The imbedded role of ethics in healthcare: a contribution from translational research

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"You've got to be carefully taught"

R. Rogers and O. Hammerstein – *South Pacific*

Abstract

*The practice of public and global health confirms that ethics is imbedded in healthcare. Although ethics may be regarded as inherent to the healthcare profession, values and trust are challenged because of the quality of product (service and delivery), inequality in the global healthcare system and rapid technological developments in healthcare. Regardless of good systems and supportive ethical codes in healthcare practices, there are nevertheless ethical challenges in healthcare. This situation necessitates an attempt to understand the dual role that ethics can play as foundation for healthcare systems based on the global accepted understanding of "*do no harm*" and as an activity alongside many other healthcare activities. This paper discusses these roles of healthcare ethics in addition to the existing, but limited, focus on the patient in the healthcare system. The argument is presented that attention should be given to the ethical needs of those people (in different roles) engaged in the delivery of healthcare. The focus of the paper is on the role that ethics can play in healthcare as a system and a service. Four developments are identified in support of this focus, namely the cost of healthcare; cultural influences on and preparedness for service; the increasing number of*

aged individuals and their healthcare needs; and ethical challenges such as informed consent. From these developments the central perspective of the paper is presented, namely that ethics should be part of any healthcare system and the promotion of the well-being of people in healthcare, rather than merely the health of the individual patient only. Glouberman and Mintzberg's identification of four worlds (cure, care, control and community) is used as context for the argument. The research is based on a translational research methodology approach to provide best practice perspectives to the healthcare industry.

Opsomming

Die praktyk van publieke en globale gesondheid bevestig dat etiek onlosmaaklik deel is van gesondheidsorg. Hoewel etiek deel is van die gesondheidsorgprofessie word waardes en vertroue uitgedaag deur die kwaliteit van die produk (diens en dienslewering), ongelykheid in die globale gesondheidsorgsisteem en snelgroeiende tegnologiese ontwikkelings in gesondheidsorg. Ten spyte van goeie sisteme en ondersteunende etiese kodes in die gesondheidsorgpraktyk bestaan daar verskeie etiese uitdagings in gesondheidsorg. Etiek se kan hier 'n tweeledige rol speel: enersyds as 'n onderbou vir gesondheidsorgsisteme en andersyds as 'n aktiwiteit naas baie ander gesondheidsorgaktiweite. Die artikel bespreek hierdie rolle in aansluiting by die bestaande, maar beperkte fokus op die pasiënt in die gesondheidsorgsisteem. Die argument word gevoer dat aandag gegee moet word aan die etiese behoeftes van verskillende rolspelers in die lewering van gesondheidsorg. Die fokus van hierdie artikel is op die rol wat etiek kan speel in gesondheidsorg as 'n sisteem en as 'n diens. Vier ontwikkelings word geïdentifiseer om hierdie fokus te ondersteun. Hierdie ontwikkelings is die koste van gesondheidsorg, kulturele invloede op en die gereedheid om diens te lewer, die groeiende aantal geriatriese pasiënte en hulle gesondheidsorgbehoeftes asook etiese uitdagings soos ingeligte toestemming.

Op die basis hiervan word die standpunt ingeneem dat etiek deel moet wees van enige gesondheidsorgsisteem en dat dit 'n bydrae moet lewer tot die welwese van al die betrokke mense in die gesondheidsorgsisteem en nie net die pasiënt nie. Glouberman en Mintzberg se vier mediese wêrelde (genesing, sorg, kontrole en gemeenskap) word as raamwerk vir die studie gebruik. Die navorsing is gebaseer op die oordaagtelike navorsingsmetode ("translational research methodology").

Keywords:

healthcare, healthcare ethics, public health, global health, care

Sleutelwoorde:

gesondheidsorg, gesondheidsorgetiek, publieke gesondheid, globale gesondheid en sorg

1. Introduction: the role of ethics in healthcare

Access to healthcare is widely regarded as a basic human right.

