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COVID-19 and Its Related Stigma: A Qualitative Study Among Survivors in Kampala, Uganda

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COVID-19-related stigma is gradually becoming a global problem among COVID-19 survivors with deleterious effects on quality of life. However, this social problem has received little attention in research and policy. This study aimed at exploring the COVID-19-related stigma among survivors in Kampala, Uganda. A cross-sectional exploratory research design was used among COVID-19 survivors in Kampala district. Thirty COVID-19 survivors were examined using in-depth interviews. Data obtained were analyzed using thematic approach. The findings of study indicated that COVID-19-related stigma is prevalent. The common form of stigma was social rejection and labeling. Results showed that the survivors of COVID-19 pandemic faced social rejection and community ostracism. Based on the results, reducing stigmatization of the COVID-19 survivors is vital to control the spread of the pandemic. Thus, an all-inclusive effort is needed to address COVID-19-related stigma and its debilitating consequences by health workers and policymakers.

Keywords: corona, discrimination, COVID-19, survivors, stigma

COVID-19 is one of the large-scale outbreaks known in the modern world affecting all nations. Since the first outbreak of the virus, a rapid spread occurred in the world with alarming numbers of infected people (Lu et al., 2020). The unpredictable nature of the disease has contributed to enormous fear, anxiety, and psychological issues (Cai et al., 2020). While each country's governments are focusing on reducing the possibility of new infections and to flatten the curve, stigma toward those infected, and survivors of the virus, is on the increase (Abdelhafiz & Alorabi, 2020; Taylor, 2020). Stigma categorized as self-stigma/internalized stigma and external/enacted stigma can be in forms of isolation, segregation, social rejection, prejudice, and labeling (Morrison, 2006).

Studies show that during pandemic or epidemic outbreaks, the infected and affected people or groups are stigmatized (Hofstraat & van Brakel, 2016). This can occur in the form of ostracism, social rejection abandonment, harassment, or violence against individuals or groups believed to be carriers, infected, or recovering from the infection (Davtyan et al., 2014). Pandemics and epidemics such as SARS, Ebola virus disease, HIV/AIDS, Hansen disease, leprosy, and others have led to stigma and discrimination, which have continued despite global efforts to stop it (Kelly et al., 2019). In the context of the COVID-19 pandemic, instances of stigma toward COVID-19 survivors have been witnessed in Malawi, Mexico, Jordan, India, and China (Abuhammad et al., 2021; Barbosa-Camacho et al., 2020; Chibwana et al., 2020; Rodríguez-Bolaños et al., 2020). The survivors have faced physical violence, insults, evictions, rejection, and denied public transport (Barbosa-Camacho et al., 2020; Chibwana et al., 2020). This may be attributed to many unknown aspects and uncertainties about the pandemic (World Health Organization, 2020). For example, beliefs that survivors are still contagious (Roelen et al., 2020) may lead to anxiety and stigma.

Based on previous studies, there are dire consequences of health-related stigma and discrimination. It may lead to psychosomatic distress, undermine community solidarity, delay early detection and treatment, and infected people may remain undiagnosed or avoid testing and treatment; all of which negatively affect the quality of life (Bruns et al., 2020; Roelen et al., 2020; Tenkorang, 2017). For example, the survivors of Ebola in West Africa have faced community ostracism and unemployment after returning to their communities (Kelly et al., 2019). These reactive behaviors compromise public efforts and make it difficult for health workers to mitigate the spread of the disease. According to the World Health Organization (2001), stigma is "the hidden burden" of disease (UNAIDS, 2016). Therefore, stigma and discrimination are likely to complicate and perpetuate the spread of COVID-19 pandemic (Muhidin et al., 2020).

COVID-19 in Uganda

On March 22, 2020, the Uganda Ministry of Health (MOH) confirmed the first case of a Ugandan citizen infected with COVID-19 (Olum & Bongomin, 2020). Since then a growing number of cases have been recorded including 44,396 cases, 40,898 recovered and 339 deaths as of April 20, 2021 (World Health Organization, 2021). The MOH has employed different means of communication to educate the public about the pandemic. However, there are still misconceptions about COVID-19 in Ugandan population (Kasozi et al., 2020). Despite the instances and history of stigma prevalence in settings of emerging infectious diseases (Abuhammad et al., 2021; Nyakarahuka et al., 2017), there is a scarcity of empirical

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This dataset is part of a bigger study. However, the data sets analyzed are available from the corresponding author on a realistic request.

There is no competing interest.

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evidence on COVID-19-related stigma among survivors. According to Abuhammad et al. (2021), there is an urgent need to conduct studies on COVID-19-related stigma in different countries. Therefore, the present study aimed to explore the prevalence and associated forms of stigma experiences of COVID-19 survivors in Kampala, Uganda.

