Autonomy, liberalism and advance care planning

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Abstract

The justification for advance directives is grounded in the notion that they extend patient autonomy into future states of incompetency through patient participation in decision making about end-of-life care. Four objections challenge the necessity and sufficiency of individual autonomy, perceived to be a defining feature of liberal philosophical theory, as a basis of advance care planning. These objections are that the liberal concept of autonomy (i) implies a misconception of the individual self, (ii) entails the denial of values of social justice, (iii) does not account for justifiable acts of paternalism, and (iv) does not account for the importance of personal relationships in the advance care planning process. The last objection is especially pertinent in light of recent empirical research highlighting the importance of personal relationships in advance care planning.

This article examines these four objections to autonomy, and the liberal theoretical framework with which it is associated, in order to re-evaluate the philosophical basis of advance care planning. We argue that liberal autonomy (i) is not a misconceived concept as critics assume, (ii) does not entail the denial of values of social justice, (iii) can account for justifiable acts of paternalism, though it (iv) is not the best account of the value of personal relationships that arise in advance care planning. In conclusion, we suggest that liberalism is a necessary component of a theoretical framework for advance care planning but that it needs to be supplemented with theories that focus explicitly on the significance of personal relationships.

(Journal of Medical Ethics 1999;25:522-527)

Keywords: Medical ethics; patient autonomy; liberalism; advance directives

A component of advance care planning, advance directives allow individuals to specify in advance the type of medical interventions they want, and do not want, to receive, and the person(s) they want to make decisions on their behalf, if or when they become incapable of making treatment decisions themselves. To date, it has been assumed that advance directives should be honoured since

they respect, or at least aim to respect, the value of patient autonomy.¹ Concern for autonomy stems from "people's interest in making significant decisions about their lives for themselves and according to their own values or conception of a good life".² By enabling a competent person to "extend" his or her autonomous decision-making capacity into a future state in which this capacity no longer exists,³ an advance directive presumably gives a person some control over the end of his or her life.⁴

Although the liberal value of autonomy has thus far been the philosophical basis of advance directives, its necessity and sufficiency have recently been challenged. Four objections suggest that autonomy, perceived to be a defining feature of liberal philosophical theory, is insufficient as a basis of advance care planning. These objections are that the liberal concept of autonomy (i) implies a misconception of the individual self, (ii) entails the denial of values of social justice, (iii) does not account for justifiable acts of paternalism, and (iv) does not account for the importance of personal relationships in the process of advance care planning. The last objection is especially pertinent in light of recent empirical research highlighting the importance of personal relationships in advance care planning. This article examines these four objections to autonomy, and the liberal theoretical framework with which it is associated, in order to re-evaluate the philosophical basis of advance care planning.

Objection I: liberal autonomy is a purely individualistic concept

The first major objection to liberal autonomy is that it implies a misconception of the self as a rational, independent agent who is ultimately "unencumbered" or "disengaged" from all social context and who is capable of making decisions in ways that are essentially detached from other human beings.⁸ An ethic of individual autonomy, critics claim, cannot serve as a basis for advance care planning unless those engaged in the planning process make treatment decisions in a way that is removed from the interests of other

But patients do not make treatment decisions strictly on a self-regarding basis and are, rather, essentially attached to the lives of others, particularly those close to them such as family members.⁹ The patient is too enmeshed in a network of relations to others to be properly singled out as a self-sufficient decision maker.¹⁰ Thus, autonomy cannot mean simply a person's right to choose for herself based on personal interests alone; others' interests are necessarily a factor in the process of decision making.

Similarly, communitarians have argued that a liberal conception of autonomy is deficient since it both wrongly portrays the individual as essentially disconnected from the rest of the community and since it demands the denial of the priority of communal values. The communitarian concept of the self is constituted by its ends—ends that are not chosen but rather are discovered by virtue of our being embedded in some shared social context. Individual identity, and hence individual capacity for choice, is not separate from but rather structured by these ends and the roles the individual assumes with respect to the community.¹¹ The communitarian self is “narrative”, ie, a self partly constituted by a life story with a certain end, or *telos*,¹² which is “intersubjective”.¹³

Accordingly, the moral agent is not properly viewed in an atomistic, dislocated way, as is associated with liberal theory, but rather is situated in a moral community from which moral identity, convictions, and judgments derive.¹⁴ The liberal autonomous self, perceived by communitarians as one able to stand apart from, question and revise its convictions of the good life, is mistakenly defined as prior to its ends and as having a virtually unlimited capacity for choice.

