

REFLECTIONS

The meaninglessness of doing bioethics: Reality check from a conflict zone

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Abstract

Running bioethics workshops one after the other can become a mundane affair, primarily because of the similarity of their content and discourse. However, conducting a workshop for participants from conflict zones such as Palestine provided an entirely new perspective for this author. While the bioethics discourse may translate into useful and actionable guidelines in the free world to help uphold human dignity, to those living in occupied territories and conflict zones, in the face of their lived lives, it appears little more than a self-serving academic exercise by “parachute bioethicists”.

Background

I have conducted more research ethics workshops than I care to remember, which is why the prospect of running another one hardly ever excites me now. While I try to be innovative in my own sessions, I realise that the various issues that need to be discussed generally remain the same, whether in Karachi or Khartoum. Discussions take place around the same old themes already discussed to death, like lack of free will, no alternatives to choose from, coercion, corruption, and exploitation of the already vulnerable, coupled with the absence of, or weak, regulatory mechanisms, regulator incompetence or a sheer lack of commitment. All of these add up to the typical brew served in research ethics workshops across the developing world, with facilitators serving the standard cookie cutter solutions, often with a sprinkle of some local *masala* to “indigenise” the discussion: emphasising respect for the gatekeepers’ authority while protecting the autonomy of the participants, underlining the importance of translating of the informed consent documents into the local language, reinforcing respect for local cultural norms, and so on.

However, a Palestinian colleague’s request, from a university in the West Bank, to collaborate in conducting a workshop designed specifically for researchers and ethics reviewers

working in conflict zones such as Palestine, Syria and similar areas seemed intriguing. Being part of the only WHO Collaborating Centre in Bioethics in the Eastern Mediterranean Region, I had an obligation to respond positively to this request. Besides, the thought of grappling with unfamiliar issues made the offer irresistible to me. I realised that this would be more a learning exercise for me than a teaching one and, sure enough, I have had an education.

Ethical issues in conducting research in conflict zones is an area that has been well explored, especially from the sociological angle, highlighting the importance of doing no (additional) harm to an already compromised population (1, 2). The inherent instability of such areas adds a layer of vulnerability to the potential research subjects, the lack of research and ethics infrastructure further compounding the potential of exploitation (3). Clearly, the wheel had already been invented, and I was just going to experience the spin.

The workshop, primarily meant for participants from Palestine, had also attracted participants from Syria, Libya, Jordan, Egypt, and Afghanistan. Since Palestine was out of bounds for the facilitators as well as the foreign participants, the organisers had to conduct the meeting in Amman, Jordan. Not only did this make it all the more difficult for the organisers to put the event together, attending it was also a challenge for the Palestinian participants who came from Gaza and the West Bank. The efforts they made to reach Amman, theoretically a mere hours’ drive away, were infinitely more difficult than my journey from Karachi, or that of my co-facilitator from Beirut.

The winding road to the workshop

The Palestinian people have been divided into three groups: There are those Palestinians who live in the West Bank and Gaza and have Palestinian nationality and carry Palestinian IDs and passports. They cannot move between the West Bank and Gaza, nor can they go into Israel or East Jerusalem, and they require special permission from Israeli authorities to move. The West Bankers can only exit the West Bank through the Hussain Bridge to Amman and then fly out of Amman airport if going abroad. For the Gazans, in the past, they were able to leave through the Airaz border going to the West Bank to the bridge to Amman, but now this option is no longer available. The only exit available for them out of this narrow strip of land is through Rafah to Cairo.

Another category is the Palestinians who live in East Jerusalem and have Israeli residence and carry Israeli travel documents,

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but do not have passports since they are not regarded as Israeli nationals despite permanent residence. They can travel freely within Israel and the West Bank. They are considered by the Israelis as Jordanian and also carry temporary Jordanian passports.

Lastly, there are the Palestinians who still live in historical Palestine (Israel) and have Israeli nationality and carry Israeli IDs and passports. They can move freely in the West Bank and Israel but not in Gaza. The Jerusalemites can leave through Tel Aviv airport or through the Hussain Bridge to Amman.

The term I use, "move freely," is actually incorrect in the context of any Palestinian. A very physical "Apartheid Wall" makes sure there is no free movement for the Palestinians, even within the zones that are meant for them. This physical barrier encroaches into Palestinian land, locking them, purely on racial grounds, into what can only be described as a large jail. They are even deprived of cultivatable land because of this barrier. According to a UN report "... it is difficult to overstate the humanitarian impact of the Barrier. The route inside the West Bank severs communities, people's access to services, livelihoods and religious and cultural amenities." (4: p 1).

After negotiating the numerous check posts along the Wall, even the short border crossing from the West Bank through King Hussain Bridge can easily be a gruelling daylong exercise for Palestinians since multiple levels of permissions are required. I was told of people having to sit in the bus in sweltering desert heat for hours with the engine switched off till the Israeli authorities let the bus move. It is obvious that these various physical as well as psychological manifestations of oppression limit access to the most basic of human rights for the people of Palestine.

The ground realities

In order to get a sense of the lived experiences for these researchers living and working under oppression and apartheid, a full afternoon was devoted to them sharing their stories. According to a recent survey looking at the challenges to health research systems in Palestine, among the issues identified included a weak stewardship function, and a missing health research structural and regulatory framework (5). Given the ground realities, this comes as no surprise, and the discussants reinforced these impressions based on their own experiences.

