discriminatory as shown below:

“I think that it was just by the grace of God that we all came out negative after being tested. I could go into the bedroom without a mask and sometimes I could wear a mask because when you put on a mask, it feels like you are stigmatising him/her.” Participant 1023 Blantyre High-Density Urban Caregiver

The use of sanitisers and masks also varied according to a family’s economic status. Some caregivers indicated that they used cloth masks and not medical masks because these were affordable and reusable, hence limiting the costs.

“The main problem is the lack of resources that we can use in taking care of the patients because a lot of households do not have sanitisers, others are reusing the disposable blue masks in the process and most people are using cloth masks and I don’t know if these masks are recommendable.” Participant 1023 Blantyre High-Density Urban Caregiver

**Practicing Isolation Measures**
The maintenance of isolation measures was also a challenge, particularly in homes that had limited space and large numbers of people. However, homes that had adequate space found it easier to isolate their patients and maintain those recommendations as shown in the two quotes below:

“We were anxious because the house is too small, it has two bedrooms and already it contains six people and how are we going to go about it? How is she going to be isolated looking at the present situation regarding the house? Then when my brother came we agreed the patient was supposed to be in one room alone and the rest of us occupied the space in the sitting room and the remaining room.” Participant 1012 Blantyre Rural Caregiver

“[Patient stayed] In the sitting room because it is a bigger room than the other bedroom. When I cooked food, I would dish my food and come to the sitting room, then she would dish out hers and goes to her room. Before dishing out my food, I would have my plates ready in my room. So before going to wash my plates I would ask “Is there anyone in the kitchen?” and if she says “no“ and I would go to the kitchen, wash my plates. On some days I would clean my room and then she cleans her room too.” Participant 1017 Blantyre Low-Density Urban Caregiver

In other cases, the patients were never isolated because of the inhumane connotations of observing these preventive measures. For some caregivers to provide a “supportive presence” they overlooked isolation measures because it was inconsistent with the way patients are managed, cognisant that ordinarily patients are never left on their own. Some caregivers stated that some amenities remained common for both the patient and caregivers such as bathrooms and others slept in the same room and bed. Over time, other caregivers got used to their role and were able to allow the patient to isolate to prevent spreading the infection. One male caregiver narrated the experience of managing his sister, he explained the dilemma he had in applying isolation measures, and how he finally got to do that after explaining to his sister the requirements:

“I was very anxious about it (isolation) and worried because I was thinking about how is she going to be alone in the same house. I was thinking that it will be hard for me to do it and it will be like I am stigmatizing her in the process, how will I be able to go about it? How will I be able to provide things for her? ... That was what I was thinking then, but suddenly I dared to go on and I had to be strong enough to go and take care of my sister. That strong voice kept on telling me to be strong and take care of her to avoid a scenario where both of us are sick. Because if we are both sick, then nobody will take care of us. So, what makes me happy is the fact that my sister understood and accepted the situation and she was the one who suggested to be in isolation she said “let me go in isolation so that we should prevent others from contracting the virus and let me protect all of you” and we accepted and started to follow the rules of the game.” Participant 1012 Blantyre Rural Caregiver

Families changed the way they related emotionally to one another as a means of minimising the transmission of the virus

“Of course, it can’t be normal, and being worried wasn’t going to work but if you always have morning hugs, then there are no more morning hugs, trying to maintain social distance even though it’s not easy.”
Participant 1007 Blantyre Low-Density Urban Caregiver
Designation of specific cutlery and plates for a patient as a preventive measure was also a challenge in some homes, especially in cases where parents needed to have designated utilities for their children.

“Everybody can use any cup at any time. So it was difficult to control them to say “No, this is only for us because we are suffering from a b c” Now, for children to accept that thing, it was like they couldn’t understand. After all, it was our norm for anybody to use any cup or any plate within the house.”

Participant 1027 High-Density Urban Caregiver

**Expectation Management**

This construct suggests that a caregiver envisions and longs for the return to normalcy. The tenets under this construct include envisioning tomorrow and spiritual reliance are linked in the presentation of the results

**Envisioning tomorrow**

Caregivers negotiated their expectations about the return to normalcy by encouraging their patients to take the necessary treatment for them to recover soon. Caregivers applied various measures to ensure that their patients recover quickly. These measures included encouraging the uptake of nutritious meals at home, making plans for the future by stocking up on what they needed if lockdown measures were enacted as well as ensuring that the patient takes all the supplements like ginger and lemons.

