



RESPECTING PATIENT CHOICES

LITERATURE REVIEW

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This is a literature review prepared for the Respecting Patient Choices project, Austin Health, by Health Issues Centre (Dr Chris Atmore and Dr Charin Naksook). The review focused on the literature about cultural issues and advance directives (ADs)/advanced care plans, including cultural attitudes and practices in relation to death and illness.

1. EXECUTIVE SUMMARY

Ninety articles were reviewed, and seven key themes were identified, along with some key lessons and suggestions for Australian research.

1.1 Impact of culture and ethnicity

Culture and ethnicity profoundly influences how people treat illness and death, and so whether they regard advance directives as useful and positive. Non-Anglo groups tend to have a lower awareness and take-up rate of ADs compared to Anglo groups.

1.2 Cultural diversity

Cultures vary considerably in people's attitudes and practices concerning illness and death, and so the appropriateness of ADs and the best strategies to encourage implementation also vary.

1.3 Support for and barriers to advance directives

Why a particular culture or community may support or oppose the use of ADs are grounded not only in differing health values and practices—particularly religious beliefs—but are also connected to specific historical and socio-political contexts.

1.4 Western autonomy versus family-based decisions

Many non-Western cultures emphasise the importance of the family over the individual, and this affects their attitudes to whether ADs are appropriate, particularly in their standard Western form. However, this does not necessarily mean that control and autonomy are not important; modified ADs, or related concepts and tools such as power of attorney, may still have a role to play. Western health professionals should also be wary of generalisations.

1.5 Cross-cutting layers of culture

There is great variation within cultures, including subcultures and power-connected differences such as age, gender and sexual identity, which can shape beliefs and practices concerning illness, death, and ADs. Cultures and communities can also vary across space (e.g. urban compared to rural) and over time, and health professionals should be wary of stereotyping.

1.6 Values, attitudes and practice of health professionals

The attitudes and practices of health professionals have an important influence on how ADs are publicised and used, and stem not only from the professional's particular sericultural location, but also from their personal values. This means that professionals' views and practices may vary as much as patients' and families', and professionals need to be aware of the impact of their own beliefs on their practice in relation to ADs.

1.7 How to better publicise and implement ADs

While research results are often mixed about 'what works' in relation to publicising and implementing ADs, some US evaluation work offers useful insights. Strategies involving local communities in education initiatives and the provision of specific resources such as videos, kits and pamphlets have all proved useful when geared to particular contexts.

1.8 Key lessons

Advance directives are subject to significant cultural resistance that cannot be simply explained as lack of knowledge; it may be associated with lack of utility. Some of the literature suggested that the focus of ADs might be better shifted from death and broadened to include non-disclosure and other alternatives such as recognition of family surrogates and durable power of attorney.

1.9 Future research

Areas needing more research include cultural complexity and conflict within cultures, especially as communities enculturate in Australia, the potential impact on these communities of broadening the focus of ADs, and attitudes and practices regarding ADs among different health professionals in Australia. There is a particular need for rich qualitative data in relation to the use of and attitudes to ADs, proxies etc. by different cultural groups in Australia. Research could also investigate how successful US techniques might be extrapolated to Australia, and what useful techniques might be borrowed from outside the health field. Australian action research would then be needed to pilot some approaches in depth.

2. SEARCH STRATEGY

2.1 Summary

The literature review is based on 90 articles. These were obtained using five search engines, the results of a search by Austin Health, and snowball additions (see Table below).

Search engine	No. of articles obtained
Informit	9
Expanded Academic ASAP	16
BioMed Central	2
CareSearch	30
Medline	6
Total via search engines	63
Austin search	19
Snowball additions	8
GRAND TOTAL	90

[For more detail, see below and Appendix 1]

2.2 The search strategy

Search engines were accessed via La Trobe University Library. Citations were also obtained via the results of an Austin search sent to us in Endnote. Additional articles were obtained through a 'snowball' technique where they appeared key to discussion in existing articles.

Potentially relevant articles that appeared to make a contribution, and were published in refereed journals, were selected for downloading or obtaining in hard copy form. All articles obtainable via La Trobe Library were read. Articles not available from La Trobe University were accessed via the Austin Library (if they were research studies).

All of the articles used in the literature review, except those from the Austin database, were entered into an Endnote database (attached). The Austin references are briefly listed in Appendix 2.

The articles selected were categorised as follows:

Type of article	Number
Research study	49
Literature review	10
Essay/discussion paper	11
Case study	7
Evaluation of tool	9
Opinion/editorial	4
TOTAL	90

[For more detail, see Appendix 3]

The majority of articles selected were based on research studies. Research with sound and well-defined methodology, either in quantitative or qualitative procedures, was given priority. For example, research using case-control

intervention, structured questionnaires, ethnographic interviews or focus groups, with a rationale for such a methodology, sample size and sampling technique, and explicit aims were considered strong studies. Essays, discussion papers and opinion pieces were largely avoided, except for those selected for this review that were linked to research or were well supported by literature.

A table summarising the methodology of each research study and evaluation is attached as Appendix 4.

Charin Naksook and Chris Atmore also attended a half-day workshop on Palliative Care and Cultural Diversity run by the Centre for Culture Ethnicity and Health on 18 October 2006. The workshop largely confirmed initial findings from the literature searches.

2.3 Limitations of the strategy

The restriction to refereed journals meant that some of the more useful aspects of the grey literature may have been missed; for example, several pieces regarding Aboriginal people. While not affecting Australian literature, some potentially useful articles were unavailable due to limitations of the La Trobe University Library and the funding available for loans via the Austin Library.

3. FOCUS OF THE ARTICLES

A few articles referred to or researched Australian issues, but most focused on the United States, with the remainder distributed across a range of countries and regions.

Country focus	No. of articles
United States	45
Australia	12
Other (including multi-country studies)	28
Not specified	5
TOTAL	90

[For more detail, see Appendix 5]

The subjects of articles ranged from national general populations to specific communities; and from patients and caregivers to health professionals. For more detail, see Appendix 6.

4. MAIN THEMES OF THE ARTICLES

The literature search revealed the following themes:

4.1 Impact of culture and ethnicity

Culture profoundly affects the way people view and handle death, and so too their attitudes to, and practices regarding, advance care directives/advance care plans¹ (e.g. Braun et al. 2001; Burchardi et al. 2005; Callahan 1995; Candib 2002; Degenholtz et al. 2002; Duffy 2000; Dula 1994; Eleazer et al. 1996; Hopp 2000; Kiely et al. 2001; Kwak and Haley 2005; Miccinesi et al. 2005; Morrison et al. 1998; Owen et al. 2001; Papadatou et al. 1996; Perkins et al. 2002; Perkins et al. 2004; Romero et al. 1997; Vincent 1999).

