

Autonomy Without Care: The History and Theory of Advance Care Plans

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Over the last fifty years medical decision-making has become increasingly complex. Associated with this has been a shift in medical ethics so that autonomy has become the dominant value. This has served to address the power imbalance between doctors and patients, but has also increased the patient's responsibilities. This is apparent in attempts to extend autonomy into incompetence through advance care plans (ACPs). By examining the development of ACPs, the different theories of autonomy and the empirical evidence regarding patients' preferences for involvement in medical decision-making, I question whether autonomy should dominate our decision-making for incompetent patients.

A woman born in Australia in 2005 can expect to live 30 years longer than a woman born in 1901 and she is much more likely to die in institutional care.¹ These changes, attributable to improved living standards, vaccinations, antibiotics and technological advances in medicine, have been associated with radical changes in the doctor-patient relationship. Dying in hospital often results in patients being actively treated leading up to their death with treatments that might stave off death, if only for a few hours or days. Decisions regarding the use of such treatments are fraught with the potential for conflict. Autonomy is hailed as the ethic to guide us through the quagmire created by these decisions, but its limitations may have been underestimated.

Changes in medicine have been accompanied by changes in the law and society. All three have played a part in altering the dynamic of medical ethics. The four foundations of medical ethics—beneficence, non-maleficence, autonomy and justice—remain, but the balance of power has shifted such that autonomy has become the dominant value. Autonomy's ascendancy is illustrated by the move to enable people to formalise their treatment preferences in advance for medical decisions that may need to be made should they become incompetent. This process is known as advance care planning. In this essay I will explore autonomy in relation to advance care plans (ACPs). I will review the historical factors that resulted in the development of ACPs, different theoretical constructs of autonomy including the tension between autonomy and ACPs, and the empirical evidence around patients' preferences for autonomy. This discussion is limited to Western culture. Space constraints prevent a discussion of the cross-cultural aspects of autonomy; suffice to say not all cultures place the same value on autonomy as Western culture.

ACPs are plans people make, when competent, regarding their preferences for medical care should they lose competence. They have two components: instructional directives, known as advance directives (ADs), and nomination of a surrogate decision-maker. The most common form of AD enables a person to indicate a desire to accept or refuse particular medical interventions in particular medical situations, although other formats have been developed.² A surrogate is someone who is able to make medical decisions on behalf of an incompetent patient. In Australia, the law regarding surrogates and ADs varies between the states and territories. Currently South Australia,

Queensland, the Northern Territory and ACT all have legislation allowing some form of AD.³ In Victoria, ADs are not legal documents. Refusal of Treatment Certificates function in Victoria but the scope of these is limited to refusal of treatment for a current condition.⁴ The Northern Territory and Western Australia are the only states which do not currently allow a competent individual to appoint a surrogate decision-maker.⁵ Throughout Australia there are alternatives for people who lose competence without nominating a surrogate.

The principle of autonomy is embodied in informed consent. Informed consent arises from the common law idea that to touch someone without their consent constitutes battery.⁶ It enshrines the right of a person to determine what happens to their own body. Our current understanding of informed consent dates back to the 1960s.⁷ Today informed consent is a legal requirement for performing any medical procedure on a patient, with provision of emergency treatment being one of a limited number of exceptions to the law.⁸ The preconditions to informed consent include that an individual is able, or competent, to consent.⁹ Competence requires that the patient is capable of understanding their condition, the risks and benefits of treatment and of refusing treatment; however, there is no uniform way of measuring competence.

Informed consent redresses medical paternalism in that competent patients have boundless freedom to consent to or refuse medical treatments, including when refusal will result in their death.¹⁰ This applies not only to people whose death is inevitable in the immediately foreseeable future—such as a person refusing further chemotherapy for advanced cancer—but also to those whose death is preventable, such as a Jehovah's Witness refusing a life-saving blood transfusion. An informed refusal cannot be disregarded even if treatment is in the patient's best interests. The pre-eminence of autonomy is illustrated by our willingness to allow a person to die rather than forcibly apply treatment that will return them to full health.

