

Clinical Ethics Cultural Competence and the Importance of Dialogue a Case Study

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Abstract

The traditional bioethical approach to addressing clinical ethical dilemmas is to apply ethical principles to analyse the dilemma to reach an ethically acceptable course of action. This paper will address the problem of what to do when the patient or patient's proxy disagree with this advice. I will argue that ethical principles have limitations in a culturally diverse world, and that best practice guidelines whilst helpful rarely address the specifics of an individual clinical dilemma, and are often not based on robust evidence. Bioethical mediation has been proposed as an important process for clinical ethics support services. Whilst I agree with the need for this my contention is that this is not a new bioethical skill but is in fact the very core of what a good consultation consists of. I will illustrate this discussion with a general practice case study of vaccination refusal. My conclusion is that an approach that accepts and respects diversity and focusses on developing a trusting relationship is the most effective way to reach the best available resolution for clinical ethical dilemmas.

Keywords: Clinical ethics; Cultural competence; Bioethical mediation

Introduction

The traditional bioethical approach to addressing clinical ethical dilemmas is to apply ethical principles to analyse the dilemma to reach an ethically acceptable course of action. This is particularly evident in the work of United States Ethics Consult Services where a majority of consults resulted in a recommendation following ethical deliberation [1].

This approach fails to address the problem of what to do when the patient or patient's proxy do not agree with the recommended course of action. In the hospital setting this has led to the practice of getting patients to sign release documents when they are "discharged against medical advice", even though this has been shown to lead to a significantly worse outcome for the patient [2]. In the outpatient setting many paediatricians in the USA refuse to provide care for the children of parents who refuse immunisation [3].

There are several reasons why we need to address this approach in more detail.

Firstly; medical culture has very much moved from a paternalistic approach to a more patient centred approach [4]. If this is the case then how can there be such a thing as being discharged against medical advice? Surely if a patient centred approach is being taken then the goal is to reach an agreed management plan that takes into account the patients values and beliefs. If the patient wishes to leave hospital then a plan needs to be developed that allows that to happen.

Secondly; there is a relatively recent realisation that people from non-dominant cultural groups often have significant health outcome disparities [5], and this has led to the development of the concept 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 [6].

The concept of culture has been defined:

Being a member of a culture surrounds a person with a set of activities, values and experiences which are considered to be real and normal. People evaluate and define members of other cultural groups according to their own norms [7].

Particularly in settler societies like the USA, Canada, Australia and New Zealand there is considerable ethnic diversity with an increased likelihood of there being a difference in values and beliefs between clinician and patient. Culturally competent care is about having insight into our own values and beliefs, and an ability to work with people who have values and beliefs different from our own. We need to understand that the concept of culture applies widely, not just to ethnicity but to sexual orientation, education level, lifestyle, age and perceived economic worth. We need to respect the views of others (which does not mean agreeing with them) [8] Rather than asserting what we think is right we need to embrace diversity and learn how to live with difference.

Finally as a consequence of this attention to the concept of culture has come a critique of medical practice.

Like most cultural groups those within the culture of medicine see their actions and views on how things should be done as "normal" and "right" and that people who do not agree with these actions and views are labelled as non-compliant. Taylor [9] summarised this:

"Medical knowledge is understood to be not merely "cultural" knowledge but real knowledge."

"To change this situation will require challenging the tendency to assume that "real" and "cultural" must be mutually exclusive terms.

Physicians' medical knowledge is no less cultural for being real, just as patients' lived experiences and perspectives are no less real for being cultural."

Many people do not share the "medical" view of the world and we need to be more humble and accept that our views are valid but not necessarily right.

Uncertainty

The recommendation for any particular clinical situation is largely dependent on two main considerations: the evidence pertaining to the clinical situation and the ethical choices available. It is usual for both the clinical evidence and the ethical choices to be dependent on the detail of that specific patient's circumstances, and that that detail usually contains many uncertainties.

Ethics

The predominant approach to clinical ethics is deontology as described by Beauchamp and Childress [10]. In New Zealand the New Zealand Medical Association (NZMA) Code of Ethics explicitly cites their work.

The moral basis for practice has its expression through what is commonly termed medical ethics. Integral to an ethical basis for professional practice is the overriding acceptance of an obligation to patients, and recognition of their autonomy.

