Bioethics: A balancing of concerns in context

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Abstract

Ethics is a philosophical approach which is increasingly being used to identify acceptable behaviour in a health context. Bioethics has emerged as a term for ethics in health and medical contexts. Bioethics is about the application of reasoning to a health context. It relies on the people in each context to reflect on ethics concerns, and to make acceptable decisions on how to behave. This paper canvasses current concerns in bioethics, and demonstrates the essential features of context, and players in the context, in ethical discussion.

Introduction

Ethics is a philosophical approach which is increasingly being used to identify acceptable behaviour in a health context. Bioethics has emerged as a term for ethics in health and medical contexts. Bioethics is about the application of reasoning to a health context. It relies on the people in each context to reflect on ethics concerns, and to make acceptable decisions on how to behave.

Ethical conduct can be thought of as being composed of two key elements: principles of conduct and judgements of value of those principles by relevant groups. Finding the 'right' answer to a dilemma involves considering the crucial principles, the issues expressed in shorthand by those principles, the context of the dilemma and key groups' preferences for action. This approach highlights the importance of interdisciplinary discussion on ethics standards and is consistent with the increasing consultation with communities on ethics standards (Berglund 1994).

The principles

The four principles espoused by Tom Beauchamp and James Childress in their book *Principles of Biomedical Ethics* have gained the most support as fundamental ethical principles (Beauchamp & Childress 1994). The principles are beneficence, non-maleficence, autonomy and justice.

Beneficence encompasses the obligation to do good and non-maleficence, the obligation to do no harm. These principles are central to the health caring professions, which aim to better the health of their patients or communities.

This obligation can be taken to different extremes, and each person has his or her own comfortable limits for caring. Some people would go wherever people need help, whenever, like those who place themselves in the front line at war, or who live in extreme conditions of deprivation. Some health professionals make themselves available for crisis counselling, or night shift, or for services at remote locations. Depending on how individuals define their duty to do good, their actions can be seen as simply fulfilling their obligations, or as a sacrifice. Those who shirk normal duties in a routine situation may be judged not to have taken their health care obligations, their obligations to beneficence, seriously.

Autonomy, as the name suggests, is the principle of self-rule, that is, of patients' self-rule. There is considerable philosophical support for autonomy, from both of the ethical frameworks of deontology and utilitarianism, From either Immanuel Kant or JS Mill, a person is thought to be best placed to choose what is best for them (Sullivan 1989; Mill 1975). Autonomy is then based on the assumption that people will act in their own best interests and, indirectly, is an expression of beneficence.

When people express their wishes, this expression generates an obligation to respect their autonomy, or to have good reason for not doing so. Each person has a different threshold for allowing autonomy. That can be demonstrated quite easily in a group situation, by asking people to pose each other a question. Each can ask the other what they would wish for if they could wish for anything. When they have heard what their partner would wish for, they consider their obligations. If the person had trouble thinking of something, or was reluctant to tell a wish, should they be 'helped' if their autonomy is to be respected, or is remaining silent an expression of autonomy? Ultimately, once a wish is heard, is there an obligation to make sure their wish comes true? There are interesting ethical differences in how far to promote autonomy, and how actively health care workers should seek and carry out expressions of will. This debate is current in relation to euthanasia (Baume 1995).

Justice is the principle of fair and equitable resource distribution. The resources which are distributed are philosophically the 'goods', like health, or happiness. These goods are delivered by health services. Justice models are available to help decide how to distribute a good when the good is limited. Justice as fairness, comparative justice and distributive justice are the three standard models which are evident in health care at different levels. Under justice as fairness, once something is decided as fair, for instance, access to health care to ensure health, all people are entitled equally to that fair distribution. On the other hand, under comparative and distributive justice, we may decide to apportion that fair thing – access to health care – unequal ways either between or within specific groups of people. It is these forms of justice which highlight the political and social contexts of ethics. The different distribution could be based on underlying conditions, stage of disease, wealth, power, age, gender or any other social difference.