Informed consent further offsets paternalism by providing patients with information and conferring decision-making authority. Rothman argues that prior to the 1950s medical decisions were largely made by doctors on behalf of patients.¹¹ Patients were not informed of their diagnosis or prognosis, especially in relation to terminal illness, and had very little input into decision-making. Beneficence and non-maleficence were the dominant medical ethics with doctors acting, or

at least purportedly acting, in the best interests of their patients. At the time far fewer investigations and treatments were available, thereby lessening the scope for decision-making and potentially minimising the potential for conflicts of interests between doctors and patients.

Advances in medicine in the last sixty years might have acted to further entrench paternalism by making medicine less comprehensible to those outside the profession. Instead, the recognition that medical decisions often require value judgements has helped to empower patients and has altered the way decisions are made. Mechanical ventilation is one development that illustrates the complexity of decision-making. Mechanical ventilation was designed in the 1950s to ventilate victims of polio, but the use of ventilators soon broadened to include people with a variety of illnesses.¹² This led to the need to make decisions about who to ventilate and what to do with those who would not recover from their underlying illness but could remain ventilated. These problems were magnified by the fact that all ventilated patients appear to be asleep but they are not, and they do not all have the same ability to return to consciousness. A key variable is the presence and extent of damage to the brain. Some ventilated patients have normal brain function. In these cases, the sleep-like state is the result of sedation that allows the patient to tolerate the discomfort of ventilation. In other cases, there is damage to the brain itself which affects the patient's prognosis. As such, the different types of brain damage needed to be defined, enabling them to be distinguished and thus assisting with treatment decisions.

At the extreme end of the spectrum of brain damage lies brain death. Although the term is taken for granted today, it only came into existence in 1968.¹³ Prior to this, death was indicated by three clinical markers: absence of consciousness, cessation of breathing or cessation of cardiac function.¹⁴ The distinction between these was of little importance because when one ceased the others invariably followed. Medical developments, like mechanical ventilation, allowed cardiorespiratory functions to be maintained independent of brain function so that these distinctions became critical. Superficially, a ventilated patient who is brain dead looks no different from a ventilated patient with a healthy brain, yet a brain-dead patient can never recover. As mechanical ventilation became more widely applied, brain-dead people were being ventilated without there being any process for managing this. Despite there being no hope for their recovery, they

could not be declared dead because they did not fit the definition of death. Withdrawing treatment would have resulted in cessation of cardio-respiratory function so that the definition of death was met, yet doctors did not want to do this. Singer argues that society is still confused by brain death, so that although we recognise and accept the term 'brain-dead', patients are often referred to as 'alive' until treatment is ceased. The fact that they look alive is a large part of this problem. In this context, it is easy to see why doctors may have wished to use all available technologies to prolong 'life' and feared being held responsible for the patient's death if they ceased treatment.

For doctors, the human difficulty in acknowledging that a person's heart may beat even in death was compounded by accusations of conflicts of interests. These had many guises, one of which was resource allocation. This related to the idea that the limited number of ventilators, and staff able to care for ventilated patients, meant that those with the potential to benefit from ventilation would be denied access if treatment was never withdrawn from patients who could never recover. The development of organ transplantation in the late Sixties further intensified this concern. Brain-dead people were potential organ donors, yet to withdraw treatment to allow their organs to be harvested appeared to create a conflict of interest for doctors. Previously the doctor was seen as only having to consider the best interests of the patient before them but these developments created the concern that they might be considering how the needs of others may be served by the death of the person before them. Redefining death to include brain death as a separate entity codified these difficulties. A process for diagnosing brain death, ceasing life support, and arranging organ donation was created to guide doctors facing these new and complex issues.

This process did not provide guidance in dealing with the other manifestations of brain damage including Post Coma Unresponsiveness (PCU), commonly known as a Persistent Vegetative State, where conflicts regarding withdrawal of treatment remain rife. A person with PCU has at least partial brain stem function but extensive damage to the higher centres of the brain. This means they have no awareness of their environment, while sleep-wake cycles and brain-stem reflexes continue to function.¹⁵ In some cases, PCU results in an inability to maintain core body function and death results despite treatment. Other patients may live for years, as long as