Contemporary liberalism, though, is not a purely individualistic ethic. Liberal conceptions of autonomy have always revealed an underlying general concept understood in terms of self-government, self-determination, or a kind of self-ownership of values, beliefs, desires, and choices—in other words in terms of a life that is not “other-governed”. Yet, contemporary liberal interpretations of autonomy are expressed in terms of negative freedom, rank-ordered desires, personal identification, and, notably, historical formation¹⁵ which highlights the broad social embeddedness of the individual.

This modern liberal concept of autonomy is an essentially historical notion in that the conditions that must be met in order for desires to be autonomous are properties of the *formation* of, and not mere identification with, those desires.¹⁶ What is crucial in the determination of whether a

desire is autonomous is the manner in which the desire was formed, which may have little to do with how the agent evaluates the desire itself.¹⁷ A person is autonomous when he or she understands the development of and changes in his or her character. What modern liberalism thus strives to preserve and promote in terms of individuals' autonomy is their ability to reflect on the manner they develop as persons and on the social and cultural conditions that shape that development through history.

Though the liberal self has been described as “atomistic” and “independent” in that “the fulcrum of the determination of autonomy remains the point of view of the agent”,¹⁸ this does not mean that individuals are able to dislocate themselves from their social and historical context. We are able to judge ourselves only in the light of our social and cultural histories and the manner in which they affect and shape our development as persons. Modern liberals recognise that it is impossible to think of ourselves except as part of ongoing communities, defined by reciprocal bonds of obligation, common traditions, and institutions. Liberal conceptions of autonomy therefore are not purely individualistic, as critics claim.

Liberals have always deplored the effects on individuals of social manipulation, the condition in which individuality is swallowed up by the collective mass.¹⁹ The liberal concept of autonomy portrays the individual as a separate being with a distinct personal point of view and an interest in being able to pursue securely his or her own conception of the good, but it does not presume that one is only accidentally and externally related to others.²⁰ Modern liberalism is not necessarily objectionably individualistic given that the liberal autonomous agent may be driven by choices whose origins are outside his or her control. Where such so called autonomous choices are expressed, the interests of the individual may be outweighed by the considerations of others, as discussed in the next section.

Objection II: liberal autonomy entails the denial of social justice

There exists a potential conflict between the principles of autonomy and justice where patients appear to have the right to claim whatever resources they want regardless of the impact of their decisions on the welfare of others.²¹ To critics who perceive liberal theory as a framework for the exaggerated promotion of individual autonomy, it may not be clear how liberalism can account for advance care planning when the

interests of society outweigh those of the individual. Practically speaking, all requests cannot and should not be honoured simply because they represent the autonomous wishes of the individual.

Although advance directives have been used mainly to limit treatment, requests for treatment may cause conflicts between competent individuals' wishes and the health services that are available to them once they become incompetent. For example, advance directives asking for scarce treatments may be overridden when a "just level" of care is exceeded and others are being denied resources.²² Patient choice also may be limited when treatment is too costly, especially given that other health needs are not met.²³

Accordingly, under a universal health care plan like that in Canada, the autonomy of patients who demand services that are not provided under the unified public plan might be restricted.²⁴ In other words, patients might not have a legitimate claim to treatment that is being withheld as part of a just rationing system.²⁵ Privileging the value of autonomy runs against a principled way of limiting the medical services that ought to be guaranteed to all individuals.²⁶ Even in Canada where the emphasis on universal access to health care services is based on collectivist principles that call for social responsibility for the basic welfare of its members,²⁷ a significant dilemma exists since the state both protects individual autonomy by providing for an individual's welfare and threatens it by making allocation dependent on the consent of the plurality.²⁸

The promotion of autonomy in advance care planning must be understood not as a guarantee that the patient will get whatever he or she wants, but rather as "the responsible use of freedom"²⁹ according to which the right course of action is not always one that promotes his or her own interests. This has been described as a "socially responsible" approach to advance directives according to which the patient is viewed as both citizen and consumer and patient self-determination is understood in the context of "informed consent" rather than in the context of "consumer sovereignty".²⁵ A "citizen ethic" according to which the patient is viewed as a citizen with rights within the health care context along with duties to make judicious and proportionate choices also has been proposed.²⁹

Though critics often assume that autonomy is the trump value within liberalism, leaving little or no room for an account of justice and equitable resource allocation, this is not a valid assumption. The contemporary liberal objective may be summarised as follows: if we are to treat people as

equals, we must protect them in their possession of certain rights and liberties.³⁰ Much has been written within liberalism on the question of which rights and liberties these are, but the moral demand of liberal equality is held prior to that of the protection of our (individual) rights and freedoms.

