

Patient perspectives regarding communication about prognosis and end-of-life issues: How can it be optimised?

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Abstract

Objective: to explore patients' perspectives across two cultures (Australia and USA) regarding communication about prognosis and end-of-life care issues and to consider the ways in which these discussions can be optimised.

Methods: Fifteen Australian and 11 US patients completed individual semi-structured qualitative interviews. A further 8 US patients participated in a focus group. Interviews and focus group recordings were transcribed verbatim and interpreted using thematic text analysis with an inductive, data-driven approach.

Results: Global themes identified included readiness for and outcomes of discussions of prognosis and end-of-life issues. Contributing to readiness were sub themes including patients' adjustment to and acceptance of their condition (together with seven factors promoting this), doctor and patient communication skills, mutual understandings and therapeutic relationship elements. Outcomes included sub themes of achievement of control and ability to move on. A model of the relationships between these factors, emergent cross cultural differences, and how factors may help to optimise these discussions are presented.

Conclusion: Identified optimising factors illustrate Australian and US patients' perspectives regarding how prognosis and end-of-life issues can be discussed with minimised negative impact.

Practice Implications: Recognition of factors promoting adjustment, acceptance and readiness and use of the communication skills and therapeutic relationship elements identified may assist in optimising discussions and help patients plan care, achieve more control of their situation and enjoy an optimal quality-of-life.

1. Introduction

Over a third of adult patients diagnosed with cancer will die prematurely of their disease and many experience less than optimal care at the end-of-life [1,2]. Many patients do not discuss their prognosis or concerns regarding end-of-life care with their doctor or family [3-5]. Lack of such discussions and sub-optimal communication can contribute to poor decision-making and outcomes at the end-of-life.

Most cancer patients want these discussions [6] and value that their physician is comfortable talking about death and dying [7], though a significant minority of patients do not wish to discuss these issues [8]. Health professionals frequently avoid providing this information because they are uncertain of how much patients want to know or fear that patients and their families will lose hope [9]. At the same time, patients are unsure what questions to ask and whether they are ready to hear the answers. Thus, these discussions frequently do not happen.

Few studies have investigated patients' perspectives regarding the barriers and facilitators of communication about end-of-life issues and prognosis. Those identified focused only on components of these discussions such as not-for-resuscitation orders, truth telling or delivery of bad news [10-12].

Further, while some studies have described challenges and facilitators of culturally appropriate end-of-life communication for ethnic minorities within the western health care system [12-14], no direct comparisons have been made between the perspectives of patients from different western countries. Yet divergent perspectives may be present due to health system and cultural differences, which may have implications for optimal care delivery. Australia and the United States of America (US), while both favouring disclosure

and discussion of prognosis and end-of-life issues, [8] have marked differences in the healthcare model for end-of-life care [15,16]. Australia has national policies on palliative and end-of-life care, and patients can access the full range of palliative services parallel to active treatment. In the US, while palliative care consultations are freely available, the full range of home support, counselling and medication services through the Medicare hospice benefit are available only to patients who forego continuing anti-cancer treatment. End-of-life care is also more integrated into mainstream care in Australian hospitals and cancer centres whereas, in the US, there is marked regional variation with hospice units less frequently co-located with other treatment facilities [16].

In this study we set out to explore the perspectives of patients regarding optimal communication about prognosis and end-of-life care issues. Participants were recruited from treatment centres in two western countries, Australia and the US, thus we also considered the ways in which these perspectives differed between patients in these two western cultures.

2. Methods

2.1 Participants and procedure

Participants were English-speaking adult patients with advanced, incurable cancer assessed by their oncologist as having a life expectancy of less than 12 months. Oncologists in one US and two Australian treatment centres were requested to identify consecutive patients meeting the selection criteria when they attended a consultation. Research assistants approached identified patients and obtained informed consent to participate. Participants were offered the option of participating in a focus group or completing an individual interview. Research assistants trained in qualitative methods conducted the individual semi-structured interviews and one US focus group. Prior to

being interviewed, participants completed a short questionnaire eliciting demographics and disease details. In accordance with established protocols in qualitative research, sampling was discontinued when information redundancy was reached, and no additional information was forthcoming after three consecutive interviews [17]. Each interview and the focus group were audio-recorded and data later transcribed verbatim, except for the de-identification of personal information.

