Commentary

When Ethics Survive Where People Do Not

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The provision of health care service in resource-poor settings is associated with a broad set of ethical issues. Devakumar's case discusses the ethical issues related to the inability to treat in a cholera clinic patients who do not have cholera. This paper gives a closer look on the context in which Devakumar's case took place. It also analyses the potential local and organizational factors that gives rise to ethical dilemmas and aggravate them. It also proposes a framework to help in the proactive handling of the factors that leads to ethical dilemmas and resolving the ethical issues as they appear. It adopts the four principles of autonomy, beneficence, non-maleficence and justice as universal and prima facie principles, but with the inclusion of a local understanding of what of each of these principles means. It is based on a collaborative approach that involves the beneficiaries and other partners in the field to help share information and resources, as well as adopting the provision of a wider service to the whole community. This is done by asking three basic questions: (a) who are the relevant stakeholders? (b) what ought to be the ethical principles in place? and (c) how should we take, implement and follow the decision about service provision?

A Closer Look at the Context

Sudan is the largest country in Africa with a surface area of 2.5 million square kilometres and an estimated population of 41 million (2008) (Central Intelligence Agency, 2009), 20 per cent of them in the south, and mostly of African and Arab ethnicities. Situated in northeastern Africa, it is surrounded by nine countries, mostly sub-Saharan African countries. It witnessed the longest civil war in Africa between the southern Sudan People's Liberation Army/Movement and the subsequent northern governments, which came to an end through the signature of the Comprehensive Peace Agreement (CPA). Since then, the 10 southern states, of the 25 Sudanese states, have gained 'semi-autonomous' status with its own government and president. This president is also the vice-president of the national Sudanese Government of National Unity for a transitional period of 6 years that will end in 2011. At that point the southern Sudanese people will undergo a referendum to decide whether to stay within a united Sudan or gain independence.

However, this 'semi-autonomous' status in relation to political and financial resources could not overcome decades of war and marginalization, during which the already deficient basic health infrastructure of southern Sudan was almost completely destroyed. For example, during the conflict the biggest hospital in the south, located in the southern capital city of Juba, had been used as the headquarters of the northern armed forces and the wards were used as accommodation for soldiers and officers until just a few years ago.

The difficulty of the situation is clearly reflected by the fact that southern Sudan's health indicators remain comparable to the worst in the world. The infant mortality, the child mortality and the under-five mortality are 102.4 per 1000 live births (MDG target is 14 by 2015), 36.6 and 135.3 (MDG target is 13 by 2015), respectively (Damian and Damundu, 2007).

The situation is further complicated by the highest illiteracy rates in Sudan, where the 'best' southern state has a literacy rate of 6.8 per cent, while three other southern states have a 0 per cent literacy (Damian and Damundu, 2007), i.e., literally, no one there can read or write. All these factors impose special difficulties in planning for and providing humanitarian aid and any peace-stabilizing projects.

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Great Expectations (and Hard Times)

In the hope of changing these miseries, there were great expectations by the southern government and people, based on the big promises made by donors and the sponsors of the CPA. Unfortunately, these needs were largely unmet due to lack of security and the decline in interest from the international media, and available humanitarian aid, in favor of the 'hot spot' of Darfur in western Sudan.

The expected roles and the primary intentions of NGOs there, as in any other humanitarian crisis, are to help people survive and to provide them with the health services that their current health system is not able to provide adequately. However, there are limited available resources that constrain their mandates, compared to the usually high expectations of the served communities. Therefore, they need to go through a process of prioritization of their service choices and clearly define their objectives and the beneficiaries of their actions (Ford *et al.*, 2010) to provide the optimum possible service to as many people as they can reach within the available resources.

Such situations are inevitably associated with a set of ethical issues that are mainly related to decisions on allocation of resources in such exceptional settings as in the case discussion of 'Cholera and Nothing More' (Devakumar, 2010). The following sections discuss this case from a broader perspective, which is the ethics of humanitarian aid interventions, and proposes a framework to help NGOs provide their health services, within what I refer to as the ethical management of populations in disaster, in complementation to the clinical management of individual patients.

How to Resolve the Ethical Issues in the Case of 'Cholera and Nothing More'?

