

# COVID-19- Related Stigma in COVID-19 Survivors in Kampala, Uganda: A Qualitative Study

Kabunga Amir (✉ [amirkabs2017@gmail.com](mailto:amirkabs2017@gmail.com))

Lira University <https://orcid.org/0000-0002-0481-2220>

---

## Research Article

**Keywords:** Corona, Discrimination, COVID-19, Survivors, Stigma, Uganda

**Posted Date:** January 19th, 2021

**DOI:** <https://doi.org/10.21203/rs.3.rs-150583/v1>

**License:**  This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

---

# Abstract

**Background:** COVID-19-related stigma is gradually becoming a global problem among COVID-19 survivors with far-reaching implications. However, this social problem has received little attention in research and policy. This study aimed at exploring the COVID-19-related stigma survivors in Kampala, Uganda

**Methods:** A cross-sectional exploratory research design was used. COVID-19 survivors in Kampala district part of the study. In-depth interviews were used to collect data and analysis was done using thematic approach.

**Results:** The results from the data showed that COVID-19-related stigma is prevalent and the common form of stigma was social rejection.

**Conclusions:** The majority of the respondent in the sample endorsed COVID-19-related stigma and such behaviors were high 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 policy makers.

## Background

COVID-19 is one of the large-scale outbreaks known in the modern world affecting all nations. It has not only caused a global public health crisis but also it has caused unprecedented panic in people (Lu et al., 2020). The statistics of infection is rapidly growing across nations associated with mortality rate of about 5.7% (Worldometers, 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 towards those infected and survivors of the virus is on the increase (Abdelhafiz & Alorabi, 2020; Taylor, 2020). This unprecedented situation of the pandemic, where disinformation and misinformation spread instantly through social media has received little attention in research and policy.

Studies show that during pandemic or epidemic outbreaks, the infected and affected people or groups are stigmatized (Hofstraat & van Brakel, 2016). This is in 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 has continued despite global effort to stop it (Kelly et al., 2019). In the context of COVID-19 pandemic, instances of stigma towards COVID-19 survivors have been witnessed in Malawi, Mexico, Jordan, India and China (Abuhammad, 2020; 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 (Abuhammad, 2020; Barbosa-Camacho et al., 2020; Chibwana et al., 2020). This may attributed

many unknown things and uncertainties about the pandemic (WHO, 2020), leading to misconceptions. There is a belief that survivors are still contagious (Roelen et al., 2020) leading to anxiety and stigma.

Based on previous studies, there are dire consequences of health-related stigma and discrimination. It may lead to psychosomatic distress, undermines community solidarity, delays early detection and treatment, infected people may remain undiagnosed, or avoid testing and treatment and negatively affects quality of life (Bruns et al., 2020; Roelen, 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). This reactive behaviors compromise public efforts and makes it difficult for health workers to mitigate the spread of the disease. According to World Health Organization (2001), stigma is “the hidden burden” of disease. 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 22 March, 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 to the tune of 33,360 cases, 10,905 recovered and 245 deaths as of December, 25<sup>th</sup>, 2020 (Worldometers, 2020). The MOH has employed different means of communication to educate the public about the pandemic. However, there is significantly low level of knowledge and misconception about COVID-19 in Ugandan population (Kasozi et al., 2020). Despite the instances and a history of stigma prevalence in settings of emerging infectious diseases (Abuhammad, 2020; Nyakarahuka et al., 2017), there is scarcity of empirical evidence on COVID-19- related stigma among survivors. According to Abuhammad et al., (2020) there is urgent need to conduct studies on COVID-19- related stigma in different countries. Therefore, the present study aimed to explore the prevalence of stigma experiences of COVID-19 survivors in Kampala, Uganda.

## **Methods**

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 many cases, deaths and recovery (Olum & Bongomin, 2020). 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 qualitative study (Saunders et al., 2018). Participants were conveniently selected to get those who were capable of giving a richer narrative of their stigma experiences. The inclusion criteria were COVID-19 survivors living in Kampala district.

