

# Advance directives and older people: ethical challenges in the promotion of advance directives in New Zealand

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## ABSTRACT

In New Zealand an advance directive can be either an oral statement or a written document. Such directives give individuals the opportunity to make choices about future medical treatment in the event they are cognitively impaired or otherwise unable to make their preferences known. All consumers of health care have the right to make an advance directive in accordance with the common law. When we consider New Zealand's rapidly ageing population, the fact that more people now live with and die of chronic rather than acute conditions, the importance given to respecting autonomous decision-making, increasing numbers of individuals who require long-term residential care, and financial pressures in the allocation of medical resources, there would seem to be a number of compelling reasons to encourage individuals to write or verbalise an advance directive. Indeed the promotion of advance directives is encouraged. However, caution should be exercised in promoting advance directives to older people, especially in light of several factors: ageist attitudes and stereotypes towards them, challenges in the primary healthcare setting, and the way in which advance directives are currently focused and formulated. This paper considers some of the specific challenges that need to be addressed if the promotion of advance directives are to improve outcomes of patient treatment and care near the end of life.

With tremendous advances in medicine's ability to cure and manage disease, ameliorate the adverse consequences of injury, and prolong life and delay death, knowing what individuals want regarding medical treatment and care has become an increasingly important aspect in medicine.

Advance directives, advance care treatment plans, 'living wills', durable powers of attorney, healthcare proxies, and various documents that indicate a patient's preferences about specific medical treatment (for instance, a surgical consent form, or a not-for-resuscitation form) allegedly give competent patients 'choice, certainty and a degree of control'<sup>1</sup> regarding medical decisions in health care.

An advance directive can be either an oral statement or a written document that gives individuals the opportunity to state their choices and preferences about future medical treatment in the event they are cognitively impaired or otherwise unable to make their preferences known. They offer individuals a way of ensuring that their preferences about medical treatment and care will be acknowledged and (hopefully) respected in the

future: an extension of one's self-determination when autonomous decision-making is no longer possible. Although broadly speaking, advance directives can instruct for different healthcare settings (for instance, in advance of surgery or childbirth), they are primarily understood as documents that affirm an individual's decisional authority about life-sustaining treatment at the end of life.<sup>2</sup> In principle it would seem that they ought to be encouraged when the goal is to improve outcomes of patient treatment and care at the end of life.

Yet advance directives have been severely criticised by many commentators. More than a decade ago, Tonelli<sup>3</sup> claimed that advance directives do not appear capable of fulfilling the task of giving competent individuals control over healthcare decisions in the event they were no longer competent to do so. He suggests it is time to 'pull the plug' on them. He claims that instructional directives 'have virtually no value in decision making for the incompetent patient while proxy directives remain practically useful but do not represent a true extension of patient autonomy'.<sup>3</sup> Perkins<sup>4</sup> argues that they are a fundamentally flawed concept: 'advance directives simply promise more control over future care than is possible'. Other commentators agree.<sup>5,6</sup>

If it is important for health professionals to know what patients would want at the end of life in the event they are unable to make their preferences known, what are some of the challenges that confront us if advance directives are to be actively promoted to older individuals? After briefly setting the context in New Zealand, I will consider three issues that present challenges to the promotion of advance directives: (1) the problem of ageism and ageist attitudes; (2) challenges in the general practice setting; and (3) the way advance directives are currently focused and formulated.

## ADVANCE DIRECTIVES IN NEW ZEALAND

In New Zealand, the Code of Health and Disability Services Consumers' Rights (hereafter, the Code), states that all consumers of healthcare 'may use an advance directive in accordance with the common law'.<sup>7</sup> Right 7(7) of the Code states that 'every consumer has the right to refuse services and to withdraw consent for services'. These rights are recognised in section 11 of the New Zealand Bill of Rights Act 1990, which states that 'everyone has the right to refuse to undergo any medical treatment'.<sup>8</sup>

An advance directive can be either verbalised or written and is only intended to come into effect

when the individual is incompetent. They do not have to be signed by the individual; neither do they need to be witnessed by a health practitioner, solicitor or justice of the peace. An advance directive is valid when four key elements are satisfied: the individual was competent to make the particular decision(s), they were free from undue influence when they made their decisions, they were sufficiently informed to make the decision, and they intended the directive to apply to the present circumstances. When all four elements are satisfied an advance directive is legally binding.