Standard treatises on medical ethics cite four moral principles: autonomy, beneficence, non-maleficence and justice [11].

Beauchamp and Childress espouse the idea of a common morality, a universal morality based on the four principles cited by the NZMA, which implies that for any particular clinical problem there is a right ethical answer. No-where do they acknowledge that this has been developed from a particular cultural viewpoint. This approach has been widely critiqued in the literature [12-14] and I do not wish to traverse this in detail so I will limit myself to the problems that stem from cultural difference.

There may be universal principles but the weighting of such principles varies considerably between cultures. Hofstede [15] has researched and written extensively describing cultural difference. His view is that cultures vary between each other on six major elements: Power Distance (egalitarian versus hierarchical) Gender Role (distinct male and female roles versus greater blurring of roles) Uncertainty Avoidance (tolerance of risk versus intolerance of risk) Long Term Orientation (compared to a short term orientation) Indulgence versus Restraint and Individualism versus Collectivism. This is descriptive work; he does not ascribe a relative value to any of these variables. As with any description of culture it is acknowledged as being a generalisation which does not apply to all the individuals within a society, but that this generalisation is practically useful. From this work it is no surprise that autonomy features prominently in principles espoused by American authors. The USA is the most individualistic country (out of 78) in their analysis. At the other extreme Ujewe [16] argues that from a Nigerian (58th out of 76 countries), perspective autonomy is a meaningless concept to him as he is unable to separate his self from his extended family. The approach to care of an American patient needs to be different from that of a Nigerian patient. Any ethical decision needs to be considered in the light of the values and norms of the patient.

Clinical evidence

The extent of conflict between doctors and their patients has been amplified by the evidence based medicine movement. [17] Whilst the proponents of this movement emphasise the importance of *"thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care"*, in practice this has become more as they feared: *"practice risks becoming tyrannised by evidence, for even excellent external evidence may be inapplicable to or inappropriate for an individual patient."*[17].

McCormack [18] examined five clinical practice guidelines from Canada (on diabetes cardiovascular disease and osteoporosis). They wanted to assess the extent to which the guidelines considered variation in patient values and beliefs and whether they provided sufficient information about harms and benefits to be able to have a meaningful discussion with patients about whether they wished to follow the guidelines. They examined the text of these guidelines and found only 99 words that related to patient values and preferences: around 0.1% of all the words. They provided limited quantitative information on benefits and harms. Particularly for the management of long term conditions like diabetes and cardiovascular disease patients need to be able to make choices based on likely benefits and harms taking into account their own values and preferences. These guidelines do not enable that to happen. The level of evidence in most guidelines is far from robust for example Shaneyfelt [19] noted that most guidelines are expert consensus reports with a recent guideline exemplifying this:

revisions of the American College of Cardiology (ACC)/American Heart Association (AHA) guidelines have shifted to more class II recommendations (conflicting evidence and/or divergence of opinion about the usefulness/efficacy of a procedure or treatment) and that 48% of the time, these recommendations are based on the lowest level of evidence (level C: expert opinion, case studies, or standards of care.

Given this uncertainty on what is ethically right and what the evidence suggests is best practice, a reliance on a traditional process of analysis to determine the best course is problematic at best.

In this paper I do not want to argue about whether there is such a thing as a common morality or a best practice for any particular clinical condition. My presumption is that the views of any particular clinician or patient will not align exactly with the common morality, and that best practice is rarely certain. So the issue if there is disagreement on management is how to resolve the difference between two people, neither of whom reflects either a common morality or best practice. Analysis of ethical problems and development of best practice guidelines focusses largely on content. My contention is that we have paid insufficient attention to process; to the importance of dialogue. This view is congruent with the views of those considering the roles of clinical ethics advisory services who are advising the use of "bioethics mediation" [20,21] drawing on literature outside of health care pertaining to mediation. My contention is that these processes and skills are already a part of medical training, we do not need to reinvent the wheel. This is what a modern medical consultation is.

Understanding the consultation

There is a large body of literature that looks at the process of the consultation that has led to training materials on how to conduct a consultation. At our medical school we use the Calgary-Cambridge

method [22]. This guide was developed from an extensive literature review particularly utilising cross cultural consultations on the premise that these were the most difficult and that any model of the consultation had to be able accommodate these.