In ethical dilemmas, such as those presented in the case discussion, there is no easy way to get answers that satisfy everyone, but there is always the chance to make ethical deliberations achieve other benefits beyond the target of 'reaching an ethically defensible decision'. These benefits will extend to include the NGOs' volunteers and funders; the served communities; and others who will share the lessons to be learned.

To ensure that any framework provides the best possible ethical outcome, it should include: (a) a definition of the involved parties (stakeholders' analysis); (b) the relevant guiding principles; and (c) a mechanism to take, implement and follow the decisions taken, collectively, by the relevant stakeholders.

Who is Involved?

First and foremost, there are the international NGOs, which, I assume, will remain international, no matter how many local staff they recruit. Inevitably, their insights into the local communities they serve are based on the lessons they have learnt by 'trial and failure' or from the accumulated experience of the longer-serving NGOs in the field. This perspective can be seen, in my view, in the case discussion of 'Cholera and Nothing More' where the ethical perspective reflects, more or less, the insight of an outsider. This is not necessarily a bad thing.

Being an outsider gives the privilege of seeing the situation in a comparative way, i.e., seeing how the current situation might change, especially when the 'insiders' never had the chance to know anything else than their current status quo. These comparisons are usually made in reference to the set of moral and living norms of the volunteers/workers in the NGO. For instance, those who were brought up in communities where every individual is free to act on his/her own account with least interference from the community could assume that everybody should have this 'right'. This sounds very helpful in the sense that raising the bar would make the volunteers work on delivering the best possible service. This means practically to make the situation in the served communities as close as possible to the workers' standards of life. Yet, in my view, this is not enough to come to a satisfactory answer on how to proceed to help people who are living (and has been living) other ways of life in a very different setting like that in a post-conflict setting, like that in south Sudan. Contrarily, it could be a part of the dilemma.

Moreover, I would argue that any service provided by an NGO in any part of the world is value-laden. What would make a volunteer cross deserts and oceans to a land thousands of miles away from his/her family to help a malnourished child or a sick woman? There should be a motive that is morally justifiable for her to do so. This is also the case with people donating part of their money to this NGO or that NGO. They do so because they are adhered to a belief or a moral value, which could be altruism, doing good for others (beneficence), protecting others from being harmed (non-maleficence), universal fraternity, etc. These values are not per se a source of ethical dilemmas; yet the contextual differences are.

The second main involved party is the served community. Their life decisions are affected by many factors, mainly that of being a member of an extended family belonging to a tribal structure that holds a set of moral norms and values that should be respected by its members at all times. They have their inherited understanding and practice of right and wrong that is related to the tribe more than any specific religion one would embrace. In general, local communities welcome the presence of NGOs, despite the fact that some practices of their staff may be viewed as unacceptable. Being strangers to the community ensures a privilege that is rarely given to others in neighbouring tribes, which explains the repeated security incidents and mutual attacks due to competition for scarce natural resources.

Both NGOs and community members are under a complex set of conditions that limit their decision-making capacity, including the limited resources available for NGOs to meet the needs of the people who in turn suffer from poverty and insecurity, among other major problems. This is further complicated by the community's inherited lack of choices due to the power of the tribal hierarchy and lack of political freedom and freedom of speech (Hussein, 2009).

Which Principles Ought to be Used as a Guide?

Despite considerable efforts to help humanitarian agencies in making decisions about the provision of services in disaster areas (Checchi *et al.*, 2007), there is still lack of guidance on the allocation of resources at a public health level (Kass, 2001). One approach is to build public health ethics on medical ethics, such as the four-principles approach developed by Beauchamp and Childress (2001) of beneficence, non-maleficence, respect for autonomy and justice. Gillon presented them as bases for global moral ecumenism. He hopes to avoid the danger that universalizing these principles may impose global moral imperialism, by calling for autonomy to be considered the overarching principle, and being 'the first among equals' (Gillon, 2003). However, his approach was scrutinized by Dawson and Garrard who used the more specific term 'moral objectivism', rather than moral imperialism (Dawson and Garrard, 2006), to describe universal values that can take account of context.

