A MULTI-DISCIPLINARY APPROACH TO ADVANCE CARE PLANNING

PILOT STUDY REPORT

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June 2006
ACKNOWLEDGEMENTS

The Bananacoast Community Credit Union is the major sponsor of the Aged Services Learning and Research Collaboration and their funding support enabled this study to be undertaken.

The input and support of the nurses and doctors involved with this study (the Advance Care Planning Group) is gratefully acknowledged:

- Nurses - Coffs Harbour Base Hospital: Leanne Bacon, Patti Condon, Deb Foote
- Nurses – Bellinger River District Hospital: Vince Carroll, Val Sims
- General Practitioners: Dr Carol Chan, Dr David Ellis, Dr John Kramer

We also wish to thank Ms Margaret Bennet, Coordinator, Coffs-Clarence Health Network/General Manager, Coffs Harbour Health Campus, North Coast Area Health Service, for her support.

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EXECUTIVE SUMMARY

In the past few decades, an ageing population, increasing levels of dementia, rising health care costs and the shift from medical paternalism to increased patient autonomy have focussed attention on end-of-life decision-making, both in Australia and internationally.

Advance Care Planning (ACP) is a process which assists competent respondents to make decisions about future health care in consultation with their health care providers, family members and other important people in their lives. The primary legislative option for ACP in NSW is the appointment of a proxy or substitute decision-maker under Enduring Guardianship legislation. In addition, respondents may complete a written document called an Advance Health Care Directive (AHCD).

AIM: The pilot study aimed to assess attitudes to ACP among older respondents in medical wards, participating in a chronic care program or attending a general practice, and to offer these respondents the option to complete ACP documents; the study findings will be used to support an application for a larger, regional study.

METHODOLOGY: An Advisory Committee was formed and ethics approval obtained from both Southern Cross University and the North Coast Area Health Service Human Research Ethics Committees. An anonymous questionnaire was provided to 65 patients aged 60 or above attending Coffs Harbour or Bellinger River hospitals or one of three GP surgeries taking part in the study, who consented to participate. Respondents who completed questionnaires were offered Advance Care Planning assistance.

Data Analysis: SPSS12 statistical package was used to record data and undertake descriptive statistical analysis.

RESULTS: From a recruited sample of 65 patients, a total of 54 completed questionnaires were received, a response rate of 83%.

Gender and Age: There were slightly more females (55%, n=29) than males (45%, n=24) among respondents (1 person did not answer this question). Ages ranged from 60 to 90+, with the majority of respondents being less than 80 years of age.

Throughout this summary, only differences by age or gender that reached statistical significance are reported.

Socio-Economic Characteristics: Just over half of the respondents were married and living with a spouse (both 56%); 75% of the males (n=18) but only 41% of the females (n=12) were currently married ($\chi^2 = 6.043, p=0.014$); 21% of males lived alone compared with 35% of females; 71% of males lived with their spouse compared with 41% of females; and only 8% of males lived with others compared with 24% of females ($\chi^2 = 4.878, p=0.087$).

Education levels of the respondents were as follows: 37% had completed primary school, 35% had completed Year 10, 6% had completed Year 12, 17% had completed a technical or
trade certificate and 4% had a University degree; 38% of 60-69 year-old respondents had some tertiary education, compared with only 10% of the 70+ age group ($\chi^2 = 5.834, p=0.016$).

Eighty percent of respondents (n=51) reported their current household income as less than $20,000 per annum, with an additional 12% having annual income between $20,000 and $29,000; only 8% of respondents had annual income greater than $30,000.

**Religion:** Seventy percent of the respondents (n=37) belonged to one of the three main Christian religions (Anglican 43%, Catholic 22%, Uniting Church 4%); 17% (n=9) said that they had no religious affiliation and 13% (n=7) listed a range of other (mostly Christian) religions.

When asked to what extent their religious or philosophical beliefs influenced their attitudes to issues such as medical decisions at the end of life, 25% (n=13) said *A great deal*, 19% (n=10) said *Somewhat* but 56% (n=29) said *Not at all*.

**Health and Happiness:** Overall, 16% of respondents considered themselves to be in excellent/very good health, 30% said that their health was good and 54% said that their health was fair/poor; 58% of respondents said that they were very happy/happy, 33% were neither happy nor unhappy and 9% were unhappy/very unhappy.

Respondents 70+ were less likely than the younger group to say that their health was excellent or very good. However, more of the younger group were likely to say that they were unhappy or very unhappy, with none of the 70+ group saying this. Females were significantly less likely than males to say that their health was fair or poor.

**TREATMENT AND RIGHTS OF TERMINALLY ILL PEOPLE**

**Personal Decision-Making Regarding End-of-Life:** Overall 46% of respondents had often thought about treatment at the end of life and a further 42% had thought about it occasionally but 12% of the respondents said that had never thought about it. Of those who had thought about it, the death of a family member or friend, or a personal illness, had instigated such thinking.

Most respondents who had thought about this issue had also discussed it, most often with a son or daughter (n=28), a spouse (n=24), a friend (n=15), their GP (n=13) or another relative (n=11). Very few respondents had discussed this issue with a minister or a lawyer. Younger respondents were significantly more likely than the older group to have discussed such matters with a friend. Males were most likely to have discussed the issue with their spouse while females were more likely to have discussed such matters with a son or daughter.

**Preferences Regarding Decision-Making if Terminally Ill:** The majority of respondents strongly agreed or agreed that they would want the opportunity to consent to or refuse treatment if they were very ill. If they were not able to make their own decisions, the order of preference for who should decide was: (1) family and/or treating doctor in discussion with the patient’s GP; and (2) equally a family member or the treating doctor. Very few respondents wanted a friend to make that decision.
Males were significantly more likely than females to say that they would prefer a family member to decide what treatment they should have and respondents 70+ were somewhat more likely than those 60-69 to say that they would prefer their GP to decide.

**Greatest Concerns Regarding Terminal Illness:** Respondents were asked how much distress (from *Great Distress* to *No Distress*) they thought a range of factors would cause them if they were terminally ill. From 9 possible causes of distress, the highest percentage of Great Distress responses was for Loss of Mental Faculties (79%), followed by Loss of Control (71%), Being a burden on Family (67%) and Loss of Independence (65%); Fear of Death was rated last (14%). When Mean scores were considered, Loss of Control assumed first place.

Although the percentage was small, the younger group (21%) were significantly more likely than the older group (7%) to think that fear of death would cause them great distress; females (79%) were significantly more likely than males (54%) to say that loss of control would cause them great distress.

**Doctor-Patient Communication:** 92% of respondents strongly agreed or agreed that most patients would welcome a discussion about end-of-life treatment issues with their doctor; 94% of respondents said that it would be very likely or likely that they would discuss any concerns they might have about medical treatment at the end stage of life with their GP, although only 6 patients had done so and in most cases it was the patient who had raised the issue. Despite this 89% of respondents said that they would be very comfortable or comfortable to raise this topic with their GP and 85% said that they would be very comfortable or comfortable if their GP raised it with them.

Finally, 64% of respondents said that they thought a doctor should tell an adult patient, who has advanced cancer and is not likely to have long to live, the truth about his or her condition “in all cases” and an additional 19% (n=10) said that the doctor should do so to allow discussion to occur.

