

SUBMISSION

on the Issues Paper:

“Rethinking Life-Sustaining Measures:
Questions for Queensland”

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Introduction

Since the Issues Paper is welcoming a cross-disciplinary response, we feel confident in presenting some philosophical considerations which inform any policy about advance directives. Though the Issues Paper addresses the consistency between common law and legislation, is there not scope to examine also the consistency between law and ethics? Given a choice between common law directives and Advance Health Directives, we should choose that which best reflects ethical reality.

The heart of the matter is our respect for the right of self-determination or autonomy.

Page 24 of the paper states that in common law, a:

“mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death”

It also explains that:

“the right to refuse life-sustaining measures could operate even if the refusal was given in advance of the medical situation arising.”

These two principles taken together imply that individuals may make decisions about their health care, which must continue to be respected even when the patient becomes incompetent.

But such an understanding fails to appreciate the nature of this ‘right to refuse to consent to medical treatment’. We must understand the basis of this right, to truly appreciate its implications.

Patient Omniscience

Some theorists have asserted that the right to refuse to consent to medical treatment is based on the belief that the patient is the most appropriate arbiter of their own best interest. Hence, only the patient can determine whether a medical treatment accords with his or her best interest. Yet the common law cited above does not place any importance on the *reason* given by the patient for refusing treatment. It is contradictory to allege that the patient can make a decision *in their best interest* based on irrational reasons, or ‘for no reason at all’.

In fact, the right to refuse to consent to medical treatment can only exist through recognition that the individual’s exercise of self-determination and autonomy is *inherently good*, regardless of the outcomes of that autonomy. The failure to respect autonomy is wrong simply because overruling an individual’s autonomy (coercion) is not good for that individual (notable exceptions include suicidal autonomy, which can be legitimately overruled – this issue is too complex to be elaborated upon here). After all, the penalty for overruling a patient’s refusal of treatment is the criminal charge of assault or battery, rather than negligence.

Furthermore, patients are only allowed to *refuse* consent to medical treatment and are not entitled to demand unnecessary treatment. Yet if the patient were truly the best judge of their own best interest, then surely doctors would also be obliged to respect their

demands for treatment, whether such demands be based on rational or irrational reasons, or no reasons at all?

Foundation of Autonomy

The right to refuse to consent to medical treatment is derived from the right to self-determination and autonomy. The exercise of self-determination is self-evidently good, just as it is self-evidently not good to coerce a competent patient, or to administer treatment against his or her will, even if such coercion is carried out with the intention of saving life. The coercive administration of medical treatment to a competent patient is considered unethical. The act of administration of treatment is ethically tainted by the coercive element.

However, it must be clarified that the right to refuse medical treatment is not an absolute. It is contradictory to exercise the right to autonomy as a means of undermining other goods and rights, such as physical health or the inalienable right to life itself. Hence suicidal or self-destructive refusal of autonomy deserves no respect, and it is unethical to coerce a health provider into complicity with a suicidal refusal of treatment. The right to refuse treatment truly comes into effect when the patient decides whether the proposed treatment is excessively burdensome, or futile, given their personal circumstances. A patient can decide this, because only they have insight into their own capacity to endure further treatment.¹ Yet this insight is applied within the greater context of objective best interests.

Understanding that the right to refuse treatment is just another aspect of individual autonomy has great implications for the rationale of advance directives. It is claimed that advance directives 'preserve' or 'extend' the autonomy of the patient, to allow refusals of treatment to be made in anticipation of future decisional incapacity. Yet this claim is spurious. Autonomy is the capacity to decide and direct one's own life and existence, to be able to make choices and to be responsible for those choices. An advance directive is one such choice, albeit designed to take effect at a later point in time with the aid of legal support or social convention. *Advance directives may preserve an autonomous decision, but they do not preserve autonomy itself.*

Some argue that differentiating between true autonomy and autonomous decisions is 'splitting hairs' in the context of advance directives. After all, our society frequently respects the autonomous decisions that guide the distribution of deceased estates, or autonomous decisions to donate organs after death. The important difference between these autonomous decisions, and the autonomous decision that amounts to an advance directive, is that the author of the advance directive is still alive, still possesses interests, and can therefore suffer harm to their interests as a result of the advance directive. The state routinely overrules autonomous decisions in determining the fairness of distribution of deceased estates,² yet this is not classed as coercion because the autonomous agent whose decisions are overruled no longer possesses either autonomy, or interests in

¹ Personal Correspondence, Dr John Fleming. Thurs. May 26th 2005.