artificial nutrition and hydration are provided. Those with PCU have been pivotal in the debate around autonomy, because these patients are alive but unable to contribute to decision-making. Withdrawing treatment will result in their death, but providing treatment prolongs their life under circumstances that may be worse than death. Conflicts regarding management of these patients are not unidirectional. There are cases where doctors wanted to provide treatment while family members wished to cease treatment and those where the situation was reversed with at least some family members wishing to continue treatment.¹⁶ These conflicts illustrate the way decision-making has changed. Previously doctors would have made these decisions unilaterally, using their medical expertise and personal values. Changes to the doctor-patient relationship mean these decisions now involve a minimum of three parties: medical staff, the patient and the surrogate decision-maker/s. Other parties, such as the media, the courts, interest groups and ethics committees, may also become involved. The fact that in these cases decision-making is routinely conceptualised as a triad, and often involves many parties, gives some indication that it is not medicine alone that has changed.

Running parallel to the developments in medicine have been changes in society and the law. In the United Kingdom consumerism appears to have been the driving force behind changes to the doctor-patient relationship, whereas in the United States of America (USA) the civil rights movements played a major role.¹⁷ Patients' rights formed part of the civil rights movements which attempted to address power imbalances like that embodied by the traditional doctor-patient relationship.¹⁸ Many factors contributed to dissatisfaction with this disparity of power, but technological advances in medicine played a part by creating two contradictory concerns for patients.¹⁹ The first of these was a fear of overtreatment.²⁰ People feared receiving treatments in situations they deemed represented an unacceptable quality of life, such as PCU. In direct opposition was the concern that doctors may cease to value the preservation of life and withdraw treatment too readily. Either of these concerns may encourage a person to complete an AD, with people using ADs to request and refuse treatment.²¹

In the USA, a case regarding withdrawal of treatment resulted in the court concluding that decisions regarding withdrawal of treatment belong to the court, not the medical profession.²² This helped create a situation where hospitals and doctors felt compelled to involve

the court when withdrawing treatment, something which happens infrequently in Australia. In the USA, the case which had the most impact on AD legislation was that of Nancy Cruzan. Nancy Cruzan was involved in a car accident which resulted in severe brain damage and left her dependent on artificial nutrition and hydration. After eight years, her parents requested her feeding tube be withdrawn. When the case went to court judgement was against her parents, on the grounds that cessation of treatment required 'clear and convincing evidence' that the patient would have wanted treatment withdrawn.²³ In making this decision, the court placed autonomy ahead of all other concerns including the wishes of Nancy Cruzan's parents and doctors.²⁴ Ultimately, verbal recollections from family and friends served as evidence in this case. Importantly they were seen as evidence of Nancy Cruzan's wishes, which once again emphasises the importance of autonomy.

Central to the propagation of AD was the concern that verbal recollections would not necessarily be acceptable evidence of a patient's wishes. The idea that ADs might serve as clear and convincing evidence of a person's prior treatment wishes created an imperative to complete one. Having people document their treatment preferences in advance involves multiple assumptions, the foremost of which is that autonomy is the value that should guide decision-making for incompetent patients.

The idea that autonomy should extend into incompetence highlights how central autonomy has become to medical decision-making. One particular theory of autonomy, known as 'traditional liberal theory', dominates medicine and has been instrumental in the construction of ACPs. This theory contends that patients make independent rational decisions without undue influence.²⁵ Although modern liberal theory may be able to incorporate social connectedness and justifiable paternalism, this is not the paradigm that dominates the medical literature.²⁶ Despite traditional liberal autonomy falling short when decisions need to be made for incompetent people, this is the mode that ACPs promote. This is illustrated by the construction of the patient-surrogate relationship, which attempts to create a contractual relationship whereby the surrogate promotes the patient's self-determination, rather than a covenant sustained by trust and discretionary authority.²⁷ The idea of a covenant does not fit with traditional liberal autonomy and, as this is the context in which

advance care planning arose, it is easy for anything which does not primarily advance self-determination to be labelled as paternalism.

