

Culturally Competent Bioethics: Analysis of a Case Study

Ben Gray

Received: 16 April 2013 / Accepted: 9 March 2015 / Published online: 28 May 2015
© Journal of Bioethical Inquiry Pty Ltd. 2015

Abstract This paper discusses the Saudi Arabian case by Abdallah Adlan and Henk ten Have, published in a 2012 issue of the *Journal of Bioethical Inquiry*, regarding a congenitally disabled child enrolled in a research project examining the genetics of her condition. During the course of the study, her father was found not to be genetically related, and the case discussed the dilemma between disclosing to the family all findings as promised in consent documents or withholding paternity information because of the likely severe social repercussions. Using Adlan and ten Have's example, this paper proposes a framework to consider cases outside of the conventional bioethics frame of reference, splitting the bioethical task into three elements: understanding the problem from the patient's and the clinician's perspective and then engaging in dialogue to decide what to do next. The process of dialogue between affected parties is vital. Presuming that there is a common morality undermines the effectiveness of the dialogue needed to find a resolution.

Keywords Cultural competence · Ethics clinical · Ethical relativism · Common morality

The Case

Abdallah Adlan and Henk ten Have (2012) describe a case from Saudi Arabia about a 13-year-old child severely disabled from a congenital disorder. The family was invited by the treating physician to participate in a genetic study for which he was the principal investigator. Both parents “consented and were fully informed that the daughter would not directly benefit” and signed consent forms individually that included a clause that “the family had the right to know all information revealed by the test” (Adlan and ten Have 2012, 404). The research showed that the child's father was not genetically related. The parents were then asked whether they had used any assisted reproductive technologies, which they denied. This left the possibility that the child was sired outside of the marriage. In their paper, Adlan and ten Have provide a discussion of Sharia law and tribal tradition, which can involve severe consequences for infidelity—at the worst involving the death of the mother but also rejection of the daughter and marriage ineligibility for the mother's sisters. Adlan and ten Have weigh the ethical value of truth-telling; the potential ramifications of letting both the father and the mother know about the paternity; and the well-being of the family, particularly the mother, the daughter, and the mother's relatives. Peer reviewers of the article were anxious about the lack of a rigorous cohesive argument (cited in Komesaroff 2012), but the article was published alongside four commentaries from other bioethicists in the same issue of the journal (Komesaroff 2012; Tsai 2012; Zabidi-Hussin 2012; Lingis 2012) and an editorial (Ashby and Rich 2012).

B. Gray (✉)
Department of Primary Health Care and General Practice,
University of Otago, Wellington, P.O. Box 7343, Wellington
South 6021, New Zealand
e-mail: ben.gray@otago.ac.nz

This case is set in a country with different social mores from that in the West. As Ashby and Rich state, “there is the possibility (however unlikely) for an ethics committee to reach a bioethically based decision, in such a case of conflicting obligation, that could result in several deaths” (2012, 373). This comment questions the adequacy of conventional bioethical processes to deal with moral dilemmas in communities that do not share the values of conventional bioethics.

In this paper, I argue that the use of principlism to resolve bioethical dilemmas relies on the parties to the dilemma largely sharing values and beliefs: the “common morality” (Beauchamp and Childress 2013). The clinician considers the problem in the light of the common morality and decides the best course of action. I describe the extent to which the values in Saudi Arabia diverge from the common morality and argue that because of this divergence the use of principlism in this case is flawed. I then argue the more general proposition that appealing to a universal principle is unhelpful in resolving particular clinical ethical dilemmas. Lastly, I propose a culturally competent framework that does not rely on agreement on a common morality but, rather, splits the clinical bioethical task into three elements: understanding the problem from the patient’s and the clinician’s perspective and then engaging in dialogue to decide what to do next. The process of dialogue between affected parties is vital.

In this paper, I use Betancourt, Green, and Carrillo’s definition of “culture”:

Culture has been defined as an integrated pattern of learned beliefs and behaviors that can be shared among groups. It includes thoughts, styles of communicating, ways of interacting, views on roles and relationships, values, practices, and customs. Culture is shaped by multiple influences, including race, ethnicity, nationality, language, and gender, but it also extends to socioeconomic status, physical and mental ability, sexual orientation, and occupation, among other factors (Betancourt, Green, and Carrillo 2002, 1).