**ADVANCE HEALTH CARE DIRECTIVES**

A definition of Advance Health Care Directives was given in the questionnaire as follows:

> Because of an accident or illness a patient may not be able to tell the doctor what life-sustaining treatments he or she wants or does not want. Some people choose to write down these preferences beforehand. This written document is and Advance Health Care Directive.

**Knowledge of Advance Directives:** 15 respondents had heard of the term Advance Health Care Directives but only 11 said that they knew what their legal status was. However, 94% (n=49) of respondents said that Advance Health Care Directives should be legally binding on health care professionals. The younger group was significantly more likely than those aged 70+ to have heard of Advance Health Care Directives (52%: 14%)

**Importance of Written Documents:** Only 4 respondents (8%) had already recorded their wishes about their medical treatment for the end stage of life but an additional 35 (66%) said that they would like to do so. A very high percentage of respondents (89%) thought that it was extremely important or important to have a written document of their wishes, yet, despite
the fact that only 4 had such a document, 31 respondents (60%) said that they were very confident or confident that their previously expressed wishes would be respected.

**Who Should Assist with Completion of Documents?** More than half of the respondents (53%, n=28) chose a GP as the most appropriate person to assist someone to complete an Advance Health Care Directive, followed by a nurse specifically trained to assist with such documents (21%, n=11).

**Barriers to Completing an Advance Health Care Directive:** Not knowing enough about Advance Health Care Directives (74%), or how to make one (71%), were considered to be the major barriers to completing such a document, with older respondents being more likely than the younger group to see this as a problem. Preferring to leave things to the doctor (61%) or preferring things to take their course (49%) were also seen as barriers by some respondents. In particular, older respondents (77%) were significantly more likely than the younger group (43%) to say that this would prevent them from completing an Advance Health Care Directive.

**Usefulness of Advance Health Care Directives:** Overall, 85% of respondents either strongly agreed or agreed that Advance Health Care Directives would make a useful contribution to medical care.

**ENDURING GUARDIANSHIP**

A definition of Enduring Guardian was given in the questionnaire as follows:

*Some people may wish to choose a trusted friend or relative to make health care decisions for them in case they are unable to do so for themselves at some time in the future. This person can be legally appointed as the person’s Enduring Guardian. The Enduring Guardian would have the legal right to make decisions about what treatment the patient should or should not receive.*

**Appointment of an Enduring Guardian:** 15 respondents (28%) said that they had appointed an Enduring Guardian to make medical decisions for them if they are no longer able to do so; males (46%, n=11) were significantly more likely than females (14%, n=4) to have appointed someone. A total of 22 people had been appointed by the 15 respondents, including adult child (n=7), spouse (n=6) and other family member (n=5). An additional 81% of respondents (n=34) said that they wanted to make such an appointment and the majority said that they would appoint an adult child (n=21), spouse (n=15), doctor (n=9), other family member (n=7) or close friend (n=5). Males (77%, n=10) were significantly more likely than females (24%, n=5) to nominate their spouse, while females (57%, n=12) were significantly more likely than males (15%, n=2) to say they would appoint an adult child.

**Barriers to Appointing an Enduring Guardian:** Preferring to make their own decisions (64%), followed by lack of knowledge (54%) were the major barriers that respondents saw as preventing them from appointing someone as their Enduring Guardian. Males were significantly more likely than females to say that preferring to make their own decisions would be a barrier to them appointing someone as their Enduring Guardian.
Appointment of Person to hold Enduring Power of Attorney for Property/ Finances: 69% of respondents (n=25) had already appointed someone to have EPA for their property/financial arrangements; males (67%, n=16) were significantly more likely than females (35%, n=10) to have done so.

Preferred Options for Advance Care Planning: The final question asked respondents to consider three possible options for Advance Care Planning; (a) write an Advance Health Care Directive; (b) appoint an Enduring Guardian, or (c) discuss the matter in advance with the doctor. Although there was support from a majority of respondents for all three options, there was almost total support from respondents for discussing the matter with their doctors. The next most favoured response was the appointment of someone to be Enduring Guardian, followed by completion of an Advance Health Care Directive.

DISCUSSION
Methodology: While the methodology used in this study worked well in relation to sample recruitment and questionnaire distribution and completion, it was less successful in relation to the follow-up procedures relating to Advance Care Planning, including assistance with completion of the Enduring Guardian or Advance Health Care Directive documents, or having copies of these returned to the hospital or GP surgery for lodgement in the patients’ records. This highlights the problem of asking already very busy health care providers to undertake additional, and potentially very time consuming tasks, and underlines the need for paid research staff to conduct at least some components of the work.

Generalisability of the sample: The demographic characteristics of the respondents appeared to reflect the wider community for these age groups in relation to marital status, living arrangements and education but not in relation to socio-economic status, which was lower than for the same age group in the wider population, with more than 80% having incomes less than $30,000 per annum. In addition, because this sample was selected from patients currently in or attending hospital for a medical condition, or attending a GP, their overall health status is not as high as the same age-group in the wider population, with males, in particular, rating their health much worse than the general population. Level of happiness by age group reflects findings in other studies, i.e. that older people are more likely than younger people to rate their happiness at a high level – not one person 70+ in this study said that they were unhappy or very unhappy.

End-of-life treatment: A range of questions about end-of-life treatment found that 12% of respondents (n=6) had never thought about what treatment they might or might not want if they were terminally ill. Given that the sample was drawn from patients 60 and older currently receiving treatment in the health care system, this is somewhat surprising. As there was no identification on respondent’s questionnaires of the group from which they came, it is possible that these six respondents were part of the GP/patient cohort, and may not have had a serious or chronic illness at this time and may also not have experienced the loss of a close friend or relative. Alternatively, they may simply have chosen not to think about such issues.

Respondents who had both thought about, and talked about, end-of-life treatment options were most likely to have talked to and adult son or daughter, their spouse or other family member, a close friend or their GP. These findings suggest that older people are not reluctant to discuss end-of-life issues and have a range of possible confidants to whom they can speak. Younger respondents were significantly more likely than the older group to have discussed these issues with friends; females were more likely to talk to their adult children while males were more likely to talk to their spouse or to nurses or a lawyer.
Causes of distress in terminal illness: It is often stated that death is the greatest concern to those with a terminal illness. This study showed that most respondents considered that factors other than death, including loss of mental faculties, loss of control and independence and being a burden on families, would cause them most distress if they were terminally ill; from nine possible factors of concern, death itself rated last. This reinforces the importance of understanding what does and does not matter to people at the end of their lives, i.e., listening to the people whose needs are being addressed. The high rating of the above factors was also confirmed by preferences expressed for who should decide what treatment the respondents received if they were terminally ill, with almost all wanting to consent to or refuse treatment, or have their doctor decide what treatment they should receive.

Trust in doctors: In this study a very high level of trust in doctors was found and this was much higher than in previous studies by members of this research team; 92% of respondents thought that most patients would welcome an opportunity to discuss end-of-life treatment issues with their GP and almost all of them said that they would be very likely to have such a discussion, although only six had so far done that and in most cases it was the patient who had raised the issue. Given that the majority of respondents said that they would be comfortable raising such issues with their doctor, or having the doctor raise such issues with them, it seems that there may be a need for more education to encourage doctors to begin such discussions with their older patients and so avoid family and staff difficulties at later times of trauma or incompetence. This was further reinforced in the study by findings that most respondents saw GPs as the most appropriate people to assist them with Advance Care Planning and discussion with the doctor was the preferred choice for such planning. It appears that these respondents felt that such discussions should occur even when the doctor has to give the patient bad news as a large percentage of respondents said that a doctor should tell an adult patient, who has advanced cancer and is not likely to have long to live, the truth about his or her condition.

