Further Considerations in Relation to the Refusal of Nutrition and Hydration

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A number of highly publicised cases in Australia and New Zealand have, once again, generated an awareness of the ethical and legal dilemmas surrounding the provision and refusal of nutrition and hydration at the end of life. Two recent cases that come most readily to mind are those of Christian Rossiter, a 49-year-old Perth man who became a quadriplegic in March 2008, and Margaret Page, a 60 year old Wellington woman who suffered a cerebral haemorrhage 20 years ago.

The cases have a number of similarities: both persons concerned wanted to be able to exercise a personal choice about whether or not they continued to live; neither person was suffering a terminal illness and neither were they dying – at the time of the debate there was no specific reason to think that either could not have continued to live for a good number of years.

The cases also differ in morally significant ways: Mr Rossiter relied on the provision of artificial nutrition and hydration while Mrs Page was able to take food and water in the normal way albeit that she relied on carer support to do that; Mr Rossiter was unable to exercise his personal choice to refuse nutrition and hydration without a mandate from an Australian court; while the Supreme Court of Western Australia affirmed Mr Rossiter's right to instruct his carers to discontinue providing him with nutrition and hydration he chose not to exercise this right and eventually died from pneumonia in September 2009. Meanwhile, in New Zealand, Mrs Page's decision to refuse food and water was judged by most as the right of any competent person upheld by section 11 of the New Zealand Bill of Rights. Mrs Page died of the effects of starvation in March 2010.

These two cases have been the occasion of a renewed discussion in Catholic circles. This article, an edited version of a longer discussion paper authored by Melbourne Catholic ethicist Associate Professor Nicholas Tonti-Filippini, is timely and valuable for the way in which it raises a number of additional questions that follow from a patient's decision to refuse nutrition and hydration; questions that have by and large not been well aired in the coverage of these and other similar cases; questions that are particularly relevant for staff and management of Catholic health-care facilities.

The Nathaniel Centre is grateful to Associate Professor Tonti-Filippini for his permission to publish this edited version of his discussion paper.

Gaps in the Discussion

I support the conclusion that a Catholic facility should not refuse to care for someone in the circumstances of the Rossiter case in Western Australia, but the matter is much more complicated than some suggest. Further, it is also my view that a Catholic facility should not refuse to care for a patient even if the facility thought that the patient's refusal was suicidal. In my view that issue is not relevant to the care being offered. Even if the refusal is suicidal, the facility should continue to offer care and by their solicitude for the patient seek to persuade them to change their view. Causing suicidal patients to be discharged would only surrender them to circumstances that may do less to try to persuade them to accept care that is in their best interests.

I am concerned about some gaps in the discussion such as:

1. What is the obligation to provide treatment that is considered reasonable care when a patient or resident has refused that treatment, and what is the obligation to continue to care for the patient in other ways?
2. Should a Catholic facility provide palliative care, including pain relief to relieve distressing symptoms caused by dehydration or starvation, when the symptoms could be relieved by hydration or feeding?
3. Should a Catholic facility persist with the course of respecting the patient's (resident's) wishes when secondary psychiatric illnesses develop as a result of dehydration or starvation that preclude the patient from functioning competently or from being able to change her mind?
4. If the patient (resident) is incompetent, and the decision not to deliver hydration or nutrition is made by a legal representative, such as a guardian, person with an enduring power of attorney for medical treatment, or the senior available next of kin, or there is a legally valid and binding advanced directive or living will refusing nutrition and hydration, should the hospital comply with that request?
5. Does the fact that in most jurisdictions the law permits reasonable force to be used to prevent suicide change anything with respect to the refusal of medical treatment that is not overly burdensome or refusal to eat because the person wishes to die?

1. The Obligation to Provide Care

I am of the view that a Catholic facility should do their best to persuade a person who is refusing nutrition and hydration in order to die to change their mind. It should call upon the best of its counselling and other services to that end, but the facility should not act coercively and neither should it withdraw care. It has a duty of care to do the best by the patient and that includes seeking to persuade them of the right course of action. Withdrawing from care so that the patient is forced to be cared for elsewhere and perhaps somewhere that did not seek to persuade them to accept feeding, would not be in their best interests.

