

Research fatigue in COVID-19 pandemic and post-disaster research: causes, consequences and recommendations

COVID-19 and
post-disaster
research
fatigue

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Abstract

Purpose – Research fatigue occurs when an individual or population of interest tires of engaging with research, consequently avoiding further participation. This paper considers research fatigue in the context of the current COVID-19 pandemic, to identify contributory factors and possible solutions for future post-disaster research.

Design/methodology/approach – The authors draw on examples from the literature and their own observations from the recruitment and data collection phases of qualitative and quantitative studies, to provide an overview of possible research fatigue in the current COVID-19 pandemic, with implications for future post-disaster research.

Findings – People affected by disasters sometimes receive multiple requests for study participation by separate teams who may not necessarily be coordinating their work. Not keeping participants informed of the research process or outcomes can lead to disillusionment. Being overburdened with too many research requests and failing to see any subsequent changes following participation may cause individuals to experience research fatigue.

Originality/value – Guidelines for researchers wishing to reduce the occurrence of research fatigue include ensuring greater transparency within research; sharing of results and using oversight or gatekeeper bodies to aid coordination. Failure to restrict the number of times that people are asked to participate in studies risks poor participation rates. This can subsequently affect the quality of information with which to inform policy-makers

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and protect the health of the public during the COVID-19 pandemic or other public health disasters/emergencies.

Keywords Research fatigue, disaster policy, COVID-19, Research methods, Pandemic, Flooding, Disaster research, Willingness to participate

Paper type General review

Introduction

The COVID-19 pandemic has seen members of the scientific community conducting research to improve our understanding of the virus and its wider impacts, providing insights into how to bring the virus under control. The overarching goal, as with all research, is to contribute high-quality scientific insight which improves knowledge, and this often utilises the strengths and expertise of individuals to form collective teams. However, COVID-19 related research is under pressure to be conducted as rapidly as possible in order to provide the evidence-base for decision makers. From rapid reviews on the psychological impact of quarantine (Brooks *et al.*, 2020) to short letters on public health response for vulnerable population (Patel and Clark-Ginsberg, 2020) and understanding the antibody response in patients (Zhao *et al.*, 2020), there have been 6,659 papers on COVID-19 published between 1st January and 3rd April 2020, of which 83% were in peer reviewed journals, and 17% came out as unreviewed pre-prints (Baker, 2020); only a small percentage of these papers do not containing primary data (COVID-19 Primer, 2020). As such, not only does the speed and amount of research have the potential to lead to a huge amount of waste from poor-quality research (Glasziou *et al.*, 2020), they can also contribute to “research fatigue,” as seen in post-disaster research (Clark, 2008; Neal *et al.*, 2015; Pagano-Therrien, 2013) negatively impacting participants and potentially confounding the results of future COVID-19-related papers.

What is research fatigue?

Low response rates in research are well-documented. Between 1975 and 1999 the average response rate to questionnaire-based studies fell from 64.4% to 48.4% (Baruch, 1999), and response rates have continued to decline over the last 30 years (National Research Council, 2013). Whilst response rates have declined, the global scientific output of research studies roughly doubles every nine years (Bornmann and Mutz, 2015). Researchers are thus chasing a dwindling pool of willing participants. Unsurprisingly there are numerous publications exploring methodologies to increase response rates (Bower *et al.*, 2009; Edwards *et al.*, 2002; Mapstone *et al.*, 2007; Millar and Dillman, 2011). However, the cumulative impact of participants being approached for multiple studies on response rates is often overlooked. Multiple participation requests can lead to people feeling exploited (Goodman *et al.*, 2018; Koen *et al.*, 2017): in other fields, for example, cases of people feeling pursued for help by multiple organisations (Morris, 2016) have drawn media scrutiny and the imposition of official guidelines (UK Cabinet Office, 2015). Furthermore, poor research quality (including poorly designed, small-scale studies) can impair efforts to mount an effective, evidence-based response to a public health emergency such as the COVID-19 pandemic (Glasziou *et al.*, 2020). Although research ethics certification exists to ensure that individual researchers treat potential participants with respect and protect them from harm (British Psychological Society, 2018), such procedures do not mitigate against multiple requests to participate in research within a short time period.

