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Aller au sommaire du numéro

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Résumé de l'article

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ÉTUDE DE CAS / CASE STUDY

Ethical Considerations Associated with Closing a Non-communicable Disease Program in a Humanitarian Setting

Handreen Mohammed Saeed[a], Lisa Schwartz[b] , Matthew Hunt[c]

Résumé
La gestion des maladies non transmissibles (MNT) dans les contextes humanitaires fragiles et touchés par des crises requiert une attention particulière car les systèmes de soins de santé primaires s'effondrent souvent ou sont compromis dans de tels contextes. Par conséquent, le traitement et la gestion de ces maladies deviennent plus difficiles. Les organisations humanitaires qui interviennent dans les situations de crise intègrent de plus en plus la gestion des MNT dans les services qu'elles soutiennent et fournissent ; cependant, elles se heurtent à une série de problèmes tels que la garantie de la qualité des soins, la durabilité des programmes et la possibilité de dommages involontaires. Cette étude de cas explore les considérations éthiques soulevées par un programme mobile de lutte contre les MNT géré par une organisation humanitaire internationale dans un pays touché par une guerre civile prolongée.

Mots-clés
urgences humanitaires, maladies non transmissibles, continuité des soins, organisations humanitaires, éthique

Abstract
Managing non-communicable diseases (NCDs) in crisis-affected and fragile humanitarian contexts requires special attention because primary health care systems often collapse or become compromised in such settings. As a result, addressing and managing these diseases become more challenging. Humanitarian organizations that intervene in crisis situations are increasingly including NCD management in the services they support and provide; however, they encounter a range of issues such as ensuring the quality of care, sustainability of programs, and the possibility of unintended harms. This case study explores ethical considerations raised by a mobile NCD program run by an international humanitarian organization in a country affected by a protracted civil war.

Keywords
humanitarian emergencies, non-communicable diseases, continuity of care, humanitarian organizations, ethics

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INTRODUCTION

Non-communicable diseases (NCDs), also known as chronic diseases, are long-term health conditions caused by a combination of genetic, environmental, physiological, and behavioral factors (1). The World Health Organization (WHO) reports that 41 million people succumb to NCDs each year, representing nearly 71% of deaths globally (1). The main types of NCDs are cardiovascular diseases (such as heart disease and hypertension), respiratory diseases (such as chronic obstructive pulmonary disease and asthma), cancer, and diabetes. 75% of global NCDs deaths, a total of 31.4 million, occur in low- and middle-income countries (LMICs). Moreover, LMICs are disproportionately affected by humanitarian crises, particularly those caused by armed conflicts (2). Patients with NCDs face many challenges and obstacles to accessing necessary care in countries affected by humanitarian emergencies as a result of wars, natural disasters, or outbreaks of infectious diseases (3).

According to the Humanitarian Coalition (4), "a humanitarian emergency is an event or series of events that represent a critical threat to the health, safety, security or wellbeing of a community or other large group of people, usually over a wide area". The WHO (3) contends that NCDs are one of the areas of healthcare most affected by humanitarian emergencies because of several factors. First, patients with NCDs require lifelong management and monitoring, which means that short-term solutions – such as when a short course of medication is dispensed for a condition like infectious diarrhea – are not applicable to the management of NCDs. Second, many patients with NCDs are dependent on a specific medication, medical appliance, or assistive device that they typically need for the remainder of their lives, raising continuity of services concerns when health systems are degraded. Third, patients with NCDs are at risk of acute exacerbations that require specialized medical care that may not be available in a crisis situation. Finally, effective NCD care and management requires close cooperation amongst healthcare providers and with other sectors, including social services and public health. Therefore, a proactive and integrated approach that ensures continuity of care for patients with NCDs across all phases of the emergency response is necessary yet challenging to achieve (3).

International humanitarian organizations (IHO) respond to the needs of populations affected by crises worldwide. Emergencies, particularly those resulting from armed conflicts, cause massive destruction of healthcare infrastructure, displacement of populations, and economic breakdowns. These features ultimately lead to severe disruption of various services, including NCD care. Due to the changing characteristics of types and contexts of crises to which they respond, IHOs have increased their

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involvement in NCD management in humanitarian crises during recent decades (2). However, the scope of activities of many IHOs is already broad and may include interventions to address food security, housing and shelter, primary and acute trauma care, health promotion, education, protection, and more. Consequently, providing all the required services to manage NCDs during the acute phase of a crisis is often unfeasible. Amidst these elevated and competing needs, IHOs must make decisions about how to distribute their available resources (2).

The interventions of IHOs are normally meant to be temporary responses. In addition to issues related to resource allocation in initiating an NCD program, decisions around project closure give rise to a further set of questions that warrant careful attention. Poorly planned departure from these projects could lead to various negative consequences and ethical challenges (5). The following case study, which is based on real-life events, will address some ethical considerations of an IHO launching – and subsequently closing – a temporary NCD program in a humanitarian setting.

CASE STUDY: MOBILE CLINIC PROVIDING AN NCD PROGRAM DURING AN ARMED CONFLICT

In a country experiencing civil war, the health care system in several regions collapsed. Tens of thousands of people in remote areas and villages were left without access to healthcare, including patients with NCDs. An IHO intervened by launching a mobile clinic to provide primary healthcare services to these communities, including care for patients with NCDs. Several remote villages were chosen for once-weekly visits from the clinic, and people from adjacent locations were invited to attend there for NCD care. Due to the mandate of the IHO which focuses on addressing the urgent needs of populations affected by crises, their strategy in such settings is to provide mobile clinic services for six to twelve months in each location. This time-limited approach permits them to shift their programs to other locations with greater and more urgent needs when necessary. The IHO is now approaching its planned time to leave the area. Ideally, the program will be handed over to a local agency to continue activities. However, there is not yet a solid commitment from another organization to assume responsibility for the mobile clinic. Closing the project could potentially leave NCD patients without access to healthcare and disrupt ongoing treatment. In addition, the organization provides a high level of care in their programs compared to what patients typically receive from either the fragile and weakened local health system, or other IHOs, and so a handover of the project is likely to result in a decreased standard of care for patients.

