Medical decision making: paternalism versus patient-centered (autonomous) care

Carlos A. Rodriguez-Osorio and Guillermo Dominguez-Cherit

Department of Critical Care Medicine, Instituto Nacional de Ciencias Medicas y Nutricion Salvador Zubiran, Mexico City, Mexico

Correspondence to Guillermo Dominguez-Cherit, MD, Department of Critical Care Medicine, Instituto Nacional de Ciencias Medicas y Nutricion Salvador Zubiran, Vasco de Quiroga No. 15, Tlalpan, C.P. 14000 Distrito Federal, Mexico
Tel: +52 55 5487 0900 x5020; fax: +52 55 5655 2510; e-mail: guidom@prodigy.net.mx

Current Opinion in Critical Care 2008, 14:708–713

Purpose of review
Medical literature has increasingly emphasized the need to observe patients' autonomy; however, not all experts agree with this principle. This discord is based on varying credence between the concepts of autonomy and beneficence. In critically ill patients, this conflict involves the patient's family and creates a particular family–physician relationship. The purpose of this review is to assess the evidence on medical decision making and the family–physician relationship.

Recent findings
The many studies published on this topic reveal that people's preferences around the medical decision-making process vary substantially. Although it is clear that a shared decision approach is popular and desirable to some, it is not universally favored; some patients prefer to leave final treatment decisions up to the doctor. This finding shows a robust moral pluralism, which requires special attention in multicultural societies. For critically ill patients, the diversity of opinion extends to the family, which creates a complex family–physician dynamic and necessitates utilization of particular interaction strategies.

Summary
Clinicians must understand the range of preferences in a society and should offer the opportunity to participate in treatment by sharing decision-making responsibility. This would involve assessing the preferences of patients and their families in order to provide care accordingly. Clinicians should then ensure proper information is provided for informed decision making and minimize factors that could have potential adverse effect.

Keywords
autonomy, family-centered care, medical decision making, paternalism, patient-centered care, relational autonomy

Curr Opin Crit Care 14:708–713

1070-5295

Introduction

A review of the last decades in the history of medicine, healthcare, and biotechnology identifies both longstanding zones of ethical conflict and areas of relatively stable social norms. Beauchamp and Childress [1] make empirical claims about the universality of common morality; however, contemporary liberal democracies are multicultural, multireligious, and pluralistic societies. In this view, there is a crucial difference between making normative claims about how humans ought to act and making transhistorical, cross-cultural claims about the empirical status of particular moral practices. In this article, we review some recent publications about patient and physician perceptions around medical decision making and the role of the family in the patient's autonomy. Finally, we propose a practical approach for medical decision making in critical-care units.

Autonomy

The word autonomy comes from the Greek autos (self) and nomos (rule, governance, or law) and was first used to refer to self-government or self-rule. Although it originally applied to society, it has become a term that is used to refer to individuals and is found in moral, political, and bioethical philosophy. Beauchamp and Childress [1] describe it as the 'personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice, such as inadequate understanding.' In a medical context, respect for a patient's autonomy is considered a fundamental ethical principle, and this belief is the central premise of the concept of informed consent. In addition, some studies have shown that the ability and opportunity to exercise autonomy improves physical and psychological health and is generally a component of a good quality of life [2].

DOI:10.1097/MCC.0b013e328315a611

A patient's freedom to decide can be impinged upon by internal factors arising from the patient's condition or by external factors. Internal factors are those that affect the ability of the patient to make decisions. For example, a patient with metastatic prostate cancer must decide about noninvasive mechanical ventilation while suffering severe bone pain. In this case, the pain functions as an internal factor and must be controlled as much as possible to assist the patient in the decision-making process. External factors, which are the focus of this review, include the ability of others to exert control over a patient by force, coercion, or manipulation. Force involves the use of physical restraint or sedation to enable a treatment to be given. Coercion involves the use of explicit or implicit threats to ensure that a treatment is accepted. Manipulation involves a deliberate distortion or omission of information in an attempt to induce the patient to accept a treatment or make a certain decision [3]. To avoid coercion and manipulation, the physician must provide accurate and relevant information. This is a significant issue, as informed patients are empowered to make decisions affecting their lives as a whole that they could not have made had they been unaware of the true nature of their condition.