This issue has been referred to as “research fatigue” also known as participation fatigue, which occurs when an individual or population of interest tires of engaging with research (Clark, 2008). This may manifest through reluctance to continue with an existing project, or refusal to engage with further research regardless of its importance. Clark (2008) suggests

three main factors driving research fatigue among highly researched populations: perceived lack of positive change following previous research participation; disinterest in some or all elements of the research project and practical barriers such as financial cost, time and lack of organisation on behalf of the researchers.

Over-research is reportedly most prevalent in poorer communities and those with high proportions of people from ethnic minority groups or who are otherwise marginalised (Sukarieh and Tannock, 2013). Several groups, including refugees (Sukarieh and Tannock, 2013), individuals with HIV (Pagano-Therrien, 2013) and individuals with a disability (Kitchin, 2000) have complained about being over-researched. Even entire towns have been subject to over-research after becoming a “symbolic location” for researchers studying socially differentiated populations (Neal *et al.*, 2015).

Why is research fatigue an issue for disaster researchers?

Globally, communities are increasingly affected by traumatic events, from disasters to terrorist attacks (CRED, 2015; Kitchin, 2000). Although each event is unique, well thought-out studies can identify needs or evaluate interventions that may be beneficial for the community in question or for future, disaster-affected communities. The current pandemic is no exception to this with numerous studies currently underway to evaluate the impact of COVID-19 on the mental health of the UK general population and specific groups such as healthcare workers or people who are of a Black, Asian or minority ethnicity background (Health Europa, 2020; NIHR Policy Research Programme Reviews Facility, 2020). Indeed, research fatigue may even be more of an issue for COVID-19 given the proliferation of potentially repetitive research investigating how people are coping. Furthermore, as COVID-19 is a universal disaster, its far-reaching impact may have led more researchers to refocus on COVID than would usually be the case with single disaster events.

Quite frequently there is a short-lived rush to identify and understand the immediate effects after high profile disasters; this has been termed a “research gold rush” (Gaillard and Gomez, 2015; Gomez and Hart, 2013; O’Mathúna, 2012). Unfortunately, coordination between research teams is often lacking. Any community, or specific occupational grouping, affected by a traumatic event or situation may be approached by multiple researchers simultaneously; survivors, their relatives, and responders may therefore potentially receive multiple requests to participate. For example, in Shatila, a Palestinian refugee camp, researchers were a constant presence in the lives of the residents, many of whom reported they had lost count of the number of interviews undertaken; over 223 academic articles and 128 books have been published about the camp (Sukarieh and Tannock, 2013). It is quite possible that the overabundance of rapidly and potentially poorly designed research (e.g. researchers with no prior background or track record in designed research topic and/or research lacks novelty and replicates what is already known) may not only reduce the impact of high quality research (Glasziou *et al.*, 2020) but may even negatively affect willingness to participate. This could limit the possibility of conducting the high-quality research needed to properly understand the impacts of the disaster in the first place. Thus whilst the “research gold rush” is understandable, it can be highly counterproductive.

Factors affecting research fatigue

In considering research fatigue, it can help to divide contributory factors into those relating to individual studies and those related to the coordination of multiple studies. These factors are based on a combination of existing research and our own experiences in conducting such studies (Figure 1).

