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Real-time Responsiveness for Ethics Oversight During

Disaster Research

INTRODUCTION

In this paper, we contribute to the conversation concerning how best to ensure sound ethical oversight of disaster research by arguing for an ethical ideal and practice we call real time responsiveness (RTR). The central aim of RTR is to lessen the potential for research conducted in the wake of disasters to create, perpetuate, or exacerbate vulnerabilities, and contribute to injustices suffered by disaster-affected populations. Well cultivated and deployed, we believe that RTR may enhance the moral capacities of researchers and REC members, and foster strength and confidence in RECs as institutions where ethical engagement is nurtured and sustained.

To make this case, we begin by describing the characteristics of disaster research that call for innovative approaches to ethics review and oversight. We then offer two fictional cases (Box 1 and Box 2) to illustrate how ethical challenges can emerge and evolve in disaster settings. We pause from the cases to show the gaps in current guidance documents aimed at addressing the limitations of prevailing research ethics committee (REC) processes and structures. From there we flesh out the meaning of RTR, understood here as both an ethical ideal *and* practice, first describing the notion of real time, and next, defining responsiveness. We then revisit the cases, offering an analysis informed by the ideal of RTR and a description of what RTR might look like in the practices of

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researchers and RECs. Finally, we conclude by identifying and addressing possible limitations and objections.

Burgeoning Research, Distinctive Concerns

In parallel to the increasing incidence of disasters,¹ disaster research projects have grown in scope and frequency.² From a field that first focused primarily on sociological inquiries, disaster research has become increasingly diverse. For example, it now frequently includes protocols ranging from surveys of cholera prevalence to investigations of new surgical techniques, to macro-assessments of aid delivery. Contributing to the surge of disaster research are calls for greater efficiency and accountability in disaster response, as well as for more evidence-based aid.³ These issues have been emphasized, for instance, in the response to the 2015 Nepal Earthquakes.⁴

¹ J. Leaning & D. Guha-Sapir. Natural Disasters, Armed Conflict, and Public Health. *New Engl J Med* 2013; 369: 1836-1842.

² J.L. Chan & F.M. Burkle Jr. A Framework and Methodology for Navigating Disaster and Global Health in Crisis Literature. *PLOS Currents Disasters* 2013.

³ P. Knox Clarke & J. Darcy. Insufficient Evidence? The Quality and Use of Evidence in Humanitarian Action. ALNAP: London; A. Ager, G. Burnham, F. Checchi, et al. Strengthening the Evidence Base for Health Programming in Humanitarian Crises. *Science* 2014; 345 (6202): 1290-1292.

⁴ T. Kirsch. We Have Too Little Data to Know How to Help Countries Like Nepal Recover from Natural Disasters. *Washington Post* May 1, 2015.

Although ongoing moral vigilance is warranted in all research, we believe that research following disasters stands out in its demand for sustained ethical attention. Research in the wake of disasters and during humanitarian crises—particularly in resource-poor settings—is likely to raise profound and distinctive ethical challenges for local communities, crisis responders, researchers, and RECs.⁵ Such research often needs to be rolled out more quickly, compressing the time between when the study protocol is submitted to the REC and when research needs to be initiated. The conditions and circumstances in which disaster research unfolds can change swiftly in unpredictable, vertiginous, and even volatile ways. In the wake of disasters, individuals also tend to be

⁵ K.E. Browne & L. Peek (2013). Beyond the IRB: An ethical toolkit for long-term disaster research. *Int J Mass Emerg and Disasters*, 31 (3): 82-120; M. Hunt, J. Anderson, & R Boulanger. Ethical Implications of Disaster Research Diversity. *Am J Disaster Med* 2012; 7 (3): 211-221; D.P. O’Mathúna. Conducting Research in the Aftermath of Disasters: Ethical Considerations. *J Evidence-Based Med* 2010; 3 (2): 65-75; A. Sumathipala, A. Jafarey, L. De Castro, et al. Ethical Issues in Post-Disaster Clinical Interventions and Research: A Developing World Perspective. Key Findings from a Drafting and Consensus Generation Meeting of the Working Group on Disaster Research and Ethics (WGDRE) 2007. *Asian Bioeth Rev* 2010; 2 (2): 124-142; National Research Council. 2002. *Research Ethics in Complex Humanitarian Emergencies: Summary of a Workshop*. Washington, DC: The National Academies Press.

in elevated and varying states of vulnerability.⁶ This vulnerability stems not only from the constantly evolving physical and material hardships resulting directly from the disaster, but also from the destabilizing effect of displacement, and the erosion, or even breakdown, of social cohesion.⁷ These conditions make risk and social value, for example, shifting targets for assessment, and complicate activities like recruitment where it has been deemed ethically acceptable to proceed. Disasters can also exacerbate underlying social and economic vulnerabilities.⁸ Even the most rigorous and informed ethical review cannot predict just how things will unfurl and how ethical concerns may evolve and shift.