Autonomy requires an appropriate relationship between patient (or family) and physician. Charles *et al.* [4] provided useful suggestions for developing a framework for the analysis of treatment-related decision making and proposed three analytical approaches: the paternalistic approach, characterized by physician control; the informed approach, also called consumerism, characterized by division of labor and preservation of patient autonomy; and the shared approach, characterized by simultaneous interaction between both the patient and physician in all stages of the decision-making process. Some studies have shown that most patients, especially in the United States, want to be completely informed about their medical situation and prefer the shared decision-making approach [5••,6,7]. However, other studies suggest that 10–20% of all patients do not want to know the details of their condition [8], and 9–17% prefer to leave decisions to their family or their physicians [5••,9]. Complete knowledge regarding one's medical condition can have negative consequences. For example, one study found that providing cancer patients with more detailed information resulted in higher anxiety levels [9], which could adversely influence medical care decisions. However, poor disclosure is typically done too hurriedly, in the wrong setting, without appreciation of the patient's circumstances and without addressing the patient's real needs and fears. For this reason, physicians should start from the assumption that all patients are able to cope with the facts and reserve nondisclosure for the less usual cases for which more harm will result from telling the truth than from not telling it. Truth should be offered, but not forced, and how and when to discuss the patient's situation should be carefully evaluated. The proper amount of information to disclose at any one time varies from patient to patient. Concerns regarding purportedly very bad outcomes of disclosure, including loss of hope, premature death, or suicide, are anecdotal and lack any real empirical foundation [10].

Despite the espoused importance of patient autonomy, there are some limitations. Beauchamp and Childress [1] have suggested four principles that may limit autonomy: the harm principle, the principle of paternalism, the principle of legal moralism, and the welfare principle. However, according to some experts, only the principle of harm would be an appropriate situation in which to consider restrictions of autonomy. According to this principle, we should restrict the freedom of those whose expressions of autonomy would result in harm to another individual. This brings to light the concept of paternalism [1,11••], which will be discussed later. Physician's beliefs are another difficulty to overcome in the context of patient autonomy. One study in the setting of critical-care medicine found that 23% of 879 American physicians had withdrawn therapy without the patient's or family's consent, 12% without their knowledge, and 3% despite their objections [12]. Therefore, it seems that although autonomy is a sought-after value, it is both hard to attain and difficult to respect.

Paternalism

Clinicians are often faced with an inherent tension between their desire to respect and foster patient autonomy and their responsibility to act in a patient's best interest (which some might call paternalism). 'Paternalism' comes from the Latin pater, meaning to act like a father, or to treat another person like a child. Beauchamp and Childress [1] wrote: 'Paternalism, then, is the intentional overriding of one person's known preferences or actions by another person, where the person who overrides, justifies the action by the goal of benefiting or avoiding harm to the person whose preferences or actions are overridden.'

Paternalism can be divided into hard and soft, broad and narrow, pure and impure, moral and welfare, and active and passive [13]. This discussion is limited to hard, soft, active, and passive paternalism. Soft, or weak, paternalism is a philosophy that believes the physician or the state can help you make the choices you would make for yourself, if only you had the strength of will and the sharpness of mind. A weak paternalist believes that it is legitimate to interfere with the means that agents choose to achieve their ends, if those means are likely to defeat those ends. But unlike hard paternalists, who ban some things and mandate others, the softer kind aims only to skew your decisions, without infringing greatly on your freedom of choice. Conversely, a hard, or strong, paternalist believes that people may be mistaken or confused about their ends and that it is legitimate to interfere to prevent them from achieving those ends. This kind of paternalism involves an individual who refuses to accept another's autonomous decision in actions or choices [13]. On the contrary, a paternalistic view may involve active or passive nonacquiescence to the patient's choices. In active nonacquiescence, the paternalist refuses to accept a patient's request for nonintervention or noninterference, whereas, in passive nonacquiescence, a paternalist refuses to carry out the wishes or choices of a patient or to assist the patient in his or her action. It is easier, *ceteris paribus*, to justify passive paternalism than active paternalism, because passive paternalism confirms the professional's autonomy, affirming they are not an instrument of their patients' wishes, and because passive paternalism leaves the patient with other options [14].