Okay, mostly, you know how you are trying to change your diet or the way you eat. Every member of the house was told “you have to be drinking this (ginger and lemon drink)” which is not exactly sweet. But now they have to be taking such a drink, they have to steam...we more or less had to have a lockdown,...We had to buy some other things that we had not planned to last for two weeks. We had to be indoors to avoid being in contact with other guys, just to avoid some unforeseen circumstances or something like that.” Participant 1009 High-Density Urban Caregiver

“Again, we could buy some of these drugs which we didn’t expect to buy all along. People were telling us to buy some Erythromycin, Zinc, and the like. In addition, we could rush to the hospital each time we observed that someone is not feeling well.” Participant 1032 Blantyre Rural Caregiver

Some of the caregivers’ plans included financial strategies for returning to normal while mitigating the losses that were incurred during the pandemic. Participants envisioned that financial restoration will take some time and feared that they may not fully recover from the losses they suffered

“I still have a couple of debts that I incurred because of this pandemic, I will be settling the gradually. That means that for us to go back to the way things were and for things to be alright, it will take time and maybe some of these things will never be sorted out as they have already veered off.” Participant 1042 Blantyre Rural Caregiver
Although caregivers maintained a positive attitude and expected positive outcomes, they stated that they were affected by the perceptions of their neighbours who expressed a gloomy picture of the possible outcome of the sickness such as death. This was aggravated by the increase in the number of deaths secondary to COVID-19.

“Another problem which we faced was the rumors that people were spreading about us saying “we do not know if they are going to make it tomorrow or have you heard about them? They have got COVID-19 and so on” Participant 1019 Blantyre High-Density Urban Caregiver

Some caregivers depended on their faith as a coping mechanism, especially in instances where the family members remained COVID-19 negative while nursing a positive patient in the home.

“I think that it was just by the grace of God that we all came out negative after being tested.” Participant 1023 Blantyre High-Density Urban Caregiver

“As a person who once had COVID-19 disease, when I heard that people are dying as a result of COVID-19, then I started to think that maybe I will also die of COVID-19 in the process, but by the Grace of God, I am still alive today and I don’t have COVID-19 in me.” Participant 1034 Blantyre Low-Density Urban Caregiver

**Role Negotiation**

Caregivers expressed that they navigated their role by getting a handle on the expected responsibilities as far as the provision of care was concerned, sharing responsibilities to ease up their role, and receiving support to perform their role.

**Getting the handle on the role and sharing responsibilities**

Even though observing isolation was a challenge in large families, reliance on household members and social networks helped to ease the caregiving roles of COVID-19 patients. Caregivers stated that in the course of managing their patients at home, they shared responsibilities within the home and among other family members external to the home. These responsibilities included purchasing items that were needed while the patient and the family were in isolation. Other domestic responsibilities were shared within the home. In other instances, when both the caregiver and patient were positive, the families relied on older children to manage the home which was also a challenge.

*Interviewer:* So how were you managing your daily welfare, for example, your daily household chores, how was it done?

*Respondent:* It was done perfectly because we were able to sweep the house, somebody would wash the plates and everything was done accordingly.

*Interviewer:* Okay. Even during her sickness?
Respondent: Yes, and to be honest with you, she wasn’t that serious because I didn’t see her down, she would complain to feel some body pains but she wasn’t down- Participant 1018 Blantyre High-Density Urban Caregiver

On the other hand, caregivers in small families stated that they had to bear domestic responsibilities, especially in cases where a female partner was a patient. While men normally invite female relations to look after their female partners when they are ill, the requirement to isolate challenged the men to embrace domestic roles. As such, male partners had to assume traditionally designated female roles in the home. Some male caregivers faced challenges to decide on suitable meals for invalids and how to prepare them. Other men felt embarrassed to undertake domestic responsibilities designated for women outside the home where neighbors could see them. They would therefore undertake such responsibilities at odd hours to avoid being seen by neighbors.

“[Home management] Quite challenging because, being a man, I am not used to buying these things (household stuff) or preparing food for the day. Yeah, it was quite a challenge...but I was doing that at odd hours because I didn’t want people to see me or before anyone notices that I have gotten out.” Participant 1027 Blantyre High-Density Urban Caregiver

“We were only the two of us and I had to work up every morning, doing everything...I had to wake up early in the morning to make breakfast and even clean the house and wash the utensils.” Participant 1003 Blantyre Rural Caregiver

Support From The Caregivers' Social Networks

Caregivers sought various kinds of support to enhance their role as they cared for a patient. The support they sought was in the form of finding helpful information, finding others to support other activities, and meeting financial responsibilities. These responsibilities included purchasing items that were needed while a caregiver and the patient were in isolation.