Choices in advance directives may be more related to ethnicity and culture than to age, education or socio-economic variables (Baker 2002). For example, ethnicity is the most important factor contributing to patients' attitudes towards being told the truth about the diagnosis and prognosis of a terminal illness (Blackhall et al. 2001).

Advance directives have a low take-up rate and awareness among non-Anglo groups, although people are not necessarily negative when they do find out about them (Dupree 2000; Kwak and Haley 2005; McAdam et al. 2005).

4.2 Cultural diversity

Respectful communication in broaching the subject of ADs is important, but cultures also vary in terms of the type of directive that works best. For instance, some communities do not believe that written advanced care directives are important. In Japan, a written legal directive may be associated with 'rights talk' and is thus seen as conflict-orientated (Akabayashi et al. 1999; Akabayashi et al. 2003). Other cultures also associate directives with conflict (Bowman and Singer 2001), or with an inappropriate focus on personal control, which is also regarded as futile (Dupree 2000; Searight and Gafford 2005b).

This may mean that for some cultures or ethnic groups, any efforts to tailor an appropriate advanced care planning system may be wasted; for example, 'Our initial objective was to develop a culturally appropriate Chinese advance directive document, but this proved to be a fruitless endeavour' (Bowman and Singer 2001: 461).

Other cultures may have a growing awareness of and interest in ADs, but wish to use them differently from their standard Western form, focusing on a more informal and surrogate function, and taking a situational decision-making stance (Akabayashi et al. 1999; Akabayashi et al. 2003; Azoulay et al. 2003; Kiely et al. 2001; Sittisombut et al. 2005). Some prefer an oral approach (Sittisombut et al. 2005), which may be lengthy by Western standards; for example, the consultation process favoured by some Aboriginal communities (Maddocks and Rayner 2003; McGrath et al. 2005).

Some cultures have a much stronger 'Doctor knows best' attitude than (now) in the West, or at the least, patients are reluctant to question the physician's authority (Burchardi et al. 2005; Dalla-Vorgia et al. 1992; Giannini et al. 2003; Maddocks and Rayner 2003). It may be regarded as natural for a patient to be passive (Lim 1997; Mak 2001), which may also be linked to various forms of power and historical developments in the country of origin, such as a Communist regime (Bowman and

¹ Abbreviated as ADs.

Singer 2001; Ersek et al. 1998; McAdam et al. 2005; McKinley and Blackford 2001; Searight and Gafford 2005b). Some of the literature discusses these kinds of beliefs and practices in non-Western and non-Anglo countries such as Hong Kong and parts of Western Europe, especially Italy (Giannini et al. 2003; Miccinesi et al. 2005; Vincent 1999). However, these may also remain relevant for recent migrants to Australia, or even for some people who have lived in Australia for a long time.

Different cultures may also have different views on what is healthy, which may affect thinking around the right time to discuss ADs (Lim 1997). There are also different cultural experiences of, and attitudes to, pain and its management (Koenig and Gates-Williams 1995; Maddocks and Rayner 2003; McGrath et al. 2004).

4.3 Support for, and barriers to, advance directives

Several studies have examined attitudes and factors influencing the use of advance care directives (e.g. Eisemann et al. 1999). Identified barriers towards end-of-life care planning include lack of knowledge; although it often goes much deeper than this.

Some cultural groups may not support ADs because they want to provide all care possible in order to prolong life (Eleazer et al. 1996; Hopp and Duffy 2000; Kagawa-Singer and Blackhall 2001; although cf Dupree 2000). A family-centred decision-making style (see 4.4) also contributes to a low completion rate of advance directives (Baker 2002).

Both individuals and families may also fear the abuse of ADs (Kiely et al. 2001; Medvene et al. 2003; Sahm et al. 2005) or be generally suspicious of the health system due to their experience of oppression (Dupree 2000; Eleazer et al. 1996; Hopp and Duffy 2000; Kagawa-Singer and Blackhall 2001; McGrath et al. 2006; McKinley and Blackford 2001), often combined with a history of typically limited access to medical care and their religious and cultural beliefs (Eleazer et al. 1996; Hopp and Duffy 2000; Kagawa-Singer and Blackhall 2001; McGrath et al. 2006; McKinley and Blackford 2001).

Some non-Western cultures and religions are very reluctant to openly address and discuss death and dying, and believe that it can be harmful to the patient and even contagious. One such group is Taoists, which include many Chinese-Australians and Vietnamese Australians (Lim 1997; Mak 2001; McGrath et al. 2004; Mehta 1999; Ong et al. 2002). Acknowledging death may be seen as accepting that the patient is being punished for sins, as Buddhist Vietnamese-Australians may believe; or as bringing bad luck (Ong et al. 2002). Doctors may use euphemisms or avoid talking about diseases like cancer in countries such as Singapore, Hong Kong and Greece. In contrast, other cultures may view it as important to know if one is dying – for example, in order for a Muslim to fulfil the obligation for pilgrimage to Mecca (Ong et al. 2002).

As illustrated above, there is often a close relationship between cultural and religious beliefs in relation to death, dying and end-of-life decisions and care. Some religions, such as Orthodox Judaism and Jehovah's Witnesses (Carter 2002; MacLean 1986), will not hasten the end of life under any circumstances except if it is a by-product of alleviating pain. Others focus more on not prolonging dying and indignity (Carter 2002; Levi 1986; Ross 1998). Still others, such as Muslims, may hold that discontinuing life support is acceptable if there has been brain death (Ankeny et al. 2005; Gatrad 1994). Some cultures may wish to delay treatment so that it takes place at a more auspicious time (Ong et al. 2002). Specific treatments may be regarded with suspicion or as particularly harmful; for instance, for some Chinese, blood-taking is viewed as diminishing the life force (Ong et al. 2002).

Respecting these issues may be more important for the patient and family than specialised Western end-of-life care (Mak 2001).

4.4 Western autonomy versus family-based decisions

Patient control and autonomy are core values in Western bioethics and important components of end-of-life care. However, the autonomy of the patient as a decision-maker may not be relevant to culturally diverse groups of people (McLaughlin and Braun 1998; Volker 2005).

Many non-Western cultures emphasise the importance of the family (usually extended) over the individual (Kwak and Haley 2005). This can affect a range of matters; for example, for some Chinese and Japanese communities it is the family who is first told the news that a patient is dying (Akabayashi et al. 1999; Bowman and Singer 2001; Mak 2001; McAdam et al. 2005; Ong et al. 2002). Other areas affected include decisions about care and who gives it (Giannini et al. 2003; McGrath et al. 2006; Ong et al. 2002; Searight and Gafford 2005b). In one study, African-American caregivers were less likely to make a decision to withhold treatment at the time of death and less likely to have their relatives die in a nursing home; and reported less acceptance of the relative's death and greater perceived loss, whereas the white caregivers experienced more relief (Owen et al. 2001).