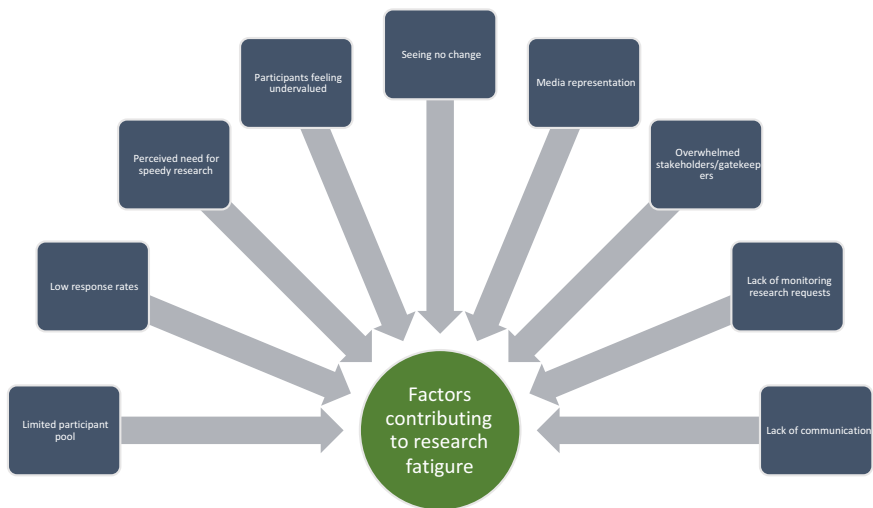


Figure 1. Summary of factors contributing to research fatigue in post-disaster research

Factors relating to individual research studies

- (1) *Limited participant pool.* Post-disaster, there are usually a finite number of participants who are able to participate in a given study (Collogan *et al.*, 2004). This is typically defined by a combination of geography (e.g. distance from the disaster centre, city or region) and exposure (e.g. direct victim, first responder or resident of affected city). Limited numbers increases the potential for individuals to be invited participate in multiple or repetitive studies (Newman and Kaloupek, 2004). During the current pandemic this is less problematic for members of a general population but still relevant for potential participants whose numbers are limited (e.g. those who have lost a close relative to COVID-19).
- (2) *Individual reticence to participate.* Communities responding to the disaster, or recovery activities, may be especially reticent to participate in research (Huizink *et al.*, 2006; Logue *et al.*, 1981) such as may be the case for current studies of essential workers. Low response rates may also be a consequence of individuals' reluctance to "relive" the traumatic event (Galea *et al.*, 2005). Individual reticence can thus require researchers to approach substantial numbers of affected people to achieve their desired sample size, which can be costly. This can, therefore, result in smaller, underpowered studies.
- (3) *Perceived need for rapid research.* Researchers often perceive that post-disaster research needs to be carried out whilst disaster response operations are ongoing (as in the COVID-19 pandemic) or as soon as possible after the incident, in order to investigate the immediate effects and what this means for the community (National Research Council, 2006). This rapid-response tradition in disaster research developed for two main reasons. The first (illegitimate) reason is the desire to be among the first to publish on the event, which represents an unhealthy predilection for novelty over substance. The other (legitimate) reason is the recognition that data on the aftermath of disasters are perishable and information collected after a delay may be distorted and incomplete (Quarantelli, 1987). Furthermore, delayed information acquisition prevents it from being useful to alter the outcome of an ongoing disaster. The desire

for speed (whether through good intentions or not) may lead to disaster studies being fast-tracked through funding bodies and ethical review boards or avoiding formal ethical review processes altogether. This sort of response can lead to oversights or mistakes, including insufficient piloting questionnaires or a lack of community feedback on recruitment approaches. Both can result in mistakes that appear at best unprofessional or at worst insulting to those affected, as well as being detrimental to the ultimate quality of the research.