Article 25 of the Universal Declaration of Human Rights states that "Everyone has the right to a standard of living adequate for the health and wellbeing ...". This right fits with the role that public health should play in the well-being of a society. Public health is generally understood as the concern with the health of the entire population rather than the health of individuals (Childress, Faden, Gaare, Gostin, Kahn, Bonnie, Kass, Mastroianni, Moreno and Nieburg, 2002). In unpacking the meaning of public health these authors identify, from the American Institute of Medicine's definition, that public health focuses not only on medical needs but also on "fundamental social conditions that affect population levels of morbidity and mortality" (Childress *et al.*, 2002:170). Holtz (2013:13) also comments that "Health is considered to extend beyond health care to include basic preconditions for health … In addition, the right to health includes freedoms from non-consensual medical treatment and experimentation." Consequently, public health services and deliveries should be of the highest standard. This standard does not only include the *quality of the product* (service and delivery) but also *values* and *trust*. This understanding places us in the realm of ethics (Childress *et al.*, 2002:170).

However, inequality undeniably marks healthcare systems around the world (Holtz, 2013:13) and one can expect that quality of the product, values and trust may be challenged.

This is especially evident in developing countries where there is often a lack of human, financial and infrastructure resources to promote quality of health and lifestyle. It would be sad indeed if the state of development were regarded as reason enough for these insufficiencies, or that there is very little that can be done to address inequality.

One positive broker is the role that global health can play in dealing with inequality. Global health embodies the idea that the health of the planet should be a concern to all, while international health is more concerned with a focused approach to combat a disease (Brown, Cueto and Fee, 2006). It is for this reason that the concept of global healthcare is supported: that is, to address inequalities in healthcare. Global healthcare assists in the understanding of new health challenges (for example the Ebola virus, Zirka virus or mad cow disease) and to question lifestyle choices (such as the consumption of fast foods) that compromise quality life. Therefore, global health cannot go without a review of ethical and moral values. Typical examples are *humanitarianism*, according to which principle societies in need are assisted (Holtz, 2013:15), and Unesco's Universal Declaration on Bioethics and Human Rights (2005), in terms of which the ethical values of different cultures are reflected (Ten Have, 2011:28).

Both public and global health highlight the important role of ethics in healthcare. This significance is further highlighted through the healthcare profession, for example, nursing that reflects moral decision making (Burkhardt and Nathaniel, 1998) and responsibility of care (Valenkamp, 2001). Schotsmans (2010:14) comments that due to the "revolution" in medical assessment and the rapid developments in medical technology, doctors and patients are by default placed in a dilemma. Creplet (2013) refers to the powerful effect of knowledge and technology on medicine, doctors and patients as the "third revolution in healthcare." One can expect, therefore, that new ethical challenges will follow the rapid development of medical knowledge and technology.

These comments confirm the *imbedded* role of ethics in healthcare.

2. Scope of the paper

Ethics plays a central role in healthcare. This is evident from the range of ethical perspectives offered on health and well-being. Typical ethical offerings will be from medical, bio-, public and healthcare ethics. The role of ethics is further promoted through universally accepted medical codes such as the *Declaration of Helsinki: Ethical principles for medical research involving human subjects* (seventh revision 2013) and organisations such as the American Medical Association. The ethical offerings and medical codes have a common point of departure: *do no harm*. Yet, there are endless examples of ethical malpractice around the world – and examples of malpractice are not limited to clinical treatment only but are also evident in moral decision making, care for patients and the challenges with regard to access to healthcare whether through policy, personal choice and/or the absence of quality healthcare (Holtz, 2013:1-16).

Another shortcoming is the attention paid to the ethical needs of those who *heal* – either through cure or care – and *manage* the healthcare system, or who give *support* to the healthcare system, as well as people engaged with this system. A growing body of evidence suggests that the healthcare worker's ethical challenges may be different from those of the patient (due to the medical condition) but are no less important than those of the patient (Vanlaere & Burggraeve, 2013; Lategan, 2014; 2015).

The management and support of the healthcare system are also not without ethical challenges and responsibility. Healthcare services are regulated by policy and challenged by economic realities. Financial evidence suggests that more money is spent on specialised treatment than on basic medical care. The disparity between public and private healthcare very often enlarges the access to healthcare due to services available and funding to support these services.