Sometimes the patient may never find out the details of their illness, or even that they are dying (Akabayashi et al. 1999; McGrath et al. 2004; Mystakidou et al. 2002; Ong et al. 2002). This may be regarded as appropriate by the family, and sometimes also by the patient (Brotzman and Butler 1991; Gabbay et al. 2005; Goldstein et al. 2002; Heath 2000; Kagawa-Singer and Blackhall 2001; Mystakidou et al. 2002; McGrath et al. 2004; Searight and Gafford 2005b). Health professionals may also be complicit (Akabayashi et al. 1999; Fetters and Masuda 2000; Ong et al. 2002; Searight and Gafford 2005a). This can be because directness is seen as cruel, with ambiguity tolerated and even viewed as appropriate (Akabayashi et al. 1999).

Disclosure and discussion can both be affected by these attitudes (Akabayashi et al. 1999; Dalla-Vorgia et al. 1992). For instance, some patients may guess their diagnosis but will not want to worry their family and therefore will not discuss it with them, instead maintaining a stoic front (Akabayashi et al. 1999; Ong et al. 2002). The family may be stoic also, due to a tradition of filial piety (Bowman and Singer 2001; Kagawa-Singer and Blackhall 2001; Ong et al. 2002).

However, Australian health professionals should beware of generalisations, because there is sometimes a discrepancy between people's views as relatives of a seriously ill person and what they would want if they themselves were dying (Akabayashi et al. 1999). Nevertheless, even where at least some members of a culture want the truth about their illness, this may not necessarily be due to the individual rights perspective favoured in the West. For example, as suggested above in relation to Muslims, some people might want to know their prognosis in order to have time to organise their life (Dalla-Vorgia et al. 1992; Mehta 1999), or to change their lifestyle and so avoid death (Dalla-Vorgia et al. 1992). Both these goals may still have a family-centred emphasis.

This also shows that the primacy of the family over the individual does not necessarily mean that control and autonomy are not important (Ejaz 2000). Many ethnic minorities such as Aboriginal families still want to negotiate about or ignore hospital rules restricting how many people can visit the sick person (Maddocks and Rayner 2003; McGrath et al. 2005; McGrath et al. 2006). It is typical for the family to want detailed information, including about issues such as procedures after death, and perhaps to be able to take home any body tissues, hair or clothing of the family

member as well as the body itself—part of cultural safety in some Aboriginal communities (Maddocks and Rayner 2003; McGrath et al. 2006).

Some cultures do not regard even the members of the family that Westerners would call 'nuclear' to be all equally entitled to information and participation in the decision-making and care processes. For example, some communities distinguish between the roles of men and women in relation to decision-making and care (McGrath et al. 2005). Others, such as some Aboriginal groups (Maddocks and Rayner 2003; McGrath et al. 2005) and Confucianists (Ong et al. 2002), have rules about who is appropriate for what task, such as expecting the eldest child to liaise with the hospital.

Where end-of-life decision-making is done as a family rather than as an individual, an unmodified concept of a living will is potentially irrelevant (Doorenbos and Nies 2003). However, a durable power of attorney may become a viable and appropriate option.

4.5 Cross-cutting layers of culture: diversity within culture, gender and sub-culture

Australian health professionals should be aware that there is great variation between and within cultures, and so should beware of stereotyping (Hallenbeck and Goldstein 1999; Kagawa-Singer and Blackhall 2001; Kiely et al. 2001; Koenig and Gates-Williams 1995; Kwak and Haley 2005; Werth et al. 2002). Times can change, as some work in Japan notes (Akabayashi et al. 1999; Akabayashi et al. 2003); and there can be significant urban-rural, elderly-young, education, marital status and other differences (Dalla-Vorgia et al. 1992). Some communities may also be quite comfortable with using a hybrid of Western and traditional approaches, such as via Aboriginal Liaison Officers in hospitals or through combining Western cancer treatment with traditional medicine (Eisenbruch and Handelman 1990). The emphasis should therefore be on remaining sensitive and open rather than having a prescription for each person based on their culture.

One article suggested that the presence of conflict (e.g. within a family over treatment options) should be treated as a cross-cultural model of the clinical encounter (Akabayashi et al. 2003). As summarised by Koenig and Gates-Williams (1995, p7 of web version): "The challenge for clinical practice is to allow ethical pluralism—a true engagement with and respect for diverse perspectives—without falling into the trap of absolute ethical relativism".

"Cross-cutting layers of culture" is the source of important variations from patient to patient that demands attention in advance care planning (Perkins et al. 2002). For example, among European, African and Mexican Americans, men's end-of-life's wishes addressed functional outcome, but women's wishes concerned other factors.

As another illustration, decisions about completing advance directives among same-sex couples are associated with commitment in relationship and disclosure of relationship to family members (Riggle et al. 2006). They may seek to use advance care planning to create rights for the partners as a way of legally recognising the relationship (Stein and Bonuck 2001).

4.6 Values, attitudes and practices of health professionals

The basic values, principles and practices of Western medicine and bioethics, like those of other regions, are historically situated and culturally determined (Jones 2005). For example, nurses' attitudes and values concerning their own death and dying affect how they care for patients at the end of life (Kim and Lee 2003). There are also inconsistencies in end-of-life treatment decisions of doctors and nurses from different countries. For instance, in one study Swedish physicians were found

to choose fewer life-prolonging interventions compared with Russian and German doctors (Richter et al. 2001; see also 4.2).

In other cross-national research (McKinley and Blackford 2001; Vincent 1999; although cf Miccinesi et al. 2005), only 58 per cent of health professionals overall applied written do-not-resuscitate (DNR) orders and there was wide variation according to country—from 8 per cent in Italy to 91 per cent in Netherlands. Eighty per cent felt that written DNR orders should be applied, but 36 per cent actually applied oral DNRs; 6 per cent would apply neither written nor oral DNRs. Only 49 per cent involved staff, patients and family in end-of-life decisions. Seventy-seven per cent discussed DNR orders with the patient's family, but only 26 per cent discussed them with the patient. The physicians also showed cultural and gender variation, with female, Catholic, Spanish, Greek, and Portuguese people being less likely to discuss. Physicians in southern Europe were less likely to apply DNR orders, withhold treatment and discuss such issues with patients, but were more likely to value the opinion of an ethics consultant.