- (4) *Participants feeling undervalued.* Failing to communicate study results to a community, or even to say thank you to participants, can lead to feelings of dissatisfaction (Clark, 2008). Unfortunately, this situation is not uncommon. One participant in our own research reported that she did not receive any “thank you” messages from researchers and that she also had to search online for the final reports, despite being told she would receive them once they were published (Patel, 2015). Seemingly small gestures such as these can make a big difference to participants, one study of participants during a pandemic found that they wanted to receive feedback about research but felt this was a neglected aspect which reduced the chance of them taking part in future (Gobat *et al.*, 2018). Feeling undervalued may lead to mistrust in researchers in general and reluctance to participate in other studies.
- (5) *Seeing no change.* Participants are often informed as to the general benefits that could be derived from their participation but often see no change or improvement in their lives afterwards. Seeing no change can lead over-researched participants to not being able to trust researchers on the benefits and scope of their studies (Omata, 2019). Participants from our previous research have indicated that this may be a contributing factor to any decision to refuse to participate in future research. For example, one participant in our flooding study reported feeling that the outputs from three research studies she took part in were the same: published reports with nothing directly helping her and her community. She stated that “if no impact or change for the best will happen to us locally, then there is no point to join even if there’s a financial incentive” (Patel, 2015). Another participant told us that “I cannot be bothered to join a study because I know that no change will happen” (Patel, 2015). Even though participants often understood the need for research, there was a sense of a “lack of trust” or a “break in trust” in how their information would actually aid their community (Patel, 2015). It may be too soon to know if this is occurring with ongoing COVID-19 research but it is important for researchers to be aware of, plan accordingly and further capture such information if it occurs.
- (6) *Media representation.* Incidents of considerable media interest are also likely to draw attention from researchers. For example, research on terrorism and terrorism-related issues has increased dramatically since the 9/11 attacks (Young and Findley, 2011). The media coverage of 9/11 has been labelled as the “largest, most compelling global media event in human history” (Grusin, 2010). In 2008, Silke (2008) noted that by 2010 over 90% of the entire terrorism literature will have been written since 9/11. Given the media coverage of the COVID-19 pandemic, it is likely that a similar bump in publications of pandemic literature will occur afterwards; along with, new found research interests in this area prompted by the media interests adding to the studies in circulation.

Factors related to study coordination

- (1) *Overwhelmed stakeholders/gatekeepers.* Following a disaster, a “gatekeeper” (e.g. local councils, human resources departments) is often available to facilitate researchers in

accessing those affected. Understandably, such organisations can find themselves overwhelmed by the necessity of dealing with the aftermath of the disaster itself and it is possible that the relevant staff may themselves have been personally affected. Understandably, gatekeepers may have insufficient time, experience or inclination to assess quality or differentiate between multiple research proposals. Additionally, recruitment could bypass gatekeepers or committees completely through online requests on websites and social media outlets.

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- (2) *Lack of monitoring of research requests.* There are two usual points of monitoring research: the gatekeeper and the ethics committee. However, despite disasters often leading governments creating registries of affected people, the confidential nature of research means it is not always easy for gatekeepers to monitor how many recruitment requests these individuals receive. Similarly, post-disaster researchers are likely to have different ethical procedures or requirements in place. For example, ethics approval may differ depending on a researcher's employer (e.g. universities or non-government organisations (NGOs)) or particularities of the research question or population of interest (e.g. the need to apply to a specific ethical board for some occupational groups such as the military). This lack of consistency in how ethical approval is obtained makes study coordination difficult as individual review boards will not be aware of other similar studies being put forward for review at other institutions. In addition, current ethical approval boards assess the ethics of individual studies in isolation and do not usually consider the ethical issues of potential competing research programmes.
 - (3) *Lack of communication.* Researchers may be unwilling to communicate with each other for various reasons such as to time constraints, not knowing who to contact, or fears of losing control over their research. One participant in our studies after the UK 2013–2014 floods informed us that she had participated in discussions organised by local officials, local non-government organisations and academic research groups and although all three groups, as a whole, asked similar questions, none of the groups were aware of each other (Patel, 2015). She gave her contact information to each lead contact of the group to help them connect with each other, but little came of it, as she recalls: “none can bother to talk to each other” (Patel, 2015).

Recommendations to limit research fatigue

Based on the above factors, we next provide recommendations to help researchers limit research fatigue in post-disaster studies.

- (1) *Increase transparency.* Researchers should ensure that the potential benefits of study participation are clearly emphasised in all communication, verbal or written, with potential participants and the organisations they work for. These might include direct benefits to individuals (such as directly improving their wellbeing), organisations (in terms of improving disaster-related policies and procedures), or wider society. Researchers should also always be transparent about their motivations; organisations and individuals are otherwise less likely to participate in studies, especially if they are concerned that responses will be misconstrued to fit a certain agenda (Crowley, 2013; Horn *et al.*, 2011). Being upfront about study aims can ease participants' potential fears by emphasising their ethical guidelines, reflexivity and the importance of unbiased research.
- (2) *Sensitivity regarding past negative experiences.* Researchers should remain cognisant that disaster affected individuals, or organisations, may have previously had poor

dealings with researchers, or with journalists, the media or politicians who may have misrepresented their communities, or the attitudes of individuals within those communities (Crowley, 2013). As well as being transparent, it is important for researchers to acknowledge any past negative experiences potential participants may have had and explain why the proposed research will be different. Researchers should be very careful to only promise to deliver what they can deliver. For instance, they should not promise that someone will be able to access timely and effective care if they answer a survey in a particular way if the research team cannot arrange that.