There are some who seem concerned that a course of action in which a hospital continues to care for persons refusing nutrition and hydration could be seen as cooperating with the evil of suicide by omission. In my view a hospital and its staff are restrained by a

person's refusal. The permission of the patient, explicitly or implicitly, directly or indirectly, is required for intervention other than emergency treatment. This view is supported by Pope Pius XII:

> "The rights and duties of the doctor are correlative to those of the patient. The doctor, in fact, has no separate or independent right where the patient is concerned. In general he can take action only if the patient explicitly or implicitly, directly or indirectly gives him permission."[1]

The issue for the facility and the treating team is different from the issue for the patient. When the treating team is confronted by a suicidal project, the problem is whether they have a right or a duty to provide treatment to prevent suicide. That issue is complicated by the fact that such intervention could only be taken against the patient's wishes. The treatment, then, is not straightforward. It is difficult to feed someone against their wishes as any parent of a two year old would testify. One way of achieving this would be by restraining the patient or resident, administering an anaesthetic and performing surgery to install a percutaneous endoscopic gastrostomy tube (PEG tube). Thereafter the PEG tube would have to be protected by physically restraining the patient from pulling it out or otherwise preventing its use. I would expect that such a course of forced anaesthesia and surgery followed by physical or chemical restraint would at least be regarded as "overly burdensome" and beyond the duty of care, even if not itself considered unethical as is suggested by the teaching of Pope Pius XII.

Force feeding the patient is thus excluded. The obligation to give witness to the truth is met by the concerted efforts of the staff to persuade the patient otherwise and by their continuing to provide care.

2. Palliative Care

A complication in the care of patients who refuse nutrition and hydration arises in regard to the moral acceptability of providing palliation to overcome the discomfort associated with dehydration or starvation, neither of which are comfortable ways to die.

Dehydration is the more problematic because it is associated with severe muscle cramps and severe headaches. Later, as the dehydration causes renal failure, other symptoms associated with the concentration of urea and other blood toxins and imbalance of electrolytes can make the patient nauseous, suffer itch and other pain. There are also cognitive effects that I discuss later.

Starvation is uncomfortable initially as the patient feels hunger, but once that hurdle is crossed at around two weeks, a state of lethargy[2] can prevail as organ shrinkage gradually

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[1] Pope Pius XII "Address to 1st International Congress on Histopathology of the Nervous System" 14/9/52

[2] Dlugoborski, Waclaw, and Franciszek Piper (eds.) (2000). *Auschwitz, 1940-1945: Central Issues in the History of the Camp* Five Vols. Oświęcim: Auschwitz-Birkenau State Museum.; Mattson MP (2005). "Energy intake, meal frequency, and health: a neurobiological perspective". *Annu. Rev. Nutr.* **25**: 237–60

occurs. The danger of major organ failure develops, including the possibility of liver or cardiac failure, and that may involve pain and distress.

Palliative care in circumstances in which the patient's discomfort would best be managed by hydration and or nutrition might be seen as cooperation in a suicidal project. It could be argued that the patient's suicidal project is being facilitated by the palliation of the distressing symptoms that follow from being deprived of proper hydration and nutrition.

Faced with an isolated case, it may well be legitimate to provide palliative care on the basis that the pain is genuine and the patient is in need of pain relief and the alternative of administering food and water is not available to the staff because it is refused. It is the issue of public scandal that makes the matter troubling. However, the issue of scandal may be dealt with by the witness that is given to the view that ending one's life in this way is immoral and by continuing efforts to persuade the patient to accept food and water.

3. Secondary Psychiatric Illness

Withdrawal of nutrition and hydration leads to secondary mental illness: The effects of severe dehydration include loss of comprehension, confusion, disorientation[3]; the cognitive effects of starvation are difficulty concentrating, apathy and poor judgment. The emotional effects of starvation may be depression, anxiety, irritability, anger, changing moods, psychotic episodes, withdrawing from friends and family and changes in personality.[4]

The patient will, in either case, pass through a phase before death in which he or she is not capable of making decisions and may be unable to review the decision to withdraw hydration and or nutrition. At that time the matter becomes an issue for a represented decision, either involving an advanced directive or a third party to make decisions on the patient's behalf. The rights and obligations of a third party, as a matter of morality or of law, may be different from those of the competent patient. The status of what may amount to a suicidal advanced directive may also be problematic.