For these sorts of reasons, physicians need to interrogate their own attitudes and beliefs (Ersek et al. 1998; Giger et al. 2006), and whether or not they are from the same culture as the patient and family (McGrath et al. 2004).

Where ADs are favoured, detailed ADs are useful in reducing conflicts between doctors' decisions and patients' wishes (Richter et al. 2001). Health professionals can also play an important role in improving the take-up rate of ADs or suitable alternatives because of their key role in treatment and palliative processes, and due to the fact that even patients who are informed and want an AD may wait to be told that it is time to make one (Bowman and Singer 2001; McAdam et al. 2005; Perkins et al. 2002; Sittisombut et al. 2005). Health professionals can assist with education and enculturation (McAdam et al. 2005), and clarify and simplify the language of ADs (McAdam et al. 2005)—therefore also requiring them to improve their communication skills (e.g. Burchardi et al. 2005).

For a physician to respect autonomy also means acknowledging that "choosing not to choose" to complete advance directives can be a valid expression of self-determination (Dupree 2000). Family involvement and communication may be more important than completing advance directives (Cox et al. 2006), and therefore professionals may need to work within a family-centred model (Akabayashi et al. 1999; Bowman and Singer 2001; Mystakidou et al. 2002) and see the process as a negotiation (Bowman and Singer 2001; Ersek et al. 1998); or use ADs in a more collective way—for example, in order to get talk about proxies happening (Fagerlin et al. 2002).

Other recommendations include doctors paying attention to the patient's values, spirituality and relationship dynamics (Searight and Gafford 2005a). Here is one possible matrix of issues to include and discuss:

Do patients value individuality and personal choice or do they focus more on family and collective choices? Do they value open communication or do they tend to draw cues from the context of the situation? Do they believe a person can and should influence their health? Do they believe in a Western biomedical view of illness or do they hold an alternative, or blended, view of illness? (Bowman and Singer 2001: 462)

Another suggestion is that the doctor get the patient's and family's views about the appropriate location and time of death and preferred roles, and consider gender and power issues within the decision-making unit (Koenig and Gates-Williams 1995). This should include paying attention to cultural layers and complexities, and

in some circumstances considering the importance of non-biological families with regard to same-sex relationships and any conflicts that may be present due to lack of recognition and respect from some biological family members (Haley et al. 2002).

More generally, it is important to consider that there may be intra-family conflicts in which the doctor may have to intervene (Akabayashi et al. 1999; Akabayashi et al. 2003; McGrath et al. 2004); as well as the impact of a raft of socio-political and historical factors (see 4.2). It is good practice to solicit information from all possible sources within the community, including religious leaders and interpreters (for other guidelines see Kagawa-Singer and Blackhall 2001; McGrath et al. 2005; Searight and Gafford 2005a; Werth et al. 2002).

4.7 How to better publicise and implement ADs

Research results are mixed, often with no significant difference between the control and the intervention groups (Hamel et al. 2002). This is probably not surprising, given much of the foregoing discussion about ADs not always being appropriate.

For example, one study found that while advance care planning increased the rate of advance directives' completion, many of the "completed" advance directives were legally invalid (Ho et al. 2000). As well, advance care planning did not improve patient satisfaction with health care.

However, there is also some limited evidence for the efficacy of specific strategies to promote the use of ADs. In a longitudinal action research study of a participatory educational program in relation to ADs (Medvene et al. 2003), a community coalition developed a program to train parish nurses, who trained (predominantly white) congregation members and provided ongoing support. Focus groups had said they were motivated to sign ADs in order to reduce decision-making burdens for families. There was a high rate of signing among Hispanics and African-Americans, probably due to home visits by a Hispanic pastor and an African-American parish nurse.

Other research has found significant differences within the US in the take-up of living wills, do-not-resuscitate orders and surrogate decision-makers, which cut across cultural differences to some extent (Kiely et al. 2001). For example, Ohio was the most likely state, across ethnic groups, to have living wills, which also shows that intervention at state-level can increase the use of ADs by non-white groups. The Ohio approach included the dissemination of patient education materials by educators and media, and a speaker kit and video available for a nominal fee, as well as free pamphlets in doctors' offices.

This might suggest that different areas within Australia (and perhaps Victoria) might affect a particular culture's attitude to and practices concerning ADs. However, it is important to note that still only 36 per cent of Ohio whites (the largest proportion of any ethnic group) had living wills.

Peer mentoring can also be useful for some ethnic groups in encouraging take-up of ADs (Perry et al. 2005), as can educational brochures about ADs (Husted et al. 1997; Husted et al. 1999; see also Molloy et al. 2000), the development of a booklet for GPs (Burgess et al. 2004) and GP chart reminders for promoting discussion of ADs in patients with AIDS (Walker et al. 1999).

Some authors point out that there is a need to address the concern that ADs are (only) about limiting treatment, rather than guaranteeing desired treatment (Haley et al. 2002), and that the issue of family-centred decision-making is really more a question of degree rather than an absolute difference with most members of white

western cultures—because patients, whether ethnic minority or not, tend to make end-of-life decisions within a family context (Haley et al. 2002; Fagerlin et al. 2002). This means that individual execution of ADs may not be satisfying for many—or, in other words, family decision-making may be more relevant for Anglos than we think (Haley et al. 2002; Fagerlin et al. 2002).

5. KEY LESSONS FROM THE LITERATURE

Regardless of the best efforts to “sell” ADs, they are subject to significant cultural resistance that cannot be explained simply as lack of knowledge or even a well-founded fear in some cases; rather it may also be associated with lack of utility (Dupree 2000; Murphy et al. 1996). This raises the issue of whether the scope of an AD should include non-disclosure (Akabayashi et al. 1999; Searight and Gafford 2005b), and other alternatives such as informal recognition of family surrogates and expanding the concept of durable power of attorney so that it is not so death-focused (Akabayashi et al. 1999; Azoulay et al. 2003; Murphy et al. 1996; Searight and Gafford 2005b; and see more generally, Singer and Bowman 2002).

A few articles extend this questioning of the focus on advance directives as the best strategy, because: even in western Anglo settings ADs are still only taken up by a minority of the population (Callahan 1995; Kiely et al. 2001; Perkins et al. 2002; Sahm et al. 2005; Searight and Gafford 2005b); knowing/supporting and having one are two different things (Kwak and Haley 2005; McAdam et al. 2005); and they are not necessarily followed (Chan 2003; Owen et al. 2001), especially if the physicians do not initiate them (Chan 2003; Giannini et al. 2003; Perkins et al. 2002; Vincent 1999) and/or because families override the patient’s wishes (Tang et al. 2005). Finally, there is also debate over whether ADs actually do save resources and costs (Callahan 1995; Chan 2003; Sittisombut et al. 2005).