Another group example illustrates the differences. After establishing who drives a car, and how many cars are held by a group, each group member can be asked if they would give their car to someone who doesn't have one. If having a car is fair, under justice as fairness, one could argue that everyone has an equal entitlement to the car. It is a resource in the community, and one person happens to have use of that resource at the moment, but others may be waiting to use it too. In a comparative model, one might consider how much each person needs a car, and the ones who need the car most would get it, at least first. Under the distributive justice model, it may depend on how much each person deserves the car, whether they can earn it in some way – like paying money for it.

There are serious decisions to be made in deciding how strictly to apply each principle, and how to resolve dilemmas which reflect a conflict between them. Increasingly, parties are meeting to discuss their concerns. Health professionals meet with others to discuss their commitment to their concept of caring, of doing good, and to discuss their commitment to client autonomy. Communities and professionals meet to decide funding priorities. Governments are elected on platforms for the distribution of health resources. The principles are useful in these discussions. At their best, the principles are a shorthand means for referring to a considerable body of thought and literature about ethics. They throw the net for considering solutions to ethical dilemmas wide around health care and community contexts. At worst, the principles are a prescriptive and narrow decision-binding tool.

There has been considerable academic discussion recently about the worth of these principles, and about the value of applying the principles to solve dilemmas. Many of those teaching ethics to health students are relying less on the principles

and more on basic philosophical texts. However, the principles can be retained, but not taught prescriptively. They can be taught as a tool, and students can make use of them if they wish; to collect and summarise issues which are of concern to the patients, to the health professions or to the community at large.

The principles are not expected to be part of the common parlance of anyone, except ethicists. But the issues that they represent and the situations to which they are applied can be expressed by all people: old or young, trained or untrained. A community survey of population views on health research found that concerns that are consistent with the principles of caring and doing no harm and autonomy can be expressed (Berglund 1994). And, increasingly, professionals are learning ethics terms in the course of their training and are expressing ethics concerns in the language of ethicists. Whatever the choice of language, it is the issues which are summarised by the ethics principles, not the principles themselves, which should have prominence in ethical discussion and ethical analysis. A presentation and discussion of the principles which are compatible with this belief are found in Raanon Gillon's recent text, *Principles of Health Care Ethics* (Gillon 1994).

The recent dissatisfaction with the principles may be that they don't necessarily provide an answer in themselves. They do not collectively form a framework. To apply them meaningfully we need to take responsibility, we might need to make decisions about whether we are more or less utilitarians or deontologists – whether we consider the outcome for the majority in the main, or the process for the individual. These are difficult philosophical decisions, and ones which are not solved by thinking of more and more crucial issues under the shorthand of the principles of beneficence, non-maleficence, autonomy and justice. Yet, the lack of consistent ready answers can be seen as a strength of the ethics principles. The reality is that ethics is dynamic. Times change. People change. Medical problems and health issues change. Social contexts change. The principles will continue to be useful tools precisely because they do not lay down strict rules to be applied whatever the situation, culture, patient or professional involved.

It is open to communities or professionals to choose to focus on outcomes, under a utilitarian framework, or to focus on process, under a deontological framework. It is open to them also to emphasise particular principles. The emphasis of principles has been the focus and has tested commitment to each principle. This dynamic debate is played out in public forums as well as in academic and health forums, as is evident in the now frequent media discussion of ethics (as above, Baume 1995; and below, Larriera 1995).

Concerns in context

Commentators and philosophers document increasing and decreasing reliance on particular principles. There has been a long-running debate between Beauchamp and Pellegrino, for instance, over the primacy of beneficence and autonomy (Beauchamp 1990). Pellegrino argues that beneficence as promoted by health professionals forms the outside limit of allowable autonomy, at least that autonomy perpetuated by health professionals. Others argue that the autonomy in itself can justify patient or consumer action or inaction. Beauchamp describes the principles as on a par, and philosophers such as Australia's own Max Charlesworth place particular value on patient choice, both in terms of long-term and short-term lifestyle and use of their own body (Charlesworth 1993).

