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Chapter 17

BIOETHICS AND THE MAJORITY WORLD

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ABSTRACT

Clinical bioethics as developed in the minority world is of limited utility to healthcare workers in the majority world. The reasons for this become clear, as one understands where personal and societal ethics originate. The work of developing clinical bioethics for the majority world began with establishing a global bioethics as articulated by UNESCO in 2005. The work of translating global bioethics principles into language and ideas that are culturally relevant has begun. As that translational work proceeds, ethical frameworks, policies, and procedures are being developed to assist healthcare workers in the majority world. The final step in developing clinical bioethics for the majority world will be monitoring and enforcement of the ethical standards that are established in each society.

Keywords: bioethics, ethics

CASE REPORT

Danielle is a third-year medical student from Canada who decided to do an elective in the majority world. She hoped to contribute in a meaningful way to the care of patients while gaining clinical and cultural experience. Her experience during the elective was deeply disturbing. She encountered doctors and nurses who were openly disrespectful of certain patients because they were women, poor, lacked formal education, or were of a certain ethnicity. While she found that behavior troubling, the healthcare providers and the patients regarded it as normal. When she tried to discuss her concerns she was told that she should not impose her cultural values on others. The clinical bioethics teaching she had received during medical school seemed irrelevant to the moral conflict she was experiencing. Upon returning

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to Canada, she wondered if she could ever work in the majority world since she could neither agree with the behavior she observed nor work to change it.

Akinyi is an 18-year-old from the majority world who recently married an older man her father chose for her. Her education ended at age 13 when her father chose to stop paying her school fees. She was disappointed that she did not get to continue in school while her brothers and some of her female friends did. But she accepts that her father is the proper decision maker in such matters. She is aware that women in other places do act more autonomously but that is not how her tribe functions. She does not think that she ought to seek to change how her tribe functions.

INTRODUCTION

What Are Ethics and Bioethics?

Ethics is simply the activity of deciding which option to choose when you have more than one option and the options differ morally. All persons capable of making decisions are capable of doing ethics. Every decision that people make involves valuing one thing over other things. If that valuing involves weighing different options according to moral standards then that decision involves ethics. Every time someone says that something “ought” to be done, they are making an argument based on ethics. Every disagreement about the “right” thing to do, has an ethical dimension.

Just as nearly every person does ethics, so does every community. “Morality ... is an essential component of every culture.” “No society, no matter how small, can survive and endure ... without pervasive perennial concern with matters of right and wrong in human conduct and behavior.”[1] Because morality and moral codes are often shared within a society, they are often regarded as “normal” and not critically examined. This leads to most people being unaware of the ethical judgments that they are making despite the pervasiveness of ethics.

Among academics, ethics is also called moral philosophy and defined as “the branch of philosophy that tries to determine the good and right thing to do”. [2] Biomedical ethics, also called bioethics, explores the practice of medicine and the biomedical sciences. Bioethics is generally divided into research ethics, organizational ethics, and clinical ethics. This chapter will be limited to exploring clinical ethics. Clinical ethics pertains to decisions made by healthcare providers as they care for their patients.

Where Do Personal and Societal Ethics Originate?

Discussions regarding ethics are most effective if all participants are aware of their own ethical standards and why they hold those standards. One’s ethics arise from one’s worldview. Worldview is a complex concept but one way to think about it is as the totality of one’s answers to the big questions. Questions like; Why am I here? How did I get here? What is my purpose? What is good? What is just? Does evil exist and how do we define it? Does

God exist and what does he or she or it or they require of me? When does life begin? When does it end? How do I know anything? Is there truth and how is it determined?

Personal and societal worldviews are formed by a variety of inputs that play a varying role for different persons and societies. For most people their worldview is shaped predominately by the culture that they are raised in. For much of human history and still in many parts of the world, religion/spirituality explained life and answered the big questions. In the minority world, philosophy has displaced religion as a major player in worldview formation. Through formal and informal education, a culture passes worldview from adults to children. The worldview you inherit is modified by your experiences in the world.

Ethics is to worldview what engineering is to math and physics. Engineers ask questions like “given what we understand of the way the physical world functions, how do we build a safe bridge?” Ethics asks questions like “given the way we understand the physical and metaphysical world to be, is it ok to tell a lie?” The concept of gravity leads to an understanding of why the behaviour of jumping off tall buildings is a bad idea. The concept of justice leads to understanding why the behaviour of mistreating the poor causes a mob to arrange for you to make such a jump. Ethics are how you believe you ought to behave or how some person or group thinks you ought to behave.

