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Health Research in Complex Emergencies: A Humanitarian Imperative

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Abstract Health researchers, research trainees, and ethics reviewers should be prepared for the special application of research ethics within complex humanitarian emergencies. This paper argues that as a precursor to published ethical guidelines for conducting research in complex emergencies, researchers and research ethics committees should observe the following primary ethical considerations: (1) the research is not at the expense of humanitarian action; (2) the research is justified in that it is needs-driven and relevant to the affected populations; and (3) the research does not compromise the humanitarian principles of neutrality, impartiality and independence. These primary considerations are in harmony with the humanitarian goals of saving lives, alleviating suffering, and *témoignage*. Furthermore, there is an important role for research in supporting humanitarian action, and the extreme vulnerability of research participants in complex emergencies demands intense research ethics scrutiny. It is important to discern which ethical considerations are essential, and which are merely desirable, as excessive research ethics requirements may impede life-saving research.

Keywords Complex emergencies · Displaced populations · Humanitarian aid · Humanitarian principles · Nongovernmental organizations · Refugee health · Research ethics · War

Setting the Scene: Complex Emergencies

War is persistent in devastating and displacing civilian populations. The Global Burden of Disease Study predicts that by 2030, injury from war and civil conflict, particularly among young adults, will account for 0.63 to 1.04 % of disability-adjusted life years (DALYs) globally. As a comparison, this is only slightly below tuberculosis which will account for 0.95 to 1.11 % of DALYS (WHO 2008). However, the actual percent of DALYs attributable to war is likely much higher, as the Global Burden of Disease Study does not

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include the farther reaching effects of war, such as psychological trauma, malnutrition, disease, and the collapse of social institutions.

Currently, more than 42 million people have fled their homes due to war and political violence (OCHA 2009; UNHCR 2009). Of these, 38% are refugees, falling under the protection of the UN High Commissioner for Refugees (UNHCR 2008). The majority 62% are internally displaced persons (IDPs). The 26 million IDPs, by definition, have not crossed an international border to obtain refugee status. Perhaps they are unable to afford the journey, the journey is too dangerous, or they are turned away at the border. Trapped within their own countries, IDPs are particularly vulnerable (Internal Displacement Monitoring Centre 2009; Salama et al. 2004). Forced displacement, violence, and unmet medical needs in the Democratic Republic of Congo, Somalia, Iraq, Sudan, and Pakistan, along with neglected medical emergencies in Myanmar and Zimbabwe, are currently some of the worst humanitarian and medical emergencies in the world (MSF 2008).

From war and displacement erupts complex emergencies, a term conveying images of displacement camps with terrifying levels of violence, panic, suffering, sickness and death (International Organization for Migration 2002). An organization like *Médecins Sans Frontières* (MSF) is a humanitarian non-governmental aid organization (NGO) whose workers respond to complex emergencies by providing life-saving assistance while adhering to humanitarian principles. MSF aid workers are entirely civilian, separate from military authority, and entirely secular, free from religious affiliation. Over 90% of aid, while coordinated by the United Nations, is provided by NGOs such as MSF (Burkle 2006).

As mentioned in the MSF Nobel Peace Prize Lecture of 1999, humanitarian action is not a contented action, nor is it charity. It is “an act of indignation, a refusal to accept an active or passive assault on the other” (MSF 1999). It stems from the notion of humanity, that all persons are entitled to dignity and equality, and to be treated humanely in all circumstances solely due to ones membership in humanity. From the notion of humanity stems the humanitarian imperative; human suffering must be addressed wherever it is found, with particular attention to the most vulnerable. There is a right to receive humanitarian assistance and a right to offer it (ICRC 1996; Pictet 1979; UNICEF 2003). University staff and students may participate in the humanitarian response with short term missions. University-based researchers have recognized the inherent vulnerability of displaced populations and have fostered a tradition of needs-driven research. Canadian universities are now providing academic centres in the related fields of health, conflict, human rights and forced migration (McMaster University 2009; University of Toronto 2009; York University 2009).

Humanitarian Action Research

An obvious question for humanitarian aid workers in complex emergencies, given the overwhelming need, is what should be done? For project planners, there is a history on which to draw, such as the institutional memory of the Red Cross or other disaster relief organizations. Historically, Red Cross workers rallied around the battle site, treating the wounded, transporting them by ambulance to field hospitals. Soon attention turned from wounded combatants and prisoners of war to civilians devastated by the direct and indirect consequences of war, still at great cost to Red Cross workers (Junod 1951).

