HUMAN RIGHTS REFLECTIONS

(Re)Humanising Health Care – Placing Dignity and Agency of the Patient at the Centre

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‘All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.’ (Article 1, Universal Declaration of Human Rights)

‘Dignity does not consist in possessing honors, but in the consciousness that we deserve them.’ (Aristotle)

The first sentence of article 1 of the Universal Declaration of Human Rights is aspirational rather than factually true. Not all human beings are born. Some die together with their mother while still inside the womb despite being mature enough to survive outside. Many more are not born free, and even more still are not born free and equal in dignity and rights.

In viewing the current situation of maternal and child health globally, and knowing what one would need when sick and in danger of losing one’s health or even life, the current quality of care delivered to poor people in poor places, especially to women and children – both the born and unborn – can best be described as veterinary. Frequently, women deliver in hospitals sharing their beds with other patients, sometimes even with more than one other patient. Also, a woman may find herself without her partner, a confidant, a doula, or even a friend at her side. A bed may be located in a room containing many more beds with women in labour, looked after by very few trained health workers who often do not have the time or the inclination to communicate with the patients. This room is therefore very reminiscent of a stable. In veterinary medicine there is a standard of health care too which is expressed in the exact same terms as we express quality of health care given to human beings, such as mortality ratios, case fatality rates, and the like.

Surely, we want there to be a difference. The difference has to lie in the respect we feel for and show to our individual human patients. The quality of respect towards a human

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being ought to be different from the respect we pay to our animal patients. Some say what makes a person human is to be seen as an individual and within a social context, but it is more than that. It is also agency: the ability to speak for oneself, to come up for oneself, to be one’s own agent. All creatures deserve respect, but humans need and deserve a different kind of respect. For instance, we need to inform our patients about who we – the health workers – are, what we can be expected to do in our health facility, and so forth. The human patient is, or ought to be, on par with the health worker: an equal and at the centre of attention. An animal patient is ‘only’ at the centre of attention, but never ‘eye to eye’ with the human health worker.

Unfortunately, not all human patients are ‘eye to eye’ with the health workers caring for them.

Dignity means worthiness. Recognising the worthiness of a patient is expressed in showing her, her baby, and her family respect. Dignity and respect are concepts as old as humankind and have been used and abused to raise and to oppress people(s) from prehistory to today.

Over the years, and for reasons that still need to be fully explored and researched, health workers and healthcare systems have dehumanised health care, especially in difficult situations. Whatever the reasons and explanations may be, none of them should be abused as an excuse. In human health care there can never be an excuse for treating patients as non-humans or for health workers to behave as non-humans. Yet, that is exactly what is happening every day. Women deliver in stable-like labour wards and rooms, treated with no consideration for their privacy or need for emotional support. Isolated from their family they are all alone with many other patients who share the same fate and who do not know one another at all. No or only insufficient information is given to the women, not to mention the lack of comfort and emotional support, often accompanied by no or insufficient pain relief. This practice is so common that it has become the norm. Many patients and health workers have been socialised within this dehumanised system that they feel this is how a hospital or other health care facility does or should operate. Reality is normative.

The task before us is therefore to (re)humanise health care. This entails actively recognising a fellow human being in the patient, born or unborn, alive or dead. This

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7 I Illich, Medical Nemesis: The Expropriation of Health (Pantheon, New York, 1982).
recognition then needs to be expressed in the way that we interact and communicate with the patients. At the centre of this interaction is the explicit expression of genuine respect. Respect for the person, her fears, wishes, demands, needs, etc. Respect for the entire person that she is, also for those parts of her personality that we do not know, nor need to know, in order to truly care and respect her. Many of these aspects, but not necessarily all of them, are rooted in the community from which she comes or in which she lives.

To achieve this, we need to first remove all the factors that dehumanise our patients. These are numerous and exist on many different levels. One factor is the physical layout and state of decay of many health facilities in the world. Another is the job establishment of those facilities where far too few health workers are responsible for far too many patients. This is such an acute and intolerable situation that health workers are almost forced to block out the blatant suffering of their patients in order to serve them at all. Yet another is the lack of choice of care faced by patients and consequently their total dependency on the only option for formal, official, or somehow regulated health care. There are many more obstacles.