Disagreeing with society’s ethical codes can bring much grief. Social consensus, or consensus among those with power in a society, about an ethical issue leads to laws, social norms, and taboos. These dictate behavior, which is prohibited and the sanction for engaging in that behaviour. There is a general consensus in humanity that it is wrong to willfully kill a person from within your society who wishes to live and has done nothing which merits death. Choosing to kill such a person will result in some form of punishment.

Professions use ethics to construct codes of conduct and practice. For example, there is a general consensus among those with power within the medical profession that it is wrong for doctors to have sex with their patients. If you choose to have sex with a patient then generally you will face professional sanction.

Sometimes a society or group can’t reach a consensus on the answer to an ethical question but may reach consensus on the most ethical process by which answers will be sought. For example, pandemics bring a host of ethical issues, which cannot be anticipated in advance. Ethics experts cannot provide answers for questions that have not been asked yet. However, there are good decision-making frameworks that ethicists have developed so when the questions do get asked, the path to an answer is already worked out and agreed upon by all involved.

Ethics is the application of worldview to how we live our lives. The most challenging ethical disputes usually arise because of fundamental differences in worldviews. When people involved in those difficult arguments cannot identify their worldview differences then the disputes usually remain intractable. Danielle’s worldview and that of the healthcare providers she interacted with in the minority world differed greatly.

Danielle’s Worldview

Danielle’s worldview was formed in Canadian society during the early 2000s. The dominant worldview of her society is referred to by anthropologists as “Late Modernity” or

“Postmodernity”. [3] That worldview started as Modernity, a worldview that arose from the European Enlightenment project of the 18th to 20th centuries.

The Modern Worldview saw nature and humans as machines to be understood through human reason alone. Such a view allowed people to pursue “objective science and universal morality and law” while expecting that “scientific domination of nature” would end “scarcity, want, and the arbitrariness of natural calamity”. [4]

The expectation that the Enlightenment project would bring utopia was shattered by the carnage of two World Wars, Stalin, and Mao,[5] colonial domination and industrial oppression. [5] That has led to deep disillusion with modernity that some anthropologists and philosophers have uncreatively labeled Late Modernity or Postmodernity. That worldview believes that the “modern perception of ‘the way things are,’ rather than being knowledge based on reason and empirical evidence is instead merely a set of self-serving ideologies constructed by those in power, ideologies that marginalize those who disagree”. [6]

By absorbing her culture’s view of nature and through the study of medicine, Danielle came to have a thoroughly Modern view of the human body and practice of medicine. She accepts without question that the body is a machine to be fixed by physical and pharmacological manipulation. When seeking truth about a medical question she consults scientific studies and rejects any medical truth claim that is not consistent with “evidence based medicine”.

Danielle is very influenced by post-modern thinking with regards to morality. She doubts that there is any universal truth regarding morality and thus takes it as normal for each person to make her own moral choices according to whatever considerations she feels are important.

Danielle’s Clinical Bioethics

Danielle’s clinical bioethics are those that she learned in medical school. That bioethics is centred on patient autonomy and focuses mainly on ethical dilemmas encountered by health care providers in technologically advanced urban hospitals. This is understandable based on its history. “The discipline of medical ethics has arisen in certain social contexts and not in others”. [7]

Rusthoven summarizes that history well in *Covenantal Biomedical Ethics for Contemporary Medicine: an alternative to Principles-based ethics*. [8] Bioethics was born in Greek society about 2500 years ago with codes such as the Hippocratic Oath dictating the behavior of physicians.

It was further developed by Judeo-Christian thinkers through the Middle Ages and Enlightenment thinkers after the 1800s. A crisis of ethics developed in the 1950s as Western society grappled with the rise of new technologies and obvious egregious ethical violations by physicians in Nazi Germany and also in the United States.