From the perspective of those who have embarked on a course of action to care for the patient and who seek to persuade the patient to accept food and water, the loss of capacity to decide otherwise is problematic. In the Rossiter case, having won the case granting him a right not to be receive food and water, Mr Rossiter decided not to exercise that right. That someone might refuse and then later change their mind, especially as the symptoms became difficult, cannot be excluded. Therefore the earlier refusal cannot be considered to be binding once the patient has become incompetent and unable to reverse the decision.

4. Represented Decisions

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[3] http://nutrition.suite101.com/article.cfm/the_effects_of_dehydration#ixzz0lE4fAb4z

[4] http://www.ehow.com/facts_5526044_physical-side-effects-starvation.html

The question of mental competence, whether prior to a person's decision to refuse nutrition or as a consequence of such a decision, raises an issue about the rights and obligations of representatives and whether their decisions can be rejected.

In the same address referred to above, Pope Pius XII notes:

> "What We say here must be extended to the legal representation of the person incapable of caring for himself and his affairs: children below the age of reason, the feeble-minded and the insane. These legal representatives authorized by private decision [power of attorney] or by public authority [guardanship], have no other rights over the body and life of those they represent than those people would have themselves if they were capable. And they have those rights to the same extent. They cannot, therefore, give the doctor permission to dispose of them outside of those limits."

Morally the representatives have a moral obligation not to bring about the death of the patient by omission, and an obligation to provide care, though not care that is ineffective or overly burdensome.

As a matter of law, in Australian jurisdictions the representatives have obligations to act in the best interests of the patient and the latter term has statutory definitions that vary from State to State. The Victorian Definition is:

> …. for the purposes of determining whether any special procedure or any medical or dental treatment would be in the best interests of the patient, the following matters must be taken into account-
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> (a) the wishes of the patient, so far as they can be ascertained; and
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> (b) the wishes of any nearest relative or any other family members of the patient; and
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> (c) the consequences to the patient if the treatment is not carried out; and
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> (d) any alternative treatment available; and
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> (e) the nature and degree of any significant risks associated with the treatment or any alternative treatment; and
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> (f) whether the treatment to be carried out is only to promote and maintain the health and well-being of the patient; and
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> (g) any other matters prescribed by the regulations.

The law in relation to representatives is thus different from the rights of the patient. The patient can refuse treatment that is in his or her best interests, but the representative may not. Thus for instance a patient could make an altruistic choice, such as to donate a kidney while alive, but someone acting on his or her behalf could not do so. The normal course of action to take in the event that a representative is acting against the interests of a patient is to apply to have their status as representative reviewed by a Court or Tribunal.

The law would thus seem to differ from the teaching of Pius XII because he clearly taught that the representative has the same obligations as the patient. There is ambiguity, however, as to whether a third party who acts outside the moral limits has the same status as a competent patient. In other words, might health professionals be able to override the represented decision of a third party even though they cannot do so when it is a matter of the patient making their own decision.

In the Australia context, I would advise that representations by third parties that are not in the best interests of the patient should be taken for revision to a Court or Tribunal.

This would then raise the prospect that, when dehydration or starvation has reached a point that the patient is no longer considered competent, a decision should be sought from a representative and challenged if he or she opted for death by omission.

The above analysis raises a further prospect of complication in situations where a patient may have documented their wish to refuse nutrition or hydration in an advanced directive or living will. It would be a matter for a Court or Tribunal to determine the status of such a directive. In these situations a key issue to be considered is whether the patient's project is suicidal or whether the representative's project is homicidal. (See the discussion below)

One of the issues that the Courts will need to resolve is that an approval of suicidal uses of advanced directives would make it very likely that people with suicidal intentions, including young people, would complete advanced directives refusing any attempt to reverse the consequences of their action.