Summary

In summary I am arguing that when confronted with a clinical ethical dilemma, doctors need to acknowledge that their ethical views on what might be right are culture bound and not right in any absolute sense, and that in addition the medical view on what constitutes best practice is rarely based solely on high level evidence and usually does not take into account the values and beliefs of patients. Resolving a clinical ethical dilemma requires considerable consultation skills. For the consultation to be effective the doctor needs to be able to accept that the patient's position is valid and to place the focus not on proving who is right or wrong, but on understanding all the specifics of the case in point, the areas of agreement, the areas of disagreement and then negotiating a way forward.

Case Study

I will illustrate the importance of process with a case study based on a consultation that I held in my general practice. A case of parental refusal of vaccination is an extreme example of disagreement between doctor and patient. In this instance the quality of evidence supporting immunisation is much higher than in most other situations. Nonetheless I argue that this approach is still the best way to achieve the best outcome. Bester's [23] paper provides more detail to support my contention.

I will describe the consultation using headings from the Calgary Cambridge guide to the medical interview [24]. They describe the consultation as being in a particular structured format starting with initiating the session, then gathering information whilst providing structure and building relationship, before moving on to explanation and planning and finally closing the session. It consists of 71 items and I will highlight numbered headings of items relevant to this case:

A 25 year old woman comes to the clinic with her partner and their 2 year old son because the child has infected sores on his legs. He is triaged by the practice nurse who notes that he has had no immunisations and refers him to the doctor for management.

From a traditional bioethical perspective this is reasonably straightforward. Clearly you start by providing treatment for the infection and then proceed to raise the issue of immunisation. The evidence supporting the use of immunisation is extensive and robust with many studies showing that it is in the best interest of the child. The parents should be informed that they should have their daughter immunised.

However if the doctor is to behave in a culturally competent, patient centred way then s/he needs to respect the patient's values and beliefs. By failing to focus on the interaction a false dichotomy is set up that you either behave in a paternalistic culturally incompetent way by insisting the child is immunised, or you abrogate your professional responsibility and accede to their wish not to have their child immunised.

Gathering information

Before proceeding any further it is important to listen to the patient (parents)(Item10 Listening: listens attentively, allowing patient to complete statements...). It is particularly important not to make assumptions. You need to find out what they know about immunisation and understand what led to their decision not to have their son immunised. It is unlikely that they will talk openly if they sense that you are being judgemental about their decision (item 26 Accepts legitimacy of patient's views and feelings; is not judgmental). Whilst they may presume that you wish to immunise their child, it is vital that you do not include your views before having gathered the information. Careful listening may uncover important history; maybe a family member was one of the few to have an anaphylactic reaction to a vaccine, maybe they already have an autistic child and worry that this might be related to immunisation. (item 17 actively determines and appropriately explores patients ideas, worries and expectations).

The mother replies that she does not think that it is necessary as she is paying a lot of attention to ensuring that his immune system is well supported, making sure he is on a good diet and getting lots of exercise. On questioning her objection is to all immunisations but she does not have a detailed understanding of all the immunisations that are available.

Explanation and planning

It is important that your explanation is couched as your perception of the issue, being careful not to imply that it is the "right" way to do things: "My understanding is...My experience is...describing specific illnesses, and how you understand that they affect people who catch them and how effective you believe the vaccine is at preventing them, perhaps starting with one or two illnesses. (Item 47 Shares own thinking as appropriate: ideas, thought processes, dilemmas; Item48 Involves patient by making suggestions rather than directives). The risk is that we expect parents to comply with the full immunisation schedule, and fail to discuss the detail. The benefits and risks of each immunisation vary considerably. There is no correct way of assessing and acting on risk. Just because I believe that the risks of immunisation are worth the benefits it does not follow that these parents agree. I know my positive view of immunisation is influenced by my past experience of patients with vaccine preventable disease.

I asked whether she knew much detail about immunisations and whether she would like me to explain why I thought they were important. She agreed that she would like to know more so I explained my understanding of tetanus as an example and how the dangerous effect it has is as a result of a toxin and that the infection itself was minor. I said it was a bit like the venom of a snake bite. I also explained my experience of having cared for a child with acute epiglottitis who nearly died and that since the vaccination against that illness had come in I had not seen another case. (Item33 Assesses patient's starting point: asks for patient's prior knowledge early on when giving information).