Justice as fairness, understood in terms of an equal share of social goods, namely, equal liberties and opportunities, is the very crux of modern liberalism.³¹ Modern liberals reject the claim that liberalism is committed merely to economic growth; the government required to ensure that growth, and a conception of life in which growth is pursued for its own sake in the form of competition, individualism, and material pursuits.³² Liberty is an important value but what is valued fundamentally is equal liberty for all citizens. Liberalism is a political theory based on an egalitarian conception of justice. Liberal theory thus able to take into account the concerns for equitable resource allocation that may arise from advance care planning.

Objection III: liberal autonomy does not account for justifiable acts of paternalism

The third major objection to liberal autonomy is that it is very difficult, if at all possible, for liberals to justify paternalistic acts. This poses a problem in defining a liberal account of advance care planning since substitute decision makers are sometimes justified in treating incompetent patients paternalistically when to honour patient's wishes as expressed when competent would pose an unnecessary risk to the patient's present welfare.

Liberals insist that in order to lead a good life "every competent adult be provided with a sphere of self-determination which must be respected by others"³³ and that "for those who pass the threshold of age and mental competence, the right to be self-determining in the major decisions in life is inviolate".³³ However, the modern liberal principle of autonomy must be qualified by a paternalistic principle of wellbeing. Paternalistic acts may be justified in our relationships with children, the demented, the otherwise temporarily incapacitated, and even, under certain circumstances, in our relationships with competent adults who exhibit "weakness of will" in doing what is in their best interests.³⁴

Liberals call attention to the distinction between "hard paternalism", which justifies the imposition of values and judgments on people "for their own good", and "soft paternalism" which holds that the state has the right to prevent self-regarding harm

ful conduct when that conduct is non-voluntary (a “non-voluntary” act is one for which consent is “missing because the subject...is incapable of giving his voluntary consent”).³⁵ Soft paternalism is a principle which suitably qualifies liberalism since it permits interference in the absence of voluntary consent. Soft paternalism defends those who are unable to give voluntary consent against threats to their autonomous self, which is quite another thing than throttling that autonomous self with external coercion. It may even defend those who are no longer “the same person” as the person who issued the advance directive. (This touches upon a further argument against advance directives—that they often apply to people who are different from those who executed them; a full consideration of this primarily metaphysical argument is beyond the scope of this article.)^{36–37} Interference on this ground is no more illiberal than interference to prevent one from harming an unwilling second party.³⁸

Liberalism may thus be qualified by a principle of soft paternalism in the form of overriding the advance directives of patients who are now incapable of providing voluntary consent to available health care options. The choices expressed by patients while competent may not have been voluntarily made due to, for example, coercion and bias from health care professional(s) and/or family members. Paternalistic decision making may be acceptable under such circumstances to defend the patient against threats to his or her autonomous self.

The choices expressed by patients while competent may not have been adequately informed either—had they foreseen and understood the nature of their now present condition, such persons may have chosen otherwise. Paternalistic decision making may be acceptable under such circumstances in order to do what is in the patient’s current best interests.

Soft paternalism is regarded as an “alternative, essentially liberal, rationale for most of what seems reasonable in paternalistic restrictions”.³⁹ Insofar as it is qualified by a principle of paternalism in defence of overriding patients’ previously expressed choices, at least where those choices were not voluntary and/or informed and now threaten their wellbeing, contemporary liberalism is able to account for justifiable acts of paternalism within the process of advance care planning.

Objection IV: liberal autonomy does not account for the importance of personal relationships

This last objection is especially pertinent in light of recent empirical research highlighting the

importance of personal relationships in advance care planning. In a qualitative study of 48 patients receiving haemodialysis, we showed that the traditional academic assumptions are not fully supported from the perspective of patients involved in advance care planning. The patients we interviewed stated that: 1) the purpose of advance care planning is not only preparing for incapacity but also preparing for death; 2) advance care planning is not based solely on autonomy and the exercise of control, but also on personal relationships and relieving burdens on others; 3) the focus of advance care planning is not only on completing written advance directive forms but also on the social process, and 4) advance care planning does not occur solely ‘within the context of the physician/patient relationship but also within relationships with close loved ones.’⁵ In a subsequent qualitative study of 140 people with Human Immunodeficiency Virus (HIV), we showed the primary goal of advance care planning was: preparing for death, which entailed facing death, achieving a sense of control, and strengthening relationships.⁶