The drug regulation overhaul and subsequent roller-coaster since the Baume Report, *A Question of Balance*, was published in 1991 (Baume 1991) are a good example of the shifting debate on autonomy and beneficence. In short, there is a recognised place for personal choices when no proven drugs are available, and drugs and drug trials can be fast-tracked to allow that choice. But there is an underlying limit to the amount of risk that people may ever choose to expose themselves to and, increasingly, there is a recognised limit of resources which can be committed to trying unproven treatments. Each proposal for increased patient participation and choice in drug trials is debated on the grounds of appropriate choice, and appropriate risk.

The leaning towards autonomy has been carried to extremes with the current consideration of allowing people without the power to consent, such as people with intellectual disabilities or dementia, to take part in drug trials (Larriera 1995). The argument is that they as a group shouldn't miss out on possible benefits simply by virtue of their condition. The danger of course is that taking part in a drug trial may not turn out to be in a person's best interest. If a person does not have the capacity to choose, and/or the treatment is not in their best interests in the end, there is an ethical problem on both scores: beneficence and autonomy.

This dilemma is not peculiar to drug trials, but is part of all research on human participants, which is why the *National Health and Medical Research Council Statement on Human Experimentation and Supplementary Notes* (1992) discusses acceptable risk, and emphasises informed consent. The dilemma is of balancing risks with likely benefits, and of allowing appropriate individual choice to take part or not in a process which, by definition, is not guaranteed to be successful for each research subject. Baume's own chosen title, *A Question of Balance*, reflects the balance which is continually a source of tension in drug regulation: a balance

between autonomy and professional obligations of caring and doing no harm, and increasingly of autonomy and justice, of allowing choice, but ensuring the maximum good is achieved with limited resources. To AIDS groups, for instance, more risk might be acceptable. To health professionals, a conservative risk could be preferable. To those charged with looking after others with dementia, they might be caught between protecting the individuals from harm, but also not precluding them from possibly beneficial treatments which might halt deterioration or restore some functioning. If our society had virtually limitless funds, or if our society trusted entirely that individuals could choose their own best path in medical treatment, no doubt the achieved balance of personal choice for radical drug proposals would be quite different.

Our cultural context is crucial in striking an acceptable balance between beneficence and autonomy. In some cultures, doctors and health professionals simply do the best they can for the patient, and the patient makes very few real decisions about their own care. In some cultures, informed consent is a fiction. It is not that people are intentionally trying to limit autonomy, or cause harm to patients, but simply that they do not think full information and choice will be most beneficial for the patient. At a time of great vulnerability, health professionals want most to care for the patient; to take the burden of decision-making so that the patient can feel secure and gather their own resources for recovery. In situations of terminal illness in some cultures, professionals routinely do not disclose the prognosis, or even diagnosis, to the patient (Brahams 1989). They may instead inform the family so that they can ensure a social context of comfort for the patient. That we, in western health care, find lack of information and choice for the patient unsatisfactory, is a product of a preference for liberty. But we would do well to remember that it was not all that long ago that patients in our culture were not told of their diagnosis of cancer at all; and even now, we can take a fairly long-winded process of preparing the patient before disclosing the diagnosis.

The difference is not a lesser commitment to care by professionals, but rather a different emphasis on autonomy, and a different expression of caring. Our own emphasis on autonomy does, though, challenge our commitment to beneficence and non-maleficence. We must continually decide whether allowing and promoting autonomy is resulting in harm to a patient. If it is, we must decide whether as health professionals we can collude in facilitation of harm. We must decide whether allowing and promoting autonomy is in itself a good, along the lines of libertarians, or whether the good is something more derived, like health.

These concerns and the debate around the principles in context result in a similar list of concerns to those set out in the alternative ethics analysis model by Jonsen,

Siegler and Winslade (1992). Their four 'boxes' for consideration of ethics concerns are medical indication, patient preferences, quality of life and contextual issues. The crucial agreement between the principles and the alternative Jonsen et al. model is that concerns are placed in context.