Indeed, as further illustrated in the cases (Box 1 and Box 2), the ethical ramifications of a disaster protocol may be neither apparent nor predictable to researchers or to REC members. This is especially likely in settings where researchers, REC members, and participants have different cultural orientations.⁹ Poor predictability of ethical ramifications is also likely where asymmetries of power play out in and across

⁶ C. Levine. The Concept of Vulnerability in Disaster Research. *J Trauma Stress* 2004; 17 (5): 395-402; D. G. Kilpatrick. The Ethics of Disaster Research: A Special Section. *J Trauma Stress* 2004; 17 (5): 361–362.

⁷ Lancet. Editorial: The Philippines: Learning Lessons from Past Disasters. *Lancet* 2013; 382: 1679.

⁸ R. Chung. A Theoretical Framework for a Comprehensive Approach to Medical Humanitarianism. *Pub Health Ethics* 2012; 5 (1): 49–55.

⁹ N. Buse, C. Bernacchio, & E. Burker. Cultural Variation in Resilience as a Response to Traumatic Experience. *J Rehabil* 2013; 79 (2): 15-23.

relationships. Such asymmetries exist not only between researchers, RECs, and participants, but also between researchers and the complex array of agents with intersecting scopes of responsibility and concern (e.g., expatriate staff of NGOs, national and local health workers and officials, and local authorities, for example).¹⁰

The fact that disaster research stands out in its ethical complexity is reflected in the emergence of a specialized subfield of research ethics.¹¹ For example, many have already questioned how best to provide research ethics review and oversight throughout humanitarian crises,¹² and innovative strategies, such as the use of pre-approved generic protocols, are gaining traction.¹³

¹⁰ E. Enarson. Through Women's Eyes: A Gendered Research Agenda for Disaster Social Science. *Disasters* 1998; 22 (2): 157-173; K. Tierney. From the Margins to the Mainstream? Disaster Research at the Crossroads. *Annu Rev Sociol* 2007; 33: 503–525.

¹¹ D.P. O'Mathúna, B. Fordijn, M. Clarke (eds). 2014. *Disaster Bioethics: Normative Issues When Nothing is Normal*. Dordrecht: Springer.

¹² L.K. Collogan, F. Tuma, R. Dolan-Sewer, et al. Ethical Issues Pertaining to Research in the Aftermath of Disaster. *J Trauma Stress* 2004; 17 (5): 363-372; D.P. O'Mathúna. Roles and Challenges for IRBs with Disaster Research. *Res Pract* 2012; 13 (5): 167-174; D.L. Rosenstein. Decision-making Capacity and Disaster Research. *J Trauma Stress* 2004; 17 (5): 373-381; J. Mfutso-Bengo, F. Masiye, A. Muula. Ethical Challenges in Conducting Research in Humanitarian Crisis Situations. *Malawi Med J*. 2008; 20 (2): 46-49.

¹³ D. Schopper, A. Dawson, R. Upshur, et al. Innovations in Research Ethics Governance in Humanitarian Settings. *BMC Med Ethics* 2015; 16(10); D. Schopper, R. Upshur, F.

Researchers themselves have reflected on the specificity of the ethical challenges raised by disaster research. In a compelling article, Browne and Peek give thoughtful attention to the unexpected ways in which disaster researchers can find themselves contributing to participants' vulnerabilities and feel compelled to respond to this elevated vulnerability.¹⁴ They offer several examples of what they call "hidden ethical landmines", which they define as "potentially explosive moments in which a poor ethical choice may produce detrimental effects on relationships with participants and on the research project as a whole".¹⁵

In many instances, the emergence of ethical concerns in disaster research may not be as obvious and dramatic as Brown and Peek's quote suggests; just as bad ethical decision-making may not necessarily be the *de facto* source of ethical concerns. It seems reasonable, however, to think that Browne and Peek capture an important aspect of the experience of disaster researchers who seek to act ethically in the context of a shifting moral landscape and encounter an ethics review system lacking the needed resources to respond.

Matthys, et al. Research Ethics Review in Humanitarian Contexts: The Experience of the Independent Ethics Review Board of Médecins Sans Frontières. *PLOS Med* 2009; 6 (7): e1000115.

¹⁴ K.E. Browne & L. Peek. Beyond the IRB: An Ethical Toolkit for Long-term Disaster Research. *Int J Mass Emerg and Disasters* 2013; 31 (3): 82-120.

¹⁵ Ibid: 89.