Achieve a shared understanding

You would acknowledge that you and the parents want the best for their son.

They have clearly thought about what they think is best and it is great that they are paying attention to diet and exercise. You would acknowledge that they are not happy with having their child immunised but were happy to receive more information on this.

Planning; shared decision making

A common response of doctors is to presume that the reason for disagreement is that the parents do not understand and that all that is required is "education". This may be the case but it is far from the sole reason for disagreement.

The father said to the mother "*I think we should do it*" the mother said "*I don't like needles*" and the father offered to hold his son whilst we gave the immunisation.

If they had not agreed to immunisations this does not preclude reaching an agreed management plan as to how to proceed. You and they might agree that they will be given some literature to read and come back at a later time for further discussion. You and they might agree that they are happy for you to raise the matter again at a later time to see if they have changed their mind. They may say that they are tired of being asked about this all the time and you agree that you are happy to continue care without asking them about immunisation unless they initiate the conversation first. If they feel respected and that you are caring towards them then they will continue to seek care from you leading to further opportunities to discuss the issue. This may or may not lead to the child being immunised. However such a process has hopefully improved the relationship; they feel listened to. (Item 51 Offers choices: encourages patient to make choices and decisions to the level that they wish.)

Discussion

My professional judgement is that it is desirable for all children to be immunised according to the national immunisation schedule. The question is; what is the best way to achieve this? We do not have the power to immunise against the parent's wishes, although in some jurisdictions some coercion is applied: for example Australia [25]. If the parents leave never to return then we lose all ability to influence the outcome for this child. My contention is that the only tool we have to increase the likelihood of childhood vaccination is the quality of the relationship we have with their parents. At the heart of the vaccination debate is whether the parent's trust the information that we provide. In a study of parents who refused vaccination [26] a large majority of the reasons they elicited boiled down to the parents trusting information from another source more than the information from the doctor. One non vaccinating patient expressed this well:

We searched for all kinds of information, and the problem is: there is too much and you do not know how to filter. What is an opinion, what is a fact? Who is trustworthy, who is not?"

Benin [27] in their qualitative analysis of vaccination noted that:

"inhibitors included feeling alienated by or unable to trust the pediatrician, having a trusting relationship with an influential homeopath/naturopath or other person who did not believe in vaccinating"

and concluded that:

"Trust or lack of trust and a relationship with a pediatrician or another influential person were pivotal for decision-making of new mothers about vaccinating their children. Attempts to work with mothers who are concerned about vaccinating their infants should focus not only on providing facts about vaccines but also on developing trusting and positive relationships."

The scandal over the fraudulent research finding that autism might be caused by the measles vaccine has had a big impact on immunisation practice [28]. This is not only because many have heard of this connection but not the subsequent retraction, but also because if we could not trust that paper published by reputable scientists in a reputable journal what papers can we trust?

If we want to influence the decision of the parents we need to develop a trusting relationship with them and no amount of information will convince a person who does not trust the person providing the information.

Understanding trust

Defining trust

Rousseau [29] defined trust as:

"...a psychological state comprising the intention to accept vulnerability based upon positive expectations of the intentions or behaviour of another"

Trust is not a behaviour (e.g., cooperation), or a choice (e.g., taking a risk), but an underlying psychological condition that can cause or result from such actions.

Lewis and Weigert [30] divided trust into three elements: cognitive, emotional and behavioural, although they noted that in practice all three are inevitably interlinked. Cognitive trust is trust gained from knowledge, and is at the heart of the concept of informed consent. Informed consent as a process however is founded on emotional trust; do you trust this person to be telling you the truth? Emotional trust depends on a relationship. Trusting a complete stranger entails risk. Behavioural trust comes from repeated positive contact.