There are other ways of considering autonomy that could accommodate ACPs. For example, the idea of identification provides a way of thinking about autonomy that is pertinent to decision-making for incompetent people because it accounts for dependence.²⁸ Stiggelbout et al suggest that if an individual identifies with the decision being made—meaning that they see the decision as consistent with their idea of self, their goals and their objectives—then it does not matter who actually makes the decision. This highlights the connections between people and allows a person to be dependent and autonomous simultaneously. Agich makes a similar point when considering the limitations of liberal autonomy in the setting of residential care for the elderly.²⁹ He contends that an individual can be dependent and autonomous so long as they are able to make meaningful choices about issues that matter to them and they can identify with the decisions that have been made. In terms of ACPs this may lead us to expect that some patients will be comfortable with decisions they identify with rather than expecting a surrogate to predict their decision or to rigidly follow previously expressed wishes. As is discussed in more detail below, a significant proportion of patients are comfortable with leeway in AD interpretation, which suggests some tension between the ideals of liberal autonomy and real world preferences.³⁰

Another way to consider autonomy is as a spectrum.³¹ At one extreme is the optional model whereby people are entitled to, but not required to be autonomous; so a patient may choose not to be informed or make healthcare decisions. At the opposite extreme is the mandatory model whereby patients are required to exercise their autonomy even if they do not wish to. Mandatory autonomy can be seen in the conclusions of a literature review exploring patients' preferences for medical decision-making, when the authors ask whether doctors should respect a patient's preference for a paternalistic style of doctor-patient relationship or try to convince the patient to engage in shared decision-making.³² There is an inherent contradiction in valuing autonomy so highly that one does not allow a person to relinquish it. When considering mandatory autonomy we can see that the changes wrought in the doctor-patient relationship have resulted in role changes for doctors and patients. Changes to the patient's role are illustrated by the argument that patients have a responsibility to

share the burden of treatment decisions³³ and the suggestion that there may exist a moral imperative for patients to become involved in decision-making.³⁴

A traditional view of liberal autonomy is represented by Emanuel and Emanuel in their evaluation of four models of the doctor-patient relationship. They argue that autonomy is more complex than the right to make decisions in that it 'requires that individuals critically assess their own values and preferences, determine whether they are desirable; affirm upon reflection, these values as ones that should justify their actions; and then be free to initiate actions to realize these values'.³⁵ Not only does this assume that patients would evaluate the models of the doctor-patient relationship in the same way as the authors do, but that they are capable and willing to put an enormous amount of work into achieving autonomy. Some patients may be prepared to undertake this task, but it is worth remembering that many important medical decisions are made by people who are unwell; and even if people's wish for autonomy remains unchanged during illness, their thinking may be impaired—particularly the abstract thinking required to evaluate treatment alternatives.³⁶ Furthermore, this ideal of autonomy can never apply to an incompetent patient. A surrogate decision-maker may be expected to consider the patient's previously expressed values but they cannot be expected to re-evaluate and affirm or renounce those values.

Autonomy has become sacrosanct. If, as Schneider suggests, autonomy is a spectrum, then optional autonomy should be at its centre, not an extreme. The extreme should be reserved for decision-making models that represent values other than autonomy. Until recently, these ideas were raised only in a cross-cultural context. It was assumed that the preservation of autonomy was the highest priority for all patients from Western backgrounds. Some models of Advance Care Planning, such as the Respecting Choices program which originated in the USA, have adopted a values-based approach.³⁷ This involves trying to ascertain patients' values rather than simple decision-making preferences and viewing the patient in a broader context. Despite these developments, the theoretical basis of these programs remains closely aligned with the original idea of promoting autonomy.³⁸ Recently, authors have started to question whether patients understand and value autonomy in the same way as those who write about it and in the same way as the courts.³⁹

Patients' understanding of autonomy matters because an AD can never be contemporaneous. An AD is completed at a point in time distant from the time when a decision needs to be made. Not only are the preferences documented in an AD unlikely to represent the exact decision that is required, but the preferences expressed by the author may have changed.⁴⁰ It was suggested that the way to overcome these limitations was by enabling another individual to assume decision-making responsibility for the incompetent patient. This person is the surrogate decision-maker.