It has been argued from within feminist theory that the overemphasised individualistic ethic which critics associate with liberalism, demands the denial of the value of personal relationships for autonomous choice. The (liberal) concept of autonomy, it is claimed, carries too many associations of isolation and independence in its portrayal of personhood to capture feminist conceptions of agency.⁴⁰ As in the case of the first objection considered earlier, liberalism is charged with defining atomistic individuals as the basic units of political and legal theory. The further objection here, however, is that liberalism thus fails to recognise the inherently social nature of human beings and the “relatedness” that is a precondition of autonomy.⁴¹

For example, relational theory, offered by “feminine theorists” from within feminist theory,⁴² argues that although appropriate to relationships between strangers and to purely professional relationships, emphasis on (liberal) autonomy is not appropriate to relationships based on “connectedness”, or “caring”.⁴³ The concern for the value of personal relationships is captured in a morality of care that challenges justice-based theories of moral development and judgment⁴⁴ (ie, those associated with the liberal tradition). Such theories have been rejected as “masculine” approaches to moral decision making and ethical analysis having little, if any, concern for the interests of women.⁴⁵ Moreover, they are often viewed as the presumption of Western (liberal) medical ethics which “often

relies on ... the context of justification for ethical decision making rather than the context within which such decision making takes place..."⁴⁶ Consequently, relational theorists have argued for the importance of context-based values such as that of personal relationships rather than abstract, universal principles. For example, it has been argued that an ethic of care is more appropriate as the foundation for theories of medical ethics than the liberal values of justice and autonomy in accounting for the significance of the value of personal relationships.⁴⁶

It may be, however, that liberalism does not fail as a theoretical framework for the value of personal relationships for autonomy since it has never been its intention to serve in this role. Liberalism (with its ideal of state neutrality and "negative" conception of freedom) is best considered a political doctrine.⁴⁷ The liberal concern for political relationships reflects a deeper agenda to protect the private choices and affairs of individuals. Modern liberalism therefore may have relevance for a theoretical account of advance care planning, not in terms of the promotion of the value of personal relationships, but rather in terms of its preservation and protection. Liberal writers do not discuss the nature and value of personal relationships, as such, though they may seek to define a liberal account of the individual as situated or embedded in community and culture. This suggests that liberalism is not inconsistent with an account of the nature and value of personal relationships in advance care planning. It is not inconsistent with the concerns and goals people who engage in advance care planning have that relate to the impact of their decision making on others.

However, a relationship ethic serves specifically as an account of the importance of personal relationships in the process of advance care planning. After all, such an ethic has explanatory power insofar as it defines moral decision making, for instance regarding certain decisions about future care, as part of particular and concrete situations in which individuals are engaged in networks of relationships with others. Insofar as it lacks a relationship ethic of this kind, modern liberalism remains insufficient in accounting for the importance of personal relationships as a factor in advance care planning.

Conclusion

Four objections suggest that the liberal value of autonomy is inappropriate as a basis of advance care planning. These objections are that the liberal concept of autonomy (i) implies a misconception of the individual self, (ii) entails the denial of

values of social justice, (iii) does not account for justifiable acts of paternalism, and (iv) does not account for the importance of personal relationships in the process of advance care planning. We have examined these four objections to autonomy, and the liberal theoretical framework with which it is associated, in order to re-evaluate the philosophical basis of advance care planning.

We have argued that (i) liberal autonomy is not a misconceived concept as critics assume. Though a necessary component of a theoretical account of the concern for personal control that persons engaged in advance care planning may have, liberal autonomy entails recognition of the social aspects of personhood and thus the social components of advance care planning. We have also argued that liberal autonomy (ii) does not entail the denial of values of social justice and that it (iii) can account for justifiable acts of paternalism in consideration of a patient's advance directive. With respect to the objection that liberalism (iv) does not account for the importance of personal relationships in the process of advance care planning, we acknowledge that liberalism remains an insufficient framework in terms of its lack of direct focus on the value of personal relationships that are a factor in the process. In closing, we suggest that contemporary liberalism needs to be supplemented with theoretical accounts—such as that offered by relational theory—that pay specific attention to the value of personal relationships towards the development of a full theoretical framework for advance care planning.

Acknowledgements

The authors are grateful to James Lavery, Douglas Martin and Barbara Secker for their comments and suggestions and to Professor Wayne Sumner for supervising Sharon Ikonomidis's doctoral thesis. This research was supported by the Physicians' Services Incorporated Foundation of Ontario. Dr Singer was supported by a National Health Research and Development Program Scholar award and is now supported by a Medical Research Council of Canada Scientist award.

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