Ethical approval was granted by Sydney South West and Northern Sydney Central Coast Area Health Services Ethics Committees in Australia and the University of Rochester Research Subjects Review Board in the US.

2.2 Measures and interviews/focus groups

Demographic and disease details elicited included age, gender, educational attainment, primary tumour site and treatments received. Interview and focus group questions were designed by an expert advisory group comprised of oncologists, palliative care physicians, psychologists, nurses, and a health services researcher. Participants were asked about their experiences of communicating about prognosis and end-of-life care issues, barriers and facilitators of such discussions and their views about how these discussions could be optimised.

2.3 Analysis

The research team reviewed and interpreted the data using thematic text analysis with an inductive, data-driven approach [17-19]. NVivo 7 was used to manage the data coding [20]. Consistent with this method, Australian and US researchers read all transcripts. Four researchers (AW, PB, PD and FB) independently developed codes to represent the underlying meanings of the text. The research team then met regularly to compare codes

and achieve consensus about code names and definitions. Codes were identified relating to adjustment and acceptance, skills, readiness and outcomes. Through iterative reading of the data grouped by codes, recurrent themes were established along with illustrative examples of these themes. Comparison was made between coded Australian and US transcripts and identified recurrent themes to discern points of commonality and divergence between the two groups. Rigor in our qualitative analysis was derived from successive rounds of iterative consensus work among multiple team members who analysed the interview and focus group transcripts and review of the coding by Australian and US team members not directly involved in developing the coding framework [21]. Included quotes were chosen based on their ability to illustrate the themes and sub-themes in the most succinct manner possible and are representative of the perspectives articulated by multiple participants.

3. Results

3.1 Participant characteristics

Fifteen Australian and 11 US patients were recruited for individual interviews with a further 8 US patients recruited for a focus group (see Table 1). Australian patients were predominantly male (80%) with an average age of 67.6 years. Most had a primary diagnosis of lung cancer (60%), while 11 of the 15 had received chemotherapy, 6 had received radiotherapy and 7 had received surgery. American patients were predominantly female (68.4%) with an average age of 58 years. While individual data were not obtained, US patients included those with primary tumours of the colon, breast, lung, pancreas or prostate who had had progression of their disease during chemotherapy. Patients were not expressly asked to indicate how soon they believed they would die, however interview responses indicated that all patients were aware that their disease was incurable and that their life expectancy was short.

Table 1 here

3.2 Themes

Two global themes were identified: **readiness** for and **outcomes** of discussions about prognosis and end-of-life issues. Two sub-themes were identified regarding factors that may foster readiness: **patients' adjustment to and acceptance of their condition** (together with seven factors promoting this) and **doctor and patient communication skills, mutual understandings and therapeutic relationship elements**. Two sub themes relating to outcomes of these discussions were also identified: **achievement of control** and **moving on**. These themes and sub-themes are illustrated in Figure 1 and discussed in detail below.

Figure 1 here

3.2.1 Readiness

Prior to a discussion of prognosis and end-of-life issues, participants felt that both the doctor and patient needed to be ready for the discussion. For the patient, this means that the desire to know the facts overrides any fear or ambivalence about discussing these issues. For the doctor, this means feeling comfortable, confident and able to discuss these issues, and clear that the patient desires this information. Readiness was felt to be necessary for discussions to achieve the best possible outcomes with the least discomfort.

