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COVID-19: 'Contagion to This World' and the Demand for Ethical Research

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Abstract

Less than a month after the current COVID-19 pandemic was first officially reported, the Nuffield Council on Bioethics produced its report *Research in Global Health Emergencies: Ethical Issues*. Shortly afterwards the World Health Organization issued guidance on ethics and research in the COVID-19 pandemic, which was influenced by the earlier report of the Nuffield Council. Here we shall highlight points from both documents. We shall emphasize the 'ethical compass' set out in the Nuffield Council's report. In particular, we shall show how the report is pertinent to research in mental health in relation to the pandemic. There is a moral imperative for research to take place, but it must be undertaken in an ethical manner which requires the overarching values set out in the ethical compass: equal respect, fairness, and the reduction of suffering.

Keywords: COVID-19, ethics, global health, pandemic, research.

Introduction

On the 31st December 2019, a pneumonia of unknown cause was reported to the World Health Organization (WHO) in China. Since then, the virus, now known as SARS-CoV-2, has indeed brought 'Contagion to this world' (Shakespeare, 1951) in the form of the COVID-19 pandemic. Less than a month later, the Nuffield Council on Bioethics (NCoB, 2020a) issued its report, *Research in Global Health Emergencies: Ethical Issues* (the Report). Two things are clear: during this outbreak research is vital and so too is cooperation (Sheather, 2020). In its discussion of the ethical issues raised by global health emergencies, the Report could not have been more timely. It is no surprise that the subsequent guidance issued by the World Health Organization (WHO, 2020a) about research in connection with COVID-19 should have drawn substantially on the Report.

In this paper we shall review some of the main recommendations relevant to COVID-19 made by both the Report and the WHO guidance. In particular, we shall draw out the relevance of this guidance for mental health research.

The need for such research in the mental health field and its potential content have been usefully set out in a position paper by Holmes et al. (2020). Identified needs include: the effect of the virus on the risk of anxiety, depression, self-harm, and suicide; how to protect mental health after the virus; the mental health consequences of lockdown measures and social isolation for vulnerable groups; the effects of the media coverage of COVID-19 on mental health; and how to maintain mental wellbeing and minimize distress whilst promoting suitable behaviours in response to the pandemic (Holmes et al., 2020). Thinking about potentially vulnerable groups (albeit later we shall suggest caution around the use of the notion of vulnerability) is particularly important: from children to older people, from healthcare workers to prisoners and the homeless, from those with pre-existing mental health (and other health) conditions to those who are socially disadvantaged by poverty, learning disabilities, refugee status, and so on. In addition, Holmes et al. (2020) point towards the relevance of neuroscientific research in understanding the effects of COVID-19 and its treatment on the brain.

We start by establishing the global applicability of the Nuffield Council's report before focusing on its ethical compass and the relevance to mental health research. We shall end by considering some of the recommendations or conclusions in the Report which do not feature in the WHO's much briefer guidance. It is worth saying that the Report itself focusses on the ethics of *research* in global health

emergencies. The ethical compass can also help practitioners navigate many of the ethical challenges arising throughout the health and humanitarian response to COVID-19.

Applicability of the Report

The majority of global health emergencies occur in the global south, and the challenges of emergency response are undoubtedly exacerbated in lower income environments. It might therefore be tempting, although simplistic, to presume that the Nuffield Council's Report (NCoB, 2020a) is relevant primarily in this context. In contrast, however, the experience of COVID-19 has illustrated vividly how issues that might have been regarded as specific to the Ebola outbreaks in recent years in Africa are now seen playing out also in the global north. For instance, in both high and low income countries there is evidence and concern that other health needs have been neglected in the face of the pandemic; one of the major concerns has been that health services, even in very well-resourced settings, would be overwhelmed; people have been dying without their families present; it has not always been possible to bury people in a dignified manner; and it is not clear who will get priority access to promising candidate vaccines. In the UK, there have been significant concerns raised about the transparency with which government decisions have been made and the lack of meaningful community engagement in early research (Wright, 2020). Moreover, we know that high income countries can dramatically fail subsections of their populations, as was seen in the aftermath of Hurricane Katrina in 2005 (Brunsma et al., 2007). In other words, principles of importance in one context in emergencies in the global south translate into important principles in a very different context in the global north. Hence, as the pandemic becomes truly global (Burki, 2020; Wells, 2020) the applicability of the Nuffield Council's Report (NCoB, 2020a) turns out to be very wide indeed.

