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**PARTICIPATING IN END-OF-LIFE DECISIONS:
THE ROLE OF GENERAL PRACTITIONERS**

Margaret Brown, Justin Beilby and Eric Gargett

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The Hawke Institute
University of South Australia
St Bernards Road
Magill
South Australia 5072
Australia
www.unisa.edu.au/hawke/institute/institute

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PARTICIPATING IN END-OF-LIFE DECISIONS: THE ROLE OF GENERAL PRACTITIONERS

Margaret Brown, Justin Beilby and Eric Gargett*

In April 1996 the South Australian Government released a policy document *Aging: a ten-year plan for South Australia*. This document emphasised the right and expectation of full citizenship for all individuals in this state from birth until death. Maintaining a sense of autonomy and dignity as one ages and faces death is integral to the nature of citizenship. More research is required to understand how this sense of autonomy and dignity can be maintained as we age. General practitioners could play an important role by introducing advance directives to their elderly patients in order to assist them and their families to face the future calmly and reassure them that control need not be lost during an serious illness or as they face death.

This study explores the issues which South Australian general practitioners must consider when introducing advance directives to their patients. An advance directive is a set of instructions given in advance by an individual about future health care decisions. It is based on the premise that if people know that their autonomy will be respected and that they can have some say about their treatment decisions when they are dying, they will be able to confront their death with less anxiety.

This is particularly relevant for the increasing number of elderly people in this state who may not want their death to be protracted unnecessarily by technological intervention. It is not death that most people fear but dying. To know that one's autonomy will be respected, if at all possible, should reduce the fear and stress associated with dying. The rationale for this argument comes from a large body of literature which demonstrates that human beings cope better with stress when they feel they have control (Shultz and Schlarb 1986).

Completing an advance directive involves a series of complex decisions and challenges individuals to think about their dying. Currently there is a lack of information to assist individuals in making these decisions. General practitioners could assist older people in understanding their choices and how advance directives might assist them in maintaining some sense of control.

* Margaret Brown is Adjunct Research Fellow at the Hawke Institute and a member of the Conflict Management Research Group. Justin Beilby is a senior lecturer in the Department of General Practice, University of Adelaide. Eric Gargett is a retired human services policy administrator.

BACKGROUND AND SIGNIFICANCE

In South Australia advance directives are legal documents which require individuals to make decisions about medical treatments such as resuscitation, turning off life support, intravenous hydration and so on (Anticipatory Direction, Schedule 2 and the Medical Power of Attorney, Schedule 1, of the *Consent to Medical Treatment and Palliative Care Act 1995*). They must be completed while one is still competent and before a serious illness occurs. An advance directive is either in the form of document which expresses one's wishes in writing (also called a 'living will'), or it involves appointing another person to make the decisions, if an individual is no longer able to do so, or a combination of the two. The term advance directive is now more commonly used than 'living will'.

The South Australian *Natural Death Act 1983* was the first 'living will' legislation in Australia. It was repealed by the *Consent to Medical Treatment and Palliative Care Act* in April 1995 and replaced with a different type of advance directive. This new Act provides for written instructions (an anticipatory direction, Schedule 2) and appointing a medical agent (a medical power of attorney, Schedule 1). Similar changes have occurred in most jurisdictions in the United States, as living wills associated with natural death Acts were found to be too narrow in application and were activated only by terminal illness.

An extensive public and professional education campaign was carried out in South Australia to inform the public and health professionals about the Act. This included a pamphlet ('It's your life—all of it ... An explanation of the *Consent to Medical Treatment and Palliative Care Act 1995*') to explain the Act (the 'community pamphlet') and a brochure to assist health professionals in understanding the implementation of the Act (the 'professional brochure').

The purpose of an advance directive is to help people avoid burdensome and futile medical treatment when they become incompetent, either during the dying process or for an irreversible condition which leaves them with severe brain damage (eg persistent vegetative state or advanced dementia). An advance directive embodies the principle of autonomy, the right to self-determination. It aims to promote empowerment, compassion and dignity. If the ethical use of such instruments results in cost savings then this is also a desirable outcome. It is important that directives stimulate communication between individuals and their general practitioners as well as their families or close friends about what they want in the event of future incompetence. An advance directive should be part of the clinical process and an integral part of the doctor-patient relationship.

