

Principal Ethical Issues for Research with Vulnerable Population during the COVID-19 Endemic

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Abstract

Background: Since the very beginning of COVID-19 pandemic, the researcher community is working day and night gathering data, writing articles to aware the general public of the various issues associated with the pandemic. However, in pursue of delivering fast and quick information to the public, in some cases ethical considerations were not properly applied. In pandemic situation the ethical considerations are more important to follow, which the current research tries to highlight.

Methods: A narrative review of previous pandemics and the ethical guidelines provided by WHO, CIOMS and other literature was studied. Based on the literature and current guidelines the research has recommended few ethical principles to follow while conducting researches during pandemic.

Results: The present study has underlined several of key recommendations which have been used in previous pandemic situations with vulnerable populations such as; that of mental health, self-harm and suicidal populations. Similarly, the study has also advised using diverse range of methods and techniques to help the participants feel emotionally and mentally relaxed during and after research.

Conclusions: Though it is important in this time of crisis to conduct researches, it is equally important to safe guard the participants mentally and physically, especially those who come under vulnerable populations. The present review has tried emphasizing certain methods which can be helpful in achieving desired goals while protecting the participants.

Keywords: *COVID-19, Ethical issues, Conducting researches, Vulnerable population, Mental health issues, Suicidal, and Self-harm.*

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Background

In this fast-paced era of change, almost everything is at stake universally like insecurity, social and physical isolation, social distancing, economic crises, mental and psychological health problems (Huremović, 2019; Ng et al., 2013). Mental health is being ensured in response to the epidemics COVID-19 by the researchers and academics (Cao et al., 2020; Holmes et al., 2020; Shuja et al., 2020).

Many of the committees like COPE, UK Medical Framework, International Society for Medical Publication Professionals and Consolidated Standards of Reporting Trials; which indulge in maintaining the ethical standards during research have also devised several strategic plans while addressing the core issues of research and data collection with vulnerable population during the current COVID-19 pandemic.

The Committee of Publication Ethics (COPE), discussed several issues of researchers being confined to their homes while others being called for more work. At the same time the burden that has been brought on to the journals and reviewers with massive surge in researches relating to the pandemic has also been discussed. However regardless of all the issues COPE encouraged researchers to maintain the ethical standards of research and data collection and limitations should be clearly mentioned (COPE, 2020; Poff, 2020). While COPE has suggested issues relating to researchers' others like UK Medical Framework have suggested strategies for protecting vulnerable population during this pandemic and providing these population with necessities to protect themselves from the pandemic (European Centre for Disease Prevention and Control, 2020).

Likewise, National Health Service (NHS) has issued guidelines on using patient's information for the purpose of research while maintaining the anonymity of the patient intact. A general notice by the Secretary of State for Health and Social Care has recently been regulated which gives researchers access on using patient's data without consent which can be accessed through NHS repositories. Also clear statement regarding transparency of patient data use during research has been advised (NHS Health Research Authority, 2020).

When investigating the epidemic, self-harm and suicide in the large context, the necessary ethical standards must be considered and valuable suggestions should be kept in mind before investigation the COVID-19 (Gunnell et al., 2020; Mazza et al., 2020). Under normal conditions research displays that taking part in a sensitive topic, such as suicide, creates an unknown significant fear and these negative effects are short-lived and self-balancing. However, we do not know that they occur in the context of a global epidemic (Lin & Anderson-Shaw, 2009; Ma et al., 2020). The American Psychological Association (APA) has also issued guideline on the matter of data collection from vulnerable population during COVID-19 pandemic. APA has encouraged researcher that researches which require face to face interaction with vulnerable populations should be halted for the time being. And the researchers have an ethical duty to provide the vulnerable population with pre-termination counseling through telephonic or video calls, while other researches like survey should be modified and

be done through online data collection (Greenbaum, 2020).