In complex emergencies, it could be argued that all available resources should go towards saving lives, full stop. Research could be considered a luxury, out of place given

such urgency. This argument implies that project implementation is determined by trial-and-error: consideration to what had worked well in the past, and what had not. Given that the lives of tens of thousands of people may depend on successful interventions, is trial-and-error a reasonable method? Failed or ineffectual projects precipitated the Sphere Project's Humanitarian Charter and Minimum Standards in Disaster Response (Sphere Project 2004). However, while minimum standards are a good starting point, aid organizations have a moral duty to strive for better evidence-informed practices (Banatvala and Zwi 2000; Brown et al. 2008; Spiegel et al. 2002).

To convey the scope of the complex emergency, there is a role for epidemiology in establishing contextual factors such as size of affected population, number of orphaned children, levels of malnutrition, and rates of disease and death, etc. Furthermore, there is an important role for epidemiological research in addressing public health questions generated in the field, such as which thresholds should be used to define outbreaks of outbreak-prone diseases, and how well do rapid diagnostic tests perform under field conditions (Brown et al. 2008). Public health interventions have the potential to prevent more deaths than primary care. For example, more lives may be saved by access to safe drinking water than by access to cholera treatment, although both are essential. Those making decisions regarding which projects to implement and how they should be conducted ought to draw from more than trial-and-error. The need for best practices opens the door for research in complex emergency settings.

Research is defined as a systematic investigation to establish facts, principles or generalizable knowledge (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada 1998). Published literature presents ethical guidelines for research in complex emergencies (Black 2003; Goodhand 2000; Jacobsen and Landau 2003; Leaning 2001; Mfutso-Bengo et al. 2008; Zwi et al. 2006). However, before individualized ethical guidelines are considered, certain preconditions ought to be considered for health research in complex emergencies: (1) the research is not at the expense of humanitarian action; (2) the research is justified in that it is needs-driven and relevant to the affected populations; and (3) the research does not compromise the humanitarian principles of neutrality, impartiality and independence (Box 1). In harmony with the Tri-Council ethics statement, and helping to frame humanitarian research ethics guidelines (Black 2003; Brown et al. 2008; Goodhand 2000; Leaning 2001; PLos Medicine Eds 2009; Schopper et al. 2009; Zwi et al. 2006), these primary considerations are particular to health research in complex emergencies.

Not at the Expense of Humanitarian Action

While the greatest proportion of resources ought to go towards direct assistance, it is reasonable that some resources go towards less central costs such as project evaluation. Project evaluation is important for establishing which measures have had the greatest

Box 1 Primary considerations for research in complex emergencies

(1) The research does not come at the expense of humanitarian action

(2) The research is justified in that it is needs-driven and relevant to the affected population

(3) The research does not compromise the humanitarian principles of neutrality, impartiality and independence

benefit, but also for providing reports to donors. These are pragmatic justifications for diverting small proportions of funding away from direct assistance, to research and evaluation studies which will inform both current projects (if ongoing) and future ones. However, costly, more intensive or longer term research studies ought to have research funding separate from that for direct humanitarian assistance, so as not to draw from humanitarian resources. Given the concerns about *value for money* (Banatvala and Zwi 2000), humanitarian funders expect the majority of their donations to go directly towards saving lives and alleviating suffering, rather than to research.

The challenge for ethics review is in the overlap; researchers need to be imbedded in projects, alongside aid workers, benefiting from their logistical infrastructure such as transportation, communications, food, housing and security, as well as from their human resources. This is ethically sound to the extent that it is acceptable to the aid workers themselves, those directly involved in delivering humanitarian aid, as it is they who are best positioned to determine if at any point the research becomes unjustly burdensome to the expense of aid delivery. Research protocols ought to have contingency plans for potential interruptions and cancelations due to insecurity and rapidly changing contexts. Rigid research methods are not suited to crisis situations.