In most cases, the antipaternalist rejects any form of paternalism. However, some antipaternalists do not reject weak paternalism. Paternalism can be justified if it provides great benefit or prevents major problems while disrespecting autonomy only slightly. According to Beauchamp and Childress [1], we should accept paternalism as a benefit for the patient only in certain situations, when the patient is at risk of a significant, preventable harm; the paternalistic action will probably prevent the harm; the projected benefits to the patient of the paternalistic action outweigh the risks to the patient; and the least autonomy-restricting alternative that will secure the benefits and reduce the risks is adopted.

Despite the fact that patient involvement in treatment-related decision making has been widely advocated and promoted in both clinical and policy-making settings, research conducted in developed and in developing countries revealed that people's preferences regarding their role in the decision-making process vary substantially [4,5••,15]. Recently, a large cross-sectional survey [5••] conducted among the American public using computer-assisted telephone interviewing found that 62% of respondents preferred shared decision making, 28% informed approach, and 9% paternalism. In another population-based survey of a representative sample of English-speaking adults conducted in conjunction with the General Social Survey in United States, nearly all respondents (96%) reported they preferred to be offered choices and to be asked their opinions. However, this was not for all situations; half of the respondents (52%) preferred to leave final decisions to their physicians and 44% preferred to rely on physicians for medical knowledge rather than seeking out information themselves [15]. These examples suggest that a collaborative model of decision making is popular and may be desirable, but that it is not held universally by the public. As noted, some respondents preferred to rely on physicians for information about their condition and others preferred to leave final treatment decisions up to the doctor. This finding could vary based on the severity of the situation, that is, when the situation involves potential mortality or when the respondents' health status is deteriorating [16•]. In addition, factors such as age, sex, and education have consistently been shown to impact patients' desire for information and decision making in several studies [17–19]. Culture also plays a role in this scenario. Studies have shown that African–American, Hispanic [5••], and Japanese [9] respondents more frequently reported that they prefer their family or physicians make final decisions.

Physicians' opinions about medical decision making

Recently, Murray *et al.* [20••] conducted a cross-sectional survey within a nationally representative sample of American physicians. They found that 75% of physicians preferred to share decision making with their patients, 14% preferred paternalism, and 11% preferred an informed approach. Older physicians (aged 50 or older) were more likely to perceive themselves as practicing paternalism. Physicians trained abroad were less likely to perceive themselves as practicing shared decision making than those trained in America, but they were more likely to report practicing either paternalism or an informed approach. Respondents from surgical specialties were less likely to report paternalism and more likely to report consumerism compared with physicians from either medical or primary care specialties.

Although paternalism could be preferred by some respondents (patients and physicians), a number of researchers suggest that individuals in long-standing relationships tend to build implicit decision-making processes frequently leading to a false sense of knowledge about another's desires and wishes. Moreover, limiting autonomy would lead to potentially negative health consequences as a result of the loss of control over one's own life, including negative physical, social and psychological outcomes, poorer health, and diminished morale and self-esteem in some patients [2].

Family-centered care

Although shared decision making and patient autonomy are desirable, the situation may be different when considering critically ill patients. These patients are often incapable of providing consent, and unless they had previously filed to the contrary, their families receive full information on their diagnosis, prognosis, and treatment, and are anticipated to make medical decisions on their behalf. For this reason, healthcare providers in ICU have devoted considerable attention to families, creating the concept of family-centered care [21,22••]. In many countries, a consensus seems to exist that the patient's natural proxy is their family. For example, family participation in end-of-life decisions is almost universal in the United States (93–100%), whereas somewhat more variable in Europe (84–47%) [23]. It must be noted, however, that this definition of family involvement may not include sharing in decision making, as 88% of families in Europe were simply told that the end-of-life policy was being enacted, whereas only 38% were asked for their opinions [24].