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CASE 1

Recent floods destroyed essential infrastructure in a large city in a low-income country situated close to the national border with another low-income country. As a result, many among the local population were displaced and are now living in a “tent city” adjacent to the urban area. Because access to staple food is direly compromised given the collapse of the food distribution system, displaced persons must register with the authorities in order to receive assistance such as potable water and food rations.

A European sociologist travels to the disaster area to study the impact of the disaster on children’s vulnerability to exploitation and abuse. The research protocol was approved by the REC at the researcher’s university. As no local REC is currently functioning, the researcher requested and received permission from the Ministry of Health (MoH) to conduct research with children amongst the flood-affected population. The Ministry has asked to be informed of the study results. The protocol specifies that the study participants are to be drawn from the temporary residents of the official tent settlement.

Once fieldwork begins, the researcher observes that there are clusters of makeshift tents set up in peripheral areas, away from the tent city managed by local authorities. The clusters have not been reported in the international media coverage of the situation. When the researcher asks residents of the official settlement about these clusters, many seem reluctant to discuss the issue and state that they are unclear as to why these tents are set up away from the main tent city. Eventually, the researcher comes to realize that these other settlements are primarily composed of undocumented migrants who are afraid to

register with the authorities in charge of the official tent settlement, for fear of being arrested and forcibly repatriated.

It is clear, however, that the unofficial settlements are in much poorer condition than the official one; because those outside the official settlement are not registered, they are not eligible for aid and rations. Concerned about the living conditions in these other settlements, the researcher succeeds in gaining access to one. During his visit, the researcher witnesses many children who seem to be in need of medical attention. As the researcher impulsively begins to write down observations, he quickly realizes that this data collection was not planned in the research protocol approved by the REC. While the temptation to begin interviewing individuals to gather data on these unofficial settlements is strong, the researcher is concerned that doing so might draw negative attention to this highly vulnerable population. In particular, rumours that authorities have elsewhere forcibly taken down unofficial settlements come to mind.

CASE 2

An earthquake has struck a poor area of a lower-middle income country. A team of researchers, including both researchers from the nation's capital and researchers from a high-income country, has been invited by the Ministry of Health (MoH) to survey a temporary displacement camp to study physical and mental health care needs. The findings are to help guide the collective response effort, as well as to better understand the population health impact of earthquakes more generally.

Most people living in the tent city are women and children, as many men have internally migrated to look for work or serve in the military. The team has designed a

house-to-house survey and received research ethics approval from the REC at the university in the high-income country and from a local institutional REC. Public healthcare workers (community health workers and nurses normally paid by the MoH) have been assigned to the team as surveyors because they speak the local language and know the local community well. The research project pays them an honorarium. The protocol requires interviewers to refer sick people to a local clinic for free treatment provided by an international NGO.

A few days into the survey, senior members of the research team begin to hear that the surveyors are not referring sick people to the NGO's clinic, but are instead providing treatment to them in their tents and collecting a fee for service. Given the resources available to the surveyors in the displacement camp, they are providing inferior care to what the international NGO offers. Most of the survey participants seem unwilling to discuss the situation with the researchers; however a few women have divulged this information to a member of the research team. The survey is not halfway complete, yet it may already have inadvertently allowed the surveyors to exploit some people and identify additional individuals who could be potential "clients".

Upon hearing of this situation, the research team leader, a resident of another country, raises the issue with an MoH official. She is surprised when the official brushes off her concerns and when, off the record, he criticizes the international NGO for "destroying the local health care business." After her discussion with the MoH official, the research team leader has the impression that if her team takes measures to stop the surveyors' practice, the MoH official will likely try to bring a halt to the research project. Either way, it is probable that the surveyors' actions will continue now that many sick

individuals have been identified. When the team leader raises the issue amongst her co-investigators, she finds a wide range of views. Some team members are very concerned about this situation while others, after verifying that the study data does not seem to be compromised, insist that “it’s not a big deal” and argue that the overall importance of the research outweighs the inappropriate behaviour that it facilitates.

GAPS IN AVAILABLE RESEARCH ETHICS GUIDANCE

The need for ongoing oversight in disaster research has been raised in at least two ethical frameworks: the Draft Statement and Guidelines for Disaster Research and the Ethical Framework for the Development and Review of Health Research Proposals Involving Humanitarian Contexts.¹⁶ Those discussions, however, have some shortcomings in terms of clarifying the nature and mechanism of ethics oversight. The Draft Statement and Guidelines for Disaster Research states that “[a]ll research should be subject to local ethics review that includes regular feedback from the researchers and

¹⁶ A. Sumathipala, A. Jafarey, L. de Castro, et al. 2011. *The Draft Statement/Guidelines for Disaster Research*. Available at: <https://globalhealthtrials.tghn.org/articles/draft-statementguidelines-disaster-research/>. [Accessed 1 June, 2014]; D.R. Curry, R.J.