Needs-Driven and Relevant to the Affected Population

Affected Population

Research questions ought to derive from the most urgent needs and issues of affected populations. Who are the affected populations? Does the term exclusively refer to those within the sample frame of the study, the particular people who may be present only for a short time? It is reasonable to argue that affected populations refer to displaced populations more generally, similar in regard to issue under study. An affected population in Chechnya may differ from an affected population in Palestine in terms of shelter needs, but not in terms of post-traumatic stress symptoms. Two affected populations in the Democratic Republic of the Congo may be similar in terms of cholera risk, but not in terms of malaria risk given different altitudes. It is a question of external validity, or *generalizability.*

Relevant

Paradoxically, a refugee camp may be a convenient place for health research. The population is often static, closely confined, dependent, and with little political oversight, presenting both immense opportunities and potential dangers. However, given the extreme vulnerability of displaced populations, it is unethical for researchers to impose additional foreseeable and unforeseeable risks for research that is not relevant to the affected population, in that the study could be conducted just as validly on less vulnerable populations (Leaning 2001). Even among and between displaced populations there is a spectrum of vulnerability for researchers to consider. Especially vulnerable persons include single women and widows, unaccompanied minors, and those with disabilities (Mfutso-Bengo et al. 2008). Complex emergencies tend to occur in unstable resource-poor countries, compounding underlying poverty and poor nutrition (Burkle 2006). It may be difficult to establish when health research pertains to affected populations because of their displacement or because of their poverty. If the research pertains to displacement, then it would be justified in that it would not be valid on non-displaced populations. If it pertains

to poverty alone, then it would not be justified in that the study could involve less vulnerable non-displaced populations. However, certain effects of displacement and poverty are intricately linked, and there is an important role for health research in elucidating these tight relationships.

Needs-Driven

For research to be needs-driven, how does one determine need? Who sets the priority? Does the intervening NGO? Do researchers or politicians? There is a spectrum where there is easier and quicker consensus on extreme life-saving needs, such as during a cholera epidemic in the emergency phase, versus more complex culturally enmeshed issues, such as addressing sexual violence in the post-emergency phase (Richard Bedell, personal communication). Given the predictable nature of the causes of morbidity and mortality, there is an accepted list of public health priorities during the emergency phase (MSF 1997; Schull and Shanks 2001). Participatory action research methodology may have a greater role in the post-emergency phase (Checkland and Holwell 1998; Sletto 1999)

Clinical trial consent forms alert participants to risks and declare that the results of the study may not benefit the participants directly, but may benefit those similar to them in the future. This may be deemed acceptable under normal circumstances, but what about displaced populations with a baseline of desperation and vulnerability? Given their circumstances, the impositions of research can only be justified by balancing the potential for direct benefit (with little or no harm). For example, retrospective analyses of routinely collected data should pose no risk and so the benefits to the actual population studied may permissibly be non-existent. If, however, the research involves an intervention entailing any risk to study participants (such as a treatment, or even an interview about a traumatic experience), then the benefits may be for future populations, but should include benefits for the study population itself (Richard Bedell, personal communication). Immediate needs are the primary consideration.

Respecting Humanitarian Principles

Humanitarian action is saving lives and alleviating suffering while ensuring respect for the individual, guided by the core humanitarian principles of neutrality, impartiality and independence (Box 2) (de Torrente 2004; Pictet 1979). Neutrality is abstaining from engaging in military operations and from taking sides in hostilities or controversies of a political, religious or ideological nature. Impartiality is providing assistance based on need alone and without discrimination, with priority given to the most urgent cases of distress (de Torrente 2004; Harroff-Tavel 1989; ICRC 1996). For MSF, neutrality and impartiality need not be passive or condone human-rights violations; the organization speaks out and condemns any party in a conflict which it witnesses breaching human rights or humanitarian law. The important distinction is that criticisms are directed against people or groups based on what they do, not on who they are (Tanguy and Terry 1999).