3.2.2 Adjustment and acceptance

A key precursor to patients achieving a sense of readiness to discuss prognosis and end-of-life issues was adjustment and acceptance. This involved being able to acknowledge

their impending death while still maintaining realistic hope and a good quality-of-life. It also involved being able to accept the uncertainty inherent in their life expectancy, symptoms and general disease trajectory.

3.2.3 Patient factors promoting adjustment and acceptance

Coping style emerged as an important patient factor promoting adjustment, with patients who took an active coping approach, characterised by a focus on problem solving and information and support seeking, and who were expressive about their needs, wants, uncertainties and concerns appearing to be better adjusted and more accepting. For example, one patient spoke positively about expressing her concerns and questions to her doctor and being active in ensuring her needs are met:

Active and Expressive Coping – *“Doctor [Name] will always ask me ‘how do I feel’ – if there’s something different, I tell her and she will explain it to me... it’s up to me to tell ‘cause she doesn’t really know unless I tell her.”* (Australian, female, 82 years)

Some patients described continuing aggressive treatment to satisfy the wishes of family despite wanting to focus on comfort care. It subsequently appeared that patients and families were constantly influencing each other as they waxed and waned in acceptance and readiness. If the family accepted the status of the patient’s illness and supported the patient’s choices it was easier for the patient to accept their illness and make appropriate choices.

Lack of Family Acceptance – *“All the medication and the terrible chemo... I’m doing predominantly for others under pressure from family and friends. If (it) was just left to me I would just stop everything and that’s the end of me, I’ve had a good run and I’ve got nothing to complain about. Everybody else becomes hysterical and they refuse to accept so I have to go through all this... for them.”* (Australian, male, 62 years)

Lack of Family Acceptance – *“My husband does accompany me to everything. He is not a medical person and he has a really hard time with all of this stuff. So, I find I hesitate asking certain things because I know that they’ll make him uncomfortable or he is not ready to hear it.”* (US, female, 65 years)

Age also emerged as a promoting factor. Older patients surmised that adjusting to a life limiting illness would be more challenging for younger patients and that because they themselves had had a long and full life, they could better accept the prospect of dying.

Age – *“It depends on their age factor... I’m a woman in my 80s so I expect something sooner or later... a younger person, say a woman in her 50s, she’s still relatively young so you can’t expect her to make the decision (to stop treatment) I made. She’d have to consider it (but) you’ve got a heap to talk about you know.”* (Australian, female, 82 years)

Having sufficient time to adjust to the disease enabled acceptance and readiness. Patients who had recently been diagnosed or who had only recently been told that their cancer was incurable seemed more ambivalent about discussing prognosis and end-of-life issues.

None expressly stated that they were unwilling to ever discuss prognosis and end-of-life care issues, but some wanted to delay these discussions.

Time to Adjust – *“It’s just a bit early and we haven’t really got to (discussing prognosis) because I’ve had two treatments and I’ve seen (the oncologist) after the first treatment and I’ll see her again next week, but whether we’re ready for that stage I’m not sure”*
(Australian, male, 60 years)

Having religious or spiritual faith also seemed to promote adjustment and acceptance, in participants’ views, as did life experience that exposed the patient to death or fostered a

pragmatic approach to situations beyond their control. For example, one patient who had served time in the army cited his experiences as a soldier when explaining his pragmatic approach to his health:

Life Experience – *“I have never had difficulty making an important decision in my entire life... you (do) not pine and grizzle, I mean... the very last thing you can do in an army unit is complain; nobody wants to hear any complaints unless you’ve got a bullet in you”*
(Australian, male, 62 years)

Exposure to the symptoms and physical evidence of their disease was also seen to promote adjustment and acceptance. While feeling well, the concept of death and dying seemed unreal and unbelievable to both patients and families. Seeing scans of the cancer growing in their bodies also promoted acceptance of the reality of their situation. Past experience of cancer or life threatening illness also promoted adjustment and acceptance as it gave the patient a point of reference against which to judge and normalise their current experiences. Past experiences could be patients’ own or those of individuals close to them. Salient experiences such as a friend or relatives’ poor quality of death due to inappropriate medical interventions acted to motivate the patient to accept their situation and discuss end-of-life care.