Advance Care Planning: The need for community education about Advance Care Planning options was highlighted by the fact that, while only 15 respondents had heard of Advance Health Care Directives (and the younger group was most likely to have done so), there was almost unanimous support for such documents to be legally binding on health care providers and to believe that they would make a useful contribution to medical care. In addition, while only four respondents (8%) had already recorded their wishes, an addition 35 (66%) wanted to do so and 89% thought it was very important to have a written document of their wishes. All health care professionals, as well as others working in this field, can play a role in community education but GPs are uniquely placed to do so, and appear to have the trust of patients that would support such work.

Barriers to ACP: The need for community education was also demonstrated by the fact that not knowing enough about Advance Health Care Directives or Enduring Guardianship forms was identified as the main barrier to their completion by the majority of respondents. Again, trust in doctors was reflected by the fact that older people also saw a barrier to their completion of an AHCD being that they would prefer to leave the decision to their doctor.

As demonstrated above in relation to talking about end-of-life issues, adult children and spouses were the most likely to have been appointed as Enduring Guardians, and were also first choice for future appointment. However, again their was concern expressed that appointing a family member as Enduring Guardian might result in too much burden on the
person chosen – a theme that emerged when examining potential causes of distress in terminal illness.

A barrier to Advance Care Planning that is often proposed by health care providers is that older people do not want to talk about end-of-life issues; that was not seen as a barrier by respondents in this study (nor has it been in other studies conducted by the Chief Investigator of this study). Perhaps it is the health care providers who do not want to talk to patients about end-of-life issues; if so, this could potentially be addressed through education.

There is now a need to extend this research to determine the attitudes and knowledge of health care providers in this region, and to extend the work into other care areas.
CHAPTER 1 – BACKGROUND

In the past few decades, an ageing population, increasing levels of dementia, rising health care costs and the shift from medical paternalism to increased patient autonomy have focussed attention on end-of-life decision-making, both in Australia and internationally.

Advance Care Planning (ACP) is a process which assists competent respondents to make decisions about future health care in consultation with their health care providers, family members and other important people in their lives. Based on the ethical principle of patient autonomy and the legal doctrine of patient consent, ACP helps to ensure that patient choice is respected if the patient becomes incapable of participating in treatment decisions. ACP involves conversations between the patient, their health care providers and their family/loved ones about their values, beliefs and goals in life, and, in light of their current health status, what medical treatments they would or would not want in the future.

Australian data on ACP is limited (Cartwright & Parker, 2004; Taylor & Cameron, 2002; Nair et al, 2000; Taylor & Tan, 2000). Although research conducted in Queensland (Steinberg et al, 1996) and the Northern Territory (Cartwright et al, 1998) demonstrated strong support from doctors, nurses and the general community for such actions, “ACP appears poorly developed in Australia” (Taylor & Tan, 2002:475). Studies in NSW (Nair et al, 2000) and South Australia (Brown et al, 2005) found very low levels of formal planning in residential aged care facilities (RACF), and very low ACP levels were also found in GP surgeries in Queensland (Hawkins & Cartwright, 2000) and South Australia (Brown, 2002).

The primary legislative option for ACP in NSW is the appointment of a proxy or substitute decision-maker under Enduring Guardianship legislation. In addition, respondents may complete a written document called an Advance Health Care Directive (AHCD). While there is no specific legislation in NSW covering AHCD, the NSW Department of Health has advised health care professionals that, because of common law provisions, failure to respect an AHCD “may constitute assault and battery” (NSW Department of Health, 2004:9). If a patient chooses not to complete these documents it is still possible to use ACP by recording their wishes, as expressed in discussions with their health care providers, in their medical records.

Difficulties accessing AHCDs have been noted in Hospital Emergency Departments (Vinen, 2002). There is currently very little ACP undertaken in hospitals or GP surgeries in the Mid-North Coast area. A chart audit of 50 patient records, conducted in 2005 at Coffs Harbour Hospital, Bellingen Hospital and a residential aged care facility in the area, found no evidence of ACP in any patient chart (Phillips J, personal communication, 2006). This pilot study is a response to a request by staff at Coffs Harbour Base Hospital and Bellinger River District Hospital, and the Mid-North Coast Division of General Practice, for assistance with ACP.

AIM: The pilot study aimed to assess attitudes to ACP among older respondents in medical wards, participating in a chronic care program or attending a general practice, and to offer these respondents the option to complete ACP documents; the study findings will be used to support an application for a larger, regional study.
CHAPTER 2 – METHODOLOGY

2.1 ADVISORY COMMITTEE:
The Advisory Committee for this study was the Advance Care Planning Group (see Acknowledgments).

2.2 ETHICS APPROVAL:
Ethics approval for the study was obtained from Southern Cross University Human Research Ethics Committee and the North Coast Area Health Service. Following ethics approval, consent for the project was given by the Chief Executive Officers of the Coffs Harbour Base Hospital and Bellinger River District Hospital.

2.3 STUDY DESIGN:
The study design used an anonymous questionnaire survey to assess knowledge of ACP, any action taken to date (i.e. appointment of Enduring Guardian [EG], discussions with family and/or doctor or written directions), and attitudes to ACP among older patients in the two hospitals and in the three GP practices in Coffs Harbour and Woolgoolga. Following completion and return of the questionnaire, all participants were offered ACP assistance to appoint an Enduring Guardian (EG), and/or complete an AHCD, and/or have their wishes recorded in their medical records.

2.4 QUESTIONNAIRE DEVELOPMENT:
The study questionnaire was developed by the Principal Investigator from a questionnaire used in two large NHMRC-funded postal surveys of health professionals and community members (Cartwright, Williams et al, 2002; Steinberg, Cartwright et al, 1996), and a GPEP-funded survey of GPs and their patients, conducted in Queensland (Steinberg, Parker et al, 1996). The questionnaire was amended to meet legislative provisions in NSW and the specific sample of this study and piloted with nurses and GPs working with older patients, including those who had been diagnosed with a chronic illness, and with three older community members; further minor amendments followed their feedback.

2.5 SAMPLE SELECTION:
Three Chronic Care nurses at Coffs Harbour Base Hospital (CH), two nurses from Bellinger River District Hospital (BR) medical ward and three general practitioners indicated their willingness to be involved in the study. The CH nurses and the GPs each agreed to recruit 10 respondents who met the selection criteria; the BR nurses agreed to recruit 10 in-patients as a team.

A training session was conducted for the recruitment team, in an effort to standardise the recruitment process. Each recruiter was provided with a Patient Record Form to record each of the processes.

Inclusion criteria: Patients aged 60 years of age or above, attended by one of Chronic Care nurses at CH Hospital or admitted to the medical ward of BR Hospital, or attending the surgery of one of the GPs during the study period.
Exclusion criteria: Patients with insufficient English, who were illiterate or who had dementia or another illness which would prevent them from understanding the questions asked, or who were too ill or frail to participate. (Note: a patient who was illiterate or frail but who wished to participate was not excluded if they had a family member or friend to assist them to complete the questionnaire).