The Ethical Compass

Research during global health emergencies is complicated by the sheer variety of organizations, from local to international, that might be involved. In itself this can set up tensions. The NCoB's working group put together an ethical compass to guide decision-making, particularly in the absence of clear shared guidelines or approaches. This was based on the views and experiences shared by those who gave evidence to the working group. The aim was to establish the values that

might help those involved in planning and implementing research, from policy-makers to front line researchers. The compass highlights three overarching values: equal respect, fairness, and the reduction of suffering. These values are relevant in a variety of ways to research to do with COVID-19, including research in the field of mental health and, as we have said, to the health and humanitarian response itself.

Equal respect

Equal respect involves treating everyone as moral equals by asking questions such as: how can we respect and protect people's dignity, agency, humanity, and human rights throughout the research? Whereas the traditional focus in research ethics has been about respect at the point of consent, a genuinely respectful relationship cannot simply be limited to consent processes but needs to be developed and applied throughout the full research endeavour, from study development to sharing of a project's findings.

Equal respect suggests the need to be sensitive to local values and for this reason too should include local involvement in the planning of research. In previous emergencies there have been concerns about samples being removed from a country to be used elsewhere. 'Helicopter research', where researchers from resource rich settings 'parachute' into health emergencies, often in the global south, and effectively export rich data and other intellectual value, has come in for sustained criticisms.

It is possible to find people putting forward the argument that the urgency of the present pandemic makes it impracticable to engage meaningfully with the communities involved, but this seems short-sighted (Wright, 2020). Indeed, it is possible to find examples of excellent public engagement, including in mental health research. Thus, for instance, the position paper mentioned above (Holmes et al., 2020) made use of public surveys early on in the pandemic to understand people's concerns, as well as an expert panel including people with lived experience of mental health issues. Reporting on this experience, Kabir (2020) has written that 'People with lived experience are an **essential** part of your team' and went on to say:

More than ever research needs to be ethically sound. There should be no cutting corners. Covid-19 does pose challenges in research terms. But this should not give anyone 'cover' to compromise ethical standards in order to ensure that research can happen quickly.

Engagement with those most concerned by research should be part of the ethical response as a sign of equal respect. Equal respect also argues that participants in research should be informed of how they have contributed to the bigger picture in terms of understanding, whether this be at the level of pathology (including psychopathology) or at an epidemiological level. People must feel, in Kantian terms, that they are ends in themselves and not mere means.

Fairness

The second value of fairness relates to equal respect in that it suggests that processes should be inclusive and transparent, that the benefits and burdens of research should be distributed equitably, and that collaborations between researchers should be fair for all. In COVID-19 the need for international collaboration and openness is imperative. However, this point of the compass highlights the requirement for results and the ensuing benefits to be distributed fairly.

There should be greater emphasis on the importance of fair collaborations, which not only enable the voices and priorities of those with local knowledge to be heard, but also help ensure that local capacity is developed for future emergency preparedness. Without this move towards fairer involvement and collaboration, inequalities within and between countries will increase. Indeed, researchers have warned (e.g. see Maja-Pearce 2020) that the poorer nations are likely to be the ones that suffer most from the current pandemic; as Goldin and Muggah (2020) have said:

“The pandemic will be especially damaging to poorer and more vulnerable communities within many countries, highlighting the risks associated with rising inequality. ... Like climate and other risks, this global pandemic will dramatically worsen inequality within and between countries”.

In the realm of mental health, at the national level in the UK, the Mental Health Policy Research Unit at University College London (UCL) is carrying out a survey aimed at contributing to understanding the impact of the COVID-19 pandemic on mental health and its management¹. Importantly, UCL

¹ <https://www.ucl.ac.uk/mental-health/mental-health-covid-19/mental-health-research>

promises to feed back 'immediately after the survey is completed to the Department of Health and Social Care and NHS England, and *to other key stakeholders and the public*' (emphasis added), which shows a commitment not only to fairness as exemplified by openness, but also to the sort of respect required by the ethical compass. Similarly, in the UK the National Institute for Health Research (NIHR) has put out a call for 'research proposals with potential for significant public mental health impact'². Important from the perspective of both equal respect and fairness is their statement that,

Collaboration with, and involvement of, people affected by the research - including patients, people with lived experience of mental health problems, carers and the public - will be imperative to bringing about real world impacts against these priority areas.