Protecting autonomy by enabling another individual to make decisions for an incompetent patient is fraught with difficulty. To manage this tension, the role of the surrogate needs to be clearly delineated. The idealised model for surrogate decision-making is known as 'substituted judgement'. This requires the surrogate to make the decision the patient would have made for themselves. The alternative, to be applied only if a substituted judgement cannot be made, is the 'best interest' model. This requires that the surrogate promotes what is good for the patient while considering what treatments a reasonable person would desire under such circumstances.⁴¹

Substituted judgment is as difficult as it sounds. A literature review of surrogate accuracy found surrogates correctly predicted patients' preferences only two-thirds of the time.⁴² Not only may it be impossible for the surrogate to perform the role expected of them, but it is not necessarily desirable. The existing models of surrogacy attempt to create a contractual relationship between surrogate and patient with the aim of promoting autonomy. Critics of this model argue that the choice of surrogate may be informed by trust and that it is impossible for surrogates to completely disregard their own wishes for the patient.⁴³ The idea that trust is important to patients is supported by research involving inpatients in Germany, which found that over 75 percent trusted their doctor and significant other/s to make the right decision for them, despite very few of the patients having spoken to these people regarding their wishes.⁴⁴

The empirical research provides insight into patients' understanding of autonomy. As a person's preference for autonomy is intangible, surrogate measures are used. Common surrogate measures include preference for information and/or involvement in medical decision-making. These variables do relate to autonomy and the distinction between them is a valid one. However, it is important to keep in mind

that this research asks participants to respond to a pre-existing framework rather than having participants outline their understanding of autonomy. A common, although by no means universal, limitation of this framework is that medical decision-making is seen as occurring exclusively within the context of the doctor-patient dyad. Patients are seen through their relationship to doctors rather than in terms of their broad social connections.⁴⁵ As a result, most studies fail to consider the influence of significant others on patients' decisions. Research participants may assume, consciously or unconsciously, that decisions made by the patient involve significant others to the extent desired by the patient. Unfortunately in survey research, it is difficult to know how participants are interpreting the questions. Despite these limitations, this body of research provides useful information regarding patients' preference for autonomy.

To summarise the findings of this research, the majority of patients express a strong preference for medical information;⁴⁶ the type of information patients desire and their preferred source of information change over time.⁴⁷ And a preference for information does not correlate with a preference for involvement in decision-making.⁴⁸

Most of the research into preference for involvement in medical decision-making does not involve end-of-life decisions or decision-making for incompetent people; yet despite these limitations it is useful to consider this body of work. A literature review exploring patients' attitudes towards medical decision-making found the only demographic variables consistently associated with a desire for autonomy are being younger, being female, and having a higher level of education.⁴⁹ Because these results arise from surveys, the meaning behind the findings remains elusive. For example, is the decreased desire for autonomy with increasing age a process of ageing itself, a social cohort effect arising from generational attitudes toward the doctor-patient relationship, or a result of illness experience? Does the effect of increased education on preferences reflect an increased sense of agency, a greater awareness of the right to be informed, or increased confidence in interpreting medical information? The research to date is limited in its ability to answer these questions.

Further complicating the interpretation of the results are the different methodologies used in different studies. Often findings appear contradictory, but it is difficult to know if these contradictions reflect real differences or methodological variation. One of the differences

is whether participants are asked to respond to general or specific statements. Some research uses global statements of preference with either dichotomous or scaled (strongly agree to strongly disagree) responses; for example, 'I prefer to leave decisions about my medical care up to my doctor.'⁵⁰

Global statements of preferences may oversimplify medical decision-making. Deber et al argued that tasks in medical decision-making could be divided into problem-solving tasks and decision-making tasks.⁵¹ In this schema, problem-solving tasks involve identifying a single correct solution to a problem, and decision-making tasks involve a number of possible alternatives and may involve trade-offs. The study found that patients tended to prefer a greater role in decision-making tasks, while preferring the doctor to assume greater responsibility for problem-solving tasks. Another study found three types of decisions existed: major, minor, and behavioural/long-term.⁵² Patients preferred shared decision-making for major and behavioural decisions whereas they preferred physicians to have more control over minor decisions. Although these findings seem surprising, they are consistent with those of Deber et al outlined above, because in this work major decisions included examples such as whether to have a foot amputated due to diabetes, and behavioural decisions included whether to cease smoking. These decisions involve value judgements and trade-offs. Minor decisions included such examples as whether to have a blood test to monitor cancer, which is a problem-solving decision requiring expertise. The qualitative research supports these findings: people are more willing to participate in decision-making if they believe medical decisions involve value judgements, and they are less comfortable if they believe there are right or wrong decisions.⁵³

