

# Directives in dementia

**Frances Oliver**

5th Year Medical Student  
School of Medicine  
University of Auckland

Frances Oliver is a 5th year medical student at the University of Auckland. This essay was written as part of the Humanities paper 'Ethics at the End of Life'. It was awarded 'Pre-clinical Prize in Medical Humanities' in 2013. Frances is currently a General Executive of the Paediatric Interest Group.

## INTRODUCTION

Advancements in life-sustaining medical care mean our ageing population is faced with an increasing plethora of medical decisions to make at the end of life. Advance care planning is arguably the "embodiment of the patient's autonomy and right of self-determination".<sup>1</sup> However, issues arise when the advance directive contradicts what is in the current best interests of the patient. This essay will prove that paternalism should over-ride advance directives if the advance directive contradicts the best medical interests of the patient. The first argument supporting this is that doctors have a duty to act in the best interests of their patient. Secondly, advance directives cannot accommodate changes in values and preferences that occur at the end of life, and therefore may not represent the patient's wishes. These arguments are opposed by justice, respect for autonomy and the fear of subjectivity. This essay highlights the need for quality advance care planning but ultimately proves that doctors must first and foremost be trusted to act in their patient's best medical interests\*.

## BACKGROUND TO ADVANCE DIRECTIVES AND DEMENTIA

Advance Care Planning is a discussion aimed to identify an individual's beliefs and values, and incorporate these into planning future health care in the form of an advance directive.<sup>2</sup> Advance directives come into action in cases where the patient does not have the capacity to make decisions regarding their healthcare, for example, dementia. Approximately 50 000 New Zealanders suffer from dementia.<sup>3</sup> By 2050, it is estimated that there will be 44 000 new cases of dementia a year.<sup>4</sup> Dementia creates specific challenges for advance directives. The slow, progressive loss of competence while remaining able to interact with the environment and express preferences creates a potential conflict between competent choice and incompetent interests.<sup>5,6</sup> Other issues relevant to advance directives, such as the role of surrogates or powers of attorney in decision making, will not be discussed.

**Doctors have professional duties that prevent them from following advance directives.**

Doctors have a professional duty to 'First, do no harm', conferred upon

them when they take the Hippocratic Oath. This maxim could be challenged by advance directives. Let us imagine an incompetent patient with a painful urinary tract infection, treatable with IV antibiotics. However, the patient has an advance directive stipulating that they do not want to receive IV antibiotics. Withholding antibiotics from the patient as requested results in the patient's suffering. Through the omission of treatment, the doctor is allowing harm to come to the patient. Is this considered 'doing harm'? In this example, the patient is being harmed by the doctor's inaction which resulted from the patient's instructions. Some argue that this is not 'doing harm', as the doctor is not doing something actively. However, an act of omission can be as culpable as an action that causes harm. Consider the actions of Professor Herbert Green and others, who intentionally delayed or did not treat women with abnormal smears, allowing cervical cancer to develop.<sup>7</sup> Similarly, in our hypothetical case of a patient with a urinary tract infection, not treating the infection contradicts the Hippocratic Oath if this leads to harm to the patient.

However, an act of omission that is usually punishable becomes accepted when it is requested by the patient. Patients are able to refuse life-saving dialysis treatment if it is their decision. However, if a doctor did not offer a patient the dialysis (and the patient was eligible to receive it, and in fact wanted it), they would be disciplined. Does a request to withhold treatment through an advance directive also make the previously unacceptable, acceptable? Potentially following the advance directive could result in suffering for the patient and hasten their death. These are serious consequences. If medical professionals are going to withhold treatment because it is requested by an advance directive, they must be sure that the directive is still valid.

**Advance directives cannot accommodate changing values and therefore have questionable validity.**

The criteria for an advance directive to be valid require the patient to be competent, sufficiently informed, and free from coercion. The patient must also have intended the directive to apply in the current circumstances.<sup>8</sup> There can be reasonable doubt about all of these aspects, however this will not be discussed further. What challenges the validity of advance directives in dementia is that the patient's preferences, values and satisfaction may have changed as a result of their condition. Critics of advance directives argue "wishes laid down in an advance directive when a patient was healthy—most particularly the limitation of life-preserving treatment—might then be no longer valid."<sup>5,9</sup>

This issue is emphasised in hypothetical cases, such as Dworkin's 'Margo problem'.<sup>10</sup> Margo is a hypothetical patient who is "happily demented". She made an advance directive when she was competent. Would it be ethical to hold her to her prior decisions if they were to hasten her death? It has been argued that through cognitive impairment, a new identity has formed. Dworkin argues that "personal identity does not sufficiently survive to

justify binding the cognitively impaired person to the decisions of his former self." David Hilfiker, with cognitive impairment himself, similarly notes that he has read stories about happiness of patients with very advanced disease. He comments "maybe most of them aren't suffering much at all".<sup>11</sup> This dilemma of 'self-hood' is key in deciding whether advance directives should be honoured. Advance directives are created with the goal of extending personal autonomy. If we have doubts over whether a new identity has formed separate from the 'past self', are we respecting autonomy by applying the advance directive? We would only be respecting the autonomy of the prior, competent patient, not the patient who is currently entrusted into our care. If we are going to respect autonomy, it should be the autonomy of our present patient, not their 'past-self'. This is consistent with current practice where patients can alter and 'opt-out' of their advance directive. They are not bound to decisions they made in advance. In the case of an Alzheimer's patient who has subsequently lost the capacity to review their advance directive, it would seem extremely unethical and unjust to hold them accountable to the decisions they made previously. Not only may they have a new personal identity, but they also do not have the ability to modify their advance directive should their wishes change.