6. AREAS FOR FUTURE RESEARCH

The literature review indicates that more research can be done in the following areas:

- 6.1** In the areas addressed in 5 above; for example, exploring the scope of ADs and even questioning why they are perceived to be the best strategy.
- 6.2** On cultural complexity and conflict within cultures, especially as communities enculturate in Australia; for example, we need to know more about how age (Rurup et al. 2006), gender (Perkins et al. 2004; Rurup et al. 2006; Sittisombut et al. 2005), the urban/rural divide (Rurup et al. 2006) and educational level (Eleazer et al. 1996) work within a culture to affect differences in attitudes and practices concerning ADs, especially in Australia. These differences also have implications for whether and how to promote ADs or their alternatives.
- 6.3** About attitudes and practices regarding ADs among different health professionals in Australia.
- 6.4** Around the need for rich (i.e. qualitative) data in relation to the use of and attitudes to ADs, proxies etc. by different cultural groups in Australia, along the lines of, for example, Dula (1994) and Frank et al. (1998).
- 6.5** On how successful US techniques (see 4.7) might be extrapolated to Australia. There is also probably much that can be learnt outside the AD area, and even the broad health field, about how to “sell” ADs and their alternatives, especially as many of the studies of how to better inform cultural minorities or implement ADs adapt mainstream methods. Action research is needed in Australia to pilot some approaches in depth.

APPENDIX 1: SEARCH STRATEGY

Search engines were accessed via the La Trobe University Library. Duplicate articles and articles which were found not to be useful have been deleted from the total number of articles elicited via each search:

1.1 An Informit search was carried out (no date limit) using the following pool of words and phrases:

(culture* or ethnic* or racial or religio* or spiritual or minorit* or NESB or CALD) and (treatment or palliative or 'medical care' or patient or famil* or relative or kin or 'advance care plan*' or choice) and (death or dying or 'end of life')

This produced a total of 9 articles.

1.2 The search strategy was adapted as appropriate to each search engine below:

Expanded Academic ASAP – 16 articles
BioMed Central – 2 articles
CareSearch – 30 articles

1.3 Following a meeting with representatives from the Austin RPC team, and due to a lack of discovered literature on Greeks or Italians and ADs, a further search was carried out using Medline (no date limits), as follows:

- (a) a thesaurus search using 'advance directives' and 'ethnology' (2 articles)
- (b) a key word search using ('advance directives' or 'end of life decision\$' or 'advanc\$ care plan\$') and (ethnic\$ or minority or Greek\$ or Ital\$ [4 articles])

In this step, only refereed articles were included, and only articles obtainable through La Trobe Library were read.

APPENDIX 2: ARTICLES OBTAINED VIA AUSTIN HEALTH SEARCH

Articles obtained via Austin Health search (Endnote file held by Austin Health)

Candib 2002
Cox et al. 2006
Degenholtz et al. 2002
Doorenbos and Nies 2003
Ejaz 2000
Fettters and Masuda 2000
Gabbay et al. 2005
Goldstein et al. 2002
Hallenbeck and Goldstein 1999
Hopp 2000
Jones 2005
Kim and Lee 2003
McLaughlin and Braun 1998
Perkins et al. 2004
Perry et al. 2005
Richter et al. 2001
Riggle et al. 2006
Searight and Gafford 2005a
Stein and Bonuck 2001

- 3.1** *Research study: Akabayashi et al. 2003; Azoulay et al. 2003; Blackhall et al. 2001; Bowman and Singer 2001; Braun et al. 2001; Burchardi et al. 2005; Chan et al. 2003; Dalla-Vorgia et al. 1992; Degenholtz et al. 2002; Doorenbos and Nies 2003; Dupree 2000; Eisemann 1999; Ejaz 2000; Eleazer et al. 1996; Feters and Masuda 2000; Gabbay et al. 2005; Giannini et al. 2003; Goldstein et al. 2002; Hopp 2000; Hopp and Duffy 2000; Kagawa-Singer and Blackhall 2001; Kiely et al. 2001; Kim and Lee 2003; Mak 2001; McAdam et al. 2005; McGrath et al. 2004; McGrath et al. 2005; McGrath et al. 2006; McKinley and Blackford 2001; Mehta 1999; Miccinesi et al. 2005; Morrison et al. 1998; Murphy et al. 1996; Mystakidou et al. 2002; Owen et al. 2001; Papadatou et al. 1996; Perkins et al. 2002; Perkins et al. 2004; Perry et al. 2005; Richter et al. 2001; Riggle et al. 2006; Romero et al. 1997; Rurup et al. 2006; Sahm et al. 2005; Searight and Gafford 2005b; Sittisombut et al. 2005; Stein and Bonuck 2001; Tang et al. 2005; Vincent 1999.
- 3.2** *Review of literature: Cox et al. 2006; Ersek et al. 1998; Fagerlin et al. 2002; Giger et al. 2006; Haley et al. 2002; Jones 2005; Kwak and Haley 2005; McLaughlin and Braun 1998; Volker 2005; Werth et al. 2002.
- 3.3** *Essay and discussion paper: Ankeny et al. 2005; Baker 2002; Callahan 1995; Gatrad 1994; Levi 1986; Lim 1997; MacLean 1986; Maddocks and Rayner 2003; Ross 1998; Searight and Gafford 2005a; Singer and Bowman 2002.
- 3.4** *Case study: Akabayashi et al. 1999; Brotzman and Butler 1991; Candib 2002; Dula 1994; Eisenbruch and Handelman 1990; Frank et al. 1998; Koenig and Gates-Williams 1995.
- 3.5** *Evaluation of tool: Burgess et al. 2004; Hamel et al. 2002; Ho et al. 2000; Husted et al. 1997; Husted et al. 1999; Medvene et al. 2003; Molloy et al. 2000; Siegert et al. 1996; Walker et al. 1999.
- 3.6** *Opinion or editorial: Carter 2002; Ong et al. 2002; Hallenbeck and Goldstein 1999; Heath 2000.