² Fagerlin, Angela and Schneider, Carl E. *Enough: The Failure of the Living Will*. Hastings Center Report. Vol. 34 No. 2 (2004):pp 35

general. We may respect the wishes of the deceased in terms of their burial plans, but even this respect is dampened with considerations for feasibility, cost, and public safety.

Loss of Autonomy

The right to autonomy is based on the recognition that the exercise of autonomy is inherently good for human beings, and therefore worthy of protection. Yet an incompetent patient is by definition incapable of exercising their autonomy; indeed, an incompetent patient may no longer have the capacity for exercise of autonomy at all. In these instances, *the right to autonomy is defunct*.

Since the right to autonomy does not apply to incompetent patients i.e. patients without autonomy, medical treatment can be applied ethically so long as it is in the best interest of the patient and complies with standards of ethical best practice.

There is therefore no ethical basis in autonomy for the application of advance directives. Any beneficial correlation between the demands of a directive and the best interest of the incompetent patient are coincidental to the true nature of advance directives, and cannot justify their existence.

The Issues Paper is only dealing with issues raised by the two existing types of law, yet it may be helpful to consider these issues from the ethical perspective we have offered. This perspective questions the claim that advance directives are worthy of the same respect as the refusal of consent for treatment by a competent patient. As we have argued: once a patient loses autonomy or competence, the right to autonomy – in this case the right to refuse to consent to treatment – is no longer relevant.

Since an advance directive is not worthy of such strong respect, it cannot be allowed to over-rule the best interest of the incompetent patient, which would be the guiding principle in the absence of an advance directive. Accordingly, we would advise that the principle of best interest be given priority over other considerations such as past directives from the patient, and the wishes of the family, unless remaining treatment decisions are not incompatible with best interest. There may be a place for advance directives to guide decision-making, but best interests must be able to override them. Each of the issues raised in the Issues Paper should therefore be answered with reference to the best interest of the patient, to ensure that there is little potential for advance directives to conflict with best interest.

Before we continue it would be prudent to make a brief clarification of the term ‘best interests’. Best interests must be based upon the fundamental human rights such as the right to life, which are to be protected and sustained without contradiction. The best interest of the patient lies in the achievement and protection of the rights and goods of human nature. These goods are not contradictory, hence the exercise of any single good cannot be emphasised at a cost to any other good. For example, the right to autonomy causes us to respect refusals of treatment, but not to respect suicidal refusals of treatment, which violate the right to life.

Unfortunately, due to time constraints, we have been unable to comment in greater detail on each of the issues raised in the Issues Paper. We have commented at least briefly on what we perceive to be the most important issues raised, and which do not require greater investment of time.

Issue 1 – Wider recognition of advance directives about health care

According to the principles outlined above, we would recommend that common law advance directives not be recognised. Recognising common law directives, which are not subject to requirements or limitations, would undermine the advance health directives (AHD) legislation. The AHD legislation is more ethically appropriate, since it limits the application of directives, thereby reducing the potential for conflict between directives and patient best interest. The legislation also has important requirements for the creation of directives, which help to guarantee their authenticity.

The arguments in favour of recognising common law advance directives presented in the Issues Paper are less convincing given our reappraisal of the lack of ethical foundation for advance directives in general. Hence the claim on page 26, that common law directives should be recognised in accordance with the right to refuse medical treatment, is refuted by our argument that the right to refuse medical treatment is lost when the autonomy and competence to refuse medical treatment is lost. As discussed earlier, the execution of advance directives is inconsistent with the concept of self-determination and autonomy.

The second argument: that the community is likely to expect advance directives to be binding in the future does not in itself mean that the law should therefore be changed to reflect community beliefs and views. Simply reflecting community views is not the priority of good public policy.