Seeing evidence of cancer – *“She will show me after the CAT scan a picture on the computer of my liver again and compare it to the previous picture after the first CAT scan. That’s how thorough she is... I sense that she should show people on the computer. I think it’s very helpful to look at it and they can see how much cancer they have.”* (US, female, 49 years)

Previous experience – *“My sister-in-law died unexpected two months ago. She had a brain aneurism and the family tore themselves apart because we didn’t know what she*

would want... I thought, I couldn't do that to my family. So I've left them lists." (Australian, female, 55 years)

Finally, mental space was also necessary for patients to engage in end-of-life discussions. Those struggling with depression or uncontrolled pain or symptoms found it difficult to focus on anything but their physical or mental suffering. A positive mood, control of pain and symptoms and an absence of unfinished business allowed patients the mental space necessary to adjust to and accept the realities of their condition.

Depression and Pain – *"I don't really want to ask those questions yet... things are a bit chaotic now like pain and all that... the last 12 months they've been trying to control the pain and that's the only part I'm really into getting fixed up because... with the pain, naturally you get depressed and you have stupid thoughts going through your brain... one of these days I'll probably carry it through... Just blow my head off."* (Australian, male, 58 years)

3.2.4 Skills, understandings and relationship elements

Patient and health professional communication skills emerged as an important factor in creating the conditions for discussion of prognosis and end-of-life issues and in the discussions themselves. Patients felt that they needed to be open and assertive and communicate their needs, persist if the information or outcomes they desired were not forthcoming and cooperate with their doctor to facilitate discussions and goal setting.

Patients' sense of self-efficacy and comfort in asking questions and communicating with their doctor also appeared to be helpful.

Patients also identified important doctor skills in this context. These included maintaining a calm and open manner in all contacts with the patient, treating the patient as an individual

and being sensitive to their individual needs. Participants also indicated that control of discussions should be actively given to the patient, but that the doctor should also take the initiative to raise complex or difficult topics such as prognosis and end-of-life issues. In discussing these issues and responding to patients' questions, participants felt that doctors should be honest, acknowledge and explain uncertainty where it exists, and relate the stories of other patients to foster hope and illustrate uncertainty.

Also contributing to adjustment and acceptance was a good doctor/patient relationship that was characterised by patients as a feeling of comfort and trust in their doctor. It was also noted that continuity in this relationship was important. The doctor skills highlighted above were seen to contribute to this relationship.

Comfort and Trust – *“I was very confident with (Doctor’s Name), I’ve got to trust someone and I’m only going to trust one person. It’s pointless going to five people to try to get the best answer. I needed to have confidence in (Doctor’s Name) and she put me (at ease)… straight away. And that’s what I wanted. I wanted to be confident with someone.”*

(Australian, male, 59 years)

Continuity – *“I’m leaving to go to Perth at the end of next month and I’ll be changing (oncologists) and the fact that I’ll be changing to somebody else is a bit of unpleasantness for me, I would much prefer to stay with (Doctor’s Name), but I also have to move.”*

(Australian, male, 62 years)

Finally, a clear and explicit agreement and permission from both parties to discuss these complex and difficult topics was highlighted as an important step towards readiness to discuss end-of-life issues. Patients recognised that not only was it important for the doctor

to invite discussion of prognosis and end-of-life issues, but also that the patient needed to give their doctor permission to raise these issues as well.

