Fostering Coping and Nurturing Hope When Discussing the Future with Terminally Ill Cancer Patients and Their Caregivers

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BACKGROUND. It is challenging for clinicians to foster coping and allow hope when discussing prognosis and end-of-life (EOL) issues with terminally ill cancer patients and their caregivers. To the authors' knowledge, little research evidence is currently available to guide clinical practice.

METHODS. The authors conducted focus groups and individual interviews with 19 patients with far advanced cancer and 24 caregivers from 3 palliative care (PC) services in Sydney, and 22 PC health professionals (HPs) from around Australia. The focus groups and individual interviews were audiotaped and fully transcribed. Additional focus groups or individual interviews were conducted until no additional topics were raised. The participants' narratives were analyzed using qualitative methodology.

RESULTS. All participant groups believed there were ways of fostering coping and nurturing hope when discussing prognosis and EOL issues. Themes identified from the transcripts regarding ways of helping patients with a limited life expectancy to cope were: 1) emphasize what can be done (namely: a) control of physical symptoms; b) emotional support, care, and dignity; and c) practical support), 2) explore realistic goals, and 3) discuss day-to-day living. Two additional themes were identified regarding ways of fostering hope: the balance between truth telling and nurturing hope, and the spectrum of hope. All these themes were raised by the patients, caregivers, and HPs. However, there were some differences of opinion within the three participant groups.

CONCLUSIONS. The results of the current study demonstrated that most participants believed there were ways of fostering coping and maintaining hope and that HPs have a role in facilitating this with terminally ill cancer patients and their caregivers. ***Cancer* 2005;103:1965–75.** *© 2005 American Cancer Society.*

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Clinicians are frequently asked questions regarding prognosis by terminally ill cancer patients, but there is uncertainty as to the optimal ways of discussing the future. When no further reasonable options for antineoplastic treatment remain, it can be very difficult for health professionals (HPs) to assist terminally ill cancer patients in coping with their situation as well as meet their informational needs with regard to prognosis and end-of-life (EOL) issues. Coping is an integral component of psychologic well-being[1] and has been defined as what an individual does in response to a perceived problem to bring about relief, reward, quiescence, or equilibrium.[2] Information itself is considered one of the general strategies that many individuals use to cope with or manage major life events[3] and open conversation

See also pages 1957–64, this issue.

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about death and dying can bring considerable relief to patients and their families. However, individual coping styles vary[4] and not all patients want information concerning their prognosis or to discuss EOL issues with their HP.[5]

Having things to hope for is an important coping strategy for terminally ill cancer patients.[6–8] Hope has been described as an essential element in human life,[6,9] one that is integral to a person's quality of life[10] and well-being.[11] Hope has been defined as the confident but uncertain expectation of a future good that appears realistically possible and is personally significant to the individual.[12] In previous oncology literature, hope has been viewed narrowly in terms of the hope for a cure or remission of disease,[13] and even as a reason to withhold information regarding the diagnosis.[14] However, in the context of a terminal illness, hope for a cure is often lost. Authors have described hope in the setting of a terminal illness as a multidimensional[12] and a dynamic process[6,15] that for most patients requires coming to terms with multiple losses in a changing reality.[6]

Therefore, how can clinicians discuss the future with terminally ill cancer patients and yet still help patients to cope and foster hope? Palliative care (PC) HPs have particular interest and experience in this arena, in part because of the centrality of these issues to their clinical practice. Furthermore, they may be a self-selected group of people who have innate skills in this area. Therefore, the views of these HPs may have particular value not only in their own setting but for general oncology. The views of terminally ill cancer patients and caregivers, who are the targets of such discussions, should arguably have the greatest influence on clinical practice. The objective of the current study was to examine the views of terminally ill patients, caregivers, and PC HPs on what, to our knowledge, is a relatively unexplored topic.