The third argument in favour of recognising common law directives is that such recognition might promote community advance care planning to a greater extent. Yet it is an uncertain achievement to encourage more extensive advance care planning by allowing a reduction in the quality and reliability of advance directives (as identified in the third argument against recognising common law advance directives on page 26-27 of the Issues Paper). Furthermore, the value in promoting a program that lacks clear benefits to patients and the community is highly dubious; unless one believes that adherence to the past wishes of patients should be the primary aim of health care, rather than pursuing the objective best interests of the patient.

Issue 2 – Limits on the operation of advance health directives

Question 3

According to the argument we have presented, advance directives have no ethical basis for interfering in the best interests of an incompetent patient. Hence it is preferable that

any advance directives legislation attempt to minimise the potential for such interference. Page 31 of the Issues Paper states that common law directives have no limitations on the scope of their operation once the directive becomes binding. This is once again supported with an uncritical interpretation of the right to self-determination. By contrast, the requirements of the AHD legislation ensure at least that the incompetent patient's condition is sufficiently dire before the directive becomes applicable. Such requirements make the AHD legislation ethically more valid than the common law directives, because it encourages application of the directive at a time when even the most absolute advance refusals of treatment will not deviate wildly from the best interests of the patient. Hence we must assert that the *Power of Attorney Act (PAA)* should continue to require that the adult's health be sufficiently poor that it meets the defined conditions before an AHD can operate.

Question 4

The exercise of autonomy can be recognised as self-evidently good, that is: exercise of autonomy contributes positively to the fulfillment of human nature; it doesn't intrinsically undermine any other elements of fulfillment; nor is it only an instrumental good, exercised for the sake of some further goal. Although autonomy does not intrinsically undermine other goods or rights, it is important to remember that some specific autonomous acts do in fact undermine goods and rights. There is no moral obligation to respect autonomous acts that do such harm. Regardless of the ethical nature of specific acts of autonomy, once autonomy disappears, the ethical problems of overruling autonomy also disappear because there is no autonomy to over-rule. But what happens when loss of autonomy is only temporary, or when it is contingent on non-treatment?

In cases where the capacity for decision-making is lost but with the expectation of recovery, the issue is no longer directly about the ethical nature of autonomous decisions, but about the best interest of the patient. Since we recognise the capacity for autonomy or self-determination as being self-evidently good, it is most certainly in the best interest of the patient to recover this capacity where possible. Best interest should by definition guide the health care provider to the greatest degree of fulfillment for their patient. If the patient has a reasonable chance of regaining the capacity for autonomy, then it is in their best interest to regain that capacity. The patient with autonomy enjoys a great deal more fulfillment by definition than the patient without autonomy.

Question 5

Essentially the same answer can be applied to the situation in which a patient's AHD specifically refuses the treatment that could restore the patient's autonomy. In this situation, the best interest of the patient demands that their autonomy be restored – in fact it is always in the best interest of the patient to have their autonomy restored – provided the means of restoring autonomy are appropriate to the same criteria of futility, burdensomeness, and ethically good medical practice. To give the ethically baseless AHD priority over restoring the patient's self-evidently good capacity for autonomy is clearly unethical.

Question 6

The distinction between nutrition and hydration, and life-sustaining measures in general, is valid. A common comparison is made between nutrition and hydration, and artificial ventilation, yet such comparisons are usually mistaken. The fact that human beings require nutrition and hydration correlates with the fact that human beings also require oxygen, regardless of the means of delivery. Hence regular nutrition and hydration is comparable to regular respiration. The fact that people sometimes cannot eat and drink because of the inability to swallow and may therefore require a PEG, is comparable to the fact that people sometimes suffer an obstruction of the respiratory tract and require a tracheotomy. The comparison ends at this stage, since artificial ventilation is a means of mechanically maintaining the function of the lungs organ. An appropriate comparison would be a device which mechanically activates peristalsis – the physical operation of the stomach in the process of digestion.