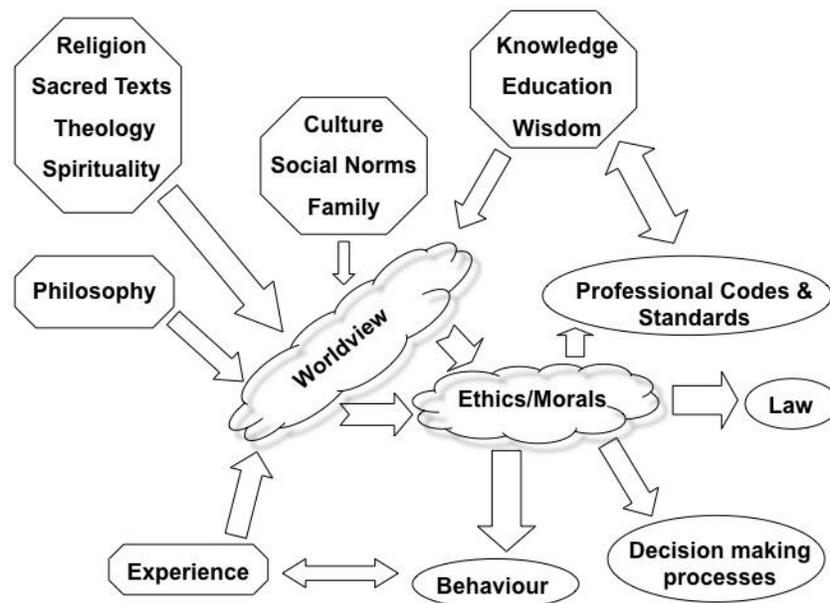
Given the diversity of worldviews present in Western society and the postmodern idea that all those worldviews are of equal worth, those that responded to this crisis sought general ethical ideas common to all those worldviews. What emerged has come to be called principlism. Principlism applies the principles of autonomy, beneficence, non-maleficence, and justice to specific cases and seeks consensus among those involved regarding a course of action.

Danielle believes that she should respect properly informed patient choices when possible (autonomy), do good for her patients (beneficence), not harm her patients or expose them to unnecessary risk (non-maleficence), and ensure that scarce medical resources are allocated fairly (justice). Those ethics served her well in the Canadian health care system but failed her as she struggled with ethical dilemmas encountered in the majority world.

Akinyi's Worldview

European powers exported the Modern Worldview around the world and it took different expressions in various cultures. [9] So there are many points of similarity between Akinyi's worldview and Danielle's. Despite this, Akinyi views the world differently than Danielle. The main differences arise because while Danielle sees society as a collection of individuals, Akinyi is group-centred.

For Danielle "self-reliance, personal achievement, individual choice and inalienable individual rights are unquestionably good" while Akinyi believes "group loyalty, self-effacement, self-sacrifice, sharing, and hospitality are cardinal virtues". [10] Akinyi would have difficulty defining what her ethics are since she would find the concept of universal moral laws foreign to her. For her, "all important norms are group norms". [10]



CLINICAL BIOETHICS FOR THE MAJORITY WORLD

Healthcare practitioners working in the minority world have the benefit of skilled bioethicists, a broad ranging bioethics literature, well-developed and specific policies and procedures regarding health care activities with ethical implications, and highly functional professional bodies enforcing ethical codes. Most healthcare practitioners working in the

majority world lack the same resources. Correcting that imbalance is a large project that has only commenced in the last 20 years. The work involves many disciplines and every level of human society.

A Global Bioethics

Those seeking to establish a global bioethics in many ways repeated the process that led to principlism becoming dominant in Western bioethics. They sought to find common norms held by all humanity. Relativism, the idea that there are no absolutes was one block to achieving that goal. Universals are necessary in bioethics. This is partly because “ethical relativism harms the most vulnerable groups in society” [11] by allowing those with power to argue that their behavior is moral according to their culture. It was argued that it was possible to “overcome the debate on whether one cultural background is superior to another ... to find a way to agree on some common norms that are based on shared values of very different traditions”. [12] Stated another way, the project was to “...find a normative bioethical approach that promotes the rights of individuals without striving for cultural assimilation and disrespect”. [12] The principle of respect for human dignity was seen as crucial but lacking the concreteness necessary to solve most of the dilemmas posed by biomedical practice. [13]

That process led to a universal bioethics statement adopted by UNESCO in 2005. [14] That document tied bioethics to universal human rights and was praised by the minority world as a useful document while being criticized by some ethicists for being too centred on individualism. [15] The tie of bioethics to human rights had the effect of extending international human rights law into the field of biomedicine and making the UNESCO statement a potential legal instrument. [13]

The principles contained in the UNESCO declaration that are relevant to clinical bioethics in the majority world are:

Article 3: Human dignity and human rights

1. Human dignity, human rights and fundamental freedoms are to be fully respected.
2. The interests and welfare of the individual should have priority over the sole interest of science or society.