Usually in those circumstances the health professionals will take emergency action to reverse the suicide attempt. The issue about advance directives and refusal normally arises later when emergency treatment has stabilised the situation and there is time to consider the issues. However, it is not unlikely that the patient's representative might be standing by the bedside refusing all emergency treatment while waving the documents endorsing that decision.

The existence of an advanced directive would require legal advice. In Australia they have a different statutory status in the different jurisdictions. In Queensland they cannot be used to refuse food and water[5] and in most States they do not have a statutory status. The refusal of medical treatment in Victoria is limited to a current condition and a lapse into incompetence would be a different condition. The structure of the Victorian

[5] *Powers of Attorney Act 1998* (Qld) and the *Guardianship and Administration Act 2000* (Qld)

legislation is to make decisions on behalf of incompetent people dependant on the appointment of someone to make decisions on their behalf; the Parliament at the time explicitly rejected the notion of giving a statutory status to an advanced directive. That was the purpose of limiting the refusal to a current condition.

Some have argued that advanced directives have common law validity, but that has been untried in Australian jurisdictions.

I would advise that when faced with an advanced directive refusing food and water, hospitals or other care facilities should seek legal advice as to whether its staff may rely on the law that allows them to intervene, forcibly if necessary, when there is a reasonable suspicion of suicide (see below).

5. Use of Reasonable Force to Prevent Suicide

In Australian jurisdictions the criminal law makes provision for reasonable force to be applied to prevent suicide when there are reasonable grounds for believing that the patient is attempting suicide. In the circumstances of imminent death, it is unlikely that a refusal of treatment, including nutrition and hydration, would be regarded as suicidal, but refusal of nutrition and hydration by an otherwise well person would be likely to be seen as suicidal and may justify intervention to prevent suicide.

For instance, the Victorian *Medical Treatment Act* (1988) explicitly mentions that the Act does not affect the operation of section 6B of the *Crimes Act* with respect to aiding and abetting suicide and section 463B of the *Crimes Act* which provides that every person is justified in using such force as may reasonably be necessary to prevent the commission of suicide or of any act which he believes on reasonable grounds would, if committed, amount to suicide. It was clearly the intention of the Victorian Parliament not to allow the law to be used to facilitate suicide.

The legal issue of using reasonable force to prevent suicide is relevant to circumstances in which a patient's refusal of what is considered ordinary or non-burdensome care would result in death. It has a particular application when the patient reaches a stage of weakness and inability to make decisions when care could be provided without difficult and the hospital would seem to have a duty of care to do so.

Conclusion

It is my preference that a Catholic facility make clear its willingness to care for a person in circumstances where they refuse to take nutrition and hydration while continuing to seek to persuade them to accept nutrition and hydration. Even if the patient's intent is suicidal, it is my view that this response offers the best chance of saving life. Provided that every reasonable effort is made to offer nutrition and hydration, then I would not consider such care to be cooperation in suicide.

There should always be a presumption in favour of nutrition and hydration. A Catholic facility should always be on the side of supporting the patient to accept it, even if it is not obligatory. At the same time it should be made clear that if the means are overly

burdensome nutrition and hydration is not obligatory and a person has the moral right to refuse it.

In circumstances where a secondary psychiatric illness develops and where there is representation by way of a third party or advanced directive not to accept food and water, then legal or tribunal advice should be obtained as to whether this is in the best interests of the patient. Likewise advice should be taken in regard to the relevance of the law that allows for the use of reasonable force to prevent suicide.

If it is the case that the law upholds a represented decision to refuse food and water, then the facility and the professional staff have an obligation not to give scandal. They should make it clear that they do not endorse the refusal of treatment which aims to cause death by discontinuing care that could readily be provided without causing undue burden. They ought also to continue to offer nutrition and to seek to persuade the patient or the representative to accept that care. But their obligation would not seem to extend to demanding the discharge of the patient or to the forceful implementation of food and water. To do so would risk the capacity of the facility and the staff to continue to provide care for the person involved.