Giving the Doctor Permission – *“I told him right at the beginning that I’m not some weepy little person and if the news is bad, I prefer to be given it without any cream or sugar. Just give it straight to me and I’d like to know how everything appears scientifically to be developing.”* (Australian, male, 62 years)

Giving the Patient Permission – *“(The doctor) broached the subject (of prognosis), instead of as something to necessarily talk about... he actually put it in a way like ‘it’s only something I’d broach when you’re ready’... Not that he was hiding it but just... it’s there.”* (Australian, male, 79 years)

3.2.5 Outcome themes

A proximal outcome of these discussions was for patients to achieve some sense of control over their situation. This equated to getting the necessary facts about the illness and developing a consensus plan for future care with all involved parties including the patient, doctor and the patient’s significant others. Patients felt there was considerable comfort in knowing that their wishes would be respected.

Consensus Planning – *“(My family) haven’t disagreed (with me). No they understand that if it gets bad I don’t want anything like respiratory (support) to keep me alive. They know, my family, we’ve discussed this and they agree with me.”* (Australian, female, 82 years)

A secondary outcome of these discussions was a sense of being able to move on. Having discussed these issues and achieved some sense of control, participants valued maintaining a sense of normality in their everyday lives and a restoration or affirmation of their identity as a whole person rather than merely as a dying patient. This in turn enabled

them to 'let go' of unrealistic expectations for future outcomes and embrace the idea of enjoying a good quality-of-life for however much time might remain to them.

Sense of Normality – *“I’m still feeling good – well, I can’t say that I came back to what I was before I got sick, but at least I’m looking after myself, I’m looking after my grandchildren, I cook, I do all the washing, I do shopping...”* (Australian, female, 73 years)

Affirmation of identity – *“Everybody knows (about my cancer) and I said don’t treat me as if I’m sick, just treat me normal like we were before.”* (Australian, female, 82 years)

3.3 Participant group differences

The themes identified appeared to apply equally to Australian and US patients with both groups presenting similar perspectives on optimising discussions of prognosis and end-of-life issues. Differences did, however, emerge in the attitudes Australian and US patients displayed towards these discussions. US patients displayed a more sceptical attitude than Australian patients towards discussions of these issues, often questioning the accuracy or worth of such information and suggesting that their doctors would avoid discussing negative issues. Where Australian patients mostly spoke of their relationship with their doctor in a personal and positive way, US patients spoke about their doctor in a more detached and neutral way, perhaps indicating differences in the doctor/patient relationship between the two cultures.

Scepticism (US) – *“To some degree I have the feeling that they want to keep things on a very positive note and don’t want to overplay the negative possibilities. So, these questions could lead to negative answers that I think the doctors are attempting to avoid to some degree.”* (US, male, 51 years)

Relationship (US) – *“The doctor I’m a little bit less comfortable (with) ‘cause she is more official. I usually see the nurse. What makes that uncomfortable with the doctor? She’s just more standoffish in a way, acting more aloof... The nurse had to tell me (that my hair would fall out), if the doctor had told me that I would have been a lot more upset because I don’t feel as close to the doctor.”* (US, female, 49 years)

Relationship (Australia) – *“I was very comfortable with (Doctor’s Name). (Doctor’s Name) is a very down-to-earth, pragmatic guy. He is the type of person that will sit there and explain everything to you, not in doctor speech, but in ordinary speech. You know he’s always there for you. And when you get someone like that who you can have access to, then by-gee that makes a difference.”* (Australian, male, 61 years)

4. Discussion and conclusion

4.1 Discussion

This study extends the previous literature by illustrating how patient and doctor aspects interact to promote adjustment, acceptance and readiness for discussions of prognosis and end-of-life issues with minimal negative impact. The input and importance of both parties, and indeed the extended family, are emphasised by the current findings.

An active, information seeking coping style was first identified as predictive of positive adjustment to stress and illness by Lazarus in 1966 [22]. In this study, patients who were expressive and sought active involvement in their care were also more likely to desire information about their disease and what will happen in the future, and so were more open to discussing their prognosis and end-of-life care issues.