The *Consent to Medical Treatment and Palliative Care Act 1995* (SA) reinforces the common law right to refuse medical treatment. It extends this right by allowing people to express their wishes in advance either in writing or by appointing an

agent, a medical power of attorney, to make those decisions. The provision for a written directive in this Act is called an ‘anticipatory direction’.

Schedule 2 of the *Consent to Medical Treatment and Palliative Care Act* sets out the following words to be used in an anticipatory direction:

I ... direct that if, at some time in the future, I am:

- (a) in the terminal phase of a terminal illness, or in a persistent vegetative state; and
- (b) incapable of making decisions about my own medical treatment,

effect is to be given to the following expression of my wishes: ...

(The person by whom the direction is given must include here a statement of his or her wishes. The statement should clearly set out the kinds of medical treatment that the person wants, or the kinds of medical treatment that the person does not want, or both. If the consent, or refusal of consent, is to operate only in certain circumstances or on certain conditions, the statement should define those circumstances or conditions.)

Although the Act provides the legal form of a written advance directive it does not offer any guidance about the types of decisions which individuals may wish to record in a written statement, such as what kinds of decisions might be required and what conditions might be appropriate to include to assist doctors and/or relatives to carry out that person’s wishes. Differences in personal preferences and uncertainties about future health care scenarios mean that it is difficult to devise a single form which is both comprehensive and accessible to the public.

Brown (1995) carried out a study on the issues associated with appointing a medical power of attorney for older people while the Consent to Medical Treatment and Palliative Care Bill was being debated in parliament. The methodology for that study was focus groups and interviews. An advance directive draft pro forma was used to give the participants some idea of how to express their wishes in writing. Although the participants agreed with the concept of expressing their wishes in advance, either in writing or through appointing a medical agent, they were concerned about how they could effectively express their wishes on paper or to another person. The medical practitioner was the professional from whom most of the participants thought they would seek advice, although some thought they would consult a lawyer as it was a legal matter. Some participants identified barriers which might inhibit doctors from assisting patients with advance directives. These included time, expense and, as one woman said, ‘doctors don’t

sort of explain very much to you unless they know you on a personal basis' (Brown 1995: 150).

The evidence presented to the South Australian Parliamentary Select Committee on the Law and Practice Relating to Death and Dying (1991a, 1991b, 1992a, 1992b, 1992c, 1992d) and the results of Brown's (1995) research indicate that there are concerns in the community about loss of control, decision-making capacity at the end of life and dementia in old age.

Similar findings were noted in Steinberg et al's work 'End-of-life decision making: community and medical practitioners' perspectives' (1997). This Queensland study involved health professionals as well as members of the community. The researchers found that 71% of the health professionals involved in the study were not sure of the process of making an advance directive and 70% were concerned about the legal implications. The researchers also noted that health professionals appeared to take a somewhat paternalistic view of some aspects of patients' decision making, for example 63% of health professionals believed that patients would prefer to leave treatment decisions to their doctor, a view that was shared by only 37% of community members.

South Australian general practitioners who participated in a study carried out for the Select Committee on the Law and Practice Relating to Death and Dying in 1991 indicated that they had concerns about raising the issue of living wills with their patients as it might be difficult to explain and it might 'make the doctor-patient relationship seem too contractual to the patient or might cause the patient to lose hope' (South Australia 1992d: 7). The results of the study indicated that less than two-thirds of general practitioners were familiar with the *Natural Death Act* 1983 (SA) which was Australia's first 'living will' legislation. Ashby, Wakefield and Beilby, in their article 'General practitioners' knowledge and use of living wills', commented on the results of the Select Committee study. They stated: 'Any form of living will, advance directive, or agency is intended to clarify what the patient wants and so should be an ally of good medical practice, not a troublesome intruder. General practitioners must be part of their development' (1995: 230).

In addition to these Australian studies, the literature on advance directives from the United States indicates that some people may need assistance from their physicians if they are to make use of their legal right to refuse medical treatment in advance. Recent studies also indicate that although the majority of people are in favour of advance directives in principle, the execution rate remains low (Collins and Weber 1991; Danis et al 1991; Emanuel et al 1991; Emanuel and Emanuel 1993).