I also use their definition of “cultural competence”:

Cultural competence in health care describes the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients’ social, cultural, and linguistic needs (Betancourt, Green, and Carrillo 2002, v).

The Limitations of Principles in This Case

Informed Consent

In the Saudi Arabian case, informed consent is problematic because the primary participant in the research is not competent to give consent. Her parents provide individual consent on her behalf (and, technically, consent for themselves as well, as they must supply their own blood samples and thus become research participants). Valid informed consent requires the consenting person to be autonomous and free from coercion (as well as of legal age). Here, the daughter does not meet any of these criteria, and the mother has significantly less power than her husband. If the information that the father is not genetically related becomes known, it will be the child, the wife, and her family who will bear the greatest consequences, not the husband nor the man who fathered the child. Assuming that the wife knew of the possibility that her daughter was not fathered by her husband, the sensible thing for her to do would have been to decline to consent to the research. However, that of itself would create the risk of her husband wanting to know why she will not consent (and also entails a clear understanding of genetics-based research, something even the savviest individual might not recognise). As the study was proposed by the daughter’s treating physician, it also may have been culturally impossible for the mother to decline because of her dependence on the physician to care for her child.

In the Saudi setting there are major limits to a woman’s autonomy, especially in relation to sexual behaviour. There will be many decisions a woman makes that easily could be affected by coercion. Relying on informed consent to ensure ethical safety is unwise in this case, as Adlan and ten Have (2012) imply.

Truth-Telling

One of the main focuses in this case is whether to tell the family the truth. Truth-telling is a central principle in bioethics (Beauchamp and Childress 2013) and is described as a part of the common morality—i.e., a universal principle. But truth-telling must be examined in the broader social context. Parekh asserts that adultery is not at all unfamiliar in Muslim society, but “because it

invites severe punishment” and “often leads to considerable hypocrisy, social blackmail and witchhunts” (1996, 280), it is very unlikely that there is widespread truth-telling in relation to extramarital sexual activity.

The ethnic background of the clinician in this case is not explicitly described; he or she may or may not have been a Saudi Arabian and/or an Arabic-speaking person. However, we do know that the treating physician is “culturally” a doctor and espouses the values and beliefs common to the international biomedical culture (Taylor 2003), such as reliance on informed consent, presumption of autonomy, and truth-telling.

Adlan and ten Have’s discussion of this case proceeds on the presumption that these two principles should be ascribed significant weight, and yet in “lay” Saudi Arabia (as opposed to “medical” Saudi Arabia) they appear to carry less weight in this particular case than might be expected.

The Problem of Universalism in Clinical Ethics

More generally, Parekh (1996) argues that moral universalism is an unhelpful approach, firstly because the claim that there is a universally valid body of values is ambitious and yet to be achieved. Secondly, even if principles were shown to be philosophically valid, some cultures still might not accept them, and if the principles included liberty and self-determination, then enforcing the values would be untenable. Thirdly, any principles need to be applied to real situations and interpreted, and here it is very unlikely that agreement would be reached.

For example, Churchill, Fanning, and Schenck studied the interactions of patients with their physicians and used this as a base to “rethink healthcare ethics” (Churchill, Fanning, and Schenck 2013, 145–146). They drew a similar conclusion about the limited usefulness of principles in resolving clinical dilemmas:

[T]he four principles ... do not and cannot address the core structure and rhythms of a patient’s engagement with a practitioner. Nor can they give guidance at the level of detail necessary to be truly helpful as patients and clinicians struggle towards maintaining healing relationships (Churchill, Fanning, and Schenck 2013, 146).

There may be universal principles, but the weighting of such principles varies considerably between cultures.

Hofstede (2010), who has researched and written extensively describing cultural difference, believes that cultures vary on six major elements: power distance (egalitarian versus hierarchical); gender role (distinct male and female roles versus greater blurring of roles); uncertainty avoidance (tolerance versus intolerance of risk); long-term orientation (compared to a short-term orientation); indulgence versus restraint; and individualism versus collectivism. This, however, is descriptive work; he does not ascribe a relative value to any of these variables. As with any description of culture, Hofstede’s model is acknowledged as being a generalisation that does not apply to all of the individuals within a society but one that is practically useful. In the Saudi Arabian case, the society is described as hierarchical, with women having less power than men. In a comparison of 76 countries (Hofstede 2010), Arabic-speaking countries are listed as the 12th-most hierarchical (with the United States ranking at 59) and 41st on the individualism index (the United States is first). From this perspective, it becomes clear that the weight put onto an ethical value such as autonomy will vary from country to country, and people from certain countries, such as the United States, are likely to value this principle more than others. At the other extreme, Ujewe (2012) argues that from a Nigerian perspective autonomy is a meaningless concept, and for him, he is unable to separate his own self from his extended family.