The family–physician relationship in the ICU is a complex interaction that requires ICU staff to provide appropriate and accurate information and the family members to function as surrogate decision makers by providing information about the patient's wishes. These components are necessary to choose the management strategy that will best fit the patient's wishes, preferences, and values. One important issue is the ability of family to know the patient's preferences and values. One study showed that surrogate decision makers for ICU patients made unwanted treatment decisions in about 20% of overall cases, with less agreement (50–88%) occurring in regard to decision making for the critically ill [25,26]. Despite this lack of the knowledge of patients' wishes, studies from the FAMIREA group in France have shown that 90% of respondents were favorable to surrogate designation if they were admitted to an ICU and 85% said they would want their surrogate to share in discussions and decisions with the intensivists. Moreover, 85% of nurses and 90% of physicians supported family involvement in care and decision making [21,27]. These results suggest that most individuals feel that proxy contribution to the decision-making process is preferable to leaving the decision entirely to the intensivists.

When families are involved in medical decision making, the family's needs and preferences should be reassessed frequently as they may change over time and cause problems in the family–physician relationship. Conflict between families and the ICU staff is not uncommon, and one study found that family members felt they received insufficient information regarding the patient's condition, the cause of death, and the methods used to relieve pain and anxiety in the patient [28]. Resolution of these conflicts can usually be achieved with sensitive negotiation; however, when these measures fail, external arbiters may have to be employed. These could include an ethics consultant (a third party not involved in the ICU care of the specific patient and not necessarily a physician) or an ethics committee [24]. Otherwise, if a clinician attempted to persuade a patient or their family to follow a particular course of action based on medical evidence and clinical judgment, and the patient or their proxy rejected their advice, the information, the involvement of family members, and final decision should be recorded clearly in the patient's chart. Additionally, similar to patients developing anxiety with too much information, family members may also experience anxiety and depression around the diagnosis, risk of death, or treatment plan of their loved ones. If the family decision maker is too affected, there is a risk of inadequate proxy decision making [22••]. For this reason, ICU healthcare workers should strive to alleviate these symptoms by establishing effective and compassionate communication. Often, identifying a key influential member of the family to be the primary discussant for the family is extremely helpful.

The role of family in patients' autonomy

Contemporary patients are faced with increasingly complex choices, some of which are expensive and/or existentially tragic. Even cases in which patients are competent and able to participate in decision making, such deliberation can be physically and emotionally exhausting. Additionally, as specialized medicine has resulted in patients being attended by more clinicians than ever before, certain medical care has become increasingly impersonal and fragmented. This is true particularly in ICU, in which healthcare team members usually only focus on their own specialty. This could cause critically ill patients to feel isolated, and is of particular concern for minority patients who may face language or cultural issues or may not be familiar with the healthcare system or western medicine [11••]. In this context, it seems that family involvement and patients' relational identity are more important than ever in preserving or restoring patients' autonomous agency and that many patients may be more inclined to trust their family's judgment over paternalistic doctors' claims.

The autonomist framework ignores patients' duties toward their family members and family members' interest around care of their loved one. When professionals pressure patients to make independent decisions, they risk severing the intimate ties that hold patients and their families together, leaving patients feeling overwhelmed in fending for themselves and families being left out of the patients' journey. Clinicians should acknowledge that self-determining patients exist fundamentally in relation to others, and that their interests involve a dynamic balance among interdependent people who have overlapping considerations [11••,22••].

Conversely, in cases in which professionals suspect that the patient may be going along with his/her family's suggestions out of familial pressure, they should privately discuss patient goals and family dynamics, examine how patients come to their decisions, and address their concerns regarding their situation at hand. In cases in which it is clear that the patient would like to be free of familial influence, clinicians could discuss various ways to support his/her interests without creating more familial animosity. Since professionals are usually unfamiliar with their patients' relational history and family dynamics, it is more important for them to follow their patients' own assessment and expressed wishes rather than to authoritatively 'free' them from their families [11••].