Furthermore, there are important differences in the relative cost and burdensomeness of the two techniques. Ventilation is an invasive procedure requiring regular manual suction on the trachea from 16-20 times a day; it represses any spontaneous breathing that might occur, and costs 24 times the average weekly wage to perform. By contrast, the treatment aspect of artificial nutrition and hydration is complete once the tube is inserted; the insertion of a PEG is one-third the cost of normal feeding, and the nutrition and hydration itself is cheaper than a hospital meal.³

Cost and burdensomeness are factors that must be taken into account with each individual case. It is clear that there are good reasons to distinguish between life-sustaining measures such as ventilation, and basic care such as artificial nutrition and hydration. Hence the requirement of good medical practice should certainly be preserved for artificial nutrition and hydration.

Issue 3 – Protection for health providers relying on invalid advance health directives & Issue 4 – Protection for health providers where no knowledge of advance health directives

Unfortunately, we do not have time to discuss these two related issues in detail. However, the issues themselves show how advance directives interfere with the usual medical priority of ‘best interest’ of the patient. Given that advance directives are ethically baseless, one might wonder if the legal difficulties created by their existence are worthwhile.

Issue 5 – Deliberate non-compliance with advance health directives: a statutory excuse?

Bearing in mind the lack of ethical basis for advance directives, there is no ethical reason why a doctor should not substitute good medical practice for the demands of a patient’s AHD. However, this does not imply that the doctor may simply substitute their own

³ Personal correspondence, Nick Tonti-Filippini. Tues. May 24th 2005.

views for their patients. The principle of best interest must continue to guide health care, therefore, we support the provisions of the PAA that allow a health provider to not comply with advance health directives that conflict with good medical practice.

The Issues Paper claims on page 46 that such provisions:

“erode one of the important functions of these documents: to make choices that others (including an adult’s health provider) may not agree with.”

But the fact remains that this ‘important function’ is a legal artifice without ethical foundation. To allow such a document to overrule the ethical principles of ‘best interest’ and ‘good medical practice’ is patently unethical.

The objection raised on page 46 of the Issues Paper states that this protection for the non-compliant health provider is inconsistent with the implications of the limitation on withdrawal of artificial nutrition and hydration:

“Stating that artificial nutrition and hydration cannot be withheld or withdrawn unless its commencement or continuation is inconsistent with good medical practice implies that good medical practice will not limit the operation of an AHD directed to other life-sustaining techniques”⁴

However, this overlooks a very simple difference in emphasis between the requirements on artificial nutrition and hydration, and the protection offered to non-compliant health providers. The requirements on artificial nutrition and hydration simply prohibit AHDs from refusing this life-sustaining measure under certain conditions; while the provisions made for the protection of health providers allows for the health provider to use their discretion in determining whether or not to comply with the AHD.

Section 103 of the PAA, quoted on page 46 of the Issues Paper states that:

“(2) The health provider does not incur any liability, either to the adult or anyone else, if the health provider does not act in accordance with the direction”

The key phrase is ‘if the health provider does not act in accordance with the direction.’

This condition distinguishes between the two provisions we are discussing. In effect, an AHD cannot refuse artificial nutrition and hydration if such refusal is incompatible with good medical practice. The health provider must not comply with this aspect of an AHD if so doing would be incompatible with good medical practice. But in all other circumstances, it is up to the health provider to decide whether or not to comply with an AHD that contradicts good medical practice, hence the conditional phrase: ‘if the health provider does not act in accordance with the direction.’ In practical terms, this allows health providers to comply with refusals of treatment that contradict good medical practice, but it also protects them if they decide not to comply. But section 36 vetoes any possibility of withdrawing or withholding artificial nutrition and hydration against good medical practice, whether or not the health provider is willing to do so.

The protection afforded to health providers who do not wish to give an advance directive preeminence over good medical practice is a worthy provision, given the lack of ethical basis for advance directives, and the potential for great conflict with the best interest of

⁴ White, B. & Willmott, L. *Rethinking Life-Sustaining Measures: Questions for Queensland*. Issues Paper. QUT Printing Services. 2005. pp 46

the patient. Even on a practical level, the potential for advance directives of any style to conflict with best interest, or to create unintended results, make it reasonable to give health providers the freedom to act in the best interest of the patient, rather than adhering to a static representation of past patient wishes. The freedom to disregard the advance directive should be a matter of common sense in circumstances where the AHD is unclear or inappropriate because of changed circumstances.

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