A Culturally Competent Ethical Decision-Making Process

None of the commentators of the Adlan and ten Have (2012) case proposes a coherent framework to resolve this problem. Tsai (2012) describes how the weighting of values would be different in Taiwan. He appeals to narrative medicine as an approach to take. Lingis notes that “the concept of ‘autonomy’ is Enlightenment European” and not necessarily as relevant in Saudi Arabia (2012, 412). Komesaroff (2012) looks at the problem as a conflict between three opposing discourse systems (three ways of judging the “right” course of action) but does not address what should be done to achieve resolution.

Instead of relying on a process of discussion among bioethicists, based on a framework of principles, I argue that a better approach is to address the dilemma through structured dialogue between the affected parties. Support for this approach comes from three different perspectives:

Dialogical Consensus

In his paper addressing how societies should address “immigrant practices that have aroused considerable disapproval” (Parekh 1996, 253), Parekh discusses five possible approaches: moral universalism, core values, no-harm principle, human rights, and dialogical consensus. He favours dialogical consensus and provides persuasive argument as to the value of this approach over the other four alternatives.

What Patients Teach

Having rejected moral principlism as discussed above, Churchill, Fanning, and Schenck go on to argue that:

An ethics of vulnerability and responsiveness that attends carefully to the ebb and flow of the interactions between patients and clinicians can give access to the everyday ethics that matter most (Churchill, Fanning, and Schenck 2013, 146).

Indigenous Research Guidelines

Indigenous people in Australia (National Health and Medical Research Council 2003), New Zealand (Pūtaiora Writing Group 2010), and Canada (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada 2010) have all responded to conventional research ethics guidelines, arguing that they are developed from a particular cultural standpoint and that as a result are poorly suited to ethical research in indigenous communities. All three emphasise the importance of trusting relationships:

Research involves groupings of people in a collaborative exercise. The soundness of trust among its stakeholders is essential to a successful and ethical outcome. Trust has to function at all levels of the research enterprise—between participant and researcher, between research partners and sponsors, between researchers, institutions and the scientific community and lastly, and perhaps most importantly, with the wider community. Where trust persists, research can be sustained (National Health and Medical Research Council 2003, 3).

[R]esearch involving Aboriginal peoples is premised on respectful relationships. It also encourages collaboration and engagement between researchers and participants. Building reciprocal, trusting relationships will take time (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada 2010, 105).

The focus is on doing research *with* rather than *on* indigenous people, with an expectation that they have involvement at every phase of the research—from the choice of research subject through research design and implementation and including the way in which results are disseminated (Pūtaiora Writing Group 2010). Such an approach can only be achieved by ongoing dialogue.

Whilst Parekh’s analysis relates to a political dialogue within a society, his discussion of how dialogical consensus would work at a societal level (a précis of which follows) translates well for a clinical ethical decision:

Political dialogue is essential to resolve deep moral and cultural disagreements and cannot occur in a vacuum. It presupposes a specific society with a specific moral structure, whose members disagree strongly about the desirability of a specific practice. The dialogue centers on the values held by the communities in dialogue. They specify what aspects of the practice are unacceptable and why, what kinds of reasons can properly be advanced in defense or criticism of it. Every dialogue must therefore begin with and center on the community’s values and show why they need to be changed or reinterpreted. In other words, there can be no dialogue without a context, and, once the context is introduced, the dialogue can no longer be free-ranging and open-ended. Furthermore a political dialogue is intended to yield a decision. Since deep disagreements cannot always be satisfactorily resolved, we need ways of reaching a decision, on which again there may be considerable disagreement (summarised from Parekh 1996, 258–259).

Harman (2007), in his defence of moral relativism, develops the useful concept of “frame of reference” (analogous to Komesaroff’s discourse system). He argues that problems need to be understood from the frames of reference of the people involved.

Multicultural Mental Health in Australia describes this from a clinical perspective and argues that an adequate assessment of a patient “requires an understanding of the behaviours and beliefs of the client within the parameters of the client’s culture rather than the clinician’s culture” (2002, 22).