MATERIALS AND METHODS

Sample

Specialist PC services are well established in Australia[16] and are comprised of teams with a range of medical, nursing, and allied HPs and volunteers. PC medicine is a distinct medical specialty in Australia with its own specific training program. Each PC service commonly provides consultations across a variety of settings including tertiary referral and district hospitals; inpatient PC units; and the community in homes, hostels, and nursing homes. Unlike the eligibility criteria for hospice care in the U.S., patients can be referred to PC services in Australia at any time from diagnosis and many still receive antineoplastic treatment with palliative intent.[17] Occasionally, patients who are receiving curative chemotherapy are seen by the PC service for symptom control. None of the patients participating in the current study had any chance of cure from their malignancy. Patients usually remain under the primary care of their family medical practitioner and often are concurrently receiving specialist care from both an oncologist and the PC team. The mean length of time that patients are referred prior to death varies in different services; for the services participating in the current study, this figure is approximately 8–12 weeks.

Three groups believed to have important input were sampled: 1) PC patients, 2) caregivers of PC patients, and 3) HPs working in PC. Patients and caregivers were eligible to take part if they were: 1) age older than 18 years, 2) English speaking, 3) well enough to take part in a focus group or interview, 4) able to provide informed consent, and 5) referred to a specialist PC service and diagnosed with a progressive illness with no chance of cure, or the caregiver of such a patient. Sampling was aimed at achieving a diverse group of participants from different socioeconomic and cultural backgrounds; hence, three PC services in Sydney with different population bases were approached to participate. Patients and caregivers were recruited from these services via hospitals, PC units, and the community.

PC physicians and community nurses identified suitable patients and caregivers and sought their approval to be contacted by a researcher. Patients and caregivers were then contacted via telephone and invited to participate in the study.

The HP participants were all currently working in PC and had at least 2 years' experience in this area. Participants were selected across a range of disciplines and from various PC centers to ensure that relevant views were represented. A snowballing technique was used[18] in which the initial participants were asked to suggest other HPs who may be willing to participate in an interview. Suitable HPs were contacted by an investigator and invited to participate.

All participants received an information sheet and signed an informed consent form.

Data Collection and Analysis

Focus groups of four to eight participants, supplemented by individual interviews with those patients unable to attend a focus group, were held separately with patients and caregivers and conducted by a PC physician (J.C.) and a clinical psychologist (P.B.) experienced in qualitative research methods. HPs were given a semistructured individual interview either face to face or over the telephone, conducted by the first author (J.C.). The focus group facilitators and inter-

TABLE 1
Focus Group and Individual Interview Discussion Format

Discussion format for health professionals

Discussions about the future in a palliative care setting are often difficult. I am referring not only to discussions about life expectancy but also the likely symptoms that a patient may face in the future and the likely mode of death.

- How do you tend to approach questions about the future from palliative care patients? How do you tend to approach questions about the future from caregivers of palliative care patients?
- How do you think information about the future should be portrayed during a palliative care consult?
- Do you ever initiate discussion about the future during a palliative care consult? In what circumstances do you think this is appropriate?
- When discussing the future with a palliative care patient or their caregiver, is there any way of communicating hope?
- If a palliative care patient (or their caregiver) asked about their life expectancy:
  - What words would you use?
  - What sort of time frames would you give (if any)?
  - Would you give any statistics?
  - Would you draw survival graphs or use any other aids?
- What advice would you give to palliative care trainees regarding discussion of the future?

Discussion format for patients and caregivers

Prognosis refers to likely future developments and life expectancy.

- What information do you think is important for your palliative care doctor to tell you (or the person you care for) about your (their) prognosis? (not necessarily during the first consult)
- What information do you think is important for a palliative care doctor to tell caregivers about the prognosis of the person they care for?
- How do you think information about prognosis should be portrayed during a palliative care consult?
- Who should initiate discussion about prognosis during a palliative care consult?
- Should palliative care doctors offer to discuss prognosis with you (for caregivers: or the person you care for or with you the caregiver) at certain times?