APPENDIX 4: RESEARCH ARTICLE METHODOLOGIES

Article	Sample groups	Sample size	Aims	Methods
Akabayashi et al. 2003	Japanese	425	To report the results of in-depth survey on the general population concerning the preferences and use of advance directives in Japan	Self-administered questionnaires
Azoulay et al. 2003	French general population	8000	Opinions on surrogate decision-makers	Telephone survey
Blackhall et al. 2001	Korean, Mexican, European and African-Americans in US	200	To examine and compare the attitudes and life experiences of people from four ethnic groups.	Quantitative and qualitative surveys followed by ethnographic interviews
Bowman et al. 2001	Chinese in Canada	40	To examine attitudes of Chinese seniors towards end-of-life decisions.	Qualitative survey with face-to-face interviews in Cantonese
Braun et al.. 2001	Caucasian, Chinese, Filipino, Native Hawaiian and Japanese in US	50 adults aged 60 years and over	To identify and measure attitudinal factors related to PAS (physician assisted suicide) support that may apply across ethnic groups	Face-to-face interviews, factor analysis
Burchardi et al. 2005	Amyotrophic lateral sclerosis patients and neurologists in Northern Bavaria	15 + 15	To look at how discussions of living wills are done	Interviews
Burgess et al. 2004	Palliative care experts and GPs South Australia	16 GPs	Not explicit	Focus groups, interviews and consultation. Booklet
Chan et al. 2003	Patients over 65 who died in Bankstown Hospital	110	Use of NFR orders and advanced care plans	Patient records
Dalla-Vorgia et al. 1992	Healthy Greek population	500	Attitudes to truth-telling issue	Questionnaire
Degenholtz et al. 2002	Nursing home residents in US	3747	To analyse the association between race and the presence of advance care plan documents	Secondary analysis of public survey data from the 1996 Medical Expenditure Panel Survey – Nursing Home Component
Doorenbos and Nies 2003	Asian Indian Hindus in US	45	To address shortcomings on a low rate of completing advance directives among ethnic minorities	Descriptive exploratory study
Dupree 2000	Black Americans	17	To describe how Black Americans view advance directives	Qualitative interviews
Eisemann et al. 1999	Swedish	600	To survey a general population's attitude towards advance directives and self-determination	Postal questionnaire

Article	Sample groups	Sample size	Aims	Methods
Ejaz 2000	Nursing home residents in US	133 cognitively alert nursing home residents	To examine the predictors of advance directives	Cross-sectional design, quantitative interviews
Eleazer 1996	White, Black, Hispanic and Asian Americans in US	1193 frail Americans in nursing homes	To assess relationship between ethnicity and health care wishes	Retrospective chart review of participants in PACE
Fetters and Masuda 2000	Japanese patients in Michigan, US	30	To describe overseas Japanese patients' preferences for participation in decisions about cancer, and to assess patients' attitudes about an advance directive for cancer disclosure	Ethnography – participant observations, interviews and lay materials
Gabbay et al. 2005	American Physicians and Japanese GPs	103 internal medicine residents in the USA and 244 GPs in Japan	To compare Japanese and US resident physicians' attitudes, clinical experiences and emotional responses regarding disclosure of incurable illnesses.	Self-administered questionnaire, in a cross sectional survey
Giannini et al. 2003	Physicians in ICUs in Milan	20 ICUs (all)	To explore end-life-decisions	Self-administered questionnaire
Goldstein et al. 2002	Greeks in Australia	29 men and 29 women	To examine attitudes to cancer, its treatment and disclosure of information among unaffected Greek adults	Four focus groups using bilingual facilitator and eight face-to-face interviews
Hamel et al. 2002	Not culturally specific but in Canada	74	To investigate whether an individualised intervention (phone call after education session) increased the discussion and/or completion of advance directives	Posttest-only experimental study
Ho et al. 2000	Not culturally specific but in Canada, with persons with HIV/AIDS	106+104	To evaluate the effect of an advance care planning intervention on the completion of advance directives and patient satisfaction.	Prospective cohort study, three face-to-face interviews
Hopp 2000	Aged adults in US, mixed races.	520	To address the need for greater information on advance care planning among older adults.	Analysis of public data from a survey conducted by University of Michigan.
Hopp and Duffy 2000	White and black Americans	540 proxy respondents (relatives of the deceased): 454 whites and 86 blacks	To identify differences in advance care planning and end-of-life decision making between whites and blacks aged 70 and older.	Telephone and face-to-face interviews while respondents were at home, using a questionnaire. With statistical analysis.

Article	Sample groups	Sample size	Aims	Methods
Husted et al. 1997	Not culturally specific but US	26 well elderly people in independent residential sites	To test an advance directive brochure designed especially for well elderly people	Literature review, qualitative method (focus groups)
Husted et al. 1999	Not culturally specific but US	20	To test an advance directive brochure designed especially for well elderly people	Individual interviews after reading the brochure
Kagawa-Singer and Blackhall 2001	African-Americans and Chinese Americans in US	2 families	To outline some of the major issues involved in cross cultural care and indicate how the patient family and clinician can navigate among differing cultural beliefs, values and practices	Case studies, qualitative
Kiely et al. 2001	US nursing home residents, retrospective cohort study	Exhaustive i.e. 100 000s	To look at racial and State differences re ADs	Database examination + analysis of other secondary materials
Kim and Lee 2003	Nurses in three acute hospitals in Korea	185	To investigate distinctive elements that would best describe good and bad death, preferences for life-sustaining treatment and advance directives	Semi-structured questionnaires
Mak 2001	Chinese in Hong Kong	33 hospice patients with terminal cancer	To gain an understanding of what it means to die a 'good death' from the perspectives of Chinese patients	Qualitative interviews, grounded theory analysis
McAdam et al. 2005	Filipino Americans and families in US	22 patients and 22 family members	To understand attitudes toward advance directives	Descriptive, correlational, cross-sectional study. Convenient samples were interviewed with the Advance Directive Attitude survey
McGrath et al. 2004	Health professionals in Australia	4 GPs, 2 palliative care nurses Vietnamese carer Western Sydney	To explore the education, training and support needs of GPs who provide palliative care to a Vietnamese Australian community	Qualitative interviews with Vietnamese Australian doctors
McGrath et al. 2005	Indigenous Australians	29 Indigenous patients and carers in NT; and 43 health workers	To explore communication issues faced by health care workers and Indigenous patients and their families in a palliative care setting	Qualitative interviews NHMRC-funded