- (3) *Sharing results.* Researchers can help build trust by involving participants in different stages of the research cycle (Involve, 2020a). At the very least, researchers should ensure that participants are kept informed about any publications or reports that arise, for example by maintaining a study website, updated at various stages of the project, for participants to look at as researchers studying the recent Zika virus outbreak have committed to do (Jorge and Albagli, 2020; Kmietowicz, 2016). Researchers may consider dissemination meetings at the end of the study where findings can be presented and recommendations discussed. Participants may even be given opportunities to help with revisions to manuscripts or the development of subsequent research or interventions. This can be part of ensuring public involvement in disaster research, whereby research is carried out “with” or “by” those that are affected rather than “to”, “about” or “for” them (Involve, 2020b).
- (4) *Plan studies ahead of time.* Carrying out “speedy research” after disasters may be helped by researchers planning studies ahead of time and having approved study protocols/measures in place for different types of disasters. Planning ahead may help improve study quality since potential difficulties can be mitigated against ahead of time. One example of this is the programme of “sleep studies” commissioned by the National Institute for Health Research (NIHR) in preparation for the next influenza pandemic (NIHR, 2016). These involve pre-approved study protocols, ready to be activated in the event of a pandemic. Additionally, these pre-approved study protocols lower the barrier of poorly designed research, which is generally determined in late-stage adjudication if the research is written for a peer-review journal.
- (5) *Communication.* Finally, it is imperative that there is good communication between researchers and their potential participants and between different research groups to reduce the chance of multiple studies examining the same topic. This should avoid duplication, increase synergy and help to prevent the same individuals receiving multiple research requests from different organisations. To facilitate this, some societies, journals and funding boards have put together repositories and data sharing for post-disasters such as for Zika outbreaks (BMC, 2020b; Jorge and Albagli, 2020; Kmietowicz, 2016; Lancet, 2020b) and COVID-19 related research (BMC, 2020a; Glasziou *et al.*, 2020; Lancet, 2020a; NIHR, 2020). Researchers should consult these repositories and also discuss new studies with those who are likely to be aware of potential overlaps or synergies, such as professional organisations, research funders and government agencies.

Future research

Notwithstanding this review, it remains that the research community still does not fully understand the precise consequences of research fatigue, although it is clear that they are negative. Future studies should therefore aim to highlight better methodologies to reduce the likelihood of research fatigue affecting study quality. Given the complexities inherent in

recruiting participants to study research fatigue, a compromise may be to incorporate this into post-disaster research. For example, qualitative studies involving disaster-affected communities could consider asking all participants whether they have been aware of other community members being annoyed or tired with research requests and asking for participants' suggestions for how the problem could be reduced. Research could also be conducted with academics to explore their attitudes towards research fatigue and recommendations for addressing this. Such research, considered alongside the factors and recommendations identified herein, may represent the building blocks of a framework of post-disaster recruitment and research coordination. Such a framework may help ensure that future studies can be proactive in reducing research fatigue.

Conclusions

While the benefits of rapid publication of evidence during or after a disaster or emergency – such as the current COVID-19 pandemic – cannot be disputed, researchers should remember that the speed and quantity of research studies carried out may create research fatigue which could negatively impact on both participation and research quality. This paper highlights the importance of transparency and communication with both participants and other researchers, as well as demonstrating sensitivity towards research participants, particularly given that many will have had traumatic experiences. Research fatigue is rarely discussed in the literature but is particularly pertinent for researchers in disaster preparedness and response. This review, which also draws on our own experience of disaster research in the UK, aims to foster stronger research in disaster preparedness and response both during the COVID-19 pandemic and beyond.

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