TABLE 2
Demographic and Disease Characteristics of Patient and Caregiver Participants

Characteristic	Caregivers participating in focus group/individual interviews (n = 24)	Patients participating in focus group/individual interviews (n = 19)
Median age (yrs) (range)	53 (23–71)	68 (36–83)
Gender		
Male	8	8
Female	16	11
Education		
School certificate or below	9	3
Completed high school but not tertiary	1	5
Tertiary education	14	11
Patient's underlying diagnosis		
Advanced cancer	24[a]	19
Primary site of malignancy		
Lung	4	7
Gastrointestinal	7	2
Breast	2	4
Melanoma	3	0
Prostate	0	2
Other	8	4
Median time since referral of patient to palliative care (range)	14 weeks (2 weeks–2.5 years)	12 weeks (3 weeks–2 years)
Current residence of patient		
Home or home of family/friends	18	16
Hostel	0	1
Inpatient palliative care unit	5	2
Other hospital	1	0
Caregiver's relationship to patient		
Spouse/de facto	11	
Son/daughter	9	
Same-sex partner	2	
Grandchild	1	
Friend	1	

[a] The underlying diagnosis of the patient for one of the caregiver respondents was both advanced cancer and motor neuron disease.

viewer for the semistructured interviews did not know any of the patient or caregiver participants prior to them taking part in the current study. The discussion format for the interviews and focus groups is outlined in Table 1. In this article we report participants' views regarding ways of 1) helping patients and their caregivers to cope with their situation and 2) fostering hope when discussing prognosis and EOL issues in a PC setting. The results of the other discussion items outlined in Table 1 will be reported elsewhere. Sociodemographic data concerning participants were collected via a brief questionnaire at the end of the interview or focus group.

The focus groups and telephone interviews were audiotaped and fully transcribed. Data analysis was informed by qualitative methodology.[19] The transcripts were read and individual points identified by the facilitators, using the participants' own language when possible. These transcripts were discussed by both facilitators to ensure the consistency of interpretation and were organized into mutually exclusive categories. Additional focus groups and/or telephone interviews were conducted until no additional topics were raised. The final categories were reviewed by all investigators and any discrepancies were resolved.

The study was approved by the ethics committees of participating institutions.

Participants

Twenty-four caregivers took part in 3 focus groups (21 participants) and 3 individual telephone interviews. Nineteen patients took part in 3 focus groups (14 participants) and 5 individual telephone interviews. The demographic characteristics of patient and caregiver participants are shown in Table 2.

Twenty-two PC HPs were interviewed including 13 physicians (7 specialist PC physicians and 6 senior PC registrars in training), 4 nurses, and 5 allied health staff (an occupational therapist, a physiotherapist, a social worker, a bereavement counselor, and a pastoral care worker). The HPs worked at 10 different PC services in 2 Australian states (New South Wales, South Australia) in a variety of settings including teaching hospital, community, and inpatient PC units (many HP participants saw patients in a combination of these settings). There was a range of PC experience among the HPs, with 7 of them (32%) having $>$ 10 years of experience (mean, 8.3 years; standard deviation, 4.9 years).

RESULTS

All participants groups believed that there were ways of fostering coping and nurturing hope when discussing prognosis and EOL issues with terminally ill cancer patients and their caregivers. Themes identified from the transcripts regarding ways of helping patients with a limited life expectancy to cope were: 1) emphasize what can be done (namely a) control of physical symptoms; b) emotional support, care, and dignity; and c) practical support), 2) explore realistic goals, and 3) discuss day-to-day living. Two additional themes were identified from the transcripts regarding ways of nurturing hope when discussing the future with terminally ill cancer patients: the balance between truth telling and nurturing hope, and the spectrum of hope. Summaries of these themes are presented below; participant quotes are shown in Figures 1 and 2.

Helping Patients and Their Families to Cope with a Poor Prognosis

Emphasize what can be done

Control of physical symptoms.

All participant groups said that it is important to reassure patients that pain and other symptoms can be controlled in the