Ethically defensible decision-making in health care: challenges to traditional practice

Dr Susan Bailey

Susan Bailey is Senior Lecturer, Partnership Co-ordinator at Deakin University and the Department of Human Services (Barwon – South Western Region), Victoria.

Abstract

The concept of paternalism is deeply entrenched in health care. Decision-making about health care can be extremely difficult at times, and many competing interests may influence the outcomes. However, ethically defensible practice aligns itself with acknowledging the patient's prima facie right to be treated as an autonomous individual. This includes the patient's right to make informed decisions or to decide that other(s), such as the close family, should make decisions on his or her behalf.

Decision-making in health care

Decision-making about health care is often fraught with difficulty. The difficulties and challenges relate to the nature of such decision-making, particularly where uncertainty exists about the efficacy of treatment.

Traditionally in medical practice, a paternalistic approach has been taken in decision-making, where the burden of decision-making has fallen on the physician. At times there may be little, if any, input from the patient him or herself or the family of the patient. Often, too, other healthcare professionals do not participate in the decision-making process.

For those patients who are critically ill, and in such cases where the burdens or benefits of treatment may be considered equivocal, the stakes of decision-making are high. Decisions in this context may potentially result either in the continued life of the patient or in the ultimate death of the patient. Is it optimal, then, in such situations, and indeed in less critical situations, that patients may be denied participation in decision-making about their treatment? It is argued in this paper that the ethical principle of autonomy should hold greater importance than the tradition of paternalism in decision making in medical practice and, therefore, that wherever possible patients ought to be afforded at least the opportunity to make an informed decision on their own behalf.

The development of healthcare technologies that allow seriously ill persons the possibility of recovery where once there was no hope has brought with it some important ethical considerations. Patient autonomy is one of these considerations of relevance to clinicians. Physicians who make unilateral decisions about the provision or withholding of treatment for individual patients might believe they are acting in accordance with one of the primary goals of health care, that is, the maximisation of the patient's well-being. However, the realisation of this goal requires that the self-determination of the patient be respected.

Self-determination (or personal autonomy) is important because of its instrumental value in allowing individuals to subjectively define well-being (President's Commission 1983). That is, it allows us to define, on an individual level, personally meaningful well-being or quality of life. It also has intrinsic value as an element

of personal worth and integrity, meaning that the state of being autonomous is valued of and for itself. Therefore, by respecting another person's self-determination we are as a consequence, other things being equal, enhancing that person's well-being.

The importance of autonomy

The term 'autonomy' is derived from the Greek terms *autos* (self) and *nomos* (law or rule), and the notions of independence, self-rule and self-determination recur in explications of 'autonomy'. Dispositional autonomy means that an individual chooses and acts freely and rationally out of his or her own life plan. Such a life plan may be shaped or influenced by society and history, and the object of the life plan is not limited to the individual him or herself, but may include certain principles and values that affect others (Childress 1982). That is, as an autonomous individual, a patient may be persuaded or pressured by his or her physician regarding a certain course of action, but the final decision must be his or hers alone. This understanding of autonomy is often referred to as 'dispositional' autonomy because it relates to the values and beliefs, hence personal dispositions, of an individual that affect the individual's life plan. Conversely, occurrent autonomy, or 'autonomy of the moment', reflects an experiential choice that has nothing to do with an individual's life plan.

Autonomy is 'instrumentally' valuable because it allows one to achieve subjectively defined well-being. Jeremy Bentham (1962) and John Stuart Mill (1975; Rosen 1987) have been attributed with valuing autonomy in an instrumental sense, underpinned by their respective utilitarian viewpoints. The classic utilitarian tradition claims that the value of autonomy lies in the utility of the goods that it makes possible. In addition, and most importantly, autonomy is 'intrinsically' valuable as an element of personal worth and integrity, or, as Robert Young (1986) states, autonomy is part of the moral basis of personhood.