The context of health care and the conditions which are being prevented or treated are also crucial to understanding the ethics of health care actions. A group exercise is useful to demonstrate how contextual evidence can be marshalled to support different ethical decisions (Berglund 1995). It is an exercise on needle stick injury, and the decision whether or not to conduct mandatory tests for HIV. Four groups are each assigned the task of putting a case for testing patients, or for testing professionals, or not testing patients, or professionals. As background, one can read a little JS Mill on the acceptable limiting of autonomy. A professional expression of needle stick risk brings the dilemma to life, although that prompt is rarely needed for working health professionals, who now live and work in the age of AIDS. This exercise is relevant for all health professionals: cleaners, to nurses, social workers to doctors and more, who are all involved in health care at or near the bedside.

This exercise demonstrates how ethics cannot give definitive answers removed from the health care context. A knowledge of risk of transmission and of gravity of the disease is needed. A knowledge of the practical impact of promoting or limiting autonomy in our health care context is needed. And a knowledge of the society's leanings for autonomy or for protection is crucial in making a final decision whether or not to impose testing. A shift in any of these factors would necessitate a re-examination of the ethical decision.

Re-examination of concerns and context

Re-examination is perhaps the one consistent theme in ethics. In Australia, we continue to reflect on informed consent, as the recent process of formulating National Health and Medical Research guidelines for informed consent shows (National Health and Medical Research Council 1993). Rather than creating new standards, those guidelines reflect and articulate current standards. In the words of Loane Skene, the guidelines:

> *acknowledge that patients are entitled to make their own decisions and that, in order to do so, they must have enough information about their condition, options for investigation and treatment, benefits of treatment, possible adverse effects of investigations or treatment, the likely results if treatment is not undertaken, and time and cost of treatment* (Skene 1993).

These levels of involvement in care decisions have been all the more poignant for health professionals with the decision of Rogers v Whitaker, at High Court level, in which the surgeon Mr Rogers was found to have breached his duty of care by not providing information of the remote risk of sympathetic opthalmia to Mrs Whitaker before operating on one of her eyes (Commonwealth Law Reports 1992). Mrs Whitaker sustained sympathetic opthalmia and as a result was almost blind. The providing of full information, and specifically information which seemed most relevant to Mrs Whitaker, would have allowed her to make the decision to have the operation or not, keeping her own concerns and best interest uppermost. As was found in court, she did not have all the relevant information available to her (Pincus 1993).

The court, as an expression of the community standard which is expected, emphasised autonomy to a far higher level than was expected by health professionals. No longer is normal professional practice an acceptable level. Each professional in each situation must ask themselves: What further information seems to be relevant to this client or this patient? What further information is this patient asking for? Deciding this may be difficult, particularly as clients or patients do not use the same language as trained professionals. They may not use the language of ethicists to say they want to maximise their autonomy. They may not use the language of health care workers to express their concerns. Even a hint of concern, or questioning in an indirect way, is now enough for professionals to give more information. So, our culture reserves the right to change ethics standards and health care expectations. It is perhaps not surprising that this judgment was handed down more than 10 years after patients were consistently renamed *consumers* and have been consistently encouraged to become progressively more active in their own health care and health care decisions.

We have grown used to looking back on the early days of health care as beneficent and paternalistic. We will look back on the 1980s as the decade of autonomy. The 1990s is turning out to be more tempered. Beneficence is increasingly limiting available patient choices, as the health care professions and the surrounding regulatory system impose limits to wishes they are comfortable with and able to grant. In a context of fragile resource systems, and fluctuating financial states, it may be that concerns of justice will lead us into the next century.

Ethics today not only tests the principles each of us holds dear, but also tests the principles which philosophically help us to choose our actions and understand the behaviour of others. It is a testing time for ethics; a time which hopefully will move health professionals and their clients forward towards critical self-reflection of their thoughts and actions, and constructive appraisal of the actions of others.

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