Case studies highlight ethical issues in a number of ways. Purnell (2013), for example, reflects on the way that religion (i.e. the Roman Catholic Church as state church), government decisions (development that can impact on natural resources or forced reallocation of people) and arthropod-borne (such as malaria, dengue fever and yellow fever), food-borne and water-borne (such as cholera and hepatitis) diseases and illnesses ethically

challenge healthcare in Panama. Toren (2013) highlights how the Israeli National Health Insurance Act and the Patient's Rights Act, for example, are good for service delivery but pose ethical challenges in that they do not cover for any medical situation, nor do they address the ongoing hiking of costs. At the same time the system needs to be managed in such a way that it is geared for terror attacks or mass-casualty events due to the conflict in the Middle-East. Such situations not only demand effective management of healthcare but also create opportunities for ethical challenges. The learning curve is thus the interrelation between, in this case, management and ethics.

The importance of understanding the complexity of the healthcare system and its potential ethical challenges cannot be ignored. Glouberman and Mintzberg (2001) assist tremendously in promoting understanding of the scope of healthcare through their identification of four worlds for healthcare: *cure* (doctors), *care* (nurses, therapists, healthcare workers), *control* (management and administration) and *community* (family, other interested parties). These four worlds are not free from ethical challenges (as already implied in this paper). Neither can ethical challenges be isolated from each other in these four worlds. From Freeman's (1984) perspective on the stakeholder society, there is no way in which the healthcare workers and services can be isolated from any discourse on ethics in healthcare. These comments support Bird's argument (2015) that leaders in the system as well as in hospitals should develop a culture where ethical behaviour is integrated and rewarded. But this cannot go without systems improvement. Guo and Hariharan (2012) looked into the resistance to process improvement in the healthcare industry mainly due to the general orientation that healthcare is more an art than a science. Two cultures, that of *process improvement* and that of *punishment* (the "bad apple theory") exist. In the case of error, the improvement culture seeks solutions to prevent the occurrence of similar events in future, while the punishment culture wants to identify whose fault it is.

The general observation is that ethics cannot be removed from the healthcare system and its services.

The scope of this paper will be delineated to the imbedded role of ethics in healthcare in view of the complexity of healthcare and the interrelatedness between various aspects of healthcare.

The argument will be presented that healthcare ethics is a binding force that influences service delivery in healthcare. The core of the argument is the role that ethics can play in the improvement of healthcare processes and

services. This view promotes the dual role ethics can play in healthcare, first as a foundation to service delivery and second as an activity alongside many other healthcare activities.

3. Research framework and orientation

Literature review

The research is based on a literature review of healthcare ethics. The literature originates from (in alphabetical order) Belgium, South Africa, the United Kingdom and the United States of America. The literature review is presented as "*status quaestionis*" meaning the state of affairs (De Wachter, Fivez and Van Soom, 2014:34-35). This review should constitute a body of knowledge from which patterns in development, line of argument and practices can be identified. A new understanding of the context and matters in hand should follow from this approach. Of particular importance are the sources of analysis and synthesis that will assist in the authorising of the text (Trafford and Leshem, 2008:68-78).

The literature review is linked to qualitative research. In his discussion of qualitative research, Kumar (2005) groups it as part of an enquiring mode. The purpose of qualitative research is to describe the situation, phenomenon, problem or event. No quantification of the results is presented. For Holloway and Wheeler (2010), qualitative research is a form of social enquiry and interpretation to make sense of social reality. Silverman (2006:43) argues that the "main strength of qualitative research is its ability to study phenomena which are simply unavailable elsewhere." These commentaries confirm the originality of information that will derive from such an approach. It is aligned with the general understanding that research is no recycling of existing knowledge but the creation of a new body of knowledge that can be regarded as information in own right (Kumar, 2005:6-8). It can therefore be confirmed that the literature review is a reliable research methodology.

Translational research

A particular feature of this paper is the reflection on the trends, knowledge patterns and developments, to contribute to an understanding of the dual role of ethics in healthcare. The intention is to provide the medical industry with user-oriented knowledge. This approach should fit the context of *translational* research. Translational research should be understood as the presentation of research results to the client, or more specifically, to business and industry.