Article 4: Benefit and harm

In ... medical practice ... direct and indirect benefits to patients ... should be maximized and any possible harm to such individuals should be minimized.

Article 5: Autonomy and individual responsibility

The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests.

Article 6: Consent

1. Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. The consent should, where appropriate, be express and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice.

Article 7: Persons without the capacity to consent

In accordance with domestic law, special protection is to be given to persons who do not have the capacity to consent:

- (a) authorization for ... medical practice should be obtained in accordance with the best interest of the person concerned and in accordance with domestic law. However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent;

Article 8: Respect for human vulnerability and personal integrity

In ... medical practice ... human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.

Article 9: Privacy and confidentiality

The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law.

Article 10: Equality, justice and equity

The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably.

Article 11: Non-discrimination and non-stigmatization

No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.

Article 12: Respect for cultural diversity and pluralism

The importance of cultural diversity and pluralism should be given due regard. However, such considerations are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms

The UNESCO declaration also calls for ethics committees to be established at various appropriate levels in order to achieve several aims, one of which is to “provide advice on ethical problems in clinical settings”. Such advice will require translating the global bioethics into culturally relevant and understandable moral guidance, policies, and procedures. That

translation will require the combined work of local healthcare providers, administrators, and societal leaders as well as sociologists, anthropologists, and philosophers.

From Global Bioethics to Clinical Bioethics at the bedside

The principles of global bioethics need to be translated into language and ideas that are culturally relevant and understandable. At the highest level, that means anthropologic, sociologic, and philosophical work to understand a society or cultures' moral codes and beliefs. One example of such work is Thaddeus Metz's work developing moral theory grounded on indigenous values salient in the sub-Saharan region. [15,16] Another is Ghiath Alahmad and Kris Dierickx's work exploring an Islamic understanding of confidentiality in medicine. [18] Much work in this area remains to be done.

Once clinical bioethics principles and grounding moral theory are worked out for a culture or society, then that knowledge needs to be applied to ethical problems being encountered at the bedside by healthcare providers. "Finding globally acceptable values ... is not enough unless we pay ... attention to their promotion in practice, in very different economic, social and political circumstances." [19] The first step in that process is to ascertain what those problems are. This work is further along for minority world healthcare providers working in the majority world than for majority world healthcare providers.

Research has shown that, while working in the majority world, minority world humanitarian and development workers experience ethical dilemmas arising from:

1. tension between respecting local values and imposing values
2. obstacles to providing adequate care
3. differing understandings of health and illness
4. questions of identity for health care workers
5. issues of excessive trust or mistrust [20]

Knowing that these are the areas of ethical conflict can direct the efforts of bioethicists seeking to create guidance for humanitarian workers in a given society or culture. One proposed framework for humanitarian and development workers is an "ethics of engaged presence". That framework emphasizes "the shared humanity of those who provide and those who receive assistance, acknowledgement of limits and risks related to the contributions of expatriate health care professionals, and the importance of providing skillful and relevant assistance." It seeks to "articulate a moral posture for expatriate health care professionals that contributes to orienting the practice of clinicians in ways that reflect respect, humility, and solidarity." The authors of the framework argues that "health care professionals whose understanding and actions are consistent with the ethics of engaged presence will be oriented toward introspection and reflective practice and toward developing, sustaining and promoting collaborative partnerships." [21]

Similar research on the sources of ethics conflicts and potential solutions has been conducted on minority world students doing clinical training in the majority world. Recognizing how training in clinical bioethics for the minority world leaves students ill-prepared for majority world, bioethicists are encouraging medical schools to develop curriculum to accompany majority world training opportunities and providing guidance on

the content of that training. Pinto and Upshur [22] note that students report ethical challenges arising from:

1. power imbalances and language barriers impeding informed consent
2. being able and accustomed to testing for diseases that can not be treated in the majority world setting
3. inadvertently offering things that are not culturally appropriate (e.g. certain forms of contraception)
4. being unsure how to act when encountering local health practices that they perceive as harmful
5. confidentiality being impossible due to physical space and family involvement with patients
6. concerns about consuming a clinician's scant resources for their own education

Pinto and Upshur's work recommends students to be more reflective by asking themselves questions which are useful for any healthcare provider working anywhere in the world:

1. Why do you hope to do this work?
2. What are your objectives, both personal and structural, short and long-term?
3. What are the benefits and who will receive them, and what are the costs, and who will bear them?
4. In the context of very limited resources for global health needs, is your elective justified? What exists close-by?
5. What do you need to do to prepare for your elective, both practical and personal?
6. Where are the weaknesses in your plan, specifically?
7. Is the work feasible, cost-effective, necessary, focused, and justified?
8. Will it work to undermine disparity, or actually contribute to it? Will there be a net benefit to the community?
9. What do you hope to bring back to your community, and whom will you share it with?
10. Is your work sustainable, and if not, will this leave a negative impact?