Waldman, & A.L. Caplan. 2014. *An Ethical Framework for the Development and Review of Health Research Proposals Involving Humanitarian Contexts. Project Final Report*.

Available at:

www.elrha.org/uploads/FINAL%20R2HC%20Ethical%20Framework_Final%20Report_24%20January%202014_0.pdf. [Accessed 1 June, 2014].

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community representatives”.¹⁷ However, it does not explain the concept of (or process for) “regular feedback”. Nor does it explain how researchers should identify and engage with community representatives on ethical concerns. As such, while the Statement identifies regular feedback as a key component of disaster ethics review, it does not provide guidance on how it should take place and what it might mean for the actions and aspirations of researchers and RECs.

Likewise, the Ethical Framework for the Development and Review of Health Research Proposals Involving Humanitarian Contexts, commissioned by the Research for Health in Humanitarian Crises group (R2HC), acknowledges the need for RECs to provide ongoing oversight of research protocols.¹⁸ Yet the operationalization of regular feedback is not clearly explained here either. In addition, the Framework’s discussion of ethics oversight conveys a narrowed focus on adverse events from vaccines, drugs, and medical procedures, a focus that does not explicitly include the range of emergent and evolving social, political and economic vulnerabilities to which researchers and RECs should ideally respond.¹⁹

To help fill the moral space (both operational and conceptual) left open by these otherwise important contributions to disaster research ethics, we argue that ethical disaster research requires of researchers and RECs a particular sort of ongoing, critical engagement which may not be warranted in less exceptional research. We elaborate upon

¹⁷ Sumathipala et al., op. cit. note 16, p. 137.

¹⁸ Curry, Waldman, and Caplan, op. cit. note 16, p. 26

¹⁹ Ibid.

how this ethical ideal and practice for disaster research review might be conceptualized and utilized using the concept of *real-time responsiveness* (RTR).

DEFINING REAL-TIME RESPONSIVENESS

Real-time

The term “real-time”, used as an adjective, hints at a process that is sustained, iterative, and cyclical. The emphasis on this type of response has gained traction in many fields in recent years; business and information technology being some of the more obvious examples. In the context of humanitarian aid, a special type of real-time response, called “real-time evaluation” (RTE), is becoming an integral element of many interventions.²⁰ RTE contrasts sharply with the *ex-post* evaluations that humanitarian agencies have historically tended to conduct. Instead, RTE aims at swiftly improving the effectiveness of an intervention when that intervention is still in process, and in an ongoing state of change.²¹ RTE, then, seeks to have rapid, direct, and ongoing influence on the humanitarian response implementation.

Just as humanitarian organizations have found that RTE is useful in identifying and evaluating corrective action,²² so might RECs and researchers find that real-time

²⁰ E. Brusset, J. Cosgrave, & W. MacDonald. Real-time Evaluation in Humanitarian Emergencies. *New Directions Eval* 2010; 126: 9-20.

²¹ M.Q. Patton. 2008. *Utilization-focused Evaluation* (3rd ed.). Thousand Oaks, CA: Sage.

²² R. Polastro. Evaluating Humanitarian Action in Real time: Recent Practices, Challenges, and Innovations. *Canadian J Prog Eval* 2014; 29 (1): 118–134; R. Polastro,

response—or, as we suggest, *responsiveness*—in ethics oversight is useful in identifying and addressing evolving ethical challenges.

Responsiveness

“Responsiveness” has been understood in various ways, yet we find special purchase in the interpretations of Tronto and Springer.²³ Tronto identifies responsiveness as one of four ethical elements of care. Without precisely defining it, she casts responsiveness as a moral capacity demanding vigilance “to the possibilities for abuse that arise with vulnerability”.²⁴ According to Tronto, responsiveness operates ideally in close connection with another element, “attentiveness”, which we discuss below.

Springer situates “responsiveness” within virtue ethics. On her view, responsive moral agency involves cultivating capacities for orienting and re-orienting ourselves “to anomalies, challenges, and disturbances within our situated experience... [and] track[ing] certain provocative phenomena that [often] resist clear representations”.²⁵ In that much of our moral experience—and most certainly disaster researchers’—involves “divergence,

A. Nagrah, N. Steen, et al. 2011. *Inter-Agency Real Time Evaluation of the Humanitarian Response to Pakistan’s 2010 Flood Crisis*. Available at:

<http://www.alnap.org/pool/files/1266.pdf>. [Accessed 20 Oct 2014].

²³ J. Tronto. 1994. *Moral Boundaries: A Political Argument for an Ethic of Care*. New York: Routledge; E. Springer. 2013. *Communicating Moral Concern: An Ethics of Critical Responsiveness*. Cambridge, MA: The MIT Press.

²⁴ Tronto, op. cit. note 23, p. 135.

²⁵ Springer, op. cit. note 23, p. 141.