In this paper the presentation is to the medical industry (as collective for the healthcare profession). Woolf (2008: 211-2013) refers to the many meanings translational research can have in healthcare. Two representative meanings are to use basis research results to development new drugs and patient treatment ("bench-to-bedside approach") and the application of the research results to practice. According to the American National Institute of Health, translational research is defined either as the application of basic research as a result of preclinical or laboratory work to clinical trials and studies on humans, or the adoption of best practices in the community.

Paradigm

The paradigm of the paper is influenced by the understanding of ethics as those principles and their values guiding and influencing behaviour and decision making (Badaracco, 1998), leading to responsible acts as an application of these principles and their values (Douma, 1999), resulting in the responsible and respectful care for others (Burggraeve, 2015) and the upholding of mutual personal relationships (Schotsmans, 2012), including society and nature (Berkhof, 1973; Conradie, 2006) to contribute to sustainable livelihoods and communities, hence societies (Verstraeten and Van Liedekerke, 2010). Ethics is very much an act of engagement with fellow persons and their context (habitat) (Lategan 2012; De Wachter, 2013) in constituting a just society.

This approach to research is based on design thinking (Brown, 2015) where multiple perspectives are used to design a new construct.

Conceptualisation

For the purposes of this paper, healthcare ethics is defined as the identification of principles, and following from these principles the application of values and norms informing the practice of healthcare.

Research focus

Based on this research framework and orientation, the central research focus of the paper will be addressed, namely the role ethics can play in healthcare as a system and as a service.

Value creation

The value creation role of the paper is to develop translational knowledge that will be useful to the healthcare industry and its stakeholders.

4. Grounding of ethical challenges in healthcare

From the literature review it is the obvious deduction that healthcare is not unchallenged as a system or a service. This authority of this claim is based on the following developments and tendencies identified in literature:

- The emerging healthcare economy forecasts that healthcare will become increasingly *expensive* in future (Remans, 2005:96-109). Amongst others, Holtz (2013), Ten Have (2011), Schotsmans (2010) and Creplet (2013) go further to sound an alert to the growing *commercialisation* of healthcare research and services, and a warning that this will not be without impact. Reports in South Africa also signal the increasing cost of healthcare. The ongoing price escalations of healthcare challenge an already fragile healthcare system. In addition, Van den Heever (2016) comments that the strategic direction around South Africa's health policy has deteriorated to almost nothing. The cost and financing, commercialisation and management of healthcare are not without ethical challenges (Remans, 2005:96-109). Caulfield and Ogbogu (2015) comment that the pressure to commercialise can challenge ethical practices. Typical examples are science hype and premature misrepresentation of results. Bok (2003) adds his concern through raising integrity issues associated with new knowledge development versus trading existing knowledge for profit. This is not to say that commercialisation should not take place: one should however be mindful that it is not without consequences.
- A study by Phalime (2014) outlines numerous challenges within the South African healthcare system. Of note are matters such as access to healthcare, the fear of technology when patients are not used to it or are ill informed, language barriers between doctor and patient, cultural values (elderly people treated by young doctors, females advising male patients) and a new generation of doctors who are either frustrated with conditions in state hospitals or who are disheartened with their profession. The medical curriculum either does not prepare future doctors, nurses and therapists well enough for the demands of the healthcare profession or does not retain the future doctors, nurses and therapists in the system. The question may also be raised as to whether future healthcare workers are well enough prepared to deal with such matters as mental health, end-life decisions, outpatient settings (outside hospitals), palliative care and physical assisted euthanasia. Consider the following examples: Burkhardt and Nathaniel (1998) rightly ask how patients should be empowered in terms of decision-making. Malan (2016) promotes the argument that doctors should be taught how to be better counsellors on