From my point of view, these principles hold globally acceptable ethical values. However, they should be understood and used within the local contexts of each community where interaction takes place between Western ethics held by many of the NGOs' workers and the tribal-based ethics of the local communities. Understanding this interaction is crucial to understand how ethical issues arise in two main aspects. First, there are the differences of interpretation of a value as to what it is or what it means. Respect for the person's 'right' to be able to take an informed decision on his/her own behalf could be interpreted as 'I have the right to decide for myself' in an individualistic community, while it means '*we* can decide what is good for each one of us, which is what is good for all of *us*' in communities where the family/tribe is the building block of the community like many of the developing countries, including Sudan where our story goes.

Second, there are the differences in implementation or materialization of the value itself. For example, a tattoo on a man's shoulder or a piercing in his ear or nose could be extremely offensive to many Sudanese tribes where these practices are only allowed for women or as tribal markings. Meanwhile, a volunteer might consider it to be a part of his/her autonomy to do what s/he wants to their body.

These differences in the interpretation and implementation of moral values, I argue, are the main causes of the ethical dilemmas that arise in global health and international research ethics. Without adequate preparation and 'stage-setting', international NGOs can easily fall into the trap of imposing the collective visions of the workers'/donors' perception of the moral values that ought to be applied. One clear example of this is the distribution of condoms among youths in the refugees' camps and in the NGOs' clinics. From the NGOs' perspective, they are protecting the adolescents from getting HIV/AIDS infection, especially young women. They are preventing harm, ethically speaking.

Contrarily, this is seen by the local leaders and communities as an encouragement for the youths to have sex without being married, which is (to them) a bigger harm than catching an infection. Their argument is that an infection will kill only one, while the spread of sex among unmarried adolescents is killing the basic structure of the community—the family.

Ethical values need to be agreed on in terms of what they mean and how they will affect the provided services. This needs to be done jointly, despite the fact that many local concepts and beliefs may seem strange or naive to an outsider. This means that NGOs need to go beyond the routine 'needs assessments' and usual meeting with the community leaders, in terms of scope. Though these meetings and assessments are crucial for logistic preparations of the humanitarian aid, this need not be the sole purpose.

Humanitarian work is not only about saving bodies; rather it is about dealing with entire humans. This includes the need to determine people's physical needs

within their spiritual and belief system. Faith makes the believers do what they believe in, regularly and keenly in direct proportion to their faith and, contrarily, they avoid what they are told to be a bad deed (according to their belief). The importance of this is two-fold. First, planning health care interventions in harmony with local beliefs would provide more local adherence to health instructions if presented as part of what the tribal leader (or god) says ought to be done. Second, it is crucial not to set plans that consume the scarce resources in activities and interventions that will be simply refused by people if they believe that it conflicts with their belief system. For example, despite all the anti Female Genital Mutilation/Cutting (FGM/C) campaigns taking place in Sudan for decades, the prevalence of FGC is as high as 69.4 and 45 per cent of women intend to do FGC for their daughters (Elabassi *et al.*, 2007). The failure to reduce the prevalence of FGM in Sudan is a classical example of how health interventions could fail when it is not planned taking the people's belief system into account.

Another example is directly related to the cholera case being discussed. Many southern Sudan tribes have a belief that a child with diarrhoea should not be washed nor given water to drink. Indeed both practices would aggravate the child's condition and increase the potential complications of acute watery diarrhoea. Thus it is not only about clinical management guidelines, it is about people, or what I prefer calling ethical management that helps to deal with humans as moral agents who can (and should) make their life decisions, and not mere sick bodies that need treatment.

Ethical considerations extend not only to the service NGOs provide, but also to the presence or absence of the NGO itself. Humanitarian NGOs usually do a very beneficial job by training the local staff, and providing them with the better incomes that their families need. However, the work of NGOs is not free from some potential 'side-effects'. Some of those were stated in Devakumar's case including dependence on foreign aid, which may also delay the development of the infrastructure of the local health system by directing donations to the NGOs' clinics (Devakumar, 2010). It also shifts the limited available local trained staff from the ministry of health (MOH) basic facilities to the NGOs, where they receive better payment. Moreover, there is also the danger of the over-served communities when many NGOs work on almost similar kinds of service in almost the same location leading to habituating them to a level of service that a resource-poor MOH cannot provide after the NGOs leave [or are expelled, as happened in Darfur (AlJazeera, 2009)].