Recommended Ethical Considerations During Research

Many international researchers have stopped working with vulnerable populations during the lockdown due to several reasons (Jones, 2020). One recent survey was conducted to assess the impact of suspension of face to face interaction on researcher community. Data from 2800 members of Research Gate community was collected during the survey and it was found that many of the researchers are busy in writing, reviewing and reading research literature online. A decrease of 72% was observed in experiments, in person data collection and professional gatherings (Fleming, 2020). However, for the development and advancement of information and understanding the full extent of the pandemic it is vital for researchers to continue their work as previously COPE and other committees have suggested while modifying their techniques and methods.

Some important things to consider while interacting with the vulnerable population during the pandemic can include: First, unnecessary burden should not be placed on those who are suffering from this epidemic. Secondly, the data collected should be checked more carefully while keeping in mind the added effect of the pandemic on the vulnerable population (Meagher et al., 2020). Third, ensuring that people who are part of that research on self-harm and suicide are completely sensible and safe during the pandemic and if anyone needs psychological consultation it should be provided through video or audio communication. Lastly, these participants should be provided with benefits which they are usually not given under normal research conditions to keep them motivated (Setiabudy, 2020).

Psychological and mental health related researches.

Mental health research on suicide and self-harm represents a significant role in any epidemic, but we must also pay attention to the ethical standards that must be observed in constant research (Amitai & Apter, 2012; Chan et al., 2006). We have found that many investigations do not provide adequate and necessary information for participants' consent (Reger et al., 2020; Shekhani et al., 2018; Thakur & Jain, 2020). Participants' first and foremost impressions are not measured and no information provided regarding the growing anxiety caused by the epidemic (Cao et al., 2020; Huang & Zhao, 2020; Shuja et al., 2020). There is not even a program that addresses the issues that arise after participating in research about the COVID-19 to mitigate the mood swings (Ma et al., 2020; Stanley & Brown, 2012).

General precautionary measures to reflect.

World Health Organization has emphasized that while researching the epidemic the particular attention should be paid to safety measures and protection of the participants (World Health Organization, 2020). It is endorsed that researches about COVID-19, self-harm, and suicide should measure and evaluate the participants' temperament and disposition before and after the study. In this context in many researches a sheer visual analogue scale can be used to good effect (World Health Organisation, 2016). These scales should additionally be practiced to pursue the research ethically and if participants

express their diminished feelings after taking part in the study, it should be discontinued with a stop-study criterion (Gostin et al., 2020; Greenbaum, 2020).

Employing Diverse Techniques and Methods

Ultimately, it is significant that all participants are instructed ways to maintain their emotions stable particularly when they are answering sensitive questions about self-harm and suicide in the context of COVID-19 (Gunnell et al., 2020). Diverse types of techniques and trial have been demonstrated to the young participants for exertion such as exam howlers, fascinating animal pictures, supportive webpages and drawings (Görizt, 2007; Pelton et al., 2020; Taylor et al., 2020; Verheyen & Goritz, 2009).

Research participants' time should be valued and encourage them for taking part in the study (CIOMS, 2016). For conducting new study and assessment of COVID-19, the research participants and patients should be respected (Greenbaum, 2020). Moreover, it is essential that patient and public participants are supported effectively, both emotionally and financially for their participation (Mazza et al., 2020).

Conclusion

The benefits of all research should outweigh the disadvantages. And people need to know who is benefiting from the research in the context of policy and practice. In this time of crisis, it is of imminent need to conduct researches and gather data for the benefit of current and future generations. However, simultaneously it is important to adhere to the ethics and safety of the participants both physically and mentally. The ethics committees can carry out their role effectively in this regard. Researchers must respond effectively to the COVID-19, but they must not ignore moral and ethical standards.

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Availability of data and materials

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

Author's contributions

KHS: study design, literature search, first draft, manuscript revisions, approval of the final version. ZS and DA: literature search, first draft, manuscript revisions, approval of the final version. ST and PU: literature search, manuscript revisions, approval of the final version.

Ethics approval and consent to participate

The integrate study was approved by the National Institute of Psychology Review Board. Written consent was obtained from all participants.

Competing interests

The authors declare to have no competing interests.

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