The sample was selected as follows: Continuous from the starting date of the study, all eligible patients (a) attending CH hospital for chronic care or visited in their own homes for chronic care, (b) currently in or admitted in the study period to the medical ward at BR Hospital, and (c) attending one of the three GP surgeries were provided with an Information Sheet about the study and invited to participate. Those who agreed to participate were asked to sign a Consent Form. Recruiters were asked to continue this process until they had each recruited 10 patients (N=70).

2.6 QUESTIONNAIRE DISTRIBUTION:
Patients who signed the Consent Form were given the questionnaire and a stamped and addressed return envelope. As the questionnaires had no identifying information on them, to ensure anonymity, participants were also given a stamped, addressed card, with their name and recruitment group on one side, which they were asked to return separately to advise the PI that they have completed and returned the questionnaire. The card also allowed participants to request feedback from the study. In-patients in BR Hospital completed the questionnaire (with assistance if required) and returned it in the sealed envelope to the recruiting nurse for forwarding to the PI.

Follow-up: As cards were received the names were listed for the specific recruitment group. At the end of each week the recruiters were sent a list of names of respondents whose cards had been returned, for marking off their own Master List. After two weeks, any patient who had not returned their card was contacted by phone and reminded to complete and return the questionnaire and card. Only one follow-up call was made to any patient.

2.7 OFFER OF ACP ASSISTANCE:
Completing the questionnaire provided participants with information about ACP. As cards were returned, the majority of participants were again contacted by the nurse or GP staff member and offered the opportunity to complete an AHCD and/or appoint an EG. If the participant wished to do so, they were provided with an AHCD and EG form and asked to complete this in discussion with family members or a close friend. (Note: This was considered to be important as a person appointed as EG must agree to this nomination). Participants who required assistance to complete the forms were offered this; all participants who chose to complete an AHCD were advised that the completed form should be signed by their GP or other treating medical practitioner, and witnessed by an independent witness (such as a JP).

It was recommended to participants that a copy of the completed AHCD and/or EG form should be placed in their medical record at the hospital or GP surgery.
2.8 DATA MANAGEMENT AND ANALYSIS

Response rate: A record was kept of the number of patients who were invited to participate in the study, the number who agreed to participate and were given a questionnaire and the number of questionnaires returned. A record was also kept of the number of participants who were offered ACP forms and/or assistance and the number who completed the forms and returned copies to be placed in their medical record.

Coding and data entry: A Code Book was set up from responses to the piloting of the questionnaire. As questionnaires were returned they were given an ID code, and were manually coded and entered into SPSS 12 statistical package, with random checking for accuracy. Descriptive statistics (frequencies and cross tabulations) were run and data cleaning undertaken where necessary, checking outliers against the original questionnaire.

The results of the analysis are reported in Chapter 3
CHAPTER 3 – RESULTS

3.1 RESPONSE RATES:
From the total recruitment team, 80 patients were invited to participate in the study and 65 (81%) accepted the invitation. The patient load and contact frequency of one Chronic Care nurse only allowed her to recruit 6 patients in the study period and one Chronic Care patient was also inadvertently recruited by one of the GPs. From the sample of 65 patients, a total of 54 completed questionnaires were received, a response rate of 83%.

The results of the demographic and health characteristics of the respondents as well as their views on health services and treatment rights, advance directives and proxies are reported in this chapter.

3.2 DEMOGRAPHIC CHARACTERISTICS

The gender, age, socio-economic characteristics and religious affiliations of the respondents are reported in this section. (Note: patients who responded by completing their questionnaire are henceforth referred to as respondents).

3.2.1 Gender and Age

There were slightly more females (55%, n=29) than males (45%, n=24) among respondents (1 person did not answer this question). Ages ranged from 60 to 90+, with the majority of respondents being less than 80 years of age (Table 3.1).

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<th>Percentage</th>
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</table>

3.2.2 Socio-Economic Characteristics

Just over half of the respondents were married and living with a spouse (both 56%); there was no significant difference by age group in relation to marital status or living arrangements but differences by gender reached significance for marital status - 75% of the males (n=18) but only 41% of the females (n=12) were currently married ($\chi^2 = 6.043, p=0.014$); and approached significance for living arrangements - 21% of males lived alone compared with 35% of females, 71% of males lived with their spouse compared with 41% of females and only 8% of males lived with others compared with 24% of females ($\chi^2 = 4.878, p=0.087$).
Education levels of the respondents were as follows: 37% had completed primary school, 35% had completed Year 10, 6% had completed Year 12, 17% had completed a technical or trade certificate and 4% had a University degree. Differences by age group in relation to education reached significance, with 38% of 60-69 year-old respondents having had some tertiary education, compared with only 10% of the 70+ age group ($\chi^2 = 5.834, p=0.016$). Slightly more females than males had had some tertiary education (24% compared with 17%) but the difference was not significant.

Eighty percent of respondents (n=51) reported their current household income as less than $20,000 per annum, with an additional 12% having annual income between $20,000 and $29,000; only 8% of respondents had annual income greater than $30,000. There were no significant differences in relation to income by age or gender.

### 3.2.3 Religion

Seventy percent of the respondents (n=37) reported that they belonged to one of the three main Christian religions (Anglican 43%, Catholic 22%, Uniting Church 4%); 17% (n=9) said that they had no religious affiliation and 13% (n=7) listed a range of other (mostly Christian) religions. There were no significant differences by age or gender in relation to religious affiliation.

When asked to what extent their religious or philosophical beliefs influenced their attitudes to issues such as medical decisions at the end of life, 25% (n=13) said A great deal, 19% (n=10) said Somewhat but 56% (n=29) said Not at all.

### 3.3 HEALTH AND HAPPINESS

#### 3.3.1 Health

Respondents were asked to rate their health on a 5-point scale (from 1 = Excellent to 5 = Poor). Overall, 16% considered themselves to be in excellent/very good health, 30% said that their health was good and 54% thought that they were in fair/poor health.

#### 3.3.2 Happiness

Respondents were also asked to rate their happiness on a 5-point scale (from 1 = Very Happy to 5 = Very Unhappy). Fifteen percent of respondents said they were very happy, 43% were happy, 33% were neither happy nor unhappy, 7% were unhappy and 2% were very unhappy.

Chi-square analysis of health and happiness responses by age and gender was undertaken. Results are presented in Table 3.2.
### Table 3.2: Self-Report of Health and Happiness: Percentage by age and gender

<table>
<thead>
<tr>
<th>HEALTH</th>
<th>ALL % (N=54)</th>
<th>AGE %</th>
<th>ALL % (N=53)*</th>
<th>GENDER %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>&lt;70</td>
<td>70+</td>
<td></td>
</tr>
<tr>
<td>Excellent/Very Good</td>
<td>16</td>
<td>29</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>30</td>
<td>21</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>Fair/Poor</td>
<td>54</td>
<td>50</td>
<td>57</td>
<td></td>
</tr>
</tbody>
</table>

\[ \chi^2 = 5.88, p = 0.071 \]

\[ \chi^2 = 9.145, p = 0.010 \]

<table>
<thead>
<tr>
<th>HAPPINESS</th>
<th>(N=54)</th>
<th>(N=53)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Happy/Happy</td>
<td>58</td>
<td>58</td>
</tr>
<tr>
<td>Neither</td>
<td>33</td>
<td>21</td>
</tr>
<tr>
<td>Unhappy/Very Unhappy</td>
<td>9</td>
<td>21</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 8.281, p = 0.016 \]

n.s.