Recent research in the United States has examined how physicians communicate with their patients about advance directives. Tulsky et al (1998) argue that the nature of the communication between the physician and the patient remains relatively unexplored. These researchers examined the communication between

physicians and their patients in the creation of a written directive. Fifty six physicians approached 56 patients who were known to them and were aged 65 years or over. The average time taken was 5.6 minutes, but although the goal of introducing the advance directive was achieved the researchers concluded that discussions infrequently dealt with patients' values and attitudes toward uncertainty (1998: 442).

Several other researchers in the United States comment on issues associated with communication between physicians and their patients. Emmanuel et al (1991) note the reluctance of physicians to initiate discussions about advance directives. Emmanuel et al (1995), in another study, described the understanding and completion of advance directives as a *process*. These researchers note that it takes time to develop a valid expression of wishes rather than a single consultation or the signing of a statutory document. Virmani et al noted in 1994 that, even though there appeared to be a slight improvement in communication about advance directives following the *Patient Self Determination Act 1991* (US), there still appears to be a lack of detailed discussion dealing with specific medical treatments and a lack of engagement in communication between the physician and the patient. Tulsky et al (1996) researched medical residents' experience with do-not-resuscitate (DNR) discussions and their attitude toward them. In conclusion these authors recommend that communication about end-of-life decisions should be treated as a medical skill and taught to physicians with the same rigour as other clinical procedures.

In 1996 the Advance Directive Study Group was successful in applying for a grant from the Palliative Care Program State-Wide Projects through the South Australian Health Commission to carry out research in the community on Schedule 2 of the *Consent to Medical Treatment and Palliative Care Act 1995* (SA). Focus groups were used to consult with members of the South Australian community about the suitability of Schedule 2 and an alternative, more structured form. The main findings from this study were that few of the participants were aware of the terms 'advance directive' or 'living will', or the *Consent to Medical Treatment and Palliative Care Act 1995*. Many of the participants had difficulty in understanding the form and in knowing what they should write down about their wishes. Some of the participants thought that they would need advice from their doctor to assist them in clarifying their decisions about future medical treatment (Brown et al 1997).

The pamphlet 'It's your life—all of it ... An explanation of the *Consent to Medical Treatment and Palliative Care Act 1995*' was released by the South Australian Government as part of the community education programme when the Act was proclaimed. As part of the Advance Directive Community Study the pamphlet was sent to the participants together with Schedule 2 prior to meeting with the focus groups. Most participants considered that the pamphlet was informative about the

Act but not helpful for those people wishing to complete an anticipatory direction under Schedule 2.

As a result of this community study the following four recommendations were forwarded to the Health Commission of South Australia:

1. Enhance the form set out in Schedule 2.
2. Provide relevant information to assist people to complete schedules 1 and 2.
3. Further inform and educate the public.
4. Conduct a follow-up study with general practitioners.

This study addresses the fourth recommendation from the Advance Directive Community Study. It is guided by the understanding that general practitioners could play an important role in introducing advance directives to their patients in order to assist individuals and their families to face the future calmly and reassure them that control need not be lost during a serious illness (Maddocks 1997).

METHOD

General practitioners in two medical practices in Adelaide were invited to participate in the study. The doctors were asked to introduce the concept of advance directives, including schedules 1 and 2, to a number of patients as part of a normal consultation, over a period of three months. The participating doctors were asked to complete patient record sheets which included the following information:

- characteristics of patients approached (eg age and diagnosis);
- patient's reaction to being approached to consider an advance directive;
- type of information required by the patient;
- time required to explain the advance directive;
- the outcome (eg was a directive subsequently completed or not).

At the end of the implementation period a follow-up interview was held with the doctors to discuss the outcomes of this process.

RESULTS

Initial Interviews

All five doctors said they were familiar with the *Consent to Medical Treatment and Palliative Care Act 1995 (SA)* and the former *Natural Death Act*. They all recognised the community brochure associated with the Act but were not aware of the professional brochure nor the content of either. None realised that the brochures had been updated in June 1998.