lifestyle issues. Counselling about non-communicable diseases and the underlying risk factors have been inadequate. Primary care providers are ill equipped to provide more than just *ad hoc* advice on how to adopt a healthy lifestyle. These perspectives relate to a supportive culture and education for healthcare (see Holtz, 2013:1-16). A major ethical challenge to eliminate health disparities is to involve communities in healthcare practice and decision making. It is for this reason that Stone (2011) argues that community *based* research instead of community *placed* research is required. A practical example is the Indiana University-Kenya Partnership addressing HIV/Aids (Quigley, 2009). This partnership accounted for especially two important discourses, namely the power of working together by bringing to the partnership one's specific expertise, and the understanding of the immediate context in which the healthcare is practised. Murray (2016) therefore rightly argues in favour of healthcare reform within countries. Pleas for healthcare reforms (in a system) and joint efforts (partnerships) should be continuously addressed towards public policy makers.

- Geriatric patients (ageism) are a growing phenomenon in society (Vanlaere and Gastmans, 2010). People can now grow older due to new lifestyles and technologies but they are also faced with many more issues. The elderly cannot be ignored. Another concern is the challenge of children growing up before their time due to poverty (children have to work to care for the family), war (children are removed from family structures) or wealth (money can buy an adult lifestyle). As a result there is no time to be a child anymore (Aduddell, 2013:463-480). This calls for a comprehensive well-being that spans generations, physical and/or mental conditions and the concomitant needs. A page can be taken from the Indiana University in Bloomington, USA, on their eight dimensions of wellness which constitute comprehensive public health. These are: physical health, social health, spiritual health, environmental health, financial health, occupational health, psychological/environmental health and intellectual health (School of Public Health, 2015-2016:7-8). Comprehensive well-being questions the quality of care – not only as a practice but also as an attitude. This calls on all to care for their neighbour as they would take care of themselves. This is a ground rule of all ethical healthcare. Burggraeve's (2015) approach to *multilateral care* can be appreciated. He promotes the central idea of being present in other people's lives. Concepts such as 'ethical sisterhood' (2015:53-54), responsibility for next generations (2015:58-60), the vulnerability of people (2015:60) and "universal brotherhood" (2015:75-76) support his

view that responsibility for others can never be removed from one's own ethical orientation. In fact, it even supersedes the current accepted norm of giving preference only to one's own needs, desires and situation.

- Healthcare deals with human health and well-being. Ethical challenges will arise almost by default. For example, from medical ethics we learn that that doctor-patient relationship may be at risk when, for example, professionalism is compromised. Medical ethics will also call for informed consent before, say, a patient will participate in treatment, or undergo an operation. Bioethics will alert as to the protection of life, whether unborn or fragile. It also questions extreme forms of bioengineering such as gene manipulation to create clones. Healthcare ethics will sensitise the healthcare profession and support services as to the means of care and the meaning and value that are added to the lives of the patients and the healthcare workers. Research ethics remind us that health and well-being are challenged not only through uncontrolled clinical testing but also through interventions such as vaccination. These questions relate to the ethical challenges within healthcare.

From these observations the following interpretation is confirmed: The healthcare profession is pivotal in the promotion of quality of health and well-being and should be respected and protected as such. At the very same time, this profession is not without its financial, management, cultural, educational and ethical challenges as outlined in the discussion in this paper. (More challenges may be added from a clinical perspective but this is not addressed due to the scope of the paper.) What is notable is that none of these activities function in isolation from each other; for example access to healthcare is very often prohibited due either to financial constraints (finance) or ignorance (education). Religious orientation (for example Jehovah's Witnesses) can prohibit blood transfusion and life can therefore be endangered.

It is therefore safe to say that healthcare cannot go without the comprehension of a range of impacting ethical activities on the healthcare system and the service.

