**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”.*

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 realize 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 either the absence of, or weak regulatory mechanisms, regulator incompetence or a sheer lack of commitment. All of these add up to make 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 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 helpi conduct a workshop designed specifically for researchers and ethics reviewers working in conflict zones such as Palestine, Syria and similar areas seemed intriguing. Beingpart of the only WHO Collaborating Centre in Bioethics in the Eastern Mediterranean Region (EMR), I had an obligation to respond positively to this request. However, the thought of grappling with unfamiliar issues made the offer irresistible to me. I realszed that this would be more of 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 are 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 organizers had to conduct the meeting in Amman, Jordan. This made it all the more difficult not only for the organizers to put the event together, but also a challenge to attend for the Palestinian participants who came from Gaza and the West Bank. The efforts they made to reaching 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 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 ID and passport. They cannot move between the West Bank and Gaza, nor can they go into Israel or East Jerusalem and 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 Gazan, in the past, they were able to leave through 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 are the Palestinians who live in East Jerusalem and have Israeli residence and carry Israeli travel documents, 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 ID and passport. They can move freely in the West Bank and Israel but not 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).

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 grueling daylong exercise for Palestinians since multiple levels of permissions are required. I was told how people have 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 very basic of human rights for the people of Palestine.

In order to get a sense of the lived life for these researchers living and working under oppression and apartheid, a full afternoon was devoted to them sharing their own experiences. 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 Medecins Sans Frontirers (MSF) which has been working in Palestine since 1989 in providing medical as well as psychological aid to the people of the West Bank and Gaza, the numerous restrictions of 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 analyzed using any existing ethics lens. And practically all 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 in the free world. This facility is the only specialized 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 from mid-teens to about 60, are not allowed access into Israel. Narrating his experience, the participant told us about a 7 year old child, diagnosed with a cancer that required surgical intervention followed by chemotherapy, 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 written informed consent being signed by the parents, 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 they are momentarily open, because of a lack of electricity, again controlled largely by Israel, phones are often not charged and nonfunctional. 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 the lived life. 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 lived realities of prison like situations where 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 the 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 naivety!

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

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

*Tum āsmāñ kī bulandī se jald lauT aanā  
hameñ zamīñ ke masā.il pe baat karnī hai*

Please do return soon from your flight in the skies

We have to tackle the challenges on the ground

Poet: Shayar Jamali, translation by this author

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