* One respondent did not answer this question

**Age**

Differences by age group approached significance in relation to health, with the major difference being that respondents 70+ were less likely than the younger group to say that their health was excellent or very good. However, differences in relation to happiness were significant; while a majority of both groups said that they were very happy or happy, more of the younger group were likely to say that they were unhappy or very unhappy, with none of the 70+ group saying this.

**Gender**

Females were significantly less likely than males to say that their health was fair or poor. There was no significant difference between females and males with respect to happiness.
3.4 TREATMENT AND RIGHTS OF TERMINALLY ILL PEOPLE

Respondents’ perspectives about terminal illness are reported in this section.

3.4.1 Personal Decision-Making Regarding End-of-Life

Respondents were asked a series of questions about personal decision-making regarding the end stage of life.

**Thinking about it:** Firstly, respondents were asked if they had ever thought about what treatment they might want, or might not want, if they were terminally ill. Overall 46% of respondents had often thought about treatment at the end of life and a further 42% had thought about it occasionally but 12% of the respondents said that had never thought about it. There were no significant differences by age or gender in relation this question.

**Significant event:** When the 46 respondents who had thought about this issue were asked whether there was some significant event in their life which started them thinking about it, the majority said that the death of a family member of friend had started the process; the next most common response was personal illness, followed by reaching a certain age.

**Talking about it:** Respondents who had thought about these issues were asked who, if anyone, they had talked to concerning treatment at the end of life. (More than one answer was possible). Respondents had most often talked with a son or daughter (n=28), a spouse (n=24), a friend (n=15), their GP (n=13) or another relative (n=11). Six respondents in each case had discussed the issue with a community nurse or another nurse at a hospital. Very few respondents had discussed this issue with a minister or a lawyer.

Chi square analysis by age and gender found the following:

**Age:** Differences by age group for this question reached significance only in relation to discussions held with friends. Of the 36 respondents who answered this question, 8 of the 16 aged 60-69 (50%) said that they had talked to friends about end-of-life treatment issues, compared with only 3 of the 20 aged 70+ (15%) ($\chi^2 = 5.132, p=0.028$).

**Gender:** Although only 30 respondents were currently married, 38 answered the question of whether or not they had ever discussed end-of-life treatment with their spouse (23 Yes, 15 No); it is assumed that some respondents had done so prior to the loss of their spouse through death or divorce. Differences by gender reached significance for discussion with spouse, with community nurse and with hospital nurse, and approached significance for discussion with son or daughter and discussion with a lawyer (Table 3.3).
Table 3.3: Discussion Re: End-of-Life Treatment: Number/Percentage Yes by Gender

<table>
<thead>
<tr>
<th>DISCUSSANT</th>
<th>n</th>
<th>FEMALE</th>
<th>MALE</th>
<th>χ², p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>23</td>
<td>8 (42%)</td>
<td>15 (79%)</td>
<td>5.397, p=0.022</td>
</tr>
<tr>
<td>Son/Daughter</td>
<td>27</td>
<td>17 (74%)</td>
<td>10 (48%)</td>
<td>3.201, p=0.069</td>
</tr>
<tr>
<td>Community Nurse</td>
<td>6</td>
<td>0</td>
<td>6 (32%)</td>
<td>6.442, p=0.014</td>
</tr>
<tr>
<td>Hospital Nurse</td>
<td>6</td>
<td>0</td>
<td>6 (33%)</td>
<td>6.839, p=0.011</td>
</tr>
<tr>
<td>Lawyer</td>
<td>4</td>
<td>0</td>
<td>4 (22%)</td>
<td>4.265, p=0.058</td>
</tr>
</tbody>
</table>

Males were significantly more likely than females to have discussed their end-of-life treatment wishes with their spouses, with community or hospitals nurses and with a lawyer (however, numbers for the latter three were very small); females were significantly more likely than males to have discussed their end-of-life treatment wishes with their children.

Of those respondents who had thought about what treatment they might or might not want, but had not talked to anyone about it, the reasons given for not doing so included that they “did not want to worry anyone”, were “not ill enough yet” and “never felt the need to”.

3.4.2 Preferences Regarding Decision-Making if Terminally Ill

Respondents were asked the extent to which they agreed (on a 5-point scale from 1 = Strongly Agree to 5 = Strongly Disagree) with a series of questions about whether or not they would want the opportunity to decide what treatment they wanted, or to refuse treatment, if they were very ill, and whether or not they would want others (family member, friend, treating doctor or family + treating doctor + GP) to decide. Table 3.4 presents responses for Strongly Agree/Agree plus Mean Scores.

Table 3.4: Preferences Re: End-of-Life Treatment: Number and Percentage Strongly Agree/Agree and Mean Score

<table>
<thead>
<tr>
<th>Q. If I were very ill I would:</th>
<th>N*</th>
<th>SA/A</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) want the opportunity to decide what treatment I wanted</td>
<td>52</td>
<td>51 (98%)</td>
<td>1.37</td>
</tr>
<tr>
<td>(b) want the opportunity to refuse any treatment that I did not want</td>
<td>51</td>
<td>47 (92%)</td>
<td>1.47</td>
</tr>
<tr>
<td>(c) prefer a family member to decide what treatment I should have</td>
<td>47</td>
<td>25 (53%)</td>
<td>2.68</td>
</tr>
<tr>
<td>(d) prefer a friend to decide what treatment I should have</td>
<td>48</td>
<td>7 (15%)</td>
<td>4.04</td>
</tr>
<tr>
<td>(e) prefer the treating doctor to decide what treatment I should have</td>
<td>49</td>
<td>26 (53%)</td>
<td>2.51</td>
</tr>
<tr>
<td>(f) prefer my family and/or treating doctor to discuss with my GP what treatment I should have</td>
<td>49</td>
<td>35 (71%)</td>
<td>2.08</td>
</tr>
</tbody>
</table>

* Not all respondents answered every question
The majority of respondents strongly agreed or agreed that they would want the opportunity to consent to or refuse treatment if they were very ill. If they were not able to make their own decisions, the order of preference for who should decide was: (1) family and/or treating doctor in discussion with the patient’s GP; and (2) equally a family member or the treating doctor. Very few respondents wanted a friend to make that decision.

**Age and Gender:** There were no significant differences by age or gender in relation to these questions except that males were significantly more likely than females to say that they would prefer a family member to decide what treatment they should have (87%:50% SA/A) ($\chi^2 = 7.668$, p=0.022) and respondents 70+ were somewhat more likely than those 60-69 to say that they would prefer their GP to decide (96%: 74% SA/A) ($\chi^2 = 5.408$, p=0.067).

### 3.4.3 Greatest Concerns Regarding Terminal Illness

Respondents were asked how much distress they thought the following issues would cause them if they were terminally ill: loss of dignity/independence/mental faculties and control, physical pain, fear of death, uncertainty about what will happen, fear of being a burden on family and fear of being a burden on society. Responses were on a 5-point scale (from *Great Distress* =1 to *No Distress* =5). Table 3.5 presents the results for Great Distress and the Mean of the responses, in order of most distress by Mean score.