### AGEING POPULATION AND AGEISM

As elsewhere in the industrialised world our population is rapidly ageing.<sup>9</sup> Currently, approximately one in eight New Zealanders is aged 65 years and older. In 20 years it has been predicted that one in four New Zealanders will be aged 65 years and older.<sup>10</sup> During the same period 'the proportion of the population aged 85 years and over will increase more than fourfold, from approximately 1.3% to 5.5%'.<sup>11</sup>

It is well established that dementia rates increase in prevalence with age. Currently, approximately 40 000 New Zealanders live with dementia. By 2050 'it is estimated there will be over 44 000 new cases of dementia a year'.<sup>12</sup> Although dementia should not be linked exclusively to old age, the prevalence of people with dementia increases considerably after the age of 70 years. From the age of 75 years, the number of New Zealand women with dementia significantly exceeds that of men.<sup>12</sup>

When we consider New Zealand's rapidly ageing population, the fact that more people now live with, and die of, chronic rather than acute conditions, the increasing numbers of New Zealanders requiring long-term care, the importance given to respecting autonomous decision-making, and increasing financial pressures in the distribution of healthcare resources, there would seem to be a number of compelling reasons actively to encourage individuals to write or verbalise an advance directive.

Indeed the promotion of advance directives is encouraged. Professional societies and consumer organisations such as Alzheimer's New Zealand Incorporated and The Voluntary Euthanasia Society of New Zealand recommend that individuals think about what they want for the future in terms of medical treatment. Both organisations encourage individuals to complete an advance directive form. The Mental Health Commission and the NZ Medical Association also provide extensive information about advance directives and both have detailed forms on-line for individuals to complete.<sup>13 14</sup>

In 2005, Dr Michael Cullen, then Minister of Finance, indicated that spending in health and education has outpaced economic growth, and that the present rate of growth in health spending, which has grown at approximately 7% a year over the past decade, is unsustainable.<sup>15</sup>

'A substantial increase in the proportion of health care resources consumed by the 65+ age group, relative to younger age groups, appears inevitable'.<sup>16</sup>

In light of this it is not implausible to suggest that moves to encourage the writing and/or verbalisation of advance directives will be directed at older New Zealanders. As the focus of advance directives is predominantly situated about withholding or withdrawing treatments at the end of life—when healthcare costs are often very high—it is not difficult to see that older individuals may come to view the active promotion of advance directives with some suspicion and scepticism. They may well be viewed as a cost containment issue; more about justifying the rationing of healthcare resources than truly reflecting an

individual's self-determined decision-making about medical treatment and care.

Of course it is self-evident that healthcare resources are finite. Few countries can provide limitless healthcare resources to their citizens. It is probably also self-evident to state that many older individuals will recognise the need for prudent financial management of these resources. Yet the concerns that advance directives could be viewed by older individuals as a way for health professionals to justify reducing health care to them must be taken seriously. This is especially so when seen through the lens of ageism and the way in which attitudes and stereotypes towards and about older individuals may have a direct impact on the medical treatment and care they receive.

Internationally, ageism within the healthcare sector is well documented.<sup>17–23</sup> The term ageism 'refers to generalisations about people who fall into a similar age bracket with these generalisations widely argued to be negative in regard to older people'.<sup>24</sup>

In their review of the literature exploring nurses' perceptions about the care of older individuals, Rees and colleagues<sup>23</sup> claim that 'ageism is probably the major source of ethical issues in the care of older patients'. They reflect that many nursing students claim that the care of older people is 'uninteresting' and 'unchallenging'.<sup>23</sup> In their study of nurses attitudes towards working with older individuals, Pursey and Luker<sup>25</sup> note that although many nurses make a positive choice to work in aged care, evidence from several studies suggests that 'the care of older people remains an unpopular choice for nurses'.

Reflecting on discriminatory practices and attitudes towards older people, Gething and colleagues<sup>24</sup> note that, 'older people are seen as 'bed blockers' who require longer hospital stays and reduce a hospital's apparent efficiency, and as failures because they cannot be cured'. They concluded from their study that stereotypes among nurses about older individuals were generally negative and the capabilities of older people were devalued and underestimated.

As nurses are the healthcare professionals most likely to be working with older persons—in hospitals, nursing homes, in primary practice, and as district nurses in the community—their attitudes towards older patients are crucial in the delivery of good medical care. Furthermore, as the population becomes increasingly older and their healthcare needs escalate, society will require additional healthcare professionals working in elder care.

Evidence suggests that cardiological investigations are less likely to be offered to older people (older women in particular) than younger persons even though the prevalence of severe cardiovascular disease is higher among older people.<sup>19 26</sup> Older people are also less likely to receive hip and knee replacements even though they have a greater need for them.<sup>27</sup>

What can be said in light of ageist attitudes and stereotypes towards older individuals in the context of encouraging the completion of advance directives? If the general attitude towards older people was that they were 'bed blockers', that their treatment and care was of low status, that they were likely to be treated less vigorously than younger people, and that as they were unlikely to be cured they were viewed as failures, then the promotion of advance directives could be seen as a cynical move to shift the burden of medical decision-making on to patients and away from healthcare professionals.