Receiving Helpful Information

Some caregivers were concerned that they had limited information on caring for their patients, and had hoped that healthcare workers would teach them about the management of COVID-19 patients at home.

“I was saying that you need a lot of things when you are taking care of a patient. When a patient has been found positive for COVID-19, they (health workers) should inform the family of the medicine to buy.” Participant 1030 Blantyre High-Density Urban Caregiver

In the absence of concrete information platforms, caregivers sought information from their social networks that included healthcare workers who encouraged them on what they needed to do.

I: How did you overcome those fears which you have at that time?
R: I met some people and some nurses who used to encourage me in my spiritual life, they were saying that I wasn’t supposed to do things like those, “just accept that you have COVID-19 with all your heart, you will not die, and you will just be fine.” Participant 1034 Blantyre Low-Density Urban Caregiver

Other caregivers attested to being counseled at the point of testing and were informed about the nature of the illness and the benefits of minimizing stress while managing the condition. This counseling assisted some caregivers in breaking the positive results to their patients.

“However, since they gave us counseling during the COVID-19 Testing, they told us that the illness doesn’t need one to be stressed up, no need for anxiety and whether you will get a positive or negative result, remove the anxiety and stress in you, for you to be able to handle the illness otherwise if you don’t remove these two, you will not be able to manage the COVID-19 illness. So, since they told us already about it, I composed myself because I was the one to inform the patient about the outcome of the COVID-19 testing.” Participant 1002 Blantyre Low-Density Urban Caregiver

Finding support to manage household needs and businesses

Caregivers depended on others to get essentials for them including caring for the patient to allow a caregiver to attend to their work. Other caregivers stated that school holidays eased up their roles because they only focused on their patients and were relieved of the demands associated with the school. In other cases, the house help assisted in managing the home while observing isolation measures so that they are not in contact with the patient but with the caregiver only.

“I was managing it (caregiving role) because at first, I was the one taking care of her for some few days, then a few of her relatives came to help in taking care of her, like when I went to work then her relatives were the ones taking care of her ...when I come back from work, we would care for her together.” Participant 1030 Blantyre High-Density Urban Caregiver

“The problems were there since we needed to go and deliver the rice so that people could take the rice. The fritters that we sell outside required us to go and buy flour, those errands are on hold. The process of making fritters requires one to buy resources like firewood, oil, and the like, and if you don’t have them, where can you go? You can’t ‘go to another person since they are already discriminating against you?’” Participant 1033 Blantyre Low-Density Urban Caregiver

Although some were able to find a person and had the finances to get essentials, some found that difficult as they had no one they could depend upon and if available, they found themselves dependent on the person’s availability to assist them. The reliance on others was a problem when the person to provide support also had a COVID-19 patient or had suffered a loss from the same.

“The only challenge was the issue of asking someone to go and buy something for you at the shops, we relied on that person’s availability to do that without forcing him/her.” Participant 1002 Blantyre Low-Density Urban Caregiver

“It was a huge burden on my sister because her husband died of COVID-19 and then her two sisters had COVID-19 as well, so I was feeling sorry for her because we all depended on her to give us support...”
Participant 1029 Blantyre High-Density Urban Caregiver
The lack of medicines and support in the public facilities forced caregivers to spend money and access the medicines to treat the symptoms they presented with from private facilities

“I was using my means, like using my money to go to the hospital, since they offer the testing without providing the treatment. So we could just go to any private clinic and get the cough and flu drugs.”

Participant 1032 Blantyre Rural Caregiver

Meeting Financial Responsibilities

Other caregivers narrated that they had no one to support them and they managed the financial responsibilities by themselves. This was easier for families that were formally employed unlike those that were not employed or were running small-scale businesses.

“We were just waiting for the salary at the end of the month and there was nobody who came and assisted us during that time... it was just me and my children and my husband but I had a lot of problems, you can imagine that it was only him (husband and patient) who is a breadwinner and then he got sick, yet we only rely on the same person who was sick, and nobody came to assist us.” Participant 1092 Blantyre Rural Caregiver

Another caregiver narrated their experience in managing with minimal resources in this way:

Respondent: We were just staying like that and we would just prepare porridge with salt only and we would eat, even eating nsima with vegetables only

Interviewer: Did you reach that level?