On the contrary, given that physician paternalism is also seen in many countries [16•,19] and numerous patients are treated in multicultural urban societies, it can be expected that significant differences regarding the role of individuals or families as decision makers will be found between patients and healthcare providers. The incompatibility of values between patients and healthcare providers and the judgments they support may result in incompatible bioethical claims. Consequently, those engaged in these substantive moral controversies who assess what is at stake, separated by incommensurable moral–metaphysical frameworks, and attempt to resolve such controversies by sound rational argument will be characterized by begging the question, arguing in circles, or engaging in infinite regress [29]. However, healthcare organizations will seek to appropriately tailor health promotion programs in order to improve understanding of the range and distribution of preferences within populations.

Thus, it has been increasingly emphasized that merely pressuring patients to decide a treatment option could have negative psychosocial consequences, if the patient does not wish to be the final decision maker; physicians should 'sound out' patients' preferences in this regard to find means for a peaceable collaboration that does not require stakeholders to abandon their moral commitments or compromise their moral integrity; this will require conscience clauses that recognize the existence of moral disparities and accept different assumptions.

Conclusion

Throughout this review, we have emphasized that physicians should offer patients the opportunity to participate in medical decision making by sharing responsibility and active engagement. Clinicians should understand that merely pressuring patients to decide certain treatment options could have negative psychosocial consequences if the patient does not wish to be the final decision maker. Doctors cannot substitute their judgments about what is important for patients to know for the patients' own judgments.

A doctor needs to specifically ask patients and/or their families to assess individual patient preferences in order to provide individualized care. When the patient or family agrees to receive the information and make a decision, clinicians should ensure that informational needs are met and should minimize the potential influences of internal and external factors to the best of their ability. Finally, understanding the range and distribution of preferences within populations is important to healthcare organizations seeking to appropriately tailor health promotion programs.

Acknowledgements

The authors appreciate the helpful suggestions of Dr Juan A. Rull in the preparation of the manuscript.

References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:
- • of special interest
- •• of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 730–731).

1 Beauchamp TL, Childress JF. Principles of biomedical ethics. Oxford: Oxford University Press; 2001.

2 Tuckett AG. On paternalism, autonomy and best interests: telling the (competent) aged-care resident what they want to know. Int J Nurs Pract 2006; 12:166–173.

3 Dykeman MJ, Dewhirst K. Voluntariness. In: Singer PA, Viens AM, editors. The Cambridge textbook of bioethics. Cambridge, USA: Cambridge University Press; 2008. pp. 31–35.

4 Charles CA, Whelan T, Gafni A, *et al.* Shared treatment decision making: what does it mean to physicians? J Clin Oncol 2003; 21:932–936.

5 Murray E, Pollack L, White M, Lo B. Clinical decision-making: patients'
•• preferences and experiences. Patient Educ Couns 2007; 65:189–196.
A large cross-sectional survey conducted among the American public using computer-assisted telephone interviewing. It found a diversity of responses regarding preferred approach. The main findings are that 62% of respondents preferred shared decision making, 28% preferred informed approach, and 9% preferred paternalism.

6 Butow PN, Maclean M, Dunn SM, *et al.* The dynamics of change: cancer patients' preferences for information, involvement and support. Ann Oncol 1997; 8:857–863.

7 Mazur DJ, Hickam DH. Patients' preferences for risk disclosure and role in decision making for invasive medical procedures. J Gen Intern Med 1997; 12:114–117.

8 Schattner A. What do patients really want to know? QJM 2002; 95:135–136.

9 Sekimoto M, Asai A, Ohnishi M, *et al.* Patients' preferences for involvement in treatment decision making in Japan. BMC Fam Pract 2004; 5:1.

10 Hebert PC, Hoffmaster B, Glass KC. Truth telling. In: Singer PA, Viens AM, editors. The Cambridge textbook of bioethics. Cambridge, USA: Cambridge University Press; 2008. pp. 36–42.