The call has highlighted the importance of potentially vulnerable groups too, which reflects the views of other researchers (Berks, 2020). Fairness involves engaging with these groups at every stage of the research process, even in the face of the difficulties this may cause. One reason for caution is that 'the vulnerable' are not a homogeneous group: within a 'vulnerable' group there is more or less vulnerability and some groups may not wish to be seen as vulnerable. There are, however, situations of vulnerability and risks of vulnerability which research might be able to lessen. Nevertheless, we see a similar concern for vulnerable groups in other countries, such as Canada, where the Canadian Institutes of Health Research (CIHR) have created funding opportunities to look at mental health issues in the COVID-19 pandemic and have emphasized those who are most likely to be vulnerable: 'Healthcare and public safety personnel; Older adults and residents of long-term care homes; People who use drugs (PWUD) and are facing converging COVID-19 and substance use and addiction epidemics; Women at risk of gender-based violence; Under-served Indigenous Peoples and communities'³.

A particular aspect of fairness is that there should be parity of esteem between mental and physical care (Millard & Wessely, 2014). This is no less important during the pandemic and relates to research as well as to treatment. Indeed, the obligation to undertake research in mental health is particularly important during a global health event which is perhaps primarily seen as biomedical. As Holmes et al. (2020) have made clear, now is not the time to neglect mental health issues. Parity of

² <https://www.nihr.ac.uk/documents/highlight-notice-covid-19-and-mental-health/24978>

³ <https://cihr-irsc.gc.ca/e/51991.html>

esteem is, as Millard and Wessely (2014) state, also a matter of respect. The importance of the point is brought out by researchers calling for parity of esteem in order to help counter the rise in domestic violence against women, a sequela of the measures taken to stop the spread of the disease (Gulati & Kelly, 2020).

Reduction of suffering

Ultimately any research in this arena should be aimed at reducing suffering. But it is worth asking, in connection with COVID-19, questions about suffering quite broadly. What are people's actual needs and how might research help? There is the obvious suffering caused by the disease itself, where developing treatment interventions and protocols in a timely manner will be obviously beneficial. Is it possible, for instance, to establish the symptoms and signs that point towards the need for earlier intensive treatment?

But a pandemic is much more than a biomedical event. It has profound implications for all aspects of our social and personal lives. Mental suffering might derive from the social measures taken to stop the spread of the disease. What is the real experience of older people who are told to self-isolate? What are the broader costs, in terms of physical and mental health, of governmental policies around work and leisure during the COVID-19 epidemic? We must think about who is determining the types of questions that are being researched. Where does power lie in the setting of the research and who benefits from it? Is enough attention paid to mental health and the challenges the pandemic poses for psychiatry (Kelly, 2020)?

Thankfully, we see a number of studies which seek to contribute to the bigger, global picture. Thus the UK Co-Space Study (Supporting Parents, Adolescents and Children during Epidemics) and its partner studies in Ireland, Iran, Denmark, the USA, and Australia aim to look at how families are coping during the COVID-19 pandemic and at what parents can do to help support their children's mental health⁴. A study entitled 'Psychological impact of COVID-19-pandemic and experience: An international survey' is also being run by Southern Health NHS Foundation in the UK and is seeking

⁴ <https://emergingminds.org.uk/co-space-study-supporting-parents-adolescents-and-children-during-epidemics/>

international participation⁵. Of course, the extent to which such studies are able to contribute to the alleviation of suffering will depend on a host of factors: how successful is the study in terms of recruitment? Has it asked the right questions? Is the dissemination of its findings robust enough to lead to implementation of effective treatments? And are policy-makers prepared to listen?

Researchers mainly from McGill University are conducting a ‘living systematic review’ looking at mental health in connection with COVID-19, i.e. a systematic review that is continually updated and provides quick access to results through online publications (Thombs et al., 2020 – in press). The research aims to evaluate mental health symptoms in relation to COVID-19, to look at factors associated with change in symptoms and at the effect of interventions during the pandemic. Reduction of suffering is a clear goal of the research, but it also satisfies the criterion of equal respect in that the review process and synthesis of evidence involved Dr. Sarah Markham as ‘a member of the team and an experienced patient advisor ... (diagnosed with anxiety and a depressive disorder) who survived a serious suicide attempt in 2007’; Dr. Markham ‘will provide commentary from a patient perspective’ (Thombs et al., 2020 – in press). The Editorial continues: ‘In addition, experts in mental health research and care will contribute outside reviews and commentary, which will be made public, as the review progresses’ (Thombs et al., 2020 – in press). Thus, the research will also show respect in its attempts to make its findings public. Again, it is key for researchers in such studies to live up to their promises, but the initial intentions of the researchers in the examples given seem to square with the points on the Nuffield Council Report’s ethical compass.