Bringing these ideas together, a prerequisite of dialogue is that it is centred on the conflicting values of the patient and the clinician in the specific case. The details of the context need to be understood. The clinician will bring his or her understanding of clinical ethics from one particular cultural context and the patient his or her own cultural context, but the details are essential, taking into account the inevitable uncertainties. In the case from Saudi Arabia, whilst the authors may describe the cultural norm with regard to women’s sexual behaviours, is it always followed? Is it likely to be followed by this particular couple? Given that the informed consent process was flawed due to (at the very least) the potential coercion of the mother, is there still an obligation to inform the family?

The dialogical consultation also needs to yield a decision. This does not mean that clinician and patient (in this case, the patient’s parents) will agree on everything, but they need to reach agreement on what to do next.

We are not given all of the information about the dialogue that took place in the Saudi Arabian case nor the subtlety of the relationships. What is the relationship between the husband and wife? Is she clearly without any autonomy, or does she appear to have significant power in the relationship? How did the couple react to the question about the use of assisted reproduction? Did they understand the implication behind this question, and if so, how did they react? It is possible that the chance that the husband is not the father is already known to the couple and that they have accepted this and moved on. Additionally, was it possible to interview the woman without her husband present? If so, what would be the balance of harm versus benefit in telling her about the paternity of her child?

The decision of what to do should come out of the dialogue. However, it is very hard to reach a good answer without being part of the dialogue. The clinicians involved will have to live with the outcome of their decision not to tell the family about the paternity. Rather than trying to justify

that decision through bioethical debate, my view is that it should have been a judgement that came out of the dialogue between the clinician and the family. If the clinicians were unsure whether the right decision was made, then had they used this framework they might have been able to focus on continuing the dialogue prior to making a final decision. It is my view that further debate among bioethicists is unlikely to be conclusive, and the elements justifying this decision would have been found in knowledge of the details of the dialogue that had taken place.

In asserting that a moral universalist approach is not effective, I am not arguing against developing and understanding ethical principles. It is from this process that clinicians will develop their view on what the right course of action is. Nor am I arguing in favour of cultural relativism where clinicians feel obliged to agree against their better judgement with the views of patients because they are from a different culture. What I am arguing is that any moral difference between clinician and patient needs to be clearly delineated before a decision on what to do next is made.

Using another example, a particularly stark area of cultural difference exists between those who find abortion acceptable for managing an unwanted pregnancy and those who are opposed to abortions being performed.

To illustrate: If my patient seeks an abortion and I find that morally unacceptable, we need to decide what happens next. If performing abortions in my country is legal, I may refer her to another clinician who may consider and carry out her request. Refusing to provide any information that could enable her to obtain an abortion would be culturally incompetent, failing to “tailor delivery to meet patients’ social, cultural, and linguistic needs” (Betancourt, Green, and Carrillo 2002, v). This would presume that my values are superior to hers. If the procedure is not legal, I will refuse to refer her, but I need to continue the dialogue. If despite full discussion she is adamant that she is going to obtain an abortion, then to provide the best care for her I need to understand what options she is considering and advise her on how to minimise harm. Her options might be to seek out a local backstreet abortionist, to travel to another country, or to acquire some misoprostol to induce an abortion at home (Women on Waves n.d.).

Depending on the circumstances, I might be agreeable to helping her find treatment in another country. If I was particularly sympathetic to her situation, I might provide a prescription for misoprostol (it is also used for treating gastric ulcers) with instructions on how to appropriately administer it. If I am personally opposed to abortion, I will have to carefully weigh up my moral distress of “colluding” with the provision of an abortion against the extent of my responsibility if the woman procures an abortion through other means and it goes badly and she dies. No matter how much I object to abortion in general, I do not have the power to prevent a determined patient from procuring one. If I retain a relationship with the woman and help her with her decision-making, I do have the power to minimise the harm that she might experience. If she appreciates that I am non-judgemental, she may be more amenable to discussing her options and, if things go badly (maybe an infection after a backstreet abortion), to return for further care. If I choose to close the dialogue by saying that I disagree with abortion and do not want to discuss the subject any further, she is likely to leave, and I will no longer have a relationship with her and will lose any ability to affect the outcome. Whether I believe abortion is immoral does not change the fact that a decision has to be made, taking into account all details of the circumstances.