The intrinsic value of autonomy is related to self-esteem and to living an authentic life. Specifically, self-esteem will be enhanced when individuals are able to shape their own lives in ways considered personally worthwhile, and will be demeaned when restrictions are placed on such activity. Self-esteem describes our sense of self-worth and self-respect – the possession of high self-esteem implies that one considers that one's life is worthwhile and of personal value. Conversely, lack of self-esteem is often described as one of the factors implicated in suicide (Hassan 1995). To live an authentic life is to live a life that is in accordance with one's true and genuine life plan.

The intrinsic value of autonomy is related to the way in which we desire to be self-determining (or autonomous) for its own sake, rather than because of any associated consequences. It can be seen that autonomy is similar to other intrinsic values, such as friendship and love – values that are pleasurable for their own sake. We do not tend to cultivate friendship (at least not true friendship) with ulterior motives in mind – we become a friend with someone because being a friend is pleasurable or valuable in its own right. It is apparent that autonomy has a similar intrinsic character to that of friendship. We gain satisfaction from the state of being autonomous because it provides us with the freedom, or opportunity, to make what we will of our own lives. Being autonomous is part of what it is to be a competent adult individual.

Paternalism in health care

When autonomy is restricted in some way in order to prevent an individual adversely affecting his or her own interests, such restriction may be referred to as being paternalistic. Paternalism refers to the restriction of an individual's autonomy in some way. Paternalism is generally thought of as coercive or forcible interference with a person's liberty of action, justified on the grounds that it will prevent harm to the individual's interests. Therefore, there are two central values at stake that must be balanced or traded off – one value is the individual's autonomy, and the other value is the perceived well-being of the individual. These values may be perceived to be in conflict at times when an individual decides upon action that does not appear to be in his or her interests (Brock 1988).

Paternalism is often conceptually considered to be of either a 'weak' kind or a 'strong' kind, and arguments for or against tend to be focused specifically on either type. Strong paternalism is defined as intervention to protect or benefit a person, despite that person's voluntary and informed denial of or consent to the paternalistic

measures proposed. An example of strong paternalism would be where cardiac resuscitation is commenced by a healthcare professional based on his or her judgement that it is in the best interests of the patient to be resuscitated, despite the patient previously requesting – when competent and fully informed – that no such intervention be undertaken. Generally, strong paternalism cannot be morally justified. Objections to strong paternalism include that it commits one to having to enforce morality, and that it violates the principle of respect for a person's voluntary choice (Feinberg 1971).

In contrast, weak paternalism is defined as interference to protect or benefit a person where there is considered to be some defect in the decision-making capacities of the person; for example, where it is considered that the person is incompetent to make such a decision (Young 1986). Therefore, weak paternalism can be justified only when the patient is unable to make an autonomous decision because in such circumstances it protects the dispositional autonomy and future opportunities available to the individual that would otherwise be denied. More simply, it protects the overall well-being of the individual (Van De Veer 1986). Weak paternalism, by definition, does not violate dispositional autonomy. A further justification of weak paternalism is found via the notion of consent – if a particular intervention would be consented to by the individual were his or her decision-making capacities restored, then weak paternalism would normally be considered justifiable (Young 1986). For the most part, however, it is strong paternalism that is of concern in relation to clinical decision-making about health care.

Contemporaneous decision-making practices in health care

Many factors constrain decision-making in clinical practice. The medical need of the patient will, most obviously, fundamentally influence treatment options. In many situations, decision-making is non-controversial and straightforward, particularly where it is clear that the patient will benefit from the imposition of a particular treatment. However, in other situations, where it is unclear whether the burden imposed by treatment regimes will outweigh any possible or conceivable benefit, decision-making becomes more difficult. When this is the case, other factors will be more likely to influence the decision. Resource allocation concerns, for example, may have an important impact on whether or not to admit a particular individual into hospital.