11 Ho A. Relational autonomy or undue pressure? Family's role in medical
•• decision-making. Scand J Caring Sci 2008; 22:128–135.
This essay argues for a re-examination of the notions of autonomy and undue pressure in the contexts of patienthood and relational identity. In particular, it examines the characteristics of families and their role in adult patients' decision making. This paper argues that family involvement and consideration of family interests can be integral in promoting patients' overall agency.

12 Asch DA, Hansen-Flaschen J, Lanken PN. Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: conflicts between physicians' practices and patients' wishes. Am J Respir Crit Care Med 1995; 151:288–292.

13 Dworkin, G. Paternalism. In: Zalta EN, editor. The Stanford encyclopedia of philosophy. Winter 2005 ed. http://plato.stanford.edu/archives/win2005/entries/paternalism/.

14 Siegler M. Metaphors and models of doctor–patient relationship. In: Childress JF, editor. Practical reasoning in bioethics. Indiana: Indiana University Press; 1997. pp. 44–56.

15 Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. A national study of public preferences. J Gen Intern Med 2005; 20:531–535.

16 Watanabe Y, Takahashi M, Kai I. Japanese cancer patient participation in and
• satisfaction with treatment-related decision-making: a qualitative study. BMC Public Health 2008; 8:77.

This study revealed that Japanese cancer patients' preferences regarding their role in treatment-related decision making varied widely from complete physician control to complete patient control.

17 Adams RJ, Smith BJ, Ruffin RE. Patient preferences for autonomy in decision making in asthma management. Thorax 2001; 56:126–132.

18 Fraenkel L, Bogardus S, Concato J, Felson D. Preference for disclosure of information among patients with rheumatoid arthritis. Arthritis Rheum 2001; 45:136–139.

19 Asghari F, Mirzazadeh A, Fotouhi A. Patients' preferences for receiving clinical information and participating in decision-making in Iran. J Med Ethics 2008; 34:348–352.

20 Murray E, Pollack L, White M, Lo B. Clinical decision-making: physicians'
•• preferences and experiences. BMC Fam Pract 2007; 8:10.

Cross-sectional survey of a nationally representative sample of US physicians. It showed the first data from a large nationally representative sample of physicians to explore physician perceptions of their preferred and perceived role in clinical decision making. The main findings are that three quarters of physicians prefer sharing decision making with their patients, with the remaining one quarter almost equally divided between the paternalist and consumerist approaches.

21 Azoulay E, Pochard F. Communication with family members of patients dying in the intensive care unit. Curr Opin Crit Care 2003; 9:545–550.

22 Berger JT, DeRenzo EG, Schwartz J. Surrogate decision making: reconciling
•• ethical theory and clinical practice. Ann Intern Med 2008; 149:48–53.

In this article, the authors outline differences between normative standards for decision making and empirical evidence of practice and offer clinicians ways in which the two can be reconciled for the patient's benefit.

23 Cohen S, Sprung C, Sjokvist P, *et al.* Communication of end-of-life decisions in European intensive care units. Intensive Care Med 2005; 31:1215–1221.

24 Levin PD, Sprung CL. Critical and intensive care ethics. In: Singer PA, Viens AM, editors. The Cambridge textbook of bioethics. Cambridge, USA: Cambridge University Press; 2008. pp. 462–468.

25 Coppolino M, Ackerson L. Do surrogate decision makers provide accurate consent for intensive care research? Chest 2001; 119:603–612.

26 Ciroldi M, Cariou A, Adrie C, *et al.* Ability of family members to predict patient's consent to critical care research. Intensive Care Med 2007; 33:807–813.

27 Azoulay E, Pochard F, Chevret S, *et al.* Half the family members of intensive care unit patients do not want to share in the decision-making process: a study in 78 French intensive care units. Crit Care Med 2004; 32:1832–1838.

28 Studdert DM, Mello MM, Burns JP, *et al.* Conflict in the care of patients with prolonged stay in the ICU: types, sources, and predictors. Intensive Care Med 2003; 29:1489–1497.

29 Engelhardt HT Jr. Critical care: why there is no global bioethics. Curr Opin Crit Care 2005; 11:605–609.