Actions oriented at prioritising the dignity of patients, especially poor or vulnerable patients – e.g. women and children – has been lacking on the part of the health work force, national government, and, the international community, and ruling bodies. Given this, change has to come from those who seem the least likely able to achieve it: the patients themselves. It may be tempting to compare patients to consumers and claim that they have the same power. Yet this is a flawed analogy. Patients cannot be considered as consumers because the former have overwhelming and frightening health needs and no real choice as to who and how these needs can be met. Moreover, vulnerable patients have no economic power to enforce the services or goods they require. Also, their so-called demands are not actually demands, but rather needs. Saying ‘needs increase demand’ in this context seems inappropriate if not cynical. Contrarily, consumers have all these characteristics. Finally, the greatest difference is that consumers have agency whereas most patients do not.

Agency is the link between the needs of the patients and meeting them. It is the first casualty when a poor person enters a health facility. The buildings and physical facilities, the attitude, the deplorable shortage of health workers, and, indeed, the very nature of being ill and requiring care all contribute to diminishing or altogether destroying a patient’s agency. This, nevertheless, does not remove the patient’s dignity. Even under such harsh circumstances, women who are without the luck and privilege of good formal education know that the treatment they so often receive is not what they deserve.

The destruction of agency has to stop if we want to provide a humane health care service for human beings, if we want to actually improve the quality of care, even if and

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when such care is measured in the traditional, current, and inappropriately numerical way. And this is what can be done:

Build a health care system that nurtures, encourages, and enables agency of the patient. This system needs to define good quality of health care explicitly and in humane terms. Such a system also needs to aim at ensuring the achieving high quality of health care.

First, quality must be redefined in such a way that the dignity and worthiness of the patient are made central to everything. Ill-health and pain diminish and potentially destroy dignity. Human beings come to health facilities because ill health makes them feel their worthiness, their dignity, their wholeness has been diminished. That is the real reason why they seek help and assistance. They come to a health facility because they perceive the reason for their diminished or reduced worthiness to lie in a health-related problem, for instance pain, or bleeding, or restricted function of their bodies or souls or both. Patients do not in fact seek help because the pain is bad, but because the pain threatens to destroy their dignity. It is the primary task of the health worker to help the patient to restore her dignity; to enable her to heal. This has to be part and parcel of what it means to be a health worker. First on the way to achieving this is to deal with the pain, the bleeding, or whatever the case may be. But this is by no means the only or even the most important aspect of the assistance given by health workers. It is merely the first and, quite often, technically difficult aspect.

How this assistance is delivered is of the utmost importance. Is it done in a humane way? Is it done in a way that puts the person at the centre of care ‘eye to eye’? Will it truly help the patient to subsequently become whole again; challenge the notion of a potential loss of dignity, rid the patient of her diminished worthiness? When assistance is done well then the primary or most important aspect of healthcare, restoration of health, of dignity, can be achieved. Health workers therefore are much more than just technicians who can fix a medical problem such as stopping a bleed. It is the way in which they stop the bleeding that they can assist the patient to restore her dignity herself.

Some might call this a paradigm shift. Others would just call it remembering what healing is all about, remembering that healing does not entail going back in time to the days when eminence-based medicine was practised. It means looking beyond the purely technical aspects of health; it means looking beyond only those aspects of health care that can be numerically measured at the moment, even though the quality of the data thus obtained is doubtful. In other words, it means looking at quality of health care that distinguishes high quality veterinary health care from high quality health care for humans.

We have no easy way, at the moment, to measure this quality. All we can do is conduct qualitative research which is costly and not practical as a monitoring tool for quality improvement or other reasons. Still, this is the way forward if we want to truly improve the quality of health care and increase the chances for women and children to regain some degree of agency and, with it, influence to control their fate and to keep or restore their dignity.

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Human rights of individuals, as the main normative and practical guide for how patients should be treated would give direction to (re)introducing the individual person, the individual patient, as a whole person, as a human being, into the centre of all efforts in (maternal and child) health care. The immediate benefit of that will not only be better quality of health care, as defined above, but will carry the justified hope that the traditional quality of care, as expressed and measured by mortality ratios for instance, will also improve over time. This hope is justified because the humane way of dealing with the patient allows for agency, which is the requisite link that we do not have at this point in time. Once this has been achieved, the situation may improve quickly.\footnote{L Hudson and M Flannes, ‘The Arab Spring: Anatomy of a Tipping Point’, Al Jazeera, (1 September 2011).}