

Vulnerability: From Protection to Empowerment

This editorial takes the opportunity provided by the commemoration of the first anniversary of Typhoon Haiyan to highlight bioethical issues arising in situations that render human beings vulnerable to the negative impact of ethical mistakes or exploitation. The first part pertains to vulnerable groups that are the subject of papers contributed to this issue of the *Asian Bioethics Review*. The second part pertains to a particular group of victims of Typhoon Haiyan that deserve special attention.

In “The Compensatory Nature of Personhood”, Alsuwaigh and Krishna set out to explore palliative care patients’ own perspectives on personhood within the context of end-of-life care. Using in-depth interviews, the authors seek to probe those perspectives as an alternative to using “tools that have not been validated within the end-of-life setting”. Their view is that determining the perspectives of palliative care patients themselves is critical because “family-centric East Asian societies ... place great value on relational ties and social interactions drawn from Confucian-inspired views of personhood”, leaving palliative care still struggling to find support within mainstream medical practice.

The interviews revolve around the question, “What makes you who you are?” The findings make for interesting comparison with concepts of personhood in academic literature. Seemingly naive and even lacking in consistency, the individual accounts nevertheless could be seen as an indication of how human beings can be rendered vulnerable in their twilight years if end-of-life decisions were to be made on the basis of “expert” or theoretical concepts of personhood that are divorced from these self-reported notions. In effect, this effort addresses the vulnerability of palliative care patients to treatment plans that seek to protect them without fully understanding what they themselves care most about. If the effort is successful, it will help future patients to get the kind of care that they themselves truly desire rather than the kind of care (or protection) that they are presumed to like. Thus, the authors seek to empower the patients to deal with their vulnerability rather than to allow physicians or

other caregivers to try to protect them paternalistically by speaking on their behalf.

In “The Philippine Reproductive Health Legislation: Politics beyond Metaphysics”, Manaloto claims that in passing the new law on reproductive health, the Philippine Supreme Court has effectively voted for “peaceful coexistence of all groups in society”, thus abandoning a metaphysical in favour of a political approach to resolving issues. According to him, the Court has sent the message that it would give a lot of weight to the legitimating effect of the process of consultation rather than delve into the metaphysical basis of reasoning. Nevertheless, one who is not convinced of a strongly metaphysical approach will recognise that the new law has been anticipated by many women who have long been rendered vulnerable by the strict implementation of the old legislation. The old legislation was supposed to protect women during periods in their lives when they are vulnerable, even when the supposed protection goes against their own sense of what is important for them. Until recently, such legislation took away from women crucial options regarding their reproductive health. The new law also responds to women’s vulnerabilities but does not take a protectionist approach that many of them do not care about. Instead, it addresses the vulnerabilities by empowering women to deal with them by making their own autonomous choices.

Foong Patrick Chee Kuen writes about the possible exploitation of women in research relating to therapeutic cloning and Somatic Cell Nuclear Transfer (SCNT). He argues that the ethical concerns can be effectively addressed through a tight legal oversight consistent with existing regulatory framework governing research involving human embryos in Australia. According to him, the Australian regulatory regime can serve as a model for other countries. He takes the view that “the revised guidelines expressly provide for the strict observance of consent principles for participation in medical research, prohibition of the buying and selling of eggs (with the exception of reimbursement of reasonable expenses for out-of-pocket expenses) and prohibition of donors in categories of unequal relationships which include employer/employee relationships”. Because of these features, Foong thinks it unlikely that the scandal that Hwang Woo Suk faced in South Korea would arise in Australia. He also expresses confidence that egg donation can thus be strictly managed while allaying fears and restoring public confidence in health research. In the event, the regulatory framework addresses the vulnerabilities of possible egg donors not by paternalistically prohibiting research using donors’ eggs but by empowering women to make their own choices based on the knowledge that safeguards are in place to protect them from exploitation.

Ragini Kulkarni presents an Indian perspective on issues and challenges facing informed consent in biomedical research involving human participants. She notes that scientists face the critical challenge of applying ethical principles for obtaining informed consent in a multicultural society like India. While observing universally applicable ethical standards for obtaining informed consent, researchers also have to consider the local cultural milieu.

Kulkarni makes the usual recommendation for training researchers and members of ethics committees so they can address ethical challenges in a way that considers the local situation as well as pertinent cultural factors. More importantly, she mentions the need to simultaneously protect the rights and well-being of study participants by making them aware of their rights when participating in biomedical research. We take this to be significant again because of the effort to empower research participants on top of the usual protection coming from researchers and ethics committee members who may not necessarily be looking at research protocols in the same way that subjects may view them.

Different in focus from the above articles is Alireza Bagheri's "Priority Setting in Islamic Bioethics: Top 10 Bioethical Challenges in Islamic Countries". The article reports the results of a questionnaire survey aiming to document the opinions of Muslim bioethicists regarding bioethics priorities in Islamic countries. The survey produced surprising results, some of which Bagheri found difficult to explain, suggesting a need for further research. In any case, the study showed that what are regarded as important bioethical issues vary significantly from one country to another. Hence, the results do not make it any easier to come up with a homogenous characterisation of Islamic bioethics.