The principle of independence stipulates that humanitarian action serves only the interests of its beneficiaries and not political, religious, or other agendas (ICRC 1996). For example, there ought not to be covert military operations or religious proselytism within the arena of humanitarian action. As importantly, there must not be external manipulation, real or perceived, of humanitarian resources. In affirmation of its independence, MSF refused funding from NATO member states for its work in Kosovo because NATO was involved in

Box 2 Key humanitarian principles

(1) Neutrality

Abstaining from engaging in military operations and from taking sides in hostilities or controversies of a political, religious or ideological nature

(2) Impartiality

Providing assistance based on need alone and without discrimination, with priority given to the most urgent cases of distress

(3) Independence

Serving only the interests of beneficiaries and not political, religious, or other agendas

hostilities (MSF 1999). Independence of humanitarian aid organizations is essential for ensuring access to populations in danger, but has come under attack by insidious military encroachment into humanitarian work. This invasion jeopardizes the safety of humanitarian aid workers and the populations they serve (Donini 2005; Pringle 2008). The threat against independence has important implications for research ethics in times of war, as research during war may be misused for serving military intelligence (McFate 2005) or devising strategies for winning hearts and minds (MSF 2004).

Beneficiary populations, those on the receiving end of NGO interventions, have their own perceptions of NGO independence. While NGOs may make efforts to introduce themselves to community leaders and distinguish their humanitarian work from other NGOs and militaries, it is easy to understand how vulnerable populations may remain skeptical and distrusting. This distrust hindered polio vaccination campaigns in northern Nigeria in 2003, when rumours spread that the vaccine was tampered and designed to sterilize girls or spread disease as part of a U.S. plot (BBC News 2003). Studies may be useful for discerning perceptions among beneficiary populations regarding the independence of the NGO, the appropriateness of proposed interventions, and the acceptance of the community to research. Acceptance to research is an important consideration, as mistrust of the research may lead to mistrust of the intervention (Richard Bedell, personal communication).

Témoignage

The medical humanitarian aid organization MSF holds at its core *témoignage*. Those that explain this word are quick to point out that there is not an adequate English equivalent, that its meaning is more profound than simply ‘to bear witness’ or ‘testimony’ (MSF 2006):

> The word ‘témoignage’ comes from the French verb, ‘temoigner,’ which literally translates as ‘to witness’. Témoignage—or witnessing—is simply the act of being willing to speak out about what we see happening in front of us. In MSF, this means willingness to speak on behalf of the people we assist: to bring abuses and intolerable situations to the public eye.

Témoignage is a component of advocacy, a rallying cry for an end to the extreme suffering experienced by civilians and witnessed in solidarity by humanitarian workers. Témoignage has credibility over hearsay and opinion, as it derives from direct evidence presented during the course of humanitarian work. The evidence stems from persons treated for measles, malnutrition, rape. Appalling case studies emanate from health care clinics, each a part of a larger story, such as from the war in Eastern Congo. As a method of

témoignage, MSF helps share these stories through its website “Condition: Critical” (http://www.condition-critical.org) (MSF 2009). Research relates to témoignage in that it can strengthen credibility and add depth. Qualitative research methodology, such as phenomenology, is applicable in this regard. It offers methods for delving further into the meaning and understanding of complex emergency experiences.

Sound Ethics Requirements

The confidentiality and protection of research participants is crucial for obvious reasons, and breaches could prove life threatening. Proposed research studies in complex emergencies ought to undergo a particularly scrutinizing ethics review customized to its unique context. It is important for reviewers to discern which ethical considerations are essential, and which are merely desirable, so as not to obstruct vital research. Research ethics committees ought to discern between necessary conditions such as informed consent and merely desirable conditions such as signed consent forms (Schopper et al. 2009); otherwise, ethically-sound life-saving research may be impeded by overly stringent criteria.

Conclusions

Humanitarian aid workers, academics and researchers have a duty to act ethically within the extreme and inhumane context of complex emergencies. Not responsible for the crisis, but living and working within it, field workers confront appalling human suffering. Given such circumstances, health research has the potential to improve ways of mitigating the devastating effects of war and displacement on civilians. As Leaning points out, “Sometimes the refugee setting raises special extreme problems that can only be addressed in that setting, and failure to improve our knowledge on how to deal with these problems is in itself unethical” (Leaning 2001). Health researchers, research trainees, and ethics reviewers should be encouraged and prepared for the special application of research ethics within complex emergencies. They must clearly understand that such research cannot come at the expense of humanitarian action, must be needs-driven and relevant to the affected populations, and must not compromise the humanitarian principles of neutrality, impartiality, and independence. Such an approach should be incorporated into university courses and into the training of members of research ethics committees who review such proposals within short timelines, with the potential benefits of the research clearly in mind.

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