Contemporary decision-making practices continue to be influenced by the traditional paternalistic medical model. Physicians have in the past been, and perhaps continue to be, more concerned with benevolence than with respecting the patient's autonomy, with acting in what they construe to be the best interests of the patient, and the best interests of others (including the hospital and society at large) whether or not the patient him or herself recognises those interests (Zussman 1992). This type of attitude towards patient care continues to prevail because society has, by default, invested doctors with the authority to make decisions regarding the provision of medical care.

Therefore, although individual patients may assume that their doctor will make a decision about treatment based on their best interests, the doctor will often, in fact, attempt to weigh up the patient's best interests with the economic interests of the hospital. Although it is ethically untenable to expect doctors to deal with such competing interests (Weinstein 2000), they none-the-less do face this situation frequently in Australian hospitals. Indeed, some doctors argue that their role has expanded, and that they consider themselves to be, at the same time, ethicist, economist and medical practitioner (Scheinkestel 1996). It is difficult to understand just how these demands can be reconciled and justified in a way that is ethically defensible.

In line with this perception of having to juggle competing interests, it is evident that the preferences of the patient him or herself may be given low priority in decision-making processes. It is common in current practice to exclude the patient or close family from the decision-making process, possibly because their inclusion may be seen to be burdensome (for the family), time intensive or perhaps troublesome. Some doctors never seek permission for treatment from close family, but rather seek 'concurrence' from the family about a particular medical plan (Fisher & Raper 1990).

The role of family in decision-making

Although at times individuals may not be able to exercise self-determination due to an impaired state of consciousness, the best interests principle of decision-making allows for the patient's close relatives to participate in decision-making processes by providing evidence about the patient's beliefs and desires for health care. The best interests principle is a guiding principle for decision-making in health care and is defined as acting to promote, as much as is possible, the good of the individual (Buchanan & Brock 1986).

As a minimum requirement, the close family of the patient ought to participate in making decisions on behalf of the patient, with the necessary support and guidance from health care professionals. Ideally, the close family of the patient ought to be ultimately responsible for making the necessary decisions on behalf of the patient about health care. Despite some potential problems associated with family decision-making, it remains the case that the patient's family is best placed to be aware of the patient's important values and beliefs that will help to inform the decision that must be made. Those people who care deeply for the patient are more likely than others to want what is best for the patient. Those people who are close to the patient will be most knowledgeable about exactly what the patient would want if he or she were able to make a decision (Hardwig 1993). In addition, many people prefer that their family make decisions on their behalf, rather than strangers (High 1988; Sprung 1996). Inclusion of close family in decision-making is the best means of supporting and respecting each individual patient's interest in self-determination.

Conclusion

The concept of paternalism in health care is deeply entrenched and rarely questioned by either medical practitioners or patients. Indeed, many patients rely on their doctor to make decisions on their behalf in order to avoid the stress often associated with the decision-making process. However, ethically defensible practice aligns itself with acknowledging the patient's prima facie right to be treated as an autonomous individual. This includes the patient's right to make an informed decision or to decide that other(s) should make the decision on his or her behalf.

Personal autonomy allows us to define personally meaningful well-being or quality of life. Furthermore, the state of being autonomous is valued of and for itself because it has intrinsic value as an element of personal worth and integrity. Therefore, the well-being of individual patients may be enhanced if we act to respect their right to self-determination by including them in decision-making processes related to health care. At times, it will be impossible for the patient to participate due to incompetence, but in these situations the close family members of the patient ought to be included because they are best able to provide information about the patient's desires and preferences in relation to health care.

Paternalism can be justified when it is compatible with respecting the individual's autonomy and the right of competent persons to direct their own lives (Young 1986; Feinberg 1986). This belief is in accord with the view that the dispositional sense of autonomy is central to a person's conception of his or her life, and must be preserved in order to maintain and promote self-esteem and personal fulfilment over the course of one's lifetime. Paternalistic interventions, therefore, should be 'instruments of last resort' (Young 1986).

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