The importance of family acceptance of the status of the patient’s illness and support of

the patient's choices has been previously acknowledged [23,24], as have the challenges of navigating family requests to withhold information from the patient or disagreements about treatment decisions, particularly amongst culturally and linguistically diverse patient groups [8,25]. Participants in this study also noted the important role of family in shaping patients' acceptance and readiness to discuss prognosis and end-of-life issues, suggesting that interventions to promote such discussion should include family. Indeed many advanced care planning guidelines emphasise the importance of involving family in such discussions [26,27].

While the relationship between age and acceptance of or anxiety about death is less than robust [28,29], older participants suggested that they would be better able to accept and discuss the reality of dying than their younger counterparts as they had had a full life. Perhaps a full life or the absence of unfinished business, also identified as contributing to sufficient mental space for these discussions, is more common for older patients, a point that deserves further examination.

Finally, participants noted the importance of time, and lived experience of disease and symptoms as contributing to their acceptance of encroaching death. Many felt there was a time and place for acknowledging death and discussing end-of-life, which could not be hurried and needed careful negotiation. Interestingly, despite previous studies identifying a significant minority of patients unwilling to discuss these issues [8], no participants in this study expressed such a preference, although some wished to delay the discussion. It may be that the preferences of patients who do not wish to discuss these issues are not fixed and alter with time and lived experience. Alternatively, our qualitative approach may have encouraged a more nuanced response to the question of preferences. Finally this may

represent a bias in the sample of patients who agreed to participate in our study, with those wishing not to discuss these issues also refusing participation.

Many of the doctor and patient skills and relationship elements identified by participants in this study have been previously described and incorporated into systematic training programs [30] and best practice guidelines [31], though few interventions have addressed systematic communication skills training of patients [32]. Patient proactivity, here identified as assertiveness and persistence in raising challenging or complex issues and communicating needs, has been highlighted as important in promoting better control of pain and symptoms and general care [33] and more effective and efficient information seeking and patient controlled communication [34].

The importance of a good doctor-patient relationship has long been acknowledged to facilitate better information provision, improved patient coping and reduced uncertainty [35]. Importantly, the current findings highlight that the facilitative skills and relationship elements identified do not operate in isolation in the context of discussions of prognosis and end-of-life issues, rather they work together to promote patients' adjustment, acceptance and readiness to consider these issues.

Our finding that patients experienced a sense of greater control when prognosis and end-of-life issues had been openly discussed echoes previous findings that have highlighted the importance of control for patients in quality end-of-life care [36]. Advance Care Planning has been acknowledged to allow individuals to express preferences for care and maintain autonomy past the point of incapacitation [37]. Patients expressed considerable relief in knowing that their wishes and preferences would be respected at the end of life.

Participants in this study also noted that having had such discussions and put plans in place, they were able to put future concerns aside and focus on present quality-of-life. Despite advancing illness, they could concentrate on day-to-day experiences and enjoy a sense of normality in their lives, a notion increasingly identified as important for quality-of-life and sense-of-self [38,39]. Patients who had not accepted their approaching death and made important decisions about the end-of-life paradoxically remained more caught up in the illness itself.

Despite health system differences between Australia and the US in end-of-life care [15,16], patients' perspectives on how discussions about prognosis and end-of-life care issues can be optimised were quite similar. Differences emerged in the more overtly sceptical attitude of the US patients towards the utility of these discussions and their doctor's willingness to discuss challenging issues. Australian patients also spoke about their relationship with their oncologist using more personal and positive language than US patients. These are nonetheless important attitudinal and relational differences that may influence the style and outcome of discussions of prognosis and end-of-life care. However, while health system factors may have contributed to these differences, it should be noted that the age and gender composition of the Australian and US patient samples was quite dissimilar and this may have had an impact on the emergent themes. Further research is needed to determine the factors underlying the observed differences.

If these differences do prove to be culturally based, it would underscore the importance of cultural sensitivity in both conducting end-of-life communication research and drawing conclusions from the findings. If even two Western cultures differ, more divergent cultures may have greater differences. People from Eastern and some European cultures have been reported to prefer non-disclosure of prognostic information [40,41], although we

found in a recent qualitative study of Chinese, Arabic and Greek immigrants in Australia with incurable cancer, that the majority of patients preferred open disclosure [42]. Direct comparisons of different cultures using identical interview schedules, as done here, would usefully add to the cross-cultural literature on these topics.