The values of respect, fairness, and the reduction of suffering should permeate the planning of research from inception to publication, and will be relevant in different ways for all those involved in research on COVID-19.

WHO and the Nuffield Council: Shared Conclusions

The influence of the three values discussed above are obvious throughout the Report (NCoB 2020a). The Report, which took about two years to produce, did not have COVID-19 specifically in mind. Other epidemics, such as the Nipah virus outbreak in Malaysia and Kerala which was first

⁵https://southernhealthnhs.fra1.qualtrics.com/jfe/form/SV_6h8XB1eTTWvkspn?fbclid=IwAR0PiZ5gENviAWLZNfuNeR5D-liwztZoFuZ6fTm9_Hu-IXt1Bs0ONpLkDD4

identified in 1998-99, the epidemic of Zika virus in Brazil and other countries in 2015, as well as the Ebola epidemic which affected western Africa between 2013 and 2016 and which subsequently emerged in the Democratic Republic of the Congo (as well as more briefly in Uganda), all feature in the report. But the remit of the Report was broader. It included all types of global health emergencies, such as those caused by the tsunami that affected Sri Lanka and other countries in 2004, as well as the on-going effects of the Syrian Civil War. So, the report and its 24 recommendations are not solely aimed at infectious disease outbreaks, but much of what it says is pertinent to the present COVID-19 pandemic.

Meanwhile, a working group of the WHO (2020a) has produced *Ethical standards for research during public health emergencies: Distilling existing guidance to support COVID-19 R&D*.

In Table 1, the main headings of the WHO's summary of guidance are given in the left-hand column. Comments from the NCoB's report, to flesh out the WHO guidance, are then given in the right-hand column. But readers might wish to consult both documents for further details (NCoB 2020a; WHO 2020a).

Table 1. Comparison of World Health Organization's Guidance on Ethics and Research in COVID-19 (WHO 2020a) and the Nuffield Council on Bioethics's report on Ethical Issues in Global Health Emergencies (NCoB 2020a)

WHO	Nuffield Council on Bioethics (Extracts from the Short Report (NCoB 2020b))
Research should be conducted only if it does not impede emergency response efforts	'People should not be asked to take part in health research when their basic health needs are not being met.' (p. 5)

<p>The need for collaborative research partnerships in emergencies</p>	<ul style="list-style-type: none"> • ‘Research institutions need to take active steps to ensure that their relationships with researchers from other institutions are as fair as possible in the circumstances. This includes establishing collaboration agreements early; making sure people are fairly credited for their work; and making sure partners working in low-income settings have access to essential resources such as libraries and training. • Funders should take active steps to connect potential collaborators, and to encourage fair arrangements within collaborations.’ (p. 11)
<p>Community engagement in emergencies</p>	<p>‘Funders should encourage and incentivise researchers to include affected communities directly in grant applications ...’ (p. 8)</p> <p>‘Study protocols should be developed with the input of local communities, in order to ensure that proposed procedures are acceptable.’ (p. 9)</p>
<p>Independent ethics review in emergencies</p>	<p>We need ‘the development of collaborative systems, at national and international level (for example within WHO regions), to support rapid and responsive review in emergencies, including access to additional ethical expertise where needed; and the inclusion of an explicit</p>

	<p>step of ethical consideration in plans for needs assessment or evaluation that raise similar ethical concerns to more formal research projects.’ (p. 9)</p>
<p>Adapting research methodologies in emergencies</p>	<p>‘It is unethical to ask people to take part in research that is unlikely to produce useful results, and hence will not help reduce suffering. This highlights the importance of scientific rigour.’ (p. 9)</p> <p>‘Study protocols should be developed with the input of local communities, in order to ensure that proposed procedures are acceptable. Even in multisite trials, there will be elements that can, and should, be implemented differently in each site in response to engagement and feedback, without prejudice to study rigour.’ (p. 9)</p>
<p>Selection of research participants in emergencies</p>	<p>‘Any exclusion criteria from studies should be clearly justified with reference to the risks and benefits for the group in question. There should not be an automatic exclusion of ‘vulnerable groups’ such as children, pregnant women, or older people. In practice, exclusion may make those groups more vulnerable.’ (p. 9)</p>
<p>Requirements for informed consent in emergencies</p>	<p>Ethics committees should consider:</p>