When ageist attitudes are prevalent in the medical setting, it is not difficult to imagine older individuals being encouraged to articulate (clearly) that they do not want 'this' or 'that' medical treatment. Rationing health care to older patients could then be

justified on the basis that 'this is what the patient requested in their advance directive'.

### CONCERNS IN THE GENERAL PRACTICE SETTING

In 1997 Robin Stent (then New Zealand's Health and Disability Commissioner) highlighted the need for general practitioners (GPs) to be involved in advance directive consultations.<sup>28</sup> It has also been claimed by Clements<sup>29</sup> that 'primary care facilities are likely the best place to have these discussions before they become medically necessary'.

Although primary care would seem to be an obvious setting in which to initiate advance directive conversations, I believe a number of challenges lie in this environment, particularly in terms of time constraints and ensuring GPs are adequately skilled at communicating with older persons about life-sustaining medical treatment issues. Furthermore, there are also a number of concerns about: high levels of uncertainty regarding some patient's future medical needs; effectively conversing with individuals for whom English is a second language; recognising that many cultures prefer collectivist decision-making (especially at the end of life) instead of an individualistic approach; increasing numbers of chronically unwell patients who are not accepted on hospital waiting lists; and the fact that New Zealand Maori obtain GP care less frequently than do New Zealand Europeans and they experience delays in getting GP care.<sup>30 31</sup> In the following discussion, I will focus on time constraints and communication skills.

In New Zealand the booked time for a GP consultation is 15 min.<sup>32</sup> In comparison, the UK, The Netherlands and Australia have average consultations times ranging between 10 and 12 min.<sup>33</sup> It would seem self-evident that effective education and communication between a GP and older patient is crucial to ensure that patients are adequately knowledgeable so they can articulate informed advance directives.

What exactly would a consultation tasked with discussing an advance directive entail? Assuming GPs are skilled and comfortable discussing them with their older patients and patients consider the topic personally relevant to them, the practitioner would need to be proficient at discussing likely future scenarios and various medical interventions at the end of life. This would include knowing about the likely outcomes of treatment (for instance a 'not-for-resuscitation' order), whether treatment would achieve specific outcomes, and the benefits and burdens of medical interventions. Although the predicted pathway of a patient's chronic condition may be estimated fairly reliably, for many patients with a number of co-morbidities, the kind of decision-making they would need to consider in order to state their preferences for medical treatment accurately may be very difficult to determine.

Crucially any discussion with a GP would also need to address the patient's concerns for self: being in control of major life decisions; the desire to maintain a meaningful existence including one's sense of dignity and respect as well as one's place in life; quality of life factors and the degree of burden and suffering.<sup>34 35</sup>

In a study undertaken by Tulsy and colleagues,<sup>36</sup> they note that the physicians involved in discussing advance directives with their patients 'rarely asked patients to define a good quality of life, and none enquired about what constitutes a burden, even though not wanting to suffer or be a burden was frequently stated as a reason for refusing life-sustaining treatment'. They concluded that 'exhortations to increase the number of outpatient discussions about advance directives are not likely

to improve patient care unless we learn how to improve communications and teach practitioners these skills'.<sup>36</sup>

The general practice setting would appear to be an obvious place to initiate discussions with patients about what their preferences may be about medical treatment and care at the end of life; however, it is doubtful such discussions would be successful given the current time constraints on GP consultations. It is likely that several 15-min consultations would be required (at a minimum) to discuss the planning and completion of an advance directive adequately. Ensuring GPs are adequately skilled at communicating with older persons about end-of-life issues so that they can make informed decisions and recognising uncertainty regarding some patient's future medical needs indicates that the promotion of advance directives in the general practice setting requires further research and deliberation.

### ADVANCE DIRECTIVES AND THEIR CURRENT FOCUS AND FORMULATION

As noted earlier, in New Zealand an advance directive can be either written or verbalised. Individuals do not have to sign their directive, neither do they need to be witnessed by a health practitioner, solicitor or justice of the peace. There is no requirement that they are regularly reviewed and re-confirmed (either signed or verbalised). An advance directive can be written down or verbally stated by an individual without their having discussed their particular medical issues with a health practitioner.

It is thus not unreasonable to assume that directives may be based on assumptions that are false, information that is incorrect, or on incomplete information about the risks and benefits of any future medical treatments or interventions. An advance directive may be vague and ultimately worthless however well intentioned.