5. Perspective development

The above-mentioned developments confirm the imbedded role of ethics in healthcare systems and service. On the basis of the discourse in this paper the following four perspectives are offered:

- Ethics is interwoven in each of the four worlds identified by Glouberman and Mintzberg (2001) and is further promoted through the stakeholder society as defined by Freeman. The scope of healthcare ethics cannot be limited to the direct intervention with the patient (cure and care) only but should be extended to the *support* to cure and care via control and community. Healthcare ethics has an encompassing role to play in the service delivery in support of a person's health. Healthcare ethics forms an integral part of a healthcare system and service and can either be a *foundation* to each of these worlds or it can be an *interrelated activity* next to the cure, care, control and community (as engagement) as activities. Healthcare ethics as foundation directs and informs the value-driven services offered by these four worlds. Healthcare ethics as interrelated activity suggests that a healthcare system and its service are not merely *clinical*. Apart from managing and supporting the healthcare system and services, ethics (in the form of principle, values and norms) should be part of all healthcare activities linked to the system and services.
- Quality of life is promoted through cure, care, control and community. By default the quality of health depends on the values associated with and performed by the four identified worlds. Quality of service is promoted through value-driven leadership evident in each of these worlds. Occasionally, one world may be more dominant due to the service required, but none of these services can be without an ethical basis. Ethics continuously verifies whether the best service is rendered in the interests of the patient and determines how this service will contribute towards quality of health.
- Ethics is a common force in healthcare especially if the focus is to promote the holistic well-being of a patient. The statement may therefore be presented that if healthcare is about promoting the physical, mental, social and environmental well-being of a person, then the ethical values associated with the quality of care should be present in all the different activities associated with healthcare implementation. What is more, the holistic healthcare of a person necessitates that ethics be present not only in cure and care but also in the support thereof, via control and community.
- The healthcare continuum of cure, care, control and community is incomplete without ethics to promote quality of system and service, value-driven system and service and well-being to promote healthy societies. Ethics in the healthcare continuum suggests that healthcare is much more than simply treatment and healing, and should also include

prevention of illness and promotion of quality of life as part of well-being fostering healthy societies. Well-being depends very much on the impact that values have on meaningful life.

6. Conclusion

This paper looked into the central role that ethics can play in healthcare. Although the concept of ethics is not new to healthcare system and service, the study by Globermann and Mintzberg, and Freeman's stakeholder society assisted us to comprehend that healthcare ethics cannot be limited to the direct interaction with a patient only. The perspectives in this paper contribute to the understanding that although healthcare is a complex activity, it is there for the improvement of the health and the well-being of a person. The health and well-being of a patient can be promoted through ethics as an interrelated activity alongside a range of service delivery activities (notably the four "Cs") or the foundation to these worlds (again the four "Cs".)

The implication for the medical industry is that verification needs to be done on exactly how ethics is presented as foundation and activity in healthcare systems and services. This paper offers the following best practices (based on translational research):

- Although there may be general agreement that ethics should be imbedded in healthcare systems and services, ample evidence exists of ethical malpractice and inequality in healthcare. The solution is not to identify who is guilty (only) but rather to investigate how the system and services can be improved. Ethical guidance cannot be disregarded in this improvement.
- Ethics may be a concern to all, but not enough is done to promote an ethical attitude through engagement. Here too the focus should not be on *whose* ethics but rather *what kind of ethics* are needed to improve the healthcare system and service.
- Healthcare ethics assists in taking the emphasis away from the patient only. It creates awareness for more stakeholders involved in the cure and care of a patient. The healthcare continuum reminds us that the health of a person supersedes the idea that only the physical health of a patient should be a concern.
- While the benefits of medical technology and commercialisation should be appreciated, ethical advice should not be neglected in these developments.

- Ethics as a factor in decision making and behaviour implies engagement with other people and society. Ethics education cannot ignore the meaning and implication of engagement with other people and society.
- Healthcare ethics should be evident in the way that a system (as a collection of people) and a service (as the product of a system) care for the general well-being of people.

7. Summary

This paper presents the argument that healthcare ethics (as overarching ethics for medical, bio- and public ethics) has an important role to play in promoting the health and well-being of society. Although one may claim that sufficient awareness exists of ethics in cure and care, awareness of control and community (linked to Glouberman and Mintzberg's four worlds) may not be sufficiently well-developed, or enough understanding may not exist, for an understanding of the role of ethics in regard to these two elements. The study concludes by proposing the proper role that ethics should play in a healthcare system and service. The translational research approach followed in this study contributes to the benefit that the medical industry can gain from the perspectives developed in this paper.

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