	<ul style="list-style-type: none"> • ‘whether the proposed consent processes are the most appropriate and sensitive that they can be in the circumstances; ... • whether, in all the circumstances, what is being asked of participants can be justified as fair.’ (p. 10)
<p>Sharing of research data and samples during emergencies</p>	<p>The report identified ‘...a number of conditions that would help promote equitable and responsible sharing – in particular the development of local systems of governance that people can trust. These include:</p> <ul style="list-style-type: none"> • developing locally and culturally appropriate approaches to consent for future uses; • establishing ‘access committees’ to decide what kinds of research can be done, and which researchers should have priority ...; and • regular feedback and information for local communities about the research being done.’ (p. 12)
<p>Sharing the benefits of research in emergencies</p>	<p>‘Distribute the benefits/burdens of research equitably’ (p. 7).</p> <p>‘Responsible sharing includes ensuring that data and samples, once shared, are used to optimum effect to help reduce suffering.’ (p. 12)</p>

It should be obvious from Table 1 that (a) the Nuffield Council's report (NCoB 2020a) and the WHO Guidance (WHO 2020a) share the same concerns; (b) they reflect the points of the ethical compass outlined above; and (c) both documents are highly relevant to mental health considerations in the COVID-19 pandemic.

Further Issues

The broader NCoB report inevitably covers more territory than the brief guidance document from the WHO. There are three further topics worth highlighting.

First, the Report talks about preparedness. Of course, each outbreak, epidemic, or pandemic will have its own characteristics. Nevertheless, there have been a number of actual or potential pandemics in recent years. We have already mentioned Nipah, Zika, and Ebola. But there has also been the Severe Acute Respiratory Syndrome (SARS) epidemic in 2002, as well as the relatively mild 2009 swine flu pandemic, and outbreaks of Middle East respiratory syndrome (MERS), such as that which affected Saudi Arabia in 2014. We know that there was psychological morbidity associated with both SARS (Cheng et al., 2004; Lam et al., 2009) and MERS (Lee et al., 2018). By looking at the literature on mental health in relation to these previous outbreaks, Rogers et al. (2020) have suggested that, whilst most patients will not have mental health problems, anyone with COVID-19 might suffer delirium in the acute phase and there is the possibility of 'depression, anxiety, fatigue, post-traumatic stress disorder, and rarer neuropsychiatric syndromes in the longer term'. Fatigue is a notable feature immediately after recovery from the infection. Hence, it would make sense for researchers in mental health to be prepared and to collaborate, given that novel infectious diseases reaching epidemic or pandemic proportions seem to appear every few years.

Secondly, there is the question of whose voices should be heard. The experience of research participants is important, especially where interventions have been expedited. Once again, the point is about effecting community engagement. However, we need to recognize that even within communities there is diversity. Different people or groups will have different amounts of power and influence. Researchers need to be alert to power dynamics between and within the communities with whom they are interacting.

Thirdly, the Report emphasizes in Chapter 10 the ethical issues in connection with front-line

workers. These may be people who are acting as both clinicians and researchers. Even if they are solely researchers, they may still be subjected to emotional and other stresses or traumas as a consequence of the work they do. Local researchers may find themselves stigmatized or disadvantaged, if it is believed for instance that they could themselves be contagious. The report notes and welcomes 'the increasing awareness of the need for ethical support for front-line workers' (NCoB 2020, 229). It also notes that those carrying out research need to exhibit a variety of virtues, that there are professional values to be upheld in research, and moral craft to be inculcated in individual researchers and amongst the research community.

Conclusions

There is a variety of imperatives created by the current COVID-19 pandemic. Many of them are practical. People need care and life-saving treatments under circumstances where healthcare resources might increasingly be scarce. But these imperatives reflect underlying ethical demands, such as those identified by the NCoB's ethical compass. We have outlined and highlighted work from the WHO and the Nuffield Council on Bioethics which sets out ethical considerations for researchers in global health emergencies such as the COVID-19 pandemic. These considerations apply no less to those working in mental health than they do to researchers in other fields. The answer to the contagion in the world is in large measure scientific, but it is also a matter of moral choices and ethical values being put into effect. The overarching values of equal respect, fairness, and the reduction of suffering are a good place to start.

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