However, as it is inevitable during such discussions, it was difficult to keep the focus only on ethical challenges in human subject research, since an even more daunting reality for many of our participants is that of providing any kind of clinical care in extremely challenging conditions. According to the humanitarian aid agency Médecins Sans Frontières (MSF) which has been working in Palestine since 1989, providing medical as well as psychological aid to the people of the West Bank and Gaza, the numerous restrictions on movement, coupled with poor civic facilities, all contribute towards the inadequacies of the healthcare sector (6).

Some of the experiences shared by the Palestinian participants during the two-day deliberations cannot even be analysed using any existing ethics lens. And practically all aspects of their plight can be linked to the conditions in which they have been forced to spend their lives. Research seems a luxury in such trying circumstances. Clearly, even the provision of basic healthcare facilities remains a challenge to them.

While describing the kind of issues they encounter as a routine, one Palestinian participant who works in a hospital in Jerusalem described a situation which is hard to imagine practically anywhere else in the world. This facility is the only specialised oncology hospital available in the entire area and is ostensibly open to Palestinian patients. However, Palestinian patients have to get permission to travel from the West Bank or Gaza to visit this hospital since it is situated in the occupied territories. As a rule, adult men and women, which means anyone from the mid-teens to about 60, are not allowed access into Israel. The participant told us about a seven-year-old child, diagnosed with a cancer that required surgical intervention followed by chemotherapy, who was referred to this facility. Both parents, because of the age restrictions, were barred from accompanying the child. With no relative available, an elderly neighbor agreed to take the boy over to the hospital. However, the hospital authorities would not let the treatment begin without the parents' signed informed consent, citing legal and, quite laughably, moral constraints.

The parents' personal appearance ruled out, cell phone contact with them was also not possible because the cell networks, controlled by Israelis, are generally jammed. Even when networks are momentarily open, because of a lack of electricity, again controlled largely by Israel, phones are often not charged and functional. The doctors could not proceed without consent since death was not imminent therefore "technically" this was not a life-threatening situation. But with every passing day, the chances of cure were diminishing. While informed consent is a moral as well as a legal imperative, how does one exercise it in such adverse circumstances? I was left wondering about the moral standing of the current construct of informed consent in such a context.

Looking at the ground realities in such conflict zones, the gulf between what "is" and the elusive "what ought to be" has never been wider. While bioethics is an academic discourse, it risks being discarded into the bin of the irrelevant if it does not offer practical solutions to the challenges thrown up by lived experiences. Campbell, while discussing academic bioethics and activism, warns that "Bioethics is surely pointless if it shuns any contact with the real world and its moral complexities." (7). Some of the strongest critics of contemporary bioethics have spoken about its limitation in the context of the free world (8, 9). However, even the most compelling arguments they make pale into insignificance when dealing with the lived realities of prison-like situations into which a generation has been born, looking at the sea from afar but not being able to reach its shores.

As is traditional after such workshops, proceedings end on an upbeat note with the recommendation of yet another set of ethical guidelines, enforcing which will surely make all the evil things go away. Ah, the naiveté!

In the context of the West Bank and Gaza, bioethics looks more like an esoteric philosophical exercise for academics sitting in comfortable conference rooms in faraway luxury hotels, rather than an instrument to protect the vulnerable.

The scepticism around the room regarding the self-serving “parachute bioethicists” was palpable.

*Tum aasmaan ki bulandi se jald lauT aanaa
hameñ zamiñ ke masaa.il pe baat karni hai*

[Please do return soon from your flight in the skies
We have to tackle the challenges on the ground]

Poet: Shayar Jamali (10), translation by this author

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COMMENTARIES

Challenges facing research ethics in fragile settings

NIVEEN ABU-RMEILEH

The first time I was introduced to the concept of research ethics was when I started my work as a research assistant at the Institute of Community and Public Health, Birzeit University (ICPH-BZU). I was fascinated by the concept and tried to read as much as I could. While reading the different guidelines and regulations, I felt they were prepared to be implemented in an ideal world without taking into account the local context. With time, the international institutions realised that “one size does not fit all.” Recently, context and topic specific guidelines have emerged.

We, at the Institute of Community and Public Health, Birzeit University, try to ensure high quality research taking into

consideration research ethics and local context specificity. As described correctly by Dr Jafarey (1), Palestinians face several challenges on a daily basis. The influence of the Israeli occupation on people's freedom of movement, safety, security and lack of basic human rights poses great challenges for health professionals serving in the healthcare system and researchers working in fragile and unstable settings. The occupied Palestinian territory can be defined as such a setting.

Ethical challenges facing researchers in fragile and unstable settings were of concern for us, researchers working at ICPH –BZU and also the staff at the Department of Reproductive Health and Research at the World Health Organization. Together we decided to conduct a training workshop to discuss challenges facing research ethics in fragile settings with researchers from these settings. With the support of Dr Jafarey from Karachi and Dr Daher from Beirut, we conducted a most interesting and rich three-day workshop. The workshop targeted members of Ethics Review Committees from the occupied Palestinian territory in addition to countries with humanitarian crises and fragile conditions.

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