Haiyan Victims: Twice Victimised

"We were spun like clothes in a washing machine" was how some women spoke of their experiences in the Philippine islands of Leyte and Samar when the world's strongest typhoon to hit land devastated their communities on 8 November 2013. The victims included pregnant women and mothers with clinging babies who were washed away by the storm surge that took thousands of lives and injured many more.

Weeks after the typhoon hit, food and water were still scarce. Donations of humanitarian aid from different countries were flown in but even those took a while to reach those in need because the local officials who were expected to distribute goods were themselves incapacitated by the surprising severity of the typhoon. The airport's capacity to receive humanitarian flights was drastically

limited and roads were rendered impassable by huge fallen trees. In the midst of the disaster, an especially vulnerable group soon stood out—sick babies. Medical missions reported through text messages that among the sick who needed medical care were babies who were placed on formula milk feeding.

In response to such calls, breastfeeding mother support groups such as *The Breastfeeding Pinays*, *Latch*, *Kalusugan ng Mag Ina* and *Arugaan* collected breastmilk donations. The donations were airlifted together with generator equipment to a government hospital, the Eastern Visayas Medical Center. All of these efforts were supported by paediatricians, convinced that breastmilk is the superior and safe food for sickly babies.

While the breastmilk drive was going on, two top government officials appealed to the public for “milk donations for typhoon survivors”. Subsequently, a deluge of formula milk donations was received and rapidly distributed to evacuation centres. Mothers and their babies were given formula milk packs and feeding bottles. What was planned to be a beneficial response to an emergency turned into a second disaster involving rights violations for the already suffering vulnerable segment of the population.

The distribution of formula milk for use with babies went on in violation of the World Health Organization (WHO)/United Nations Children’s Emergency Fund (UNICEF) *International Code of Marketing of Breastmilk Substitutes, Breastmilk Supplements and Related Products*. This Code was passed by Ministers of Health around the world at the World Health Assembly in 1981. Consequently, the Philippines translated provisions of the Code into a law titled *The Philippine National Code to Regulate the Marketing of Breastmilk Substitutes, Breastmilk Supplements and Related Products*. Signed into law in 1986, it is more popularly referred to as *The Milk Code*. It disallows formula milk donations because it will undermine breastfeeding practices.

American milk companies under the Pharmaceutical Health Association of the Philippines sued the Secretary of Health and his undersecretaries when the Philippine government issued its strict *Milk Code Implementing Rules and Regulations* (IRR) in 2006. Nevertheless, in 2007, the Philippine Supreme Court upheld the IRR that came with the Department of Health’s Administrative Order 2006. It is understandable then that breastfeeding advocates felt deeply disappointed when the gains won in several legal tussles were negated during that period when this vulnerable population consisting of very young children was exploited under the guise of “emergency” and “disaster”.

According to breastfeeding advocates, the Secretary of the Department of Social Work and Development remarked, “You must be joking!” in response to a resolution by UNICEF officers to provide relactation intervention. On the

other hand, the Secretary of Health was accused of consistently skipping media interviews on breastfeeding and the Milk Code.

The WHO Western Pacific Regional Office was so alarmed by the mishandling of infant and young child feeding that it supported intervention by the country's Breastfeeding Experts Support Team in order to show that the emergency should not be regarded as an excuse to do something that exploited the vulnerable victims even more.

The emergency response included breastfeeding counselling through home visits in the communities as well as cluster counselling inside the evacuation tents. Mothers who were feeding children with formula underwent a relactation process. The process was facilitated by the Breastfeeding Expert Counsellor applying a mother to mother support approach. The bottlefeeding mother underwent special relactation massage to enhance her lactation supply while her bottlefeeding baby breastfed/wetnursed on an experienced breastfeeding mother so that the baby became accustomed to breastfeeding. After the lactation massage, the bottlefeeding mother got her baby back for breastfeeding initiation while expressed donor's breastmilk was being spoon dripped on her breast. Her baby thus relearned breastfeeding on her biological mother. Another approach in the relactation process involved cross/switch nursing where both mothers exchanged babies for each other to learn the breastfeeding process. Both approaches to relactation have proved to be efficient and easy during emergencies as evidenced by experiences reported by *Arugaan* BEST.

One thing that this relactation procedure teaches us is that there can be almost no excuse for babies not to be breastfed. Breastfeeding serves to protect a child's right to food security and medicine. Temporary lack of food and water in emergency conditions in a disaster-stricken area cannot be presumed to justify the prescription of formula for babies. In such situations, the health risks to which the babies are already exposed can only be exacerbated when panic sets in and authorities unjustifiably offer formula as an emergency response. Such a panic-driven response only leads to victims being victimised twice over.

Leonardo D. de Castro, with Ma. Ines Av. Fernandez

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