One of the two doctors interviewed individually was familiar with the terms ‘advance directives’, ‘living wills and anticipatory directives’, ‘medical agent’, ‘medical power of attorney’ and ‘proxy’ and the other was not. One of these doctors had had patients who completed a direction under the *Natural Death Act* and the other had been approached by patients about completing the schedules to the 1995 Act. Some of these patients had learned about the forms from their friends, a few of them had a terminal illness and the majority were elderly. When asked if they had helped the patients to understand the forms one doctor replied that she had difficulty with the term ‘measures for my comfort only’. Both these doctors were involved in providing palliative care and attended patients at the Mary Potter Hospice.

In the group interview none of the doctors had used the schedules to the Acts before but wanted clarification about the good palliative care orders and the ways in which they differed from advance directives. All were in favour, in principal, of the idea of introducing the concept of advance directives to patients.

One doctor stated that ‘one of the bugbears [in general practice] is that we are overwhelmed with forms. The office is full of forms (we hate them) and it’s a space issue. Now it’s the computer age can we have them on disk? Most organizations have not thought about it.’

One doctor thought involvement in this study may be a good way of introducing the concept to patients. These doctors considered that discussions about advance directives were part of a doctor–patient consultation. However the time limitations in general practice were a problem brought up by all five doctors. They described the ‘balance between time and what you want to do—more time or drop your standards. This sort of thing does take time, you can’t just shove it under their nose’. Another doctor suggested that ‘we can charge for an extended consultation’.

None of the doctors had completed an advance directive themselves. One smiled as he answered the question and said: ‘No. But I’ve taken one home for my mother-in-law’. Another thought she might if she were 70.

Patient record sheets

All of the doctors had approached patients that they felt would be receptive to the advance directive. A total of thirty patients were approached, however, one doctor had approached four patients but had not completed the patient record sheets. The following information relates to the twenty-six patients for whom record sheets were completed.

Summary of the patients participating

There were nineteen females and seven males. The average age was 77 years, the youngest patient approached was 51 and the oldest 93. Table 1 provides the details of the patients for each doctor.

Table 1: Gender and age of patients

Doctor	Patients' gender	Age range	Average age
1A	5 females 3 males	61–84	75
1B	10 females	61–87	80
1C	1 female 1 male	69–90	80
2	3 females 3 males	51–93	75

The youngest patient approached by Dr 1B had been diagnosed with breast cancer four years ago. Another patient's sister had recently been diagnosed with cancer (Dr 2). The youngest patient approached by Dr 1A accompanied her husband and she was included in the discussion about advance directives. In the case of Dr 1C the youngest patient actually initiated the discussion.

Reason for introducing the schedules to the patient

Only fourteen of the twenty-six patients had a diagnosis recorded on their record sheets. Of these, four had a malignant condition, and ten had chronic conditions such as diabetes, hypertension, cardiac failure, asthma and aortic stenosis. The doctors recorded other reasons why they had introduced the schedules for eighteen patients. These included:

1. the patient requested or initiated a conversation about advance directives (4);
2. the doctor thought the patient would respond positively to or be interested in advance directives (4);
3. the patient had made comments about euthanasia or quality of life (3);

4. the patient's relative was recently diagnosed with a malignancy (1);
5. the patient's wife had joined the discussion when her husband had been introduced to the concept during a consultation (1);
6. the patient's age (more than 70 years) (4);
7. the patient lived alone (1).

Patient's reaction and questions raised

Patients generally reacted positively to the introduction of the use of an advance directive. Ten patients asked questions such as:

1. What should I write? (2)
2. Do doctors consult with other doctors before making serious treatment decisions? (1)
3. Is there a hidden agenda behind this issue? (3)
4. Why do I have to do it? (1)
5. How different is it from a medical power of attorney? (1)
6. Will my children need to know? (1)
7. Who can be a medical agent? (1)

Time taken to introduce and discuss the schedules

Doctors were asked to estimate and record how long it took for them to introduce the schedules during the consultation. The time ranged from 1 to 14 minutes; 64% (16) of the consultations took 5 minutes or less (Table 2).

Table 2: Estimation of time taken to introduce schedules during consultation

Time in mins	N	%
1	1	4
3	4	16
5	11	44
6	1	4
8	1	4
10	5	20
12	1	4
14	1	4
Total	25*	100

* Data was missing in one case.