<table>
<thead>
<tr>
<th>FACTOR</th>
<th>N*</th>
<th>Great Distress n / %</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Loss of Control</td>
<td>52</td>
<td>37 (71%)</td>
<td>1.37</td>
</tr>
<tr>
<td>(2) Loss of Mental Faculties</td>
<td>48</td>
<td>38 (79%)</td>
<td>1.40</td>
</tr>
<tr>
<td>(3) Loss of Independence</td>
<td>52</td>
<td>34 (65%)</td>
<td>1.46</td>
</tr>
<tr>
<td>(4) Being a Burden on Family</td>
<td>51</td>
<td>35 (67%)</td>
<td>1.53</td>
</tr>
<tr>
<td>(5) Loss of Dignity</td>
<td>50</td>
<td>28 (56%)</td>
<td>1.68</td>
</tr>
<tr>
<td>(6) Physical Pain</td>
<td>50</td>
<td>27 (54%)</td>
<td>1.76</td>
</tr>
<tr>
<td>(7) Uncertainty about what will happen</td>
<td>51</td>
<td>20 (39%)</td>
<td>2.12</td>
</tr>
<tr>
<td>(8) Being a Burden on Society</td>
<td>51</td>
<td>24 (47%)</td>
<td>2.29</td>
</tr>
<tr>
<td>(9) Fear of Death</td>
<td>49</td>
<td>7 (14%)</td>
<td>3.37</td>
</tr>
</tbody>
</table>

*Not all respondents answered every question*

The highest percentage of Great Distress responses was for Loss of Mental Faculties, followed by Loss of Control, Being a burden on Family and Loss of Independence. Fear of Death was rated last. However, when the Mean of the scores was considered the order of the first 4 results changed somewhat, with Loss of Control assuming first place; this indicates a marginally wider distribution of scores on the 5-point scale.

**Age and Gender:** Chi square analysis was undertaken comparing Great Distress/Not Great Distress. Differences among respondents by age group reached significance only in relation to Fear of Death (21% of 60-69 year-olds said fear of death would cause them great distress, compared with 7% of those aged 70+ - $\chi^2 = 6.075$, p=0.048), and by gender for Loss of Control.
(79% of females said that loss of control would cause them great distress, compared with 54% of males - $\chi^2 = 7.641$, p=0.022). Differences approached significance by age group in relation to Loss of Dignity (67% of 60-69 year-olds said loss of dignity would cause them great distress, compared with 40% of those aged 70+ - $\chi^2 = 5.610$, p=0.060).

3.4.4 Doctor-Patient Communication

Respondents were asked to what extent they agreed that most patients would welcome the opportunity to discuss issues regarding end-of-life with their doctor. Responses were on a 5-point scale (from 1 = Strongly Agree to 5 = Strongly Disagree); 43% strongly agreed, and 49% agreed (92% SA/A), that most patients would welcome such a discussion.

They were next asked how likely they would be to discuss any concerns they might have about medical treatment at the end stage of life with their GP. Responses were on a 5-point scale (from 1 = Very Likely to 5 = Very Unlikely); 64% of respondents said it was very likely, and 30% said it was likely (94% VL/L), that they would have such a discussion with their GP. However, only 6 patients said that they had discussed their preferences for treatment in the event of a future illness with their doctor and in 80% of cases it was the patient who had raised the issue.

Respondents were asked how comfortable they would feel raising the subject of death and dying with their doctor, and how comfortable they would feel if the doctor raised the subject with them. Responses were on a 5-point scale (from 1 = Very Comfortable to 5 = Very Uncomfortable); slightly more respondents said that they would be very comfortable if they raised the topic (n=20) than if the GP did (n=14). However, once the second option was added there was very little difference, with 46 respondents (89%) saying that they would be very comfortable or comfortable to raise the topic themselves and 44 (85%) saying that they would be very comfortable or comfortable if their GP did so.

Finally, respondents were asked if they thought a doctor should tell an adult patient, who has advanced cancer and is not likely to have long to live, the truth about his or her condition. The majority of respondents (64%, n=34) said that the doctor should do so in all cases, an additional 19% (n=10) said that the doctor should do so to allow discussion to occur. Some respondents had reservations about this as 11% (n=6) said that the doctor should only do so if s/he thinks that the patient can cope while the remaining 6% (n=3) thought that the doctor should only do so if the patient asks.

**Age and Gender:** Differences between respondents did not reach significance by age or gender in relation to any of the above questions.
3.5 ADVANCE HEALTH CARE DIRECTIVES

A definition of Advance Health Care Directives was given in the questionnaire as follows:

Because of an accident or illness a patient may not be able to tell the doctor what life-sustaining treatments he or she wants or does not want. Some people choose to write down these preferences beforehand. This written document is an Advance Health Care Directive.

3.5.1 Knowledge of Advance Directives:
Respondents were asked if they had heard of the term Advance Health Care Directives before reading the questionnaire and whether or not they knew if such documents are legally enforceable in New South Wales; 15 of the 49 respondents who answered the question (i.e. 31%) said that they had heard of them but only 11 respondents said that they knew what their legal status was. However, when respondents were asked whether, in their opinion, Advance Health Care Directives should be legally binding on health care professionals, 49 of the 52 respondents (94%) said that they should be.

Age and Gender: Differences between respondents did not reach significance by age or gender in relation to any of the above questions except that respondents aged 60-69 were significantly more likely than those aged 70+ to have heard of Advance Health Care Directives (52%: 14%) ($\chi^2 = 8.199, p=0.005$).

3.5.2 Importance of Written Documents:
Respondents were asked: (a) if they had already written down their ideas/wishes about their medical treatment for the end stage of life, (b) how important they thought it would be to have a written document explaining the level of care they wanted, in case they were unable to communicate their wishes (on a 5-point scale from 1 = Extremely Important to 5 = Not at all Important), and (c) how confident they were that if they had previously expressed their wishes for health care, these wishes would be carried out in the event that they were not capable of making their own decisions (again on a 5-point scale, from 1 = Very Confident to 5 = Not at all Confident). Only 4 respondents (8%) had already recorded their wishes but an additional 35 (66%) said that they would like to do so; 14 respondents (26%) said that they did want to do so. A very high percentage of respondents (89%) thought that it was extremely important or important to have a written document of their wishes, yet, despite the fact that only 4 had such a document 31 respondents (60%) said that they were very confident or confident that their previously expressed wishes would be respected.

3.5.3 Who Should Assist with Completion of Documents?
From a comprehensive list of people who could possibly assist a person to complete an Advance Health Care Directive, more than half of the respondents (53%, n=28) chose a GP as the most appropriate person, followed by a nurse specifically trained to assist with such documents (21%, n=11). A small number of respondents (11%, n=6) selected a counsellor specifically trained to assist with Advance Health Care Directives; only 3 respondents selected family, 2 each said spouse or minister and only 1 respondent considered a lawyer to be the most appropriate person.

Age and Gender: Differences between respondents did not reach significance by age or gender for any questions on the importance of written documents, nor on choice of person to assist.
3.5.4 Barriers to Completing an Advance Health Care Directive
Respondents were asked to consider a list of possible barriers that could prevent them from making an Advance Health Directive (Yes/No responses). Table 3.6 presents the overall results, as well as responses by age group. (Note: As there were no significant differences by gender, results are not provided in the Table).

