Case 8.3: Studying the Impact of COVID-19 on Vulnerable Populations

This case study was written by members of the case study author group.

Keywords Vulnerability and inclusion; Researcher roles and responsibilities; Resource allocation; Boundaries between research, surveillance and clinical care; Qualitative research; Digital and remote healthcare and research

In March 2020, an African country confirmed its first cases of COVID-19 and introduced measures to curb the spread of the virus. The initial control measures included promoting regular hand-washing and social distancing, and required that schools, religious institutions, offices and shops close, permitting only essential services to continue. A full lockdown was instated, with a ban on the use of all private and public transport, and a night curfew. From June 2020, most offices and shops were allowed to reopen, provided social distancing was observed and hand-washing facilities were available, and face coverings were required in public places. Private and public transport resumed with a limited number of persons per vehicle. Schools, religious institutions, sports facilities, arcades and places of entertainment remained closed until October 2020, then gradually reopened, and closed again from June until July 2021 during a second lockdown. Apart from examination-year students, who were allowed to return to school in October 2020, all other children remained at home between March 2020 and December 2021, and the night curfew remained in place.

The COVID-19 response has had a marked impact on the health and education of vulnerable populations, as well as on their economic situation and their psychosocial well-being (Kansiime et al. 2021). To understand the impact of COVID-19 and the associated public health response on vulnerable populations, researchers in the country collected information from mothers and children from impoverished backgrounds and fishing communities, families of children with disabilities, and young sex workers, all of whom were participating in other on-going research studies. Through phone interviews, the impact study, which started in June 2020, assesses participants' knowledge of and concerns about COVID-19, the impact of the COVID-19-related public health response on participants' daily lives, and suggested actions to reduce spread and support participants.

While planning and conducting the impact study, during the first months of the pandemic, the research team encountered several ethical issues. During the first lockdown period, on-going studies were paused by the national regulatory authorities and the review of new research protocols was delayed as organizations adjusted to working in lockdown. This meant that some studies where ancillary care was usually provided to participants during scheduled study visits were unavailable (Kapumba et al. 2021; Kapumba et al. 2022). As soon as the research team was able to start the phone follow-up and COVID-19 impact interviews in June 2020, it was extremely careful about how it presented what the study was doing, to avoid raising expectations or making promises that would make the participants feel let

down. The researchers clearly explained the purpose of the study, clarified their institutional links and listened to any concerns, in order to maintain trust. Nevertheless, various problems brought up by participants caused ethical concerns and raised questions about previously clear boundaries between research activities and public health responses. For example, many participants had not earned any income at all during the first lockdown, and some had run out of food. Others were not able to obtain medication for chronic conditions and had started feeling ill but could not get to a health facility as there was a ban on public and private transport. Ethical issues also arose around access to care in cases where a participant presented with COVID-19 symptoms, as services were limited (Singh et al. 2020). Although the government distributed some food, most participants did not receive any. As the lockdown continued, multiple research teams had to decide what kind of support could be offered as part of their duty of care as a research institution. When study participants presented with emergency situations, the research teams responded by organizing modest food and medicine deliveries to participants' homes. In exceptional cases ambulance services were arranged for critically ill study participants.

Questions

- 1. What responsibilities do research teams have to respond to the pandemic-related emergency health and nutritional needs of participants?
- 2. Should researchers' responsibilities differ depending on whether or not participants' needs relate directly to the study question(s) and methods? Why?
- 3. In a pandemic should the responsibilities of researchers and public health responders be different from the boundaries observed in normal times? Why?
- 4. If you were a member of a research ethics committee responsible for reviewing this study, what would you request the study team to do in advance, by way of preparation?

References

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