Another consideration is whether illness experience or severity of illness influence desire for participation. Population surveys have found that people who report their general health to be poor prefer a more passive role in decision-making compared to those who report their health to be fair or better.⁵⁴ Studies comparing patients with the general population, or with the person accompanying them to clinic, have found that patients prefer a less active role in decision-making.⁵⁵ Similarly, patients with a new diagnosis of breast cancer seem to prefer a more passive role than those with a new diagnosis of benign breast disease.⁵⁶ From this research it appears that being unwell decreases desire for control of medical decision-making. In direct

contrast, research involving women with ovarian cancer found that the majority preferred shared decision-making, and if a woman perceived her disease as serious or had metastatic disease she was significantly more likely to prefer shared decision-making.⁵⁷ Preference may change over the course of an illness; patients attending for their first consultation are more likely to prefer an active role than those attending for follow-up when their condition has changed.⁵⁸

Preference for involvement in end-of-life decision-making may be quite different from preference for involvement in medical decision-making generally. Research into preference for involvement in end-of-life decisions found that a third of participants prefer shared decision-making, while approximately a quarter prefer an active role but not complete control.⁵⁹ These findings are similar to those in studies which find that a significant proportion of people are comfortable with leeway in AD interpretation.⁶⁰ This is supported by the finding that patients adhere less strictly to ADs than doctors and nurses.⁶¹ Participants' comfort with leeway in AD interpretation varies in relation to the instructions contained in the AD; participants in one study were more willing to allow leeway in the face of instructions to 'do everything' rather than instructions to 'do nothing'.⁶² These findings suggest that AD completion is not about maintaining control—although it should be noted that participants in this study were asked about allowing leeway if it was in their best interests. We do not know how people regard leeway that meets the needs of others.

Despite the fact that different methodologies create difficulties in interpreting these studies, it is safe to conclude that age, gender, education and illness experience all impact on patients' preferences for decision-making. Patients are likely to feel less comfortable with decisions they see as requiring expert knowledge and are more likely to desire involvement in decisions involving value judgements. There is enormous variation in how much leeway people are willing to allow in AD interpretation.

Changes in medical technology, the practice of medicine, society and the law have changed medical ethics so that autonomy is now the pre-eminent value guiding medical decisions.⁶³ There are different theoretical constructs of autonomy, which vary in their ability to accommodate social connectedness, dependence and individual variation in preference for control in decision-making. Because the traditional liberal model of autonomy dominates the medical literature,

most of the discussion presupposes a strong preference for autonomy, and a willingness and ability to work toward achieving this. ACPs resulted from a wish to extend autonomy into incompetence, and they contain assumptions about the value of autonomy in medical decision-making. Empirical research has found patients vary widely in the amount of autonomy they wish to exercise, with preferences varying in response to individual patient factors and the type of decision required. There is no way to predict a patient's preferences, and it is likely that an individual's preference will vary over time and in response to illness. A preference for active involvement is not synonymous with preferring less intensive treatment at the end-of-life.⁶⁴

The implications of these findings include the need to accept the limitations of the traditional view of autonomy in respect to ACPs. The first limitation is that patients have connections to those around them that will influence their decision-making when they are competent, and it is probable that they would like those factors to be considered if they lose competence. The second limitation is that understanding autonomy is personal. If the literature tells us anything, it is that there is no single model of medical decision-making that is preferred above all others. Some people desire a great deal of autonomy, wishing to make decisions independently when competent, documenting their preferences and wishing to have them followed rigidly if they are incompetent. Others prefer that someone else takes most of the responsibility for decision-making; they are willing to allow a great deal of leeway in the interpretation of any preferences documented in advance. Even if we establish an individual's preference, it may change over time. Third, it needs to be acknowledged that it is impossible to be truly autonomous, in any sense, while incompetent.

The idea of considering incompetent patients' treatment preferences is sound, but these need to be considered in a way that takes into account their medical and social context. To expect people to express preferences in advance and to be bound by these is to deny the complexity of medical decision-making and the anguish surrogates experience when making a decision for a loved one. This does not mean autonomy should be discarded, but rather that it should be tempered by other values including those that are allied with caring such as beneficence and non-maleficence. Autonomy without care may be as undesirable as justice without mercy. ❖

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