ANALYSIS AND DISCUSSION

In situations of conflict, International Humanitarian Law (IHL) grants protection to healthcare that is aligned with medical ethics (6) and directs humanitarian organizations to provide impartial care that addresses the suffering of injured and sick individuals and is aligned with international norms of medical ethics (7). Central to medical ethics are the commitments of health professionals to act in their patient's best interests when providing care, to seek to avoid or minimize risks of harm while respecting and upholding people's capacity to make choices for themselves, and to act impartially (8). For example, Médecins Sans Frontières (MSF) describes its commitment to medical ethics as seeking "to provide high-quality care and to act always in the best interest of patients; to respect their confidentiality, their right to make their own decisions and above all, to do them no harm" (9). More broadly, humanitarian principles direct organizations to act impartially and independently while seeking to alleviate suffering wherever it is found, and to operate in a neutral manner (10).

The possibility of closing the NCD program presents tensions among several core principles of healthcare ethics and has implications at the level of individual patients and their families, and within and across communities (2). Members of the IHO team are faced with questions of how to optimize benefits while minimizing risks. For patients and communities with whom they are already working, they may be concerned about non-abandonment, and their obligations for ensuring continuity of quality care. At another level, the assistance of the IHO may be needed in other crisis settings and patients with NCDs in other communities may have greater needs and access to fewer services, and concerns of equity and impartiality may direct them to reorient their programs toward areas of elevated needs.

The principle of beneficence represents doing good and encompasses a commitment to promote patient well-being and the duty of care required of healthcare practitioners once they assume the responsibility of providing healthcare to individuals. Non-maleficence requires healthcare practitioners to avoid doing harm by any action they take, including interventions that will potentially leave patients in a worse situation than before (11); it is recognized as an important guide for both medical (8) and humanitarian ethics (12). Beneficence might take the form of a duty to respond to medical needs during an acute crisis, whereas non-maleficence would entail non-abandonment of patients, especially since NCDs are not short-term medical needs. In this scenario, beneficence guides IHOs to intervene and seek to alleviate the suffering of patients, regardless of external factors such as the duration of the intervention, and nonmaleficence supports maintaining these services since their absence could bring harm to the patients. Moreover, the active involvement with particular communities creates obligations based on the relationships and expectations that have been formed, and the absence of alternatives for individuals with NCDs to access the care that they need (13). From this perspective, withdrawing from the program would require a handover to an organization ready and willing to maintain the standard of care and reach of the program to avoid deterioration of patients' physical and mental health. While the health education and promotion aspect of delivering NCD services is critical and could potentially have lasting benefits even beyond project closure, patients would still lack crucial tools to help them stay physically and mentally healthy, such as proper medical assessment, tests, and treatments.

Considering the case study from the perspective of the principle of justice opens additional features for consideration. As a matter of distributive justice, social goods such as healthcare services should ideally be made accessible in ways that are proportionate to need (11). This is also consistent with the humanitarian principle of impartiality. Following a consequentialist logic, scarce healthcare resources, especially in crisis settings, could then justifiably be rationed in a way that beneficial healthcare services are withheld sometimes from some if the greater overall benefit is achieved by shifting them to others (in this case, other communities or districts) across the population (11) – but how to decide? In this case, staying in one community indefinitely will mean other communities will not have access to the limited healthcare resources, which is arguably unjust. IHOs could understandably claim that their resources are limited and that they have a mandate to respond to emergency situations only, and when these emergencies are deemed to be over (or at least, that the situation has become more stable), they must leave to respond elsewhere, and the local authorities should assume the responsibility for providing services to the community (14).

An additional factor to consider is that were the IHO to remain and continue to provide those services, the local authorities would have few incentives to assume responsibility for addressing these health needs of their citizens, possibly choosing to invest strained resources in other areas such as restoring safe infrastructure. What continuing obligation does the IHO have in this regard? From this perspective, IHOs have been described as “second-best actors” and governments, as the primary duty-bearers, should thus assume these responsibilities when and as able (15).

In some sense at least, IHOs become ethically responsible for the communities they serve once they become involved in their care, regardless of the time period or type of intervention. It is worth considering the harms that can follow from withdrawal and the responsibilities that IHOs owe to the communities they serve. The impacts for humanitarian workers could be psychological, including moral injury. Greater still, the consequences for patients and communities as a whole could be lasting physical deterioration that, in the long term, is harmful to their well-being. On the other hand, lingering in a community almost certainly restricts the IHO from responding to other communities or impedes other services from being established.

QUESTIONS

1. How should ethical challenges that arise from temporary interventions be addressed in a manner that aligns with principles of health and humanitarian ethics?
2. How should IHOs plan their projects so as to do the least harm when it is time to withdraw?
3. How should such policy decisions be made and who should be involved in the decision-making and implementation processes?

CONCLUSION

NCDs are a major global health challenge and growing quickly in many LMICs. Humanitarian emergencies have also increased over recent decades due to patterns of armed conflict, increased forced migration, climate change-related disasters, and other factors. Humanitarian funding has not kept pace (16). Consequently, there is increased pressure and competing demands placed on IHOs responding to those emergencies. These organizations respond on multiple levels and to various challenges, including the management of NCDs, which can conflict with their intentions to provide a short-term, urgent medical response. This tension reveals ethical challenges for agencies designed to respond in acute settings.

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