## **Instrument**

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

## **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 minutes and responses from the participants were recorded using a voice recorder. Participants were asked to give narratives of experiences related to 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 were transcribed. A seven phase data analysis framework described by (Braun & Clarke, 2013) was used. After reading and transcription of recorded data into written document, data was coded which enabled the researchers 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' age ranged from 24-59 years. 13 were males and 17 were females. Eighteen were married, seven were single and five were divorced.

### **Prevalence of COVID-19 related Stigma among Survivors**

While there is a history of stigma prevalence in settings of emerging infectious diseases (Nyakarahuka et al., 2017), few studies have explored COVID-19- related stigma. This study explored the 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 really 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 novel disease with so many dynamics. The general public is still skeptical on 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 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 year 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 and discrimination**

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 of 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 neighbors. But I could visibly see suspicious faces from my own family members and it was worse with the neighbors. They (neighbors) did not come to the house see me. This was unlike before when every time I came home, the immediate neighbors would come to greet me and we could have a chat.*

Some respondents' narratives show that COVID-19 survivors were treated as social outcasts. The following 26 lady respondent explains how difficult it is to come out and tell the public that she is 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 infection*

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 woman 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 literally 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. May be 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. In fact 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 a number of COVID-19 survivors have won the battle with the virus, they are grappling with another scourge; stigma arising out of panic and misinformation surrounding the pandemic.

## **Discussion**

COVID-19 pandemic is not just a public health concern that impacts the quality of life in the individuals but the survivors are facing yet another scourge; stigma arising out of panic and misinformation surrounding the pandemic (Ramaci et al., 2020). The pandemic has caused a state of fear and stigma towards the affected, infected and survivors (Ramaci et al., 2020). In the present study, the prevalence of 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., 2020; Singh & Subedi, 2020). The findings corroborate with report of stigma that emerged during other pandemic (Denis-Ramirez et al., 2017). According to (Singh & Subedi, 2020) stigmatizing 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., 2020).

There are dire consequences of health-related stigma and discrimination. It undermines community solidarity, delays early detection and treatment and it is detrimental to support societies' recovery from the pandemic ((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, 2020; Stangl et al., 2019; Tenkorang, 2017).

The current study also explored the forms of stigma experienced by the survivors of COVID-19. The results from the data revealed that the 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 situations (Denis-Ramirez et al., 2017; Lee et al., 2005). The results of the present study mirror instances of stigma towards COVID-19 survivors in Malawi, Mexico, Jordan, India and China

(Abuhammad et al., 2020; Barbosa-Camacho et al., 2020; Chibwana et al., 2020; Rodríguez-Bolaños 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., 2020; 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 community (Brooks et al., 2020). The results resonate with common forms of stigma reported by other infectious diseases survivors (James et al., 2019). COVID-19-related stigma may be attributed to 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 respondent in the sample endorsed COVID-19-related stigma and such behaviors were high 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 policy makers.

This study had its own 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 would provide a comprehensive conclusion on the topic. Nonetheless, the consistent reports of perceived stigma show that the problem does exist. This is the first qualitative study on stigma among COVID-19 survivors in the Ugandan context. In addition, the narratives of the respondents in this study are consistent with other studies

## **Declarations**

### **Ethics approval and consent to participate**

Ethical clearance was granted by institutional review board of Gulu University (GUREC-047-20). A 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.

### **Consent for publication**

This manuscript doesn't any personal data of the participants

### **Availability of data and material**

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

### **Competing interests**

There is no competing interest

### **Funding**

The author(s) received no financial support for the research, authorship, and/or publication of this article

### **Authors' contributions**

AK conceptualized the study and was involved in the data collection, analysis, and drafting of the manuscript.

### **Acknowledgment**

The researcher acknowledges all those who accepted to participate in this study. We also acknowledge the graduate students of Lira University for data collection.