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uncertainty, and confusion”²⁶ or outright “upheaval”,²⁷ familiar moral vocabularies and manoeuvres (such as judging or trying to regulate action) may find little traction or be inappropriate. The moral capacity of responsiveness, by contrast, involves a process of “extend[ing] a temporally continuous thread of attention”.²⁸

Ethical attention, or attentiveness, also essential in Tronto’s account, is a capacity closely aligned with responsiveness that involves openness to and recognition of others’ needs and concerns. Recognizing and rightly understanding needs and concerns is a moral achievement in any context.²⁹ Yet in settings where norms differ, asymmetries are rife, and a disaster is evolving, it may be one that is especially hard-won. Attentive moral agents nurture and employ critical self-awareness and keen perception, engaging with the “social fabric of action” and “taking stock of relationships, background expectations, and the ways in which [they] could come across”.³⁰ The “aptness”, or ethical success, of a response hinges on whether and how adequately the hearer (here, the disaster researcher and the responsible REC) recognizes concerns and gives them sustained attention.³¹

²⁶ Ibid.

²⁷ Ibid: 30.

²⁸ Ibid: 137.

²⁹ N. Fraser. Taking about Needs: Interpretive Contests as Political Conflicts in Welfare-state Societies. *Ethics* 1989; 99 (2): 291-313; I.M. Young. Asymmetrical Reciprocity: On Moral Respect, Wonder, and Enlarged Thought. *Constellations* 1997; 3 (3): 340-363.

³⁰ Springer, op. cit. note 23, p. 9.

³¹ Ibid: 82.

We posit that an *attentive, responsive* researcher and REC enter into the relationship with a community affected by disaster with moral perception directed toward a set of conditions that can be expected to prevail, including for example: tensions and inequalities between social groups, displacement, temporary shelter, food insecurity, health care services that are inadequate, and the functioning of various informal and perhaps exploitative economies. They are sensitive to the possibility that these, and perhaps other, now unimaginable, conditions will worsen at least partly as a consequence of the research. The researcher in the field tries to fine-tune these perceptive capacities to the local context, keenly aware that he may miss many particulars and misunderstand much that is ethically significant. Yet he and the REC remain open—and convey this openness through their actions and interactions—to opportunities for ethical engagement and sustained attention.

We identify three targets of this sort of attention: first, the research project itself as it evolves; second, the ethical concerns that surfaced throughout the project and their roots; and third, the structures and processes in place for giving guidance.

With this general description of the disposition of the attentive, responsive researcher and REC, we return to the cases.

Case 1 – Continued

The responsive researcher identifies the shelters erected in the unofficial settlements, and develops awareness of the potential negative consequences of drawing attention to those living there should he expand his project. The responsive researcher is

also driven by concern for the public health situation, and wishes to take steps to ensure the health and safety of these displaced people, particularly the children in need.

By taking a step back and communicating with the overseeing REC, in this case at his university, the researcher demonstrates a commitment to responsiveness. By acknowledging the risk of attracting negative attention, the researcher proves sensitive to the possibility that his actions might lead to the worsening of vulnerabilities if the research process is not well managed.

In this case, suppose that the researcher's university REC is not set up to provide ongoing guidance. However, the REC recognizes the expertise and legitimacy of an independent group of ethics consultants that has experience collaborating with researchers in post-disaster settings. As such, the consultants are in a good position to discuss immediately the implications of the various alternatives open to the researcher. They might, for example, assist with assessing how to engage the MoH given concern for the precarious status of the population living in the unofficial settlement. They might suggest ways of working with NGOs, to help ensure an accurate, independent appraisal of the immediate health and safety of the populations in the unofficial settlements could be made.

If the medical situation in the unofficial settlement is better than the researcher initially perceived, and he opts to expand his mandate to include these settlements, the ethics consultants could suggest that the researcher partner with local and/or international NGOs to monitor conditions and advocate for protection. The ethics consultants might also suggest a detailed communication plan in order to pre-empt any stigmatization or resentment by national populations if the plight of undocumented migrants is put in the

spotlight. They might also raise concerns about whether or not the researcher is adequately equipped to take on this new component of the research. They might recommend closer collaboration with local researchers or, more specifically, with researchers with expertise working with undocumented migrants, and a more participatory approach for this component of the revised research program.

Should the researcher be unable to expand his research project, or should it be judged that the political context is so fraught that the conduct of research would very likely make the situation of the undocumented migrants worse due to time lags between data collection, analysis, and dissemination, the ethics consultants might help the researcher work through some alternatives, both to help assuage his moral distress and to ensure that the situation of the undocumented migrants does not deteriorate. Such discussions should be conducted in a way to promote the empowerment of vulnerable populations. In this case, it would mean engaging the population of undocumented migrants to the extent possible in the deliberations about the research and the scope of the responsibility of the researcher.³²

Once the researcher feels more confident about the course to follow, he can request their rapid approval of any modifications. Having to wait for the next meeting of the REC to submit a protocol amendment might let the small window of opportunity close.