Conclusion

Adlan and ten Have’s (2012) Saudi Arabian case is an illustration where using conventional bioethical processes and centring the discussion on universal principles failed to provide an acceptable framework to make a decision. I have argued that universalism is unhelpful in resolving particular dilemmas. Whilst universal principles may have wide acceptance, the exact weighting to be given to such principles in specific circumstances with particular people varies to the degree that it is impossible to reach a good outcome no matter how well the principles are debated. In addition, given that there is no agreed-upon list of universal principles, it is culturally incompetent for the clinician to presume that his or her ethical standpoint is superior to that of the patient. Instead, I argue that an approach of structured dialogue between the parties affected by a dispute is likely to lead to a better outcome.

References

- Adlan, A.A., and H.A.M.J. ten Have. 2012. The dilemma of revealing sensitive information on paternity status in Arabian social and cultural contexts. *Journal of Bioethical Inquiry* 9(4): 403–409.
- Ashby, M.A., and L.E. Rich. 2012. Cases and culture: The benefits and risks of narrating “life as lived.” *Journal of Bioethical Inquiry* 9(4): 371–376.
- Beauchamp, T.L., and J.F. Childress. 2013. *Principles of biomedical ethics*, 7th ed. New York: Oxford University Press.
- Betancourt, J.R., A.R. Green, and J.E. Carrillo. 2002. *Cultural competence in health care: Emerging frameworks and practical approaches*. The Commonwealth Fund, October. http://www.commonwealthfund.org/usr_doc/betancourt_culturalcompetence_576.pdf.
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. 2010. *Tri-council policy statement: Ethical conduct for research involving humans*. Ottawa: Interagency Secretariat on Research Ethics. http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf.
- Churchill, L.R., J.B. Fanning, and D. Schenck. 2013. *What patients teach: The everyday ethics of health care*. Oxford: Oxford University Press.
- Harman, G. 2007. Is moral relativism correct? Yes. In *Taking sides: Clashing views on moral issues*, 14th ed. expanded, edited by S. Satris, 4. Dubuque, IA: Dushkin Publishing Group.
- Hofstede, G. 2010. *Cultures and organizations: Software of the mind: Intercultural cooperation and its importance for survival*, 3rd ed. New York: McGraw-Hill.
- Komesaroff, P.A. 2012. Cross-cultural issues in ethics: Context is everything. *Journal of Bioethical Inquiry* 9(4): 417–418.
- Lingis, A. 2012. The rationality of values. *Journal of Bioethical Inquiry* 9(4): 411–412.
- Multicultural Mental Health in Australia. 2002. *Cultural awareness tool: Understanding cultural diversity in mental health*. Parramatta, BC: West Australian Transcultural Mental Health Centre, The Royal Australian College of General Practitioners WA Research Unit, Commonwealth Department of Health and Ageing, and Multicultural Mental Health Australia. <http://www.mhima.org.au/mental-health-information-and-resources/clinical-tools-and-resources>.
- National Health and Medical Research Council. 2003. *Values and ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research*. Canberra: Commonwealth of Australia. https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e52.pdf.
- Parekh, B. 1996. Minority practices and principles of toleration. *International Migration Review* 30(1): 251–284.
- Pūtaiora Writing Group. 2010. *Te ara tika: Guidelines for Māori research ethics: A framework for researchers and ethics committee members*. Auckland: Health Research Council of New Zealand. <http://www.hrc.govt.nz/sites/default/files/Te%20Ara%20Tika%20Guidelines%20for%20Maori%20Research%20Ethics.pdf>.

- Taylor, J.S. 2003. Confronting “culture” in medicine’s “culture of no culture.” *Academic Medicine* 78(6): 555–559.
- Tsai, D. 2012. Reflections from Taiwan on unsought truth-telling: Comparison with lessons from Saudi Arabia. *Journal of Bioethical Inquiry* 9(4): 415–416.
- Ujewe, S.J. 2012. *Ought-onomy and African health care: Beyond the universal claims of autonomy in bioethics*. Thesis, Master of Health Sciences, University of Otago.
- Women on Waves. No date. How to do an abortion with pills (misoprostol, cytotec)? <http://www.womenonwaves.org/en/page/702/how-to-do-an-abortion-with-pills-misoprostol-cytotec>. Accessed July 15, 2014.
- Zabidi-Hussin, Z.A.M.H. 2012. Does nondisclosure of genetic paternity status constitute a breach of ethics? *Journal of Bioethical Inquiry* 9(4): 413–414.