## **References**

- Abdelhafiz, A. S., & Alorabi, M. (2020). Social stigma: the hidden threat of COVID-19. *Frontiers in Public Health, 8*.
- Abuhammad, S. (2020). Parents' knowledge and attitude towards COVID-19 in children: A Jordanian Study. *International Journal of Clinical Practice, e13671*.
- Abuhammad, S., Alzoubi, K., & Khabour, O. (2020). Fear of COVID-19 and Stigmatization toward Infected People among Jordanian People. *International Journal of Clinical Practice, e13899*.
- Barbosa-Camacho, F. J., García-Reyna, B., Cervantes-Cardona, G. A., Cervantes-Pérez, E., Chavarria-Avila, E., Pintor-Belmontes, K. J., Guzmán-Ramírez, B. G., Hernández-Bernal, A., Ibarrola-Peña, J. C., & Fuentes-Orozco, C. (2020). *Comparison of Fear of COVID-19 in Medical and Nonmedical Personnel in a Public Hospital in Mexico*.
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. sage.
- Brooks, S. K., Webster, R. K., Smith, L. E., Woodland, L., Wessely, S., Greenberg, N., & Rubin, G. J. (2020). The psychological impact of quarantine and how to reduce it: rapid review of the evidence. *The Lancet*.
- Bruns, D. P., Kraguljac, N. V., & Bruns, T. R. (2020). COVID-19: facts, cultural considerations, and risk of stigmatization. *Journal of Transcultural Nursing, 31(4)*, 326.

- Cai, H., Tu, B., Ma, J., Chen, L., Fu, L., Jiang, Y., & Zhuang, Q. (2020). Psychological Impact and Coping Strategies of Frontline Medical Staff in Hunan Between January and March 2020 During the Outbreak of Coronavirus Disease 2019 (COVID-19) in Hubei, China. *Medical Science Monitor: International Medical Journal of Experimental and Clinical Research*, *26*, e924171-1.
- Chibwana, M. G., Jere, K. C., Kamn'gona, R., Mandolo, J., Katunga-Phiri, V., Tembo, D., Mitole, N., Musasa, S., Sichone, S., & Lakudzala, A. (2020). High SARS-CoV-2 seroprevalence in Health Care Workers but relatively low numbers of deaths in urban Malawi. *MedRxiv*.
- Davtyan, M., Brown, B., & Folayan, M. O. (2014). Addressing Ebola-related stigma: lessons learned from HIV/AIDS. *Global Health Action*, *7*(1), 26058.
- Denis-Ramirez, E., Sørensen, K. H., & Skovdal, M. (2017). In the midst of a 'perfect storm': Unpacking the causes and consequences of Ebola-related stigma for children orphaned by Ebola in Sierra Leone. *Children and Youth Services Review*, *73*, 445–453.
- Hofstraat, K., & van Brakel, W. H. (2016). Social stigma towards neglected tropical diseases: a systematic review. *International Health*, *8*(suppl\_1), i53–i70.
- Huberman, A. M., & Miles, M. B. (2002). Narrative analysis. *The Qualitative Researcher's Companion*. Thousand Oaks, CA: Sage Publications.
- James, P. B., Wardle, J., Steel, A., & Adams, J. (2019). Post-Ebola psychosocial experiences and coping mechanisms among Ebola survivors: a systematic review. *Tropical Medicine & International Health*, *24*(6), 671–691.
- Kasozi, K. I., MacLeod, E., Ssempijja, F., Mahero, M. W., Matama, K., Musoke, G. H., Bardosh, K., Ssebuufu, R., Wakoko-Studstil, F., & Echoru, I. (2020). Misconceptions on COVID-19 Risk Among Ugandan Men: Results From a Rapid Exploratory Survey, April 2020. *Frontiers in Public Health*, *8*, 416.
- Kelly, J. D., Weiser, S. D., Wilson, B., Cooper, J. B., Glayweon, M., Sneller, M. C., Drew, C., Steward, W. T., Reilly, C., & Johnson, K. (2019). Ebola virus disease-related stigma among survivors declined in Liberia over an 18-month, post-outbreak period: an observational cohort study. *PLoS Neglected Tropical Diseases*, *13*(2), e0007185.
- Lee, S., Chan, L. Y. Y., Chau, A. M. Y., Kwok, K. P. S., & Kleinman, A. (2005). The experience of SARS-related stigma at Amoy Gardens. *Social Science & Medicine*, *61*(9), 2038–2046.
- Lu, H., Stratton, C. W., & Tang, Y. (2020). Outbreak of pneumonia of unknown etiology in Wuhan, China: The mystery and the miracle. *Journal of Medical Virology*, *92*(4), 401–402.
- Muhidin, S., Vizheh, M., & Moghadam, Z. B. (2020). Anticipating COVID-19-related stigma in survivors and health-care workers: Lessons from previous infectious diseases outbreaks—An integrative literature review. *Psychiatry and Clinical Neurosciences*, *74*(11), 617–618.