In conclusion to this section, the four principles provide a common ground that both the NGOs and the local community leaders are able to understand and discuss in fora that fairly represent the served community in terms of sex and age distribution. Should these values contradict, they are preferably ranked by the community members, if needed, and these will shape the ethical directives of the NGOs' plans of action.

How Ought we Make the Decision, Implement it and Follow it Up?

This framework presents a multi-stage approach to operationalization of the ethical principles into practical actions. It is a dynamic process in which each level of action is associated with interaction and feedback from the other level. This is already taking place in most international NGOs where the headquarters usually reflect the needs reported by the field offices as the needs of the people that they serve. This includes, for example, working on provision of drugs and supplies from pharmaceutical companies, UN agencies and other sources. Then it is the role of the field offices to communicate with the communities that they serve to determine which service is provided where and to whom, which is the second stage.

In the second stage, I suggest a process similar to that of taking consent in clinical/research ethics. First, served communities need to know the relevant information to help them come to a joint decision with the NGO. This is best done through open sustainable channels of communications, preferably direct regular meetings. Relevant information should include an update on the situation of the available drugs, supplies, staff and future plans. They should be given a chance to ask questions and to have them adequately answered and to have time to consult among themselves. It is crucial to be alert to the power gradient between the beneficiaries who need the service and the NGO who has the service, which carries the potential of undue influence or coercion from the implicit fear to lose the NGO's services should they come to refuse an intervention or a given type of service. The different alternatives should be made available for them, including the level of risk in terms of how many people may get sick and how many may die, and whether there are alternative service providers. More details are indeed needed in specific situations, e.g., the definition of a disease like cholera where a cholera clinic is proposed. It is important though that the NGO advocates for the vulnerable whose rights could be taken lightly, especially the women's and children's rights to have best possible access to health care.

Implementation of the service provision should aim at maximizing the benefit to as many as possible. For example, treating a patient with cholera is one thing that cholera centres do all the time by treating the individual patient. This needs to be adjusted to hosting the patient as a part of a family that will suffer from his/her absence. From a personal experience as a Primary Care Officer for a UN agency, our surveillance teams not only collected data and samples, but also provided other simple services such as reassurance of family members, two bars of washing soap, a few tablets of chlorine and some health education messages with emphasis on children's personal hygiene and excreta disposal. By so doing, the agency showed respect and understanding, and provided a tangible help at less than one dollar per patient. We were not only protecting people from cholera but also giving them life-long skills that will protect them from many other diseases. It also reduces the feeling of guilt for those who did not receive direct care from the clinic.

Networking with other service providers is both an ethical and an operational need. The NGO can communicate with other nearby NGOs that provide services that the cholera centre does not. For example, in southern Sudan, World Vision provides primary care and food donations that some patients presenting to the cholera clinic may need (World Vision, 2009); while HelpAge International provides community-based health and nutrition services (HelpAge International, 2007).

It is crucial to set the community up to take eventual ownership of the program itself, e.g., training community members on how to sustain the service provided by the NGO should be a part of the exit strategy of any NGO. Spoon-feeding and providing every possible available service only because the NGO has the resources or the money to do it is not ethically justifiable. It has potentially negative future implications (what we might call 'delayed maleficence') on the served communities. NGOs can start with simple self-practised activities like safe disposal of wastes, and personal hygiene like tooth brushing and hand washing that can make a sustainable healthy change.

This approach is not free of pitfalls and practical difficulties. However, I argue, that it will eliminate many of the ethical dilemmas and violations appearing in such conditions and help resolve the rest of them as they appear. When interventions take place in such a collaborative integrated approach, pitfalls of the process will accordingly appear to the NGOs and the communities, who can agree, through the established channels, on further improvements.

In conclusion, there are many inevitable factors that make the allocation of resources and provision of health services in a resource-poor setting, particularly in a post-conflict setting like southern Sudan, difficult and should be acknowledged. However, the collaborative approach to service provision will make the situation clearer to the beneficiaries and probably make their expectations more realistic. It would also provide relief to the first-line health service providers by having their moral load shared and their deeds ethically guided and justified.

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