Method

The study setting was Kampala district, Uganda's capital city. Kampala is Uganda's national and commercial capital bordering Lake Victoria, Africa's largest lake. Kampala District is the epic center of COVID-19 pandemic with the highest cases of infections, deaths, and recovery (Olum & Bongomin, 2020). Besides, it was easy to access the participants. A cross-sectional exploratory research design was employed to explore the COVID-19 related stigma among the survivors of COVID-19. The period of data collection was November 2020.

Participants

Study participants were survivors of COVID-19 within Kampala district. A total of 30 survivors of COVID-19 participated in the study. The sample size was estimated using saturation principle as applied in a qualitative study (Saunders et al., 2018). Participants were conveniently selected to obtain those who were capable of providing a richer narrative of their stigma experiences. The participants were identified through hospital records and then interviewed. The inclusion criteria were COVID-19 survivors living in Kampala district.

Instrument

Data were collected using an interview guide comprising of two main sections: sociodemographic characteristics and COVID-19-related stigma. The researcher developed the interview guide using guidelines provided by (Huberman & Miles, 2002). Also, the development of the interview guide was based on the literature on stigma with input from experts who had experiences in infectious-related stigma.

Ethics Approval and Consent to Participate

Ethical clearance was granted by the institutional review board of the university. Written informed consent was obtained from all the participants before data collection. Privacy and confidentiality were maintained during the entire process of data collection and analysis. Interviews were audio-taped with participants' permission. Standard operating procedures of COVID-19 prevention were maintained including observance of social distancing and wearing of face masks.

Procedure

Lira University graduates trained in micro-research and fluent in both English and Luganda conducted face-to-face in-depth interviews in a private setting. The interviews lasted for 20–30 min and responses from the participants were recorded using a voice recorder. Participants were asked to give narratives of experiences of COVID-19 related stigma. Interviewers continuously probed and watched the body language of respondents to elicit rich and accurate perspectives on COVID-19 related stigma experiences.

Data Analysis

Audio recording of the interviews was transcribed. A seven-phase data analysis framework was used (Braun & Clarke, 2013). After reading and transcription of recorded data into a written document, data were coded which enabled the researcher to identify categories and patterns within data. Different codes were used to distinguish between themes. Thereafter, themes were identified, reviewed, and named. Lastly, synthesis of the themes, analysis of data, and interpretation of results followed to provide an understanding of COVID-19 related stigma experiences among COVID-19 survivors.

Results

Thirty respondents participated in this study. In-depth interviews were conducted with 30 COVID-19 survivors in Kampala district. Participants' ages ranged from 24 to 59 years. Thirteen were males and 17 were females. Eighteen were married, seven were single, and five were divorced.

Prevalence of COVID-19 Related Stigma Among Survivors

The respondents were asked whether stigma was prevalent in their communities. The participants' narratives reflect instances of experiencing severe COVID-19-related stigma. The following excerpts explain this further.

> Yes, there is COVID-19 related stigma and it has affected us as survivors. We cannot pretend that it doesn't exist. People have treated us differently and we do not know how to deal with it (37-year-old man)

COVID-19 pandemic is still a novel disease with so many dynamics. The general public is still skeptical about how long a patient remains contagious after recovery. There is a general public fear that the COVID-19 survivors might be infectious even after clearance by health officials and other authorities. A 46 year vividly describes it:

> The pandemic has led to unprecedented panic in Ugandans. As survivors, we have become natural targets in the community. We are facing substantial stigma as a result of fear about the infection of the public. People believe that we are sources of infection.

> In my area of residence, I have had instances where I faced harassment because am perceived as at greater risk of transmission, says a 35-year survivor

The respondents reported hearing insensitive comments made by other people in the family and community. Some people in the community believe that COVID-19 pandemic is a death sentence. Another respondent aged 53 years old said:

> Where I stay it is just a mess. My brother told me that I have brought a killer disease to the family.

From the narratives above, it is quite clear that COVID-19-related stigma is prevalent in the community.

Forms of Stigma

Social Rejection

The social rejection was a big part of the negative experiences COVID-19 survivors went through in the community. These survivors were considered contagious. The respondents became subject to peoples' conversation. This is typified by a response from a 39-year-old respondent:

> When I was discharged from the hospital after cure, I could feel something unusual. I was sure that I was cured and I had no traces of the disease, I expected a warm reception from my family and neighbours. But I could visibly see suspicious faces from my family members and it was worse with the neighbours. They (neighbours) did not come to the house see me and know how I was fairing. This was unlike before when every time I came home, the immediate neighbours would come to greet me and we could have a chat.

The following 26-year-old female respondent explained how difficult it was to come out and tell the public that she was a COVID-19 survivor.

