

Talking to patients about death and dying

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INTRODUCTION

Talking about death and dying, either with patients terminally ill or well, presents challenges for the general practitioner. There are few Australian educational resources and little Australian research into this area.

METHODS

We undertook two focus groups, an interview process, and a final consultation with palliative care experts and GPs.

RESULTS

General practitioners felt they needed support and education in talking about death and dying. This is separate from discussions about 'Advanced Health Care Directives'. General practitioners were open to learning new ways to help patients and families approach dying, but require support and education around initiating discussions, asking the right questions and accessing services. Participating GPs emphasised the importance of utilising palliative care supports and resources to provide ongoing spiritual and physical care. Many were particularly concerned with access to support for dying patients for both indigenous patients and those from other cultures. Advance Health Care Directives were regarded by participating GPs to be tools to facilitate a discussion around death and dying, rather than their primary purpose.

DISCUSSION

We developed a booklet to provide practical, useful guidelines for GPs in their daily practice.

The general practitioner can, with open and ongoing communication, help allay patients' fears and minimise pain and suffering when a terminal illness is diagnosed.¹ The 'National Palliative Care Strategy' has focussed attention on end of life care,² as has the euthanasia debate,^{3,4} the increasing recognition of patient autonomy in the health care process,⁵ and the issue of Advance Health Care Directives (AHCDs) (legal documents in which patients can define the care they wish to receive at the end of their life).^{6,7} As a consequence, GPs need to develop confidence in talking about death and dying, and strategies to cope with change in societal views of death and dying.

We responded to this need by developing the 'Talking to Patients about Death and Dying' project in South Australia. We observed that some patients in the terminal stages of their illness had not discussed dying with either their GP or their family. Despite the Consent to Medical Treatment and Palliative Care Act in South Australia,⁸ there has been little uptake of AHCDs.⁹

We concluded that a booklet would provide a cost effective and practical way to disseminate information to South Australian GPs (GPs were involved in its design). The first draft of the booklet was developed following a literature review. Patient perspectives on quality end of life care were identified from the literature (*Table 1*) and the importance of patient-doctor communication (particularly empathic listening and the use of open ended questions to explore patient needs)¹⁰ and spiritual and social issues in end of life care were emphasised.^{11,12} The booklet was distributed to GPs who participated in a

series of focus groups and interviews. The first focus group consisted of a convenience group of 4 men and 2 women GPs with experience of caring for dying patients. The second focus group (conducted by teleconference) consisted of 5 men and 2 women rural GPs nominated by local palliative care teams. Finally, 2 men and 1 woman urban GP undertook structured interviews about the booklet.

Following the focus groups and interviews, a second draft of the booklet (incorporating the GPs' suggestions) was distributed with an evaluation form to the focus group GPs, other GPs who had expressed an interest in the project, palliative care teams, palliative care specialists, the Palliative Care Council of South Australia and the South Australian Department of Human Services.

We found that open and ongoing communication, and education and support for GPs in this area was important. These GPs felt that practical steps on how to initiate and maintain this communication were difficult in everyday practice. They thought AHCDs could provide a framework for such a discussion. Some participating GPs believed that many of their patients could not face a discussion about their death (*Table 2*). One GP noted that the reluctance of some GPs to work with dying patients may reflect their own fear of death and that GP information resources should acknowledge this.

We received 22 responses following the distribution of 35 draft booklets. The respondents said there was a need for such information. Some suggested information about patients requesting euthanasia (but we felt this to be beyond the project), and copies of Anticipatory Directions and Medical Power

of Attorney^a be distributed with the booklet.

Many of the questions suggested by GPs for inclusion in the booklet were closed questions (not allowing exploration of the patients' feelings or needs). General practitioners recognised the importance of introducing spiritual and/or religious issues into the discussion of death and dying, and agreed that end of life care is an ongoing process requiring more than one discussion. However, many GPs felt that most patients could not face a discussion of death and dying: 'only 25% of patients could do it; most of the rest

don't want to face it, or still have hope'. The sample of GPs used in the focus groups and consultations had a pre-existing interest in palliative care and may have been more receptive to the concept of a booklet.