There is reason to be circumspect of verbal advance directives especially potential conflicts of interests from others. It is not implausible to imagine a family member (with a vested interest in the patient's estate) claiming that the patient had verbalised no antibiotics were to be administered in the event she (the patient) developed pneumonia. Although an enduring power of attorney cannot, 'refuse consent to the administering to that person of any standard medical treatment or procedure intended to save that person's life or to prevent serious damage to that person's health',<sup>37</sup> a verbal advance directive is legally binding when four key elements are satisfied: the individual was competent to make the particular decision(s); they were free from undue influence when they made their decisions; they were sufficiently informed to make the decision; and they intended the directive to apply to the present circumstances. One wonders how a health professional determines the validity of a verbal advance directive if they had not known the patient previously. How, for instance, could one be certain undue influence had not occurred, that the patient had been sufficiently informed and competent, and that they wanted the instructions to apply in the current circumstances? It is perhaps self-evident to claim that verbal advance directives should be treated cautiously by health professionals when articulated by family members, as the potential for abuse is obvious.

Of course it is also possible that a written advance directive could be presented as the patient's own when it is not: the patient's signature is not required for an advance directive to be valid. While one could object that a health practitioner may, and in fact should, look beyond the instructions of a verbal and/or written directive and take into consideration the views of other

health professionals with whom the patient had a relationship, or the extended family in helping to determine the validity of a directive, one may then reasonably question the purpose of an advance directive in the first place; either it stands as a competent patient's preferences or it does not. If physicians feel compelled to rely on the observations of others, the value and purpose of an advance directive becomes questionable.

Moreover a patient's verbal preferences concerning medical treatment should not be left to the health practitioner's memory: the information is too important to be left to recall. Therefore, it is not unreasonable to claim that verbal directives should be formally written in patients' medical records.

Although these latter concerns have relevance for all individuals writing or verbalising any kind of instructional directive, when seen in conjunction with widespread ageist attitudes and the particular challenges that confront the general practice setting, we cannot ignore the implications the promotion of advance directives has for older individuals.

## CONCLUSIONS

In theory an advance directive offers a 'relatively simple and morally defensible way of guiding medical decision-making in accordance with the formerly competent person's values and beliefs' (J Manning, unpublished conference paper). In principle they are to be encouraged when the aim is to improve the outcomes of patient care—especially near the end of life.

Yet ageist attitudes and stereotypes about older individuals, time constraints and the challenge of effective communications skills about end-of-life issues in the general practice environment and concerns about how advance directives are currently focused and formulated suggest a need to proceed carefully in actively and widely promoting them to the older population. This has particular relevance for policy makers, GPs, healthcare professionals working with older individuals, and medical educators involved in the training of healthcare professionals (both at undergraduate and postgraduate levels across the medical spectrum).

The way in which advance directives are promoted to older people needs careful attention if they (instructional directives) are to realise their goal of improving outcomes of patient care at the end of life. Despite the fact that an advance directive is most obviously relevant to older persons, they are pertinent to all individuals who have informed preferences about medical treatment. Yet locating the primary healthcare setting as the most appropriate place to initiate conversations about advance care planning brings with it a number of practical challenges. These include training GPs to communicate relevant information about medical choices at the end of life with older patients in the context of advance care planning, recognising and addressing attitudes and stereotypes towards older individuals at both the institutional and personal level, coping with increasing numbers of people who wish to discuss their advance care plans, formalising preferences in patients' medical notes, and funding the development and promotion of advance directives. All this requires a serious commitment from the government to invest in training and funding at the primary healthcare level.

While concerns about unscrupulous relatives misrepresenting the medical preferences of an individual near the end of life may be comparatively rare, the ways in which advance directives are currently expressed ought to be reassessed in the light of potential abuses.

Although one can envisage possible abuses at the bedside where a family member (or members) has self-interested motives

in an older person receiving or not receiving certain medical treatment, one can also see potential challenges in other settings. For instance, in the emergency environment where a paramedic is approached with a verbal directive allegedly instructing for the withholding of blood products to an unconscious patient. It would seem advisable, given the potential implications for older persons, that any instructional directives be formally written down, either in an individual's medical records, or in a signed and dated document that is known to family members and health professionals (ideally accessed electronically). This would go some way to reassure physicians and patients that the preferences expressed were accurately represented. Considering that acting on a person's preferences could result in a hastening of their death, a reasonable degree of certainty about the provenance of those preferences would seem essential.

If advance directives are to be viewed positively by older New Zealanders (and subsequently completed), a number of challenges need to be addressed before their active and widespread promotion is encouraged. Otherwise, at best they may be seen as irrelevant, at worst as cynical and possibly abusive attempts to justify healthcare rationing near the end of life.

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