> . . . . what can I say, it's like I have become an outcast in the community. Members of the community refer to the survivors of COVID-19 with belittling terms. Trust me this is discouraging many people to test or seek treatment even when they suspect an infection

Labeling

The families of the survivors are too facing taunts and social stigma. Some members of the community label the COVID-19 survivors as "corona family" or COVID-19 patients. A 41-year-old female respondent discussed how her child was mistreated when she went to the shop in the neighborhood.

> When I sent my child to the shop to buy a matchbox, she was rudely received by the shop attendant. She was told to drop the money in a container and not come closer to the shop. The matchbox was thrown to her. My daughter does not want to go back to the same shop and she has been confining herself to the house for some time now. Maybe this is a blessing in disguise; the disease will not find her in the house.

There was also fear of associating with COVID-19 survivors as expressed by many participants. The survivors are shunned by loved ones, colleagues, and neighbors. A 33-year-old man said:

> Well, one of my cousin sisters rejected me at first. She even took her children to the village because she believed I might give them the disease. I kind of thought everyone else was about to leave. But time heals everything, am now free with everybody and the children have returned.

The above narratives show that although several COVID-19 survivors have won the battle with the virus, they are grappling with another scourge; stigma arising out of panic and fear surrounding the pandemic.

Discussion

The COVID-19 pandemic impacted the quality of life of individuals in this study. However, the survivors of the pandemic are facing yet another scourge; stigma related to the virus which has been expressed by rejection and community ostracism (Ramaci et al., 2020). The pandemic has caused a state of fear and stigma toward the affected, infected, and survivors (Ramaci et al., 2020). In the present study, the prevalence among the COVID-19 pandemic survivors in Kampala district was explored. The results revealed that respondents were subjected to stigma and discrimination. This was consistent with previous studies which showed that the prevalence of stigma among COVID-19 survivors was high (Abuhammad et al., 2021; Singh & Subedi, 2020). The findings corroborate with a report of the stigma that emerged during other pandemics (Denis-Ramirez et al., 2017). According to Singh and Subedi (2020), stigmatization of COVID-19 pandemic survivors is a global concern. However, stigma among the survivors is an indication that many people lack a clear understanding of the virus and how it is transmitted (Abuhammad et al., 2021).

There are dire consequences of health-related stigma and discrimination. COVID-19 related stigma undermines efforts to mitigate the disease and can be detrimental to early detection and treatment (Bruns et al., 2020; Roelen et al., 2020). Additionally, it impedes health-seeking behaviors, undermines adherence, leads to mental problems, and ultimately undermining efforts to counteract the pandemic (Roelen et al., 2020; Stangl et al., 2019; Tenkorang, 2017).

The present study also explored the forms of stigma experienced by the survivors of COVID-19. The results revealed that a common form of stigma was social rejection. This is not surprising because survivors of other infectious diseases like Ebola in West Africa and SARS pandemic in Asia faced similar challenges (Denis-Ramirez et al., 2017; Lee et al., 2005). The results of the present study mirror instances of stigma toward COVID-19 survivors in Malawi, Mexico, Jordan, India, and China (Barbosa-Camacho et al., 2020; Chibwana et al., 2020; Neto et al., 2020). In these countries, the survivors of COVID-19 have faced physical violence, insults, evictions, rejection, and denied public transport (Abuhammad et al., 2021; Barbosa-Camacho et al., 2020; Chibwana et al., 2020). Similar results were reported by another qualitative study which showed that survivors of COVID-19 experienced suspicion and isolation by the community (Brooks et al., 2020). The results resonate with common forms of stigma reported by other infectious disease survivors (James et al., 2019). COVID-19-related stigma may be attributed to the unpredictable nature of the virus, perceived risk of infection, fatality, and non-availability of the treatment. They are ostracized which leads to social isolation. This may lead to increased psychological problems and reduced quality of life (Turan et al., 2017).

Conclusion

The majority of the respondents in the sample endorsed COVID-19-related stigma and such behaviors were common in the community. The COVID-19 pandemic survivors indicated that they faced social rejection and community ostracism. Thus, reducing COVID-19-related stigma is vital to control the spread of the virus. An all-inclusive effort is needed to address COVID-19-related stigma and its debilitating consequences by health workers and policymakers.

This study had its limitations. Firstly, convenient sampling was used which could be susceptible to research bias. Secondly, the sample included only COVID-19 survivors. The infected people and contacts were excluded, yet the topic might have affected them. Lastly, this was a qualitative study which focused on perceptions of the respondents. A mixed research design would provide a more

comprehensive examination of the topic. Nonetheless, the consistent reports of perceived stigma show that this problem does exist. This is the first qualitative study on stigma among COVID-19 survivors in the Ugandan context, and the narratives of the respondents in this study are consistent with other studies.

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