Article	Sample groups	Sample size	Aims	Methods
McGrath et al. 2006	Indigenous Australians in Northern Territory	29 IA+43 health workers	To find out what works (not explicit)	Open-ended qualitative interviews with members of the community in NT and health professionals
McKinley and Blackford 2001	Australian nurses	6	To explore nurses' experiences of caring for CALD families when their child dies	Co-participatory method, focus groups conducted at 6 weekly intervals.
Medvene et al. 2003	Faith community members, Wichita Kansas	17 faith communities, several mainly white, 2 mainly African-American, one mainly Hispanic	Whether participatory educational program re ADs promotes signing	Longitudinal study, action research
Mehta 1998	Chinese, Malays and Indians, aged 70-84, not living in nursing homes, in Singapore	45	To identify the major patterns of ageing, the factors that explain these patterns and the coping strategies used by the respondents.	Qualitative, multiple long interviews, regarding life story, attitudes and beliefs
Miccinesi et al. 2005	Physicians in 6 European countries + Australia	10 000+	Physicians' attitudes to end-of-life decisions	Questionnaires
Molloy et al. 2000	Veterans in Canada	150	To evaluate the feasibility and effectiveness of implementing an advance care directive education program among veterans	Intervention and follow-up study
Morrison et al. 1998	African-Americans, Hispanic Americans and Anglo Americans in US	197	To examine barriers to completion of health care proxies for different ethnic groups	Questionnaires
Murphy et al. 1996	African-Americans, European Americans, Korean Americans and Mexican Americans in US	800 individuals aged 60 and over	To explore the relationships between ethnicity and attitudes toward, knowledge of, and completion of advance directives for healthcare	Face-to-face interviews in participants' language
Mystakidou et al. 2000	Greek patients, in Athens	146 Greek relatives	To investigate the attitudes, perceptions and pattern of choices in the management of terminal stage cancer patients	Questionnaires done in hospital
Owen et al. 2001	African-Americans and White family caregivers in Alabama	47 White and 16 African-American caregivers	To describes characteristics of caregivers' approach to end of life issues and AD decisions (Alzheimer's).	Structured interviews and a series of questionnaires in caregiver's home.

Article	Sample groups	Sample size	Aims	Methods
Papadatou et al. 1996	Greek women	15	To investigate the experiences and needs of Greek mothers who cared for a child dying of cancer at home or in the hospital	Semi-structured interviews conducted by a psychologist, and patient medical records
Perkins et al. 2002	In-patients in medical wards, San Antonio Texas: Mexican Americans, European Americans and African-Americans	26 + 18 + 14	To characterise cultural attitudes influencing advance care planning decisions	Structured, open-ended interviews
Perkins et al. 2004	Ethnic inpatients in US	18 European American, 14 Mexican American	To investigate whether gender affects patients' attitudes about advance care planning.	Face-to-face interviews by trained bilingual interviewers
Perry et al. 2005	American dialysis patients	203 dialysis patients	To explore the impact of peer mentoring on end-of-life decision making	Controlled randomised intervention study
Richter et al. 2001	Physicians in Sweden, Germany and Russia	535 physicians	To investigate how end-of-life decisions are influenced by cultural and socio-political circumstances	Questionnaires
Riggle et al. 2006	Gays and lesbians in US	131 same-sex couples	To prove hypotheses regarding factors around decisions on advance care planning documents	A web-based survey
Romero et al. 1997	Hispanic and non Hispanic in US	414 Hispanic, 469 non Hispanic	(concise report of a study - letter to editor) To investigate self-reported understanding of and completion of advance directives and individual preferences for life sustaining measures	In-home, in-person interviews by trained personnel
Rurup et al. 2006	Dutch population, Netherlands	Three groups: 1051 aged below 60, 1874 over 60 and 87 relatives of patients who died after euthanasia or assisted suicide.	To investigate the prevalence of advance directives and to determine which factors are associated with the formulation of advance directives	Strong quantitative methodology: Postal questionnaire for the younger group; data from previous longitudinal study for the older group; face-to-face interviews for the last group
Sahm et al. 2005	German cancer patients, healthy controls, physicians and nursing staff	100 x 4	To investigate knowledge about and willingness to accept advance directives	Structured questionnaire

Article	Sample groups	Sample size	Aims	Methods
Searight and Gafford 2005b	Bosnian immigrants in America	12, aged 22-68	Not clearly stated.	Qualitative focus group interviews using interpreters
Siegert et al. 1996	Americans (veterans in North Carolina)	36	To examine the effects of an advance care videotape on patient comprehension of advance directive concepts and preference for resuscitation	Pilot study, randomised cohort trial
Sittisombutt et al. 2005	Ambulatory medical in-patients in Thailand	200	To investigate attitudes regarding advance directives for CPR	Multiple interviews
Stein and Bonuck 2001	Gays and lesbians in New York, US	575	To ascertain the preferences of gay and lesbian community regarding approaches to end-of-life care	64-item survey instrument
Tang et al. 2005	Terminally ill patient-caregiver dyads in Taiwanese hospitals	617	To examine the extent of concordance in preferences for end-of-life care goals and life-sustaining treatments	Patient medical records and in person interviews
Vincent 1999	European physicians from 15 Western European countries	504	To determine current views of European intensive care physicians regarding end-of-life decisions	Questionnaire
Walker et al. 1999	Patients with AIDS and physicians in US	74 +10	To determine if use of a physician chart reminder improves the rate of physician-initiated discussion and subsequent completion of advance directives	Controlled study

APPENDIX 5: FOCUS OF THE ARTICLES

The vast majority of articles were based in the US:

Baker 2002; Blackhall et al. 2001; Braun et al. 2001; Brotzman and Butler 1991; Callahan 1995; Candib 2002; Degenholtz et al. 2002; Doorenbos and Nies 2003; Dula 1994; Dupree 2000; Ejaz 2000; Eleazer et al. 1996; Ersek et al. 1998; Fetters and Masuda 2000; Frank et al. 1998; Giger et al. 2006; Hallenbeck and Goldstein 1999; Heath 2000; Romero et al. 1997; Hopp 2000; Hopp and Duffy 2000; Husted et al. 1997; Husted et al. 1999; Kagawa-Singer and Blackhall 2001; Kiely et al. 2001; Koenig and Gates-Williams 1995; Kwak and Haley 2005; Lim 1997; McAdam et al. 2005; Medvene et al. 2003; Morrison et al. 1998; Murphy et al. 1996; Owen et al. 2001; Perkins et al. 2002; Perkins et al. 2004; Perry et al. 2005; Riggle et al. 2006; Romero et al. 1997; Ross 1998; Searight and Gafford 2005a, 2005b; Siegert et al. 1996; Stein and Bonuck 2001; Volker 2005; Werth et al. 2002.

A small number of articles focused on Australia:

Ankeny et al. 2005; Burgess et al. 2004; Chan et al. 2003; Carter 2002; Eisenbruch and Handelman 1990; Goldstein et al. 2002; Levi 1986; Maddocks and Rayner 2003; McGrath et al. 2004; McGrath et al. 2005; McGrath et al. 2006; McKinley and Blackford 2001.