In contrast to our data, most opinions expressed in the literature emphasise the importance of open ended questions. Similarly, patients' wishes to discuss their death, again referred to in the literature, was not appreciated by these GPs.^{1,10,13}

In South Australia, legislation provides specific Anticipatory Directions and Medical Power of Attorney forms, however, different states in Australia have differing legislation, and this needs to be considered in developing strategies for initiating discussions at this time. We attempted to address these concerns as well as including discussion about AHCDs in the '75+ health assessment'.

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Conflict of interest: none declared. Copies of the booklet can be found at: www.generalpractice.adelaideuni.org/talk.pdf

Implications of this study for general practice

- Most patients expect their doctor will initiate discussion around death and dying.
- AHCDs can provide a framework for discussing death and dying.
- Open ended questions and empathic listening are essential.
- There are a variety of palliative care supports available for the patient and the GP.
- An appropriate time to initiate discussion about AHCDs may be during the 75+ health assessment.

Table 1. Quality end of life care (patient perspectives)

- Receiving adequate pain and symptom management
- Avoiding inappropriate prolongation of dying
- Achieving a sense of control
- Relieving burdens and strengthening relationships with loved ones
- Clear decision making
- Preparation for death
- Completion (attending to unfinished business and saying goodbye)
- Affirmation of the whole person (being seen as a person not an illness)
- Contributing to others

Table 2. Key themes arising from the focus groups/interviews

- The need for guidance when talking to patients about death and dying
- Discussion around death and dying was usually initiated following diagnosis of a terminal illness, and an AHCD providing a framework for such a discussion was supported
- The need for guidance about talking to well people about their wishes in the event that they could not make decisions themselves
- GPs provided much of the language and suggestions for the wording of questions for patients
- Consultations with urban and rural GPs revealed no difference in the issues around talking about death and dying or the needs of GPs and patients
- Many GPs believe that patients are not able to face discussion around death and dying
- When initiating discussions, GPs tended to ask closed questions rather than open ended ones, thus not allowing patients to explore their emotions
- The 75+ health assessment was identified as an appropriate time for the discussion of AHCDs
- Talking about death and dying and the practicalities of signing an AHCD were perceived as requiring separation in any booklet
- Many GPs do not make use of the variety of palliative care supports available for both themselves and their patients
- GPs were particularly concerned with access to support for dying patients from other cultures

References

1. Latimer EJ. Ethical care at the end of life. *CMAJ* 1998;158:1741-1747.
2. National Palliative Care Strategy. A National Framework for Palliative Care Service Development. Canberra: Commonwealth Department of Health and Aged Care: Publications Production Unit, 2000.
3. Khuse H, Singer P, Baume P, Clark M, Rickard M. End of life decisions in Australian Medical Practice. *Med J Aust* 1997;166:191.
4. Wadell C, Clarnette R, Smith M, Oldham L, Kellehear A. Treatment decision making at the end of life: a survey of Australian doctors' attitudes towards patients' wishes and euthanasia. *Med J Aust* 1996;165:540.
5. Kellehear A. Health promoting palliative care. Melbourne: Oxford University Press, 1999.
6. Vaughan K. Advance Health Care Directives in General Practice: A Pilot Study. The Central Sydney Division of General Practice: CSAHS, 2000.
7. Clarnette R, Molloy W. Let Me Decide. Australia: Newgrange Press, 1996.
8. Consent to Medical Treatment and Palliative Care Act, 1995. Available at: http://www.austlii.edu.au/au/legis/sa/consol_act/ctm-tapca1995420/s1.html. Accessed 26/6/2000.
9. Brown M, Beilby J, Gargett E. A Study of Advance Directives with General Practitioners. Report. Adelaide: The Hawke Centre, 2000.
10. Balaban RB. A physician's guide to talking about end of life care. *J Gen Intern Med* 2000;15:195-200.
11. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky J. In search of a good death: observations of patients, families and providers. *Ann Intern Med* 2000;132:825-832.
12. Singer PA, Martin K, Kelner M. Quality end of life care. *JAMA* 1999;281:163-168.
13. Singer PA, Martin DK, Lavery JV, Theil EC, Kelner M, Mendelssohn DC. Reconceptualising advance care planning from the patient's perspective. *Arch Intern Med* 1998;158:879-884.

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