Patients' feelings about discussion with family or friends

Sixteen patients indicated they would like to discuss the concept of an advance directive with their family, eight indicated they did not need to discuss their intention to complete an advance directive with their family, and two did not indicate their wishes.

Outcome

A total of six of the twenty-six patients had completed an advance directive at the end of the data collection period. Of the four patients who had requested or initiated a conversation about advance directives only one completed an advance directive. Three of the four patients whom the doctor thought would respond positively had completed an advance directive when they attended a follow-up consultation and the fourth patient was in the process of completing her directive. She had wanted to consult with a friend who was a lawyer before finalising the copy. Of the three patients who had made comments about quality of life and euthanasia two had completed a directive. None of the remaining patients had completed an advance directive but one had a medical power of attorney.

Follow-up interviews

After a three-month implementation period the five doctors were interviewed separately.

Initiating and discussing the schedules

The main factors discouraging doctors from initiating discussion about the schedules were time limitations and difficulty remembering to introduce the

schedules to a patient whom they thought might be appropriate. One doctor was surprised that she had received an overall positive approach from patients to whom she introduced the schedules. Another commented that he was careful to whom he introduced the schedules: 'I was very choosy. I only chose the people that I knew, or I thought would be quite receptive.' This doctor was also more likely to approach people because of their personality rather than their diagnosis. Two doctors received a negative response from patients.

Differences in issues for schedule 1 and 2

Only one of the doctors specifically highlighted for patients the difference between schedules 1 and 2. Some patients expressed confusion between the two schedules, in particular one patient who had already completed Schedule 1 and appointed a medical power of attorney. The other doctors did not specifically comment that they had explored the differences between the two schedules. One doctor commented that they had found explaining the difference between the schedules difficult and therefore patients may have been reluctant to ask specific questions. Two doctors were concerned about the difference and overlap between a medical power of attorney and an enduring guardianship under the *Guardianship and Administration Act 1993*. One patient had seen a solicitor to assist with the completion of an enduring guardianship form.

Information issues

Patients appeared to have difficulty deciding what to write in the section that refers to the person's wishes about medical treatment (Schedule 2). The doctors also had difficulty explaining this section. 'It is really quite hard to tell them exactly what, because it is up to them, I didn't want to put words in their mouth'. One patient had wanted to write, 'I just want to be left to die naturally' and did not realise that this would not be specific enough. To assist patients to complete the directives one doctor covered issues which he thought probably needed to be included. These included resuscitation, surgery, antibiotics and intravenous nutrition. Another doctor commented that one nursing home with which she was familiar offers patients several structured pro formas which provide questions about treatment options that residents can choose from. She thought this may assist the doctor in explaining this section.

One doctor commented that a patient did not understand the term 'medical management'. Another doctor responded to the question 'what information is lacking which impeded the consultation?' with 'It is what to put on that paragraph; it came up over and over again'. One patient thought that some information from the brochure should also be on the form.

Two doctors whose patients were predominantly from non English-speaking backgrounds (NESB) felt that brochures in different languages might be helpful,

although they also commented that in many instances literacy rates are quite low and therefore this may not alleviate the problem. ‘Sixty per cent of my patients are Italian and probably about 80% illiterate.’ But the difficulties also included a cultural dimension. ‘If you actually raise this issue you actually jinx them. ... These issues are best left alone’.

Other issues included patients wanting to know where the forms would be kept after completion, especially if the person was rushed to hospital in an emergency. ‘Would anyone know that you had completed an advance directive?’ The doctors were not aware of the fact that the forms can be registered with MedicAlert.

Suggestions for improving the process

Suggestions from the doctors on how to raise awareness of the importance of introducing advance directives to suitable patients included an intensive campaign targeting not only general practitioners but the public as well. For general practitioners suggestions included:

1. Intensive training with a follow-up reminder every three to six months.
2. A reminder in the Australian Medical Association newsletter six-monthly.
3. Advertisements in other publications such as *Australian Doctor* or *Medical Observer*.

The training for doctors should include information about the questions people are likely to ask and the most appropriate reply.