Respondent: Yes, do you expect our relatives to be helping us every day? We reached that far and there was nothing we could do about it... so you can't force a relative to buy something for you when he/she doesn't have anything to offer. So, if we have flour and salt but without no sugar, we would eat porridge and we would eat nsima with vegetables only. The problem is that we are used to eating vegetables, meat, beans, small fish and the like, so if we don't have them, we would eat whatever is available.

Participant 1019 Blantyre High-Density Urban Caregiver

Other caregivers left off their businesses to be managed by their friends and would only collect the money as needed. As the patients got better, some caregivers resumed their income-generating activities so that they could build back their economic base.

“I left my business with some friends so that they could be selling them on my behalf and I was able to get some money after the sales. Participant 1012 Blantyre Rural Caregiver”

Discussion

The main finding from this study on lived experiences of caregivers of COVID-19 patients was that a family's economic status largely influenced the caregiving roles and abilities. Furthermore, the results
show that caregivers were committed to their role despite being ill-prepared and scared about managing a COVID-19 patient at home. In their commitment to care for the patient, they prioritised the health of their patient by ensuring that they are present and meeting the nutritional and medical demands related to the illness. In some instances, they found practicing preventive measures challenging to implement because of financial challenges and cultural factors. The expectation of having their patients healed was shaken by the increasing number of deaths that occurred in their areas of residence and they depended more on their spiritual links to avoid despair. Caregivers managed their role by sharing responsibilities, getting better at their role with time, and getting support from social networks to cover aspects like accessing helpful information, finding support to help in meeting other needs and financial responsibilities.

The finding that economic status determined the caregiving experience as illustrated in this study is consistent with earlier findings that the lack of finances created unmet needs for the family [7, 16, 17], especially in cases where the patient was a breadwinner and was not formally employed [7]. The excessive expenditures by families that were observed in our study were also experienced by other caregivers in Iran where they spent more money on nutrition and medical needs [8]. Our findings differ slightly from earlier findings where there was a strong call for the government to support the families [7]. In our study, the participants, despite desiring such assistance, were also unsure of the feasibility of that support. We contend that with proper planning and assessment of the ultra-poor and vulnerable households, the Malawi Government could implement social support for such families. There is a need to adopt a vulnerability assessment scale that can assess a household's access to cash and food that can apply to a Malawian setting [18]. A review on the impacts of cash transfers, which is a social protection measure, concluded that they are effective in increasing food expenditures and yield positive impacts such as improvement in health and nutrition indicators as well as the use of health facilities [19].

Specifically for Malawi, unconditional cash transfers have shown to be effective in health-seeking when ill as well as improvements in the nutritional status [20], which would be consistent with the goals if implemented in the context of COVID-19 infection. Notably, developed countries could cushion their caregivers in the face of COVID-19 with the provision of flexible leaves, financial assistance, and protective wear. Although Malawi implemented the Malawi COVID-19 Urban Cash Intervention, none of our participants accessed it because it occurred between April to June of 2020 before the commencement of the study. However, it provides lessons to develop more support from this exercise that provided a minimum wage equivalent bill at the time and was only done for three months [21].

Our study showed that caregivers were committed to caring for their patients even though they were scared. This result is consistent with findings from an Iranian study that reported that caregivers were scared of the fluctuating symptoms that their patients presented with and the unpredictability of the diseases [7]. Furthermore, earlier studies showed that caregivers were scared of contracting the virus [8], which was also expressed in our study. Although caregivers expressed such fears, the practice of implementation of preventive measures was impeded by economic factors and the fear of portraying a discriminatory attitude towards the patient. Our study occurred during the second wave of COVID-19 in Malawi when more deaths and illnesses exacerbated caregivers' anxiety levels. The practice of
publicising the deaths as a measure of informing the public on the trends of the pandemic ought to be done conscientiously to avoid creating an alarm for those that are infected or nursing such patients [22].