<table>
<thead>
<tr>
<th>BARRIERS</th>
<th>N</th>
<th>TOTAL</th>
<th>60-69</th>
<th>70+</th>
<th>(\chi^2/p) Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t know enough about ADs</td>
<td>46</td>
<td>74</td>
<td>62</td>
<td>84</td>
<td>2.890; p=0.086</td>
</tr>
<tr>
<td>Don’t know how to make one</td>
<td>42</td>
<td>71</td>
<td>67</td>
<td>76</td>
<td>n.s</td>
</tr>
<tr>
<td>It might upset my family</td>
<td>40</td>
<td>25</td>
<td>30</td>
<td>20</td>
<td>n.s</td>
</tr>
<tr>
<td>Prefer things to take their course</td>
<td>39</td>
<td>49</td>
<td>42</td>
<td>55</td>
<td>n.s</td>
</tr>
<tr>
<td>Prefer to leave decisions to doctor</td>
<td>43</td>
<td>61</td>
<td>43</td>
<td>77</td>
<td>5.324; p=0.022</td>
</tr>
<tr>
<td>Prefer to leave decisions to family</td>
<td>39</td>
<td>31</td>
<td>30</td>
<td>32</td>
<td>n.s</td>
</tr>
<tr>
<td>Prefer not to think about end-of-life issues</td>
<td>37</td>
<td>27</td>
<td>28</td>
<td>26</td>
<td>n.s</td>
</tr>
<tr>
<td>Language/culture may make it difficult</td>
<td>40</td>
<td>15</td>
<td>15</td>
<td>15</td>
<td>n.s</td>
</tr>
<tr>
<td>May not understand treatment issues, even with help from doctor/nurse</td>
<td>39</td>
<td>44</td>
<td>35</td>
<td>53</td>
<td>n.s</td>
</tr>
</tbody>
</table>

Older respondents were significantly more likely than the younger group to say that they would prefer to leave decisions about their medical treatment to their doctor, and also to consider that not knowing enough about Advance Health Care Directives would prevent them from completing one. While the results were not statistically significant, the older group was also more likely to say that they would prefer things to take their course, and to be concerned that they may not understand the medical treatment issues sufficiently to complete an Advance Health Care Directive, even with assistance from a doctor or nurse.

3.5.5 Usefulness of Advance Health Care Directives
The final question relating to Advance Health Care Directives asked respondents to what extent they agreed that such documents would make a useful contribution to medical care. Responses were on a 5-point scale, from 1 = Strongly Agree to 5 = Strongly Disagree. Overall, 85% of respondents either strongly agreed or agreed with this concept.

Age and Gender: There were no significant differences by age or gender to this question, but the younger group was somewhat more likely than the older group (87%: 83%), and females were somewhat more likely than males (86%: 83%) to strongly agree or agree that Advance Health Care Directives would make a useful contribution to medical care.
3.6 ENDURING GUARDIANSHIP

A definition of Enduring Guardian was given in the questionnaire as follows:

*Some people may wish to choose a trusted friend or relative to make health care decisions for them in case they are unable to do so for themselves at some time in the future. This person can be legally appointed as the person’s Enduring Guardian. The Enduring Guardian would have the legal right to make decisions about what treatment the patient should or should not receive.*

Respondents were further advised that “some people may want to appoint an Enduring Guardian as well as writing an Advance Health Care Directive”.

3.6.1 Appointment of an Enduring Guardian

Have made appointment: Respondents were asked if they had appointed an Enduring Guardian to make medical decisions for them if they are no longer able to do so; 15 respondents (28%) said that they had done so, 36 (68%) had not and 2 respondents (4%) said that they did not know if they had appointed someone.

Age and Gender: There was no significant difference by age in relation to this question but males (46%, n=11) were significantly more likely than females (14%, n=4) to have appointed someone to be their Enduring Guardian.

Who appointed: Those who had made Enduring Guardian appointments were asked who they had appointed. As it is possible to appoint more than 1 person to this position, respondents were asked to nominate everyone who had been appointed. A total of 22 people had been appointed by the 15 respondents, including adult child (n=7), spouse (n=6), other family member (n=5), close friend (n=3) and doctor (n=1).

Age and Gender: There was no significant difference by age or gender in relation to this question.

Want to make appointment: Respondents who had not yet appointed an Enduring Guardian were asked if they wanted to do so. Although 15 people had already made such an appointment (potentially leaving 39 to answer the question) 42 respondents replied. Of these, 81% (n=34) said that they did want to make such an appointment, 17% (n=7) said that they did not and 1 respondent was not sure.

Age and Gender: There was no significant difference by age in relation to this question but females (71%, n=20) were significantly more likely than males (58%, n=14) to say that they wanted to appoint someone to be their Enduring Guardian.

Who to appoint: Respondents who wanted to appoint someone were asked who they would appoint, and again could nominate more than 1 person. A total of 58 people were nominated by respondents, as follows: adult child (n=21), spouse (n=15), doctor (n=9), other family member (n=7), close friend (n=5) and minister (n=1).
Age and Gender: Taking account of first preferences only, males (77%, n=10) were significantly more likely than females (24%, n=5) to nominate their spouse, while females (57%, n=12) were significantly more likely than males (15%, n=2) to appoint an adult child (overall $\chi^2 = 10.509, p=0.015$).

3.6.2 Barriers to Appointing an Enduring Guardian
Respondents were asked to consider a list of possible barriers that could prevent them from appointing an Enduring Guardian (Yes/No responses). Table 3.7 presents the overall results, as well as responses by Gender. (Note: Although there was only one response by gender that reached significance, results for all options are given to allow comparison between the two groups. As there were no significant differences by age group, results are not provided in the Table).

<table>
<thead>
<tr>
<th>BARRIERS</th>
<th>N</th>
<th>TOTAL % Yes</th>
<th>Female</th>
<th>Male</th>
<th>$\chi^2$</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t know how to do so</td>
<td>24</td>
<td>54</td>
<td>47</td>
<td>67</td>
<td>n.s</td>
<td></td>
</tr>
<tr>
<td>Prefer to leave decisions to doctor</td>
<td>22</td>
<td>41</td>
<td>33</td>
<td>57</td>
<td>n.s</td>
<td></td>
</tr>
<tr>
<td>Too much burden on person chosen</td>
<td>21</td>
<td>43</td>
<td>50</td>
<td>29</td>
<td>n.s</td>
<td></td>
</tr>
<tr>
<td>Wouldn’t know anyone suitable to ask</td>
<td>22</td>
<td>23</td>
<td>14</td>
<td>38</td>
<td>n.s</td>
<td></td>
</tr>
<tr>
<td>Prefer to make own decisions</td>
<td>25</td>
<td>64</td>
<td>50</td>
<td>100</td>
<td>5.469</td>
<td>0.024</td>
</tr>
<tr>
<td>Prefer not to think about end-of-life issues</td>
<td>21</td>
<td>24</td>
<td>14</td>
<td>43</td>
<td>n.s</td>
<td></td>
</tr>
</tbody>
</table>

Overall, respondents thought that preferring to make their own decisions and not knowing how to appoint someone would be the major barriers to doing so.

Age and Gender: As noted above, there were no significant differences by age group in relation to this question. Differences between males and females reached significance only in relation to respondents preferring to make their own decisions, in which case males were significantly more likely than females to say that this would present a barrier to them appointing someone as their Enduring Guardian. Although several of the response comparisons appear to be sufficiently different to be significant, the small numbers in the sample mean that they are not. Nevertheless, for all responses except concern about being a burden to the person chosen, males were more likely than females to see these barriers as preventing them appointing someone as their Enduring Guardian.

3.6.3 Appointment of Person to hold Enduring Power of Attorney (EPA) for Property/Finances
Respondents were asked if they had already appointed someone to have EPA for their property/financial arrangements; 25 respondents (69%) had done so.
Age and Gender: There was no significant difference by age group in relation to this question but males (67%, n=16) were significantly more likely than females (35%, n=10) to have appointed someone to have EPA.