In general the doctors felt that the onus should be on the individual to approach their doctor about completing an advance directive. This would necessitate a public awareness campaign. Suggestions to raise awareness included articles in the local Messenger press. Doctors gave examples of patients discussing new treatments that they have read about in these papers. Education for the public could also include asking for a longer time when scheduling appointments. One doctor had a patient who had asked for an hour-long appointment because she had heard about advance directives and wanted to allow enough time for discussion.

Reflections on the process of initiating discussions about advance directives

All the doctors had been cautious in the selection of patients they chose to introduce the advance directives to. One was concerned that he might target the ‘wrong’ person ‘who’s not perhaps in tune with this part of life and causing confusion and consternation and dragging the consultation way, way over time and causing my stress levels to go up’. Another doctor had approached a patient who responded with a ‘blank face; she just didn’t want to know’.

Another doctor thought introducing the schedules at the end of a consultation may discredit their worth and value and suggested that they should be raised in a separate consultation. This was particularly pertinent if the person was attending for a relatively trivial matter: was it better to raise the issue at the beginning or end of the consultation?

It was also acknowledged that a 'one-off session' may not be adequate for people to grasp all the issues involved. As one doctor said, 'one needs to just listen to as many people as possible and think about it and maybe fill it out in stages'.

Continued use of schedules 1 and 2

All the doctors indicated they would continue to introduce the schedules to appropriate patients. One doctor indicated that having the forms available on the internet or having them on a computerised management system might encourage doctors to use them. The section in which the patient's specific wishes must be documented was seen as a deterrent in some ways because of the time it would take to properly explain the options. It was agreed that the brochure does not assist people in the process of completing the schedules. One doctor indicated that she would prefer to offer patients a more structured pro forma which would suggest treatment options for them to consider.

DISCUSSION

This study offers some insight into the issues for older people who may wish to consult their general practitioners for assistance with completing an advance directive. Advance directives are particularly relevant for the increasing number of elderly people who may be able to confront their death with less anxiety if they feel that the dying process will not be protracted unnecessarily by technological intervention. To know that their autonomy will be respected and that they will be involved in decisions surrounding their death, if at all possible, should reduce the fear and stress associated with dying.

It is often people in the older age group who are least aware of technological advances in health care. A substantial number of people aged 65 and over in Australia die in hospital where the more rigorous medical treatments are most likely to occur and hence the right to refuse treatment becomes more critical. Therefore, executing an advance directive to make future decisions about health care is most appropriate for this cohort of people. This assists in maintaining the autonomy of these older people, which is an important aspect of citizenship.

This study focuses on the issues associated with introducing advance directives to patients in general practice. One of the main issues was time. The time required to introduce the concept of advance directives to patients who are not familiar with the issues depends on the level of explanation the doctor feels is necessary. In this

study the estimated time ranged from 1 to 14 minutes, with an average of 6.3 minutes. However, 16 of the 25 interactions in this study took 5 minutes or less. There is no explanation of why this time should vary so much and it raises questions about the adequacy of the explanations given by some doctors.

Most of the doctors thought it would be preferable if the patients were informed beforehand and were responsible for initiating the discussion. This process could be facilitated if the patients planned ahead and made time for a long consultation. This would require increased publicity and information campaigns to educate the public so that general awareness is increased. The doctors were conscious of the stress involved in raising the topic to patients who may not be receptive or for some reason felt threatened by the subject. Hence their caution in whom to approach was a bias in the study which was predicted by the researchers.

In this study the doctors were asked to select who they thought might be appropriate, this meant a subjective selection and in some cases the selection was governed by the doctor knowing that it would only take 'me three minutes to get the brochures out and tell them what it was about and ask them if they wouldn't mind thinking about it'.

The selection of patients by the doctors was not only by diagnosis, nor by age (even though the average age was 77). All of the patients were known to the doctors concerned, hence familiarity with the patient could be considered to be an influential factor. This is supported by the work of Tulskey et al (1998) which was discussed in 'Background and significance', above. In both this South Australian study and Tulskey et al's research, all the patients were known to the doctors, but in the American research all were aged 65 years or over. The conclusion reached in the American study also applies here: the discussions were brief and infrequently dealt with patients' values and attitudes toward uncertainty (Tulskey et al 1998: 442).