In addition Rousseau added the concept of "Institution based trust", (Rousseau et al.,) [29]. Trust in an institution (a hospital, a profession) can also be divided into cognitive, emotional or behavioural. It is not uncommon for some minority cultural groups to lack trust in the hospital because of past experience of family members having died in hospital. Hospitals function on the premise that patients trust the institution. Care is provided by so many different individuals that it would be very difficult for a patient to develop an emotionally trusting relationship with all the individuals they encounter. In many countries there have been medical scandals that have diminished public trust in doctors. The New Zealand example was where Professor Green conducted an experiment on women without their knowledge and consent to determine what the course of cervical cancer was if left untreated. This led to a parliamentary inquiry [31] which made recommendations that became the basis of our structure for patient rights and research ethics. In her commentary on the findings Paul [32] noted:

"The revelations of the inquiry have damaged this trust and good faith not only in the National Women's Hospital but also elsewhere in New Zealand. ... The trust that existed has been shown not only to have been misplaced but to have been dangerous to the women concerned..."

Patients will welcome more information and a greater chance to make informed decisions about their treatments, but I suspect that both doctors and patients will continue to worry about the lack of trust. People who are ill need to be able to trust their medical advisers, but that trust is not bestowed with a higher degree; if it has been abused it will need to be earned again.

The NZMA Code of Ethics [11] assumes that people trust doctors “In return for the trust patients and the community place in doctors, ethical codes are produced to guide the profession and protect patients.” Consequently there is no focus on how trust might be developed or maintained.

Cultural differences with trust

How we reach a decision to trust another person varies a great deal between individuals and between cultural groups. Some would build their trust around their religious faith and find it easy to trust a person who shared their faith and much harder to trust a person from another religious tradition. Others are rationalists; they make their decision predominantly on the information available. An important distinction is the difference between more individualistic societies (as defined by Hofstede [15]) and more collectivist societies such as, for example, New Zealand Māori. This is nicely illustrated by Māori tradition.

Māori have deeply held traditions around how ‘hui’ (meetings) should be conducted. Whilst this is most clearly expressed on the ‘marae’ (Māori traditional meeting house and grounds), the way of living implicit in these traditions flows over into all walks of life for Māori. In his book looking at the dynamics of Māori Health, Durie [33] devoted a full chapter based around these traditions to try to elucidate Maori psychology.

Seldom however is there full appreciation of the potential of marae encounters for shaping thinking and behaviour and providing guidelines for codes of living.

The Marae ātea(courtyard) is used as a stage for clarifying the terms under which parties agree to come together. Formal debate (whaikōrero) a hallmark of encounters on the marae ātea is essentially about the negotiation of relationships.

Lacey et al. [34] have responded to Durie’s view that marae encounters can provide guidelines for codes of living by developing the “Hui Process” as a framework for clinical encounters with Māori patients. One of the four elements of this process following the initial greeting is “*Whakawhanaungatanga*” (noun- process of establishing relationships, relating well to others.) [35] Literally it is the process of becoming family. The detail that Lacey et al. [34] provide makes it clear that this maps very closely to establishing emotional trust. Only after this has been achieved can you proceed to *Kaupapa* (the business of the encounter).

The moral philosopher Annette Baier [36] suggested that ‘trust is appropriately placed in those who for whatever motives, welcome the equalisation of power, who assist the less powerful and renounce eminence of power.’

The corollary of this view is that any attempt at coercing the parents into immunising their child is likely to undermine trust. Conversely an approach that deliberately avoids any suggestion of coercion: by listening closely to their concerns, respecting their right to choose, by presenting information as my opinion rather than the truth, and by avoiding trying to pressure them into a decision, is more likely to enhance trust.

In the case study I did not have an existing relationship with the family. They did have a relationship with our service as registered patients, and had developed some trust in the service. Trust develops over time. Had they not agreed to immunisation at that consultation there remains the possibility that they might agree at some later time.

Conclusion

We live in a diverse community. It is likely that there will be more situations where there is disagreement between doctor and patient. This could stem from a disagreement of values (I do not believe in abortion so there is no point screening for Downs’ syndrome), or from not trusting the doctor prescribing a course of action. Whilst bioethical analysis is essential for the clinician to reach their own conclusions as to what to recommend, this is of little help if they have failed to get a good history from the patient of the detail of the problem. It provides little help if the patient disagrees with your conclusion. In the end it is the patient’s journey; they will do what they think is right. It is our job to accompany them along their journey and help them to avoid pitfalls that we are able to see.

I have argued that an approach that accepts and respects diversity and focusses on developing a trusting relationship is the most effective way to reach the best available resolution for clinical ethical dilemmas.

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