### Counter Arguments – Justice, Respect for Autonomy, Fear of Subjectivity

Arguably, life's many experiences change us all so that we develop into new 'selves'. Yet our advance directives made at a prior time, by a prior 'self', are followed. Why should we treat the demented self any different? Without entering the philosophical discussion of whether dementia patients have a new identity, there are many reasons that support following the advance directive, even when it conflicts with the current patient's best interests.

Firstly, in principle, we should respect autonomy. Not honouring advance directives denies patients any autonomy over their medical decisions and paternalism takes over. Section 11 of the New Zealand Bill of Rights Act supports this: "Everyone has the right to refuse to undergo any medical treatment".<sup>12</sup> We create injustice by disregarding directives as people with dementia can therefore not refuse treatment.

Secondly, patients may have valid reasons to create advance directives that will hasten death and are purposefully not in their best medical interests, but rather represent personal values. A person may decide that any treatment prolongs suffering and is therefore undesirable, any treatment prolongs the requirement for care which may create a financial burden to the family, and any treatment allows the patient to progress further into a disease state which they may wish to protect their family from seeing. With such reasoning, it may be appropriate to follow the advance directive even if it contradicts the patient's current best interests. However, the 'worthiness' of reasoning should not be a requirement for the advance directive to be followed if the directive is deemed valid. Medical practice carries out a competent patient's wishes, for example, the refusal of life-sustaining intervention, regardless of how unreasonable the request. Therefore, to act consistently, we must also carry out a directive that is not in the patient's best interests if the directive is valid.

Thirdly, if doctors disregard directives and instead act in the patient's best interests, there is potential for subjectivity and bias. A survey of 500 American physicians found that race influenced physician attitudes towards advance directives and end of life treatments. While 58% of 'white' physicians believed tube feeding in terminally ill patients is 'heroic', only 28% of 'black' physicians agreed.<sup>13</sup> With ethnicity resulting in such differing views on treatment, there is likely to be huge variation in what doctors decide is the patient's best medical interests. Similarly, decisions of whether to treat inevitably involve judging the patient's quality of life. There is evidence that healthy people rate quality of life for those with chronic illness lower than the patients themselves.<sup>14</sup> For these reasons, some argue it is better to be bound by a decision you made yourself, than to be bound by the will of a third party.<sup>15</sup>

### Rebuttal of Counter Argument

Even though the counter arguments above support following the advance directive, society has placed a duty on the doctor to protect life. A survey conducted on cancer patients, healthy controls, nurses, and physicians in Germany showed one quarter of patients, and one third of the other

groups, feared 'dictatory' use of advance directives. That is, where physicians use the advance directive without taking into account their knowledge about illness type and prognosis.<sup>16</sup> This supports society wanting doctors to ultimately act in the best interests of the patient, rather than solely respecting autonomy. Combining this societal 'duty' with doubts about the validity of advance directives and self-hood, there is compelling support for doctors to act with beneficence for the patient entrusted in their care. Erring on the side of life is consistent with court rulings for cases where advance directives have been unclear. One such case is that of *HE v A Hospital NHS Trust* (2003). In this case, the incompetent patient required a blood transfusion to survive. However, she had signed an advance directive indicating refusal of blood transfusion because she was a Jehovah's Witness. Since the creation of the advance directive, there was evidence that she had rejected her faith and become Muslim. The court ruled that "doubts must be resolved in favour of the preservation of life".<sup>17</sup> The *Taking Care: Ethical Caregiving in Our Ageing Society* (2005) report argues that a person's prior wishes should be considered in decisions about care. This report was produced following the case of Terri Schiavo, a woman who was kept on life support for fifteen years due to uncertainty about her wishes. However, to give "those wishes trumping power may force caregivers to forgo doing what is best for the person who is now entrusted to their care; as moral agents themselves, caregivers cannot simply do what they were told but must also try to do what is best".<sup>18</sup> Perhaps doctors are protecting their consciences, and, in America, their legal obligations by favouring life. A survey of American physicians investigating what influenced their compliance to an advance directive, found 52% believed there was less liability in maintaining someone alive against their will than mistakenly allowing them to die (only 30% disagreed).<sup>19</sup>

### FUTURE OF ADVANCE DIRECTIVES

The focus of advance directives to extend autonomy is impractical unless we want to "privilege competent choice over incompetent interests".<sup>5</sup> Our focus should not be on patients trying to imagine future scenarios and what care they would like to receive. Instead, increased effort should be put into developing trust between patients and medical professionals. Except in cases of specific religious beliefs where certain procedures are unacceptable, perhaps patients would not require advance directives if they were able to believe that medical professionals would always act in their best interests. Some argue that "[advance directives] make autonomy and self-determination the primary values at a time of life when one is no longer autonomous or self-determining, and when what one needs is loyal and loving care".<sup>18</sup> Another critic argues that even though it is frightening that "there may come a time when we will be unable to direct our lives... assuaging this fear with illusion of the advance directive does the patient a disservice".<sup>9</sup> Issues with advance directives may mean that people have to accept that dependency and lack of control is inherent to many diseases.

### CONCLUSION

As our ageing population is offered a multitude of life prolonging medical treatments, advance directives are important in ensuring our right to refuse treatment is respected. However, this essay has illustrated how doctors must act in the best interests of the patient that is currently in their care. This is supported by the doctors' professional duties of non-maleficence and beneficence, combined with exploring changing identity and 'self-hood' relevant to patient autonomy. Justice, respect for autonomy, and fear of subjectivity create strong counter arguments in support of following directives. These arguments are outweighed by the trust society places in doctors to ultimately support life when it is in the best interests of the patient.

\* Throughout this essay, 'best interests' specifically means 'best medical interests'.

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