Other articles were located in:

- Asia and Pacific: McLaughlin and Braun 1998
- Hong Kong: Mak 2001
- Canada: Bowman and Singer 2001; Hamel et al. 2002; Ho et al. 2000; Molloy et al. 2000.
- Korea: Kim and Lee 2003
- Netherlands: Rurup et al. 2006
- Germany: Burchardi et al. 2005; Sahm et al. 2005.
- Greece: Dalla-Vorgia et al. 1992; Mystakidou et al. 2002; Papadatou et al. 1996.
- Singapore: Mehta 1999; Ong et al. 2002
- Japan: Akabayashi et al. 1999; Akabayashi et al. 2003; .
- Japan and US: Gabbay et al. 2005
- Taiwan: Tang et al. 2005
- Thailand: Sittisombut et al. 2005
- UK: Cox et al. 2006; Gatrad 1994; Jones 2005.
- Western Europe: Vincent 1999
- France: Azoulay et al. 2003
- Belgium, Denmark, Italy, Netherlands, Sweden, Switzerland, Australia: Miccinesi et al. 2005
- Russia, Sweden and Germany: Richter et al. 2001
- Sweden: Eisemann et al. 1999
- Italy: Giannini et al. 2003

Not specific: Fagerlin et al. 2002; Haley et al. 2002; MacLean 1986; Singer and Bowman 2002; Walker et al. 1999.

Subjects of the articles**6.1 Patients and families:**

- African-American and white family caregivers of Alzheimer's patients: Owen et al. 2001.
- White and Black relatives of people who died: Hopp and Duffy 2000.
- African-American, European American, and Mexican American patients: Perkins et al. 2002; Perkins et al. 2004.
- African, Hispanic and white American 65+ outpatient clinic attendees: Morrison et al. 1998.
- African-American and white relatives of deceased: Hopp 2000.
- African-American woman patient: Dula 1994.
- African-American and Chinese American patient families: Kagawa-Singer and Blackhall 2001.
- African-American and Chinese American dying patients: Koenig and Gates-Williams 1995.
- Greek-American patient and son: Heath 2000.
- American dialysis patients: Perry et al. 2005.
- American nursing home patients: Siegert et al. 1996.
- Greek mothers caring for child dying of cancer: Papadatou et al. 1996.
- Canadian Chinese seniors: Bowman and Singer 2001.
- Hong Kong Chinese terminal cancer patients: Mak 2001.
- South-East Asian cancer patients: Ong et al. 2002.
- Japanese cancer patients in US: Fetters and Masuda 2000.
- Taiwanese terminally ill patient- caregiver dyads in hospitals: Tang et al. 2005.
- Greek relatives of terminal cancer patients: Mystakidou et al. 2002.
- German ALS patients and neurologists: Burchardi et al. 2005.
- Northern Thai ambulatory medical in-patients: Sittisombut et al. 2005.
- Australian (Bankstown) hospital patients over 65, deceased (31% NESB): Chan et al. 2003.

6.2 Physicians and healthcare personnel:

- Australian Vietnamese doctors, nurses, carers: McGrath et al. 2004.
- South Australian GPs and palliative care experts: Burgess et al. 2004.
- Australian nurses: McKinley and Blackford 2001.
- Korean nurses in Korea: Kim and Lee 2003.
- Physicians from 15 western European countries: Vincent 1999.
- Physicians in Belgium, Denmark, Italy, Netherlands, Sweden, Switzerland and Australia: Miccinesi et al. 2005.
- Italian physicians in Milan ICUs: Giannini et al. 2003.
- Doctors in Russia, Sweden and Germany: Eisemann et al. 1999; Richter et al. 2001.
- Japanese and US doctors: Gabbay et al. 2005.

6.3 General population, other than any characteristics specified (e.g. 'African-American' means African-American general population)

- African-Americans: Dupree 2000.
- African-American, European American, Korean American and Mexican American 60+: Murphy et al. 1996.
- American Jewish: Ross 1998.
- American culture: Callahan 1995.
- American, range of communities: Candib 2002.
- American well elderly: Husted et al. 1997; Husted et al. 1999.
- Asian Indian Hindus in the US: Doorenbos and Nies 2003.
- Bosnian Americans: Searight and Gafford 2005b.

- Caucasian, Chinese, Filipino, Native Hawaiian and Japanese Americans 60+: Braun et al. 2001.
- Elderly Korean American: Frank et al. 1998.
- Filipino Americans: McAdam et al. 2005.
- Hispanic and non-Hispanic Americans: Romero et al. 1997.
- Hmong American: Brotzman and Butler 1991.
- Korean American, Mexican American, European American and African-American: Blackhall et al. 2001.
- White, Black, Hispanic and Asian American frail elderly in nursing homes: Degenholtz et al. 2002; Eleazer et al. 1996.
- Jewish, Catholic and Protestant cognitively alert in US nursing homes: Ejaz 2000.
- White, African-American and Hispanic members of faith communities: Medvene et al. 2003.
- White, Black, American-Indian, Alaskan native, Asian, Hispanic American nursing home residents: Kiely et al. 2001.
- Gay and lesbian community in America : Riggle et al. 2006; Stein and Bonuck 2001.
- Jehovah's Witnesses: MacLean 1986.
- Asian and Pacific Islander: McLaughlin and Braun 1998.
- Canadian veterans (not ethno-specific): Molloy et al. 2000.
- Canadian older adults: Hamel et al. 2002.
- Canadian patients with HIV/AIDS: Ho et al. 2000.
- Chinese, Malay and Indian Singaporean elderly: Mehta 1999.
- Dutch: Rurup et al. 2006.
- French: Azoulay et al. 2003.
- Japanese: Akabayashi et al. 1999; Akabayashi et al. 2003..
- Greek: Dalla-Vorgia et al. 1992.
- Muslims in United Kingdom: Gatrad 1994.
- Swedish: Eisemann et al. 1999.
- UK: Cox et al. 2006; Jones 2005.
- Australian (Top End) Aboriginal: Maddocks and Rayner 2003.
- Australian (NT) Aboriginal: McGrath et al. 2005.
- Australian (NT) Aboriginal community and health professionals: McGrath et al. 2006.
- Australian Cambodian: Eisenbruch and Handelman 1990.
- Greek in Australia: Goldstein et al. 2002.
- Australian Jewish: Carter 2002; Levi 1986.
- Range of religious perspectives in Australia: Ankeny et al. 2005.

6.4 Culture not specified:

Baker 2002; Ersek et al. 1998; Fagerlin et al. 2002; Giger et al. 2006; Haley et al. 2002; Hallenbeck and Goldstein 1999; Kwak and Haley 2005; Lim 1997; Sahm et al. 2005; Searight and Gafford 2005a; Singer and Bowman 2002; Volker 2005; Walker et al. 1999 (physicians); Werth et al. 2002.