As expressed in this study, the challenging social relationships build on findings from previous studies that showed that COVID-19 disrupted relationships due to the implementation of isolation measures that impose a lack of interaction which impedes the support that a family could have received [23]. Furthermore, the implementation of isolation measures created stress among caregivers as was reported earlier [24, 25], and also affected their livelihoods especially the ability to get essentials or run their businesses as earlier reported [25]. An earlier review reported that people that were in isolation and caring for a COVID-19 patient harbored the greatest fear about the condition and its effects [26]. In our study implementation of isolation measures were constrained in homes with limited space and this is consistent with assertions made earlier that crammed spaces pose a challenge in the implementation of precautionary measures [27]. We argue that the current Malawi COVID-19 home management guidelines should differentiate isolation measures across the various forms of households to ably guide caregivers appropriately [28]. To achieve higher rates of usage of preventive measures in the course of providing care at home, there is a need to support vulnerable families with protective wear such as masks including soap and water or sanitisers [16].

The lack of support in the form of finances, information, and guidelines in managing COVID-19 patients as expressed in this study, is consistent with previous studies [8]. As expressed in this study, the lack of support from health care workers remains an area of concern raised by earlier studies [29, 30] and is likely to cause stress [31]. Earlier studies have asserted that caregivers suggested the provision of professional support as they rendered the service [30] and are likely to follow the instructions for managing their patients [16]. Going forward, there is a need to make information about COVID-19 widely available, closer to the broader population, and accessible through various platforms including the issuance of fact sheets and follow-up phone calls to the caregivers [32]. This information ought to be actionable, hope-oriented in a visual format [33], and should come from trusted sources which are health institutions [22] unlike social media is saturated with wrong information [32]. Earlier studies have shown that some caregivers accessed contradicting information which has the potential of compromising the care they render as well as exacerbating their anxiety levels [9]. The provision of the right information is critical in the context of COVID-19 because it mitigates the potential for stigma and confusion which is associated with minimal and misaligned information [22].

Caregivers in our study drew strength from their spiritual links which have been reported before [8]. Going forward, the religious fraternity and other public entities [22] with proper training can be leveraged for the provision of psychological and spiritual support to caregivers in pandemics like COVID-19. Religious institutions are trusted entities with the capability to offer support to the caregivers at home and also strengthen the levels of hope in both the caregivers and patients as a coping mechanism [22, 34]. Social support is an important aspect of care that needs to be incorporated into the management of COVID-19 cases to avert stress and optimise psychological health [35].
Strengths And Limitations

The use of telephonic interviews limited the observations that could be noted from the caregiver as they narrated their experience, however, the research assistants probed for more information on the subject so that they capture a broader and deeper perspective. The strength of this study lies in collecting information from caregivers from varied residential areas which broadened the scope of responses.

Conclusion

The economic status of a household determined the experiences of caregivers as they managed their COVID-19 patients at home. Caring for confirmed cases of COVID-19 demanded commitment from the caregivers while ensuring that the transmission of the virus is minimised. There is a need to support households while in isolation with the right information on how to manage their patients and streamline social support for the ultra-poor. The existing community structures are a platform that can be used to support the affected households.

Declarations

Ethics approval and consent to participate

Ethics approval was obtained from Kamuzu University Research Ethics committee, College of Medicine Research and Ethics Committee (CoMREC) (P.05/20/3046). The Director of Health and Social Services for Blantyre granted the research support to conduct the study in Blantyre. All participants provided verbal informed consent cognizant that these were telephonic interviews. All data were anonymised and participants were identified by a code and not their names. All methods were carried out in accordance with relevant institutional guidelines and regulations

Consent for publication

Not Applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

Funding

The project was funded by the National Institute for Health and Care research under the Global Effort on COVID-19 (GECO) Health Research
Authors’ contributions

ALNM led the qualitative work package of the project and developed the methodology and supervised the investigation, data analysis, and drafted the original paper with support from DN, and VM. LSK and MC coordinated data collection activities and contributed to the investigation and analysis WN, LC and RS, collected all the data and contributed to the analysis. All authors have read and approved the manuscript.

Acknowledgements

This manuscript is part of the “SARS-CoV-2 infection, transmission dynamics and household Impact in Malawi (SCATHIM)”. The authors are grateful to the Medical Research Council for their support, the study participants for their voluntary participation, and the Director of Health and Social Services for Blantyre for institutional support.

References


Figures
Figure 1

Lived Experiences of Caregivers of COVID-19 patients in Blantyre, Malawi

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- SupplementaryFile2EnglishInterviewGuideforCaretaker.docx
- Supplementaryinformation1COREQChecklist1.pdf