4.2 Conclusion

Discussing prognosis and end-of-life care issues can enable development of a plan of care that maximises clinical and quality-of-life outcomes. The identified optimising factors illustrate patients' perspectives of how these challenging and complex issues can be discussed at the most appropriate time, in the most appropriate manner and with minimum negative impact. While some differences emerged in Australian and US patients' perspectives regarding these discussions and their relationships with their doctors, the pattern of factors and conditions necessary for positive discussions and the desired outcomes appeared to be the same for both participant groups. Further exploration of how health system and individual difference factors contribute to and maintain such attitudes and experiences is warranted.

4.3 Limitations and future directions

Patients were recruited from only 2 institutions in Australia and 1 in the US. The attitudes expressed by participants may therefore not be representative of general attitudes towards discussion of prognosis and end-of-life issues. Future studies could test the generalisability of these findings, seek the input of health professionals and patients' significant others who are also involved in such discussions and develop and test interventions designed to address the optimising factors identified here. Additionally, while participation was restricted to patients with advanced cancer in this study, communication about prognosis and end-of-life care is equally relevant for any patient with an advanced,

life-limiting disease. Future studies should explore these concepts amongst other patient samples.

Information about primary tumour site was not collected from all patients; though amongst the patients from whom these data were collected, tumour site did not appear to impact upon the attitudes and experiences they described. However, individual characteristics such as primary tumour site, age and gender may impact upon patients' attitudes and experiences, and a larger sample would better allow sub-group analyses to discern the impact of such variables.

All US patients approached agreed to participate though two were deemed ineligible when screened. Seven Australian patients approached did not participate; one who withdrew after consent believing the material covered to be too personal, one who could not be contacted and five who declined to participate. Though the highest standards were followed in the sampling procedure, bias introduced by enlisting oncologists to identify potential participants cannot be ruled out. Finally, as noted above, it is possible that patients who wished not to discuss prognosis or end-of-life issues may have refused participation, resulting in a biased sample. Patients who do not wish to discuss these issues may identify a different pattern of barriers and facilitators to these discussions to the participants in this study.

4.4 Practice implications

Recognition of patients' adjustment and acceptance of their condition together with the factors that promote this and use of communication skills, mutual understandings and therapeutic relationship elements that promote readiness to discuss prognosis and end-of-life issues may assist patients and health professionals to address these issues at the

most appropriate time and in the most appropriate manner. These discussions can give patients a sense of control over their situation and help them to maintain a sense of personal identity and enjoy a good quality-of-life.

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Table 1: Patient demographic and disease characteristics		
	Australian (n=15*)	US (n=19*)
Age		
Mean	67.6	58
Range	54-86	34-75
	N (%)	N (%)
Gender		
Male	12 (80)	6 (31.6)
Female	3 (20)	13 (68.4)
Education		
Year 10 or below/elementary/some high school	3 (20)	3 (15.8)
Year 12/HSC/GED/high school graduate	2 (13.3)	5 (26.3)
Professional qualification/some university/college	8 (53.3)	4 (21)
Undergraduate degree	1 (6.7)	5 (26.3)
Postgraduate degree	1 (6.7)	1 (5.3)
Primary tumour site		
Lung	9 (60)	
Bladder	1 (6.7)	
Prostate	4 (26.6)	
Kidney	1 (6.7)	
Treatments received		
Chemotherapy	11 (73.3)	
Radiotherapy	6 (40)	
Surgery	7 (46.7)	

*Note: ns varied due to missing data. Individual data for primary tumour site and treatments received were not collected for US patients

Figure 1: Relationships between optimising factors, discussions of prognosis and end-of-life issues and outcomes