- Nyakarahuka, L., Skjerve, E., Nabadda, D., Sitali, D. C., Mumba, C., Mwiine, F. N., Lutwama, J. J., Balinandi, S., Shoemaker, T., & Kankya, C. (2017). Knowledge and attitude towards Ebola and Marburg virus diseases in Uganda using quantitative and participatory epidemiology techniques. *PLoS Neglected Tropical Diseases*, *11*(9), e0005907.
- Olum, R., & Bongomin, F. (2020). Uganda's first 100 COVID-19 cases: trends and lessons. *International Journal of Infectious Diseases*, *96*, 517–518.
- Organization, W. H. (2001). Mental health problems: the undefined and hidden burden. *Fact Sheet*, *218*.
- Organization, W. H. (2020). Social Stigma associated with COVID-19. A guide to preventing and addressing social stigma. *World Health Organization*.
- Ramaci, T., Barattucci, M., Ledda, C., & Rapisarda, V. (2020). Social Stigma during COVID-19 and its impact on HCWs outcomes. *Sustainability*, *12*(9), 3834.
- Rodríguez-Bolaños, R., Cartujano-Barrera, F., Cartujano, B., Flores, Y. N., Cupertino, A. P., & Gallegos-Carrillo, K. (2020). The Urgent Need to Address Violence Against Health Workers During the COVID-19 Pandemic. *Medical Care*, *58*(7), 663.
- Roelen, K. (2020). Receiving Social Assistance in Low-and Middle-Income Countries: Negating Shame or Producing Stigma? *Journal of Social Policy*, *49*(4), 705–723.
- Roelen, K., Ackley, C., Boyce, P., Farina, N., & Ripoll, S. (2020). COVID-19 in LMICs: The Need to Place Stigma Front and Centre to Its Response. *The European Journal of Development Research*, 1–21.
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity*, *52*(4), 1893–1907.
- Singh, R., & Subedi, M. (2020). COVID-19 and stigma: social discrimination towards frontline healthcare providers and COVID-19 recovered patients in Nepal. *Asian Journal of Psychiatry*.
- Stangl, A. L., Earnshaw, V. A., Logie, C. H., van Brakel, W., Simbayi, L. C., Barré, I., & Dovidio, J. F. (2019). The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, *17*(1), 31.
- Taylor, L. (2020). Covid-19 misinformation sparks threats and violence against doctors in Latin America. *Bmj*, *370*.
- Tenkorang, E. Y. (2017). Ebola-related stigma in Ghana: Individual and community level determinants. *Social Science & Medicine*, *182*, 142–149.

Turan, B., Budhwani, H., Fazeli, P. L., Browning, W. R., Raper, J. L., Mugavero, M. J., & Turan, J. M. (2017). How does stigma affect people living with HIV? The mediating roles of internalized and anticipated HIV stigma in the effects of perceived community stigma on health and psychosocial outcomes. *AIDS and Behavior*, *21*(1), 283–291.