3.6.4 Preferred Options for Advance Care Planning

The final question asked respondents to consider three possible options for Advance Care Planning: (a) write an Advance Health Care Directive; (b) appoint an Enduring Guardian, or (c) discuss the matter in advance with the doctor. Respondents were asked to answer Yes or No to each option. Table 3.8 presents the overall results, as well as responses by Gender. (Note: Although there no significant differences by age group or gender, results for all options are given by gender to allow comparison between the two groups).

Table 3.8: Options for Advance Care Planning: Overall Yes Responses, plus Percentage Yes by Gender

<table>
<thead>
<tr>
<th>OPTION</th>
<th>N</th>
<th>TOTAL % Yes</th>
<th>Female</th>
<th>Male</th>
<th>$\chi^2$ Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Write and Advance Health Care Directive</td>
<td>36</td>
<td>69</td>
<td>71</td>
<td>67</td>
<td>n.s</td>
</tr>
<tr>
<td>(b) Appoint an Enduring Guardian</td>
<td>45</td>
<td>87</td>
<td>78</td>
<td>96</td>
<td>n.s</td>
</tr>
<tr>
<td>(c) Discuss matter with doctor</td>
<td>41</td>
<td>95</td>
<td>96</td>
<td>94</td>
<td>n.s</td>
</tr>
</tbody>
</table>

Although there was support from a majority of respondents for all three options, there was almost total support from respondents for discussing the matter with their doctors. The next most favoured response was the appointment of someone to be Enduring Guardian, followed by completion of an Advance Health Care Directive.

NOTE: Chi square analysis was also undertaken by the other relevant variables of health, happiness, marital status, living arrangements, income, education and religion in relation to all questions asked in the study. There were almost no significant differences by any of these variables to the questions asked, and where results did reach significance, the small number in the sample meant that many cells had a count of 0 or 1, so chi square results would be unreliable. Results are therefore not reported.
CHAPTER 4 - DISCUSSION

Methodology: While the methodology used in this study worked well in relation to sample recruitment and questionnaire distribution and completion, it was less successful in relation to the follow-up procedures relating to Advance Care Planning, including assistance with completion of the Enduring Guardian or Advance Health Care Directive documents, or having copies of these returned to the hospital or GP surgery for lodgement in the patients’ records. This highlights the problem of asking already very busy health care providers to undertake additional, and potentially very time consuming tasks, and underlines the need for paid research staff to conduct at least some components of the work.

Generalisability of the sample: The demographic characteristics of the respondents appeared to reflect the wider community for these age groups in relation to marital status, living arrangements and education but not in relation to socio-economic status, which was lower than for the same age group in the wider population, with more than 80% having incomes less than $30,000 per annum. In addition, because this sample was selected from patients currently in or attending hospital for a medical condition, or attending a GP, their overall health status is not as high as the same age-group in the wider population, with males, in particular, rating their health much worse than the general population. Level of happiness by age group reflects findings in other studies, i.e. that older people are more likely than younger people to rate their happiness at a high level – not one person 70+ in this study said that they were unhappy or very unhappy.

End-of-life treatment: A range of questions about end-of-life treatment found that 12% of respondents (n=6) had never thought about what treatment they might or might not want if they were terminally ill. Given that the sample was drawn from patients 60 and older currently receiving treatment in the health care system, this is somewhat surprising. As there was no identification on respondent’s questionnaires of the group from which they came, it is possible that these six respondents were part of the GP/patient cohort, and may not have had a serious or chronic illness at this time and may also not have experienced the loss of a close friend or relative. Alternatively, they may simply have chosen not to think about such issues.

Respondents who had both thought about, and talked about, end-of-life treatment options were most likely to have talked to and adult son or daughter, their spouse or other family member, a close friend or their GP. These findings suggest that older people are not reluctant to discuss end-of-life issues and have a range of possible confidants to whom they can speak. Younger respondents were significantly more likely than the older group to have discussed these issues with friends; females were more likely to talk to their adult children while males were more likely to talk to their spouse or to nurses or a lawyer.

Causes of distress in terminal illness: It is often stated that death is the greatest concern to those with a terminal illness. This study showed that most respondents considered that factors other than death, including loss of mental faculties, loss of control and independence and being a burden on families, would cause them most distress if they were terminally ill; from nine possible factors of concern, death itself rated last. This reinforces the importance of understanding what does and does not matter to people at the end of their lives, i.e., listening to the people whose needs are being addressed. The high rating of the above factors was also confirmed by preferences expressed for who should decide what treatment the respondents received if they were terminally ill, with almost all wanting to consent to or refuse treatment, or have their doctor decide what treatment they should receive.
Trust in doctors: In this study a very high level of trust in doctors was found and this was much higher than in previous studies by members of this research team; 92% of respondents thought that most patients would welcome an opportunity to discuss end-of-life treatment issues with their GP and almost all of them said that they would be very likely to have such a discussion, although only six had so far done that and in most cases it was the patient who had raised the issue. Given that the majority of respondents said that they would be comfortable raising such issues with their doctor, or having the doctor raise such issues with them, it seems that there may be a need for more education to encourage doctors to begin such discussions with their older patients and so avoid family and staff difficulties at later times of trauma or incompetence. This was further reinforced in the study by findings that most respondents saw GPs as the most appropriate people to assist them with Advance Care Planning and discussion with the doctor was the preferred choice for such planning. It appears that these respondents felt that such discussions should occur even when the doctor has to give the patient bad news as a large percentage of respondents said that a doctor should tell an adult patient, who has advanced cancer and is not likely to have long to live, the truth about his or her condition.

Advance Care Planning: The need for community education about Advance Care Planning options was highlighted by the fact that, while only 15 respondents had heard of Advance Health Care Directives (and the younger group was most likely to have done so), there was almost unanimous support for such documents to be legally binding on health care providers and to believe that they would make a useful contribution to medical care. In addition, while only four respondents (8%) had already recorded their wishes, an addition 35 (66%) wanted to do so and 89% thought it was very important to have a written document of their wishes. All health care professionals, as well as others working in this field, can play a role in community education but GPs are uniquely placed to do so, and appear to have the trust of patients that would support such work.

Barriers to ACP: The need for community education was also demonstrated by the fact that not knowing enough about Advance Health Care Directives or Enduring Guardianship forms was identified as the main barrier to their completion by the majority of respondents. Again, trust in doctors was reflected by the fact that older people also saw a barrier to their completion of an AHCD being that they would prefer to leave the decision to their doctor.

As demonstrated above in relation to talking about end-of-life issues, adult children and spouses were the most likely to have been appointed as Enduring Guardians, and were also first choice for future appointment. However, again their was concern expressed that appointing a family member as Enduring Guardian might result in too much burden on the person chosen – a theme that emerged when examining potential causes of distress in terminal illness.

A barrier to Advance Care Planning that is often proposed by health care providers is that older people do not want to talk about end-of-life issues; that was not seen as a barrier by respondents in this study (nor has it been in other studies conducted by the Chief Investigator of this study). Perhaps it is the health care providers who do not want to talk to patients about end-of-life issues; if so, this could potentially be addressed through education.

There is now a need to extend this research to determine the attitudes and knowledge of health care providers in this region, and to extend the work into other care areas.
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