Pinto and Upshur have observed that students can mitigate risk of ethical breaches by working with local practitioners and community members to understand local standards of care and practice. A similar strategy is recommended and explained in detail by Rebecca Reisch. [23] That solution is available to all minority world healthcare providers working in the developing world.

While this work on the challenges faced by minority world healthcare providers working in the majority world is useful and will benefit them and majority world patients, there is also a desperate need to examine the ethical challenges experienced by majority world healthcare providers. That investigation has barely begun but has already yielded some useful literature. One theme that arises when local healthcare providers are asked about providing care ethically is the importance of outsiders not undermining local health care systems, even in emergency situations. As care is delivered, sustainability must remain an important consideration. [24]

Ethics research in the majority world needs to explore what local providers believe ought to be done, what is actually done, and how providers deal with situations when the two do not match. One such study investigated a rural anti-retroviral treatment (ART) clinic in Lesotho. Providers were aware of how a fair system of ART ought to work. Despite this, clinicians operated on a first-come, first served basis. They acknowledged that “first-come, first-served” allowed social, economic, and geographic limitations to unfairly deny many patients access. But the clinicians saw no means by which they could address social, economic, and geographical issues and so believed they were doing the best they could within their limitations. The study authors “question [the] relevance of trying to achieve fairness and equity when the gap between need for care and capacity to provide it remains so large”. [25] Asking that kind of question allows ethical guidance for majority world healthcare providers to be realistic and thus useful.

A second study involving ART in Cambodia explored how Cambodians (citizens and healthcare providers) viewed how ART ought to be allocated and contrasted this with guidelines for allocation written in the minority world. While minority world guidelines suggest allocating first to those with severe infection, Cambodians favoured allocating according to importance of the patient from a familial point of view. [26] That work illuminates a potential cause of misunderstanding to avoid when planning and implementing ART programs in the majority world.

As researchers explore what local providers believe is ethical behavior, there will arise a need to challenge beliefs and behaviors. Efforts to change beliefs and behaviors will be most successful if lead by local healthcare providers and bioethicists. An example of one such person is Xinqing Zhang. When made aware of a case of “family consent” resulting in the unnecessary death of a pregnant patient, Dr Zhang conducted research that showed disconnect between the conduct of physicians regarding family consent and the expectations of their patients. He uses this difference of patient expectations and physician behavior, as well as culturally relevant moral arguments to seek to change physician behavior. [27]

Some of the literature developing from ethics research in the minority world is very concrete. For example, Tracy MacIntosh has explored the use of clinical photography in the majority world. She notes the need to “combine existing clinical photography guideline from the North with ongoing clinical ethics debates in the South ... to establish photography guideline throughout the world that will be sensitive to the privacy and dignities of all patients”. [28]. Once culturally relevant ethics guidelines, policies, and procedures are worked out for various societies in the majority world, the last step will be to educate healthcare providers, monitor for compliance, and sanction for ethical breaches. In the case of clinical photography, research shows that even the guidelines that exist are often not followed or enforced. [28]

CONCLUSION

Danielle and Akinyi

After reflection on her experience in the majority world, Danielle decided that she wished to return but needed to be better prepared. A physician she encountered after the elective

pointed her to the ethics literature regarding minority world students working in the majority world. Danielle also spent some time learning more about the culture and history of the region she wanted to return to work in.

When Danielle returned to the majority world as a physician, she was determined to work closely with local physicians and to improve care sustainably. When Akinyi failed to progress in her first labour, she came under Danielle's care. The two women became friends and Danielle came to understand the local culture mainly through her relationship with Akinyi. Through her relationship with Danielle, Akinyi came to believe that women can make decisions and take actions that improve their lives. Together with Akinyi, Danielle begins to work on improving the care of women in the community, ensuring the medical care respects human dignity, and making the allocation of resources more just.

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