One of the major difficulties experienced by the South Australian doctors was how to advise patients to express their wishes about 'the kinds of medical treatment that the person wants or the kinds of medical treatment the person does not want, or both'. This includes specifying the 'circumstances or conditions' to which these decisions apply (*Consent to Medical Treatment and Palliative Care Act 1995*). As with the Tulskey et al study, the exploration of the patients' wishes and values were not really dealt with during the consultation. As one doctor noted, it takes time for people to think through their decisions. Completing an advance directive is a process and may require several consultations with the doctor. This is supported by the work of Emmanuel et al (1995) in the United States, as discussed above.

Introducing an advance directive to a patient who is not familiar with the concept requires time, patience and a sound knowledge of the legal and social implications of the advance directive. According to the literature from the United States

mentioned above, one of the essential ingredients in this process is effective communication between the doctor and the patient. According to Tulsky this requires skill which may need to be taught. The doctors in this study believed that more information about the process and the decisions which need to be made would assist them in communicating with their patients.

The lack of information to assist with completing this section and the limitations of the community pamphlet was also identified in the Advance Directive Community Study (Brown et al 1997). The results of this earlier study indicated that not all of the participants would want to discuss their treatment choices with a doctor. Many considered it more appropriate to discuss their decisions with family members and some people thought they would prefer to consult a lawyer as the schedules are legal documents. Involving lawyers raises questions which are yet to be addressed. For example, how do lawyers assist individuals in making decisions about their future medical treatment?

Not all the participating doctors were familiar with the complexities involved and the difference between a medical power of attorney and an enduring guardianship in South Australia. This overlap and confusion needs to be addressed more fully at the legal and policy level.

The concerns about where a completed schedule should be kept were also identified in the Advance Directive Community Study and Brown's research in 1995. Although the 1998 community pamphlet clearly states that forms can be recorded with MedicAlert, the central register in SA, few people are aware of this or take the opportunity to register their advance directive. The number of people who registered their directive in 1997 was 27; it was 11 in 1998 and 1 in 1999. An enduring guardianship can also be registered as an advance directive, but as the President of the Guardianship Board of South Australia stated in response to our letter of enquiry, 'the availability of a central register is only useful if people use it. The initial cost of \$55.00 and an annual charge of \$15.00 act as powerful disincentives to widespread public use of the register' (T Lawson, personal communication, 20 July 1999).

This study is an initial step in providing some insight into the issues and barriers for general practitioners when introducing advance directives to their patients. The results cannot be generalised, but they identify issues which require further in-depth research. This study had some limitations, including the small number of doctors who participated and the fact that the practices which were approached were known to have at least one doctor who was interested in palliative care. This meant that some of the doctors had some degree of knowledge about the issues associated with advance directives and the legislation. This bias is acknowledged. However, it is the first study in Australia which has involved general practitioners in the introduction of advance directives within a consultation. It raises issues

which require further exploration if advance directives are to facilitate the decision-making process amongst the increasing number of older people in this state.

RECOMMENDATIONS

1. The South Australian government should conduct a further and ongoing public education program to increase community awareness about advance directives and the *Consent to Medical Treatment and Palliative Care Act 1995 (SA)*.
2. This program should draw attention to the limitations of the 1998 community pamphlet, which explains the Act but does not assist with the completion of the advance directive schedules.
3. The College of General Practitioners should be approached to run an education program for general practitioners including:
 - a. the development of a computer package with information to assist general practitioners in developing their knowledge about advance directives and their skill in introducing advance directives to patients. This should include the questions people are likely to ask and appropriate replies.
 - b. access to the education package on disk and a web page.
 - c. publicising the availability of the package in the appropriate medical literature such as the Australian Medical Association newsletter, the *Australian Doctor* and the *Medical Observer*.
4. There is a need for more in-depth research to assist with the understanding of the role of advance directives in general practice and ways to improve the communication between doctors and their patients.
5. Further research should examine the role of lawyers in assisting people to complete advance directives about future medical treatment.

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Hawke Centre Director: Ms Elizabeth Ho

Telephone +61 8 8302 0371

Facsimile +61 8 8302 0420

Email hawke.centre@unisa.edu.au