Case 2 – Continued

³² Solidarity groups, where available, might mediate such interactions. See

<http://picum.org>.

Attentiveness to the experiences of research participants first enables the researcher to identify what appears to her to be intimidation and exploitation, mostly of women.

Attentiveness also gives her appreciation for how this exploitation is, if not necessarily created, at least facilitated by the research project. Attentiveness further brings awareness of the potential for privacy violations and harms to familial and social relations in the short and longer-term, in ways that she might not fully understand.

Responsiveness might manifest itself in many ways in this case. At minimum, it calls for the suspension of the survey and discussion with the surveyors regarding their rationale and intent for providing fee-for-service healthcare. Perhaps they consider the NGO healthcare culturally inappropriate or substandard. Or perhaps surveyors have not been paid by the MoH and are acting out of financial desperation. The outcome of the discussion could be shared with the RECs to help determine whether it is appropriate for the surveyors to continue in their role (assuming they agree to observe the approved research protocol), and whether replacement surveyors would be likely to continue the same practice.

Responsiveness also involves consulting others with relevant ethical expertise on or outside the local REC and the researcher's university's REC to better understand the ethical, cultural and social dimensions of the situation. Responsiveness further calls for mapping out ways to better ensure timely, effective and appropriate health care for participants and protect against the possibility for making them targets of later retribution. If any changes need to be made to the protocol following the RTR process, the local and international RECs should both approve the amendments.

OPERATIONALIZING REAL-TIME RESPONSIVENESS

Real-time responsiveness is more robust in several respects than the notion of regular feedback between researchers and RECs. Below we highlight key features and discuss each in relation to the responsibilities of researchers and RECs.

Temporally, RTR calls for a compressed period for review, and also extends the ethical focus over an extended timeframe throughout the lifespan of a research project—in contrast with, say, annual updates to RECs. In addition, RTR calls for ongoing, open channels between researchers, the research ethics community (through involvement of the relevant RECs and/or ethics consultants), and community members to address issues that are *predictably unpredictable* as research unfolds. Such communication then allows for the timely review and approval of protocol changes throughout the lifecycle of the project. This point resonates with Aultman’s suggestion concerning the importance of establishing and preserving a dialectical relationship between RECs and researchers.³³

Epistemologically, RTR makes it possible to welcome a wider community of contributors—not just members of the research team or REC—to help identify ethical concerns. Attentiveness and responsiveness are grounded, indeed, in a relational conception of epistemic and moral agency. RTR, therefore, conceives of the agency of researchers and REC members as unfolding and evolving, as Springer would put it, “in dialogue”³⁴ with the agency of participants. Attentive, responsive researchers are prepared and open, yet it will often be others who aid them and REC members in

³³ J. Aultman. Building Global Inter-IRB Trust: A Cultural Immersion Challenge. *Am J Bioeth* 2014; 14 (5): 9-10

³⁴ Springer, op. cit. note 23, p. 17.

recognizing, understanding, and effectively addressing concerns given inevitable partialities of knowledge and asymmetries in play. On our account, community members who may see issues surfacing and raise concerns may or may not be those identified and appointed by research teams as community representatives. We hasten to add that in this respect, our proposal is not merely protectionist; it is also empowering because it calls upon the moral agency of all those who may be attentive to vulnerabilities.

It is important to add at this point that, whereas other contributors enumerate specific ethical obligations and considerations for disaster research ethics—drawn from well-established philosophical traditions and research ethics principles³⁵—RTR allows for greater flexibility and avoids early closure in defining what is at stake ethically. For in settings where norms diverge, and asymmetries and volatility prevail, initial evaluation of what is ethically at stake may prove inadequate and shared descriptions of concerns elusive. RTR requires a certain sort of attention and engagement on the part of all who may witness vulnerabilities; it does not, however, demand shared understanding or swift resolution. Even in cases where understanding and resolution seem within reach, responsiveness calls for a posture “that is perpetually poised to call for a revisiting of the scenario and its practical implications”.³⁶

The wider epistemic and ethical community may also include research ethics consultants, particularly when there is no operating REC, when there is a need for expertise that goes beyond the REC members’ capacities, when the REC’s resources are overly stretched, or when on-site assessments are advisable. References to research ethics

³⁵ Browne and Peek, and Sumathipala, *op. cit.* notes 14 and 16

³⁶ Springer, *op. cit.* note 23, p. 137.

consultants in the literature go as far back as 25 years, and they have increased over the past decade.³⁷ In the context of disaster research, published experience remains scarce. But in the context of more typical research, a number of models – particularly institution-based – have been described and sustained,³⁸ and appetite is growing for the development of an evidence base appraising the value of research ethics consultations to the research enterprise more generally.³⁹

Structurally, once RTR becomes a guiding principle, ethical oversight stops being merely a scheduled REC event to become a more nimble process that is receptive and adaptive to emergent concerns, especially to the ways vulnerabilities evolve in disasters. As noted above, the REC and its members are, long beyond the initial review, attuned to the possibility of both identifiable and as-yet unimagined vulnerabilities, and open to ongoing interaction with disaster researchers (themselves trying to be responsive).

³⁷ L. Neskow, C. Grady, A. Iltis, J. et al. Points to Consider: The Research Ethics Consultation Service and the IRB. *IRB* 2009; 31 (6): 1-9.

³⁸ M.K. Cho, S.L. Tobin, H.T. Greely, et al. Strangers at the Benchside: Research Ethics Consultation. *Am J Bioeth* 2008; 8(3): 4-13; J.V. Lavery, S.K. Green, S.V.S. Bandewar, et al. Addressing Ethical, Social, and Cultural Issues in Global Health Research. *PLOS Neglect Trop D* 2013; 7 (8): e2227; D. Resnik. Research Ethics Consultation at the National Institute of Environmental Sciences. *Am J Bioeth* 2008; 8(3): 40-W6.

³⁹ J.B. McCormick, R.R. Sharp, A.L. Ottenberg, et al. The Establishment of Research Ethics Consultation Services (RECs): An Emerging Research Resource. *Clin Transl Sci* 2013; 6(1): 40-44.

Responsiveness more generally, though, is forward-looking. Ethical attention is directed not only toward the relationships at hand but also toward the development of research ethics capacity over time. The responsive committee strives to build relevant capacity in the form of education and expertise for researchers and members and to provide resources as needed. A responsive system for research ethics review and oversight, for example, might design a registry of RECs with experience reviewing disaster research, especially in resource poor settings, to create opportunities for networking and education across institutions. Responsiveness might also involve scrutiny and reform of institutional, provincial, or federal policy pertaining to research ethics review and oversight.

LIMITATIONS AND POTENTIAL OBJECTIONS

We have proposed that ethical research in the wake of disasters requires RTR, an ongoing, critical engagement on the part of researchers and RECs, to remain sensitized to shifting vulnerabilities and the potential need for rapid revision of research protocols. A number of objections might be raised.

A first objection to RTR might be that it demands too much of REC members in terms of time and human resources. Indeed, REC members are already strained.⁴⁰ Keeping the communication channels open with researchers throughout the course of a study may be taxing for small (often volunteer) committees. Ways to address this concern might be for RECs to get support from research ethics consultation services or to develop

⁴⁰ E. Whittaker. Adjudicating Entitlements: The Emerging Discourses of Research Ethics Boards. *Health* 2005; 9 (4): 513-535.

specialized committees to oversee disaster research, especially in places where such protocols are frequently seen.

In the field, a major concern is the potential for research efforts to drain qualified personnel from providing clinical care or other forms of assistance. The invocation of RTR could worsen this problem by diverting the attention of local REC members with clinical skills from urgent needs for the provision of care. In our view, research in humanitarian settings should never be conducted at the expense of humanitarian action. This argument has been elaborated elsewhere.⁴¹ Here, we simply assert that local REC members with essential skills should prioritize humanitarian assistance and that other responsible RECs provide supplemental support.

A second concern with our proposal might be that it could be difficult for researchers and RECs to determine what they are responsible for being attentive and responsive to. We agree that boundaries will be difficult to discern in some cases. Yet our position is that researchers and RECs are obligated to attend to the ways a given project, once underway, may in the immediate, near, and longer term create vulnerabilities and/or perpetuate or heighten existing ones, and to revise the research plan accordingly. In addition, if researchers identify an impending crisis in the course of their work, they have a duty to warn appropriate authorities, that is, those with the capacity and intent to safely and effectively respond.

In Case 1, for instance, there are two possible crises: health of children and forced expulsion. Addressing the first one might lead to the second. Trying to prevent the second

⁴¹ J.D. Pringle and D.C. Cole. Health Research in Complex Emergencies: A Humanitarian Imperative. *J Acad Ethics* 2009; 7(1-2): 115-123.

might lead to the deterioration of the first. It is beyond the scope of responsibility (and likely, expertise) for researchers and RECs to assess which of these is the greater threat. RTR calls for them to be attentive to the potential for harm and to respond in a manner that aims to prevent or mitigate it. In this case, attentiveness generates a response from the researcher aimed at seeking an improved assessment of medical needs, and medical care if necessary. Depending on the level of assessed urgency of these needs, this may or not involve local health authorities given the concerns about expulsion. In concert with a responsive REC and external consultants, the researcher can sort out these concerns and take steps to keep matters from deteriorating. Ideally, he may be able to improve them.

Some might also object that we have failed to consider the shifting vulnerabilities of researchers themselves, and their own—not just their participants’—potential needs for responsiveness in the midst of disaster. In a recent exchange, Heidebrecht and Denholm debated the question of whether the REC’s mandate includes attending to the potential harms to which researchers and research staff may be subjected.⁴² We are concerned about the widespread absence of a meaningful mechanism to address issues like threats to research team members’ safety. While we do not intend to suggest here that labour standards for researchers and research staff fully falls under the purview of the REC, we do recognize that RECs may have a role to play given their (often unique) access to data from the projects they oversee. The nature and precise parameters of this role call for further discussion, but the involvement of actors other than the REC—for example, institutional risk management officials—seems essential.

⁴² C.L. Heidebrecht. Time for Research Ethics to Broaden Its Scope. *Int J Tuberc Lung D* 2014; 18 (9): 1133-1134

An additional line of argument might be grounded in concern for scientific validity. If scientific validity is a condition for ethical research, one might consider that any risk to research staff that thwarts effective completion of a project should fall under this condition. If we accept this view, assessment of risks to researchers could also be included. We are committed to the view that, at the very least, RECs should be responsive to researcher and staff concerns in so far as this may represent a way to protect participants.

As a final point here, we think that RTR has potential to help build the moral capacities of health researchers and help them better address the ethical issues that emerge in the course of disaster research. By strengthening their moral repertoire, and in particular, capacities for attentiveness and responsiveness in *real-time* and *over time*, they are less likely to experience feelings of ethical impotency often associated with dire ethical challenges in disaster contexts.⁴³

Others might be concerned that the on-going interaction between researchers and RECs associated with RTR will foster undue closeness and blur the boundaries of responsibility and authority between researcher and REC, thereby compromising the independence of RECs. Rigorous practices of record keeping, already expected of RECs, should help alleviate such concern. In cases where it is felt that additional measures are necessary, resorting to non-binding independent research ethics consults could offer the advantage of helping the REC maintain a certain distance. In general, however, RTR

⁴³ M. Hunt; L. Schwartz; J. Pringle; R. Boulanger; E. Nouvet; & D. O'Mathúna. A Research Agenda for Humanitarian Health Ethics. *PLoS Currents Disasters* 2014 (August 12): doi: 10.1371/currents.dis.8b3c24217d80f3975618fc9d9228a144

helps us move away from envisioning RECs and researchers as being in opposition, recasting their relationship in light of the complementary roles of RECs and research teams in promoting social advancement. We might hope, indeed, that close ties serve the ends of ethics in better bringing concerns into view and crafting sensitive and sustainable responses.

Finally, there will inevitably be variability among researchers and RECs in their capacities for attentiveness and, in turn, what they perceive as warranting and constituting responsiveness. This variability is inevitable and not necessarily an ethical liability. Were RTR to be adopted by RECs as an ethical ideal and practice, it would be necessary to develop training that helps researchers and REC members nurture these moral capacities. It is also entirely plausible that experience with employing RTR over time might actually bring more consistency.

THE SCOPE OF RTR

As we noted at the outset, topics investigated in the course of disaster research are highly diverse, and do overlap with those pursued in non-disaster circumstances. In addition, disaster research shares characteristics with research conducted in low-resource settings generally and research conducted during public health emergencies, including the ease for exploitation of highly vulnerable populations. Consequently, some of the issues disaster research raises are not unfamiliar in research ethics. For example, many social science studies involve significant asymmetries between researchers and participants and heightened levels of vulnerability. Many of the potentially ethically problematic aspects of disaster research may have less to do with the disasters themselves and more to do

with the vulnerability they enable by creating, perpetuating, or worsening resource scarcity and inequality. Therefore, while disaster research calls for applying an RTR approach because of its likely unpredictable course, there is good reason to believe that RTR might benefit other types of research.

CONCLUSION

Given the expanding field of disaster research, we have argued the need for attentive and responsive research ethics oversight. The rise of accountability as a core principle of aid agencies, combined with the push for humanitarian action to be more evidence-based, ensures that disaster research will continue to receive attention and scrutiny. We have proposed enriching ethical oversight through the ideal and practice of real-time responsiveness. RTR seeks to lessen the potential for research conducted in the wake of disasters to create new vulnerabilities, or perpetuate or exacerbate existing ones, thereby diminishing the potential for (among other things) injustice. RTR has the potential to enable researchers, REC members, and RECs as institutions, to enhance their own ethical capacities to be ever-more attentive to the vulnerabilities of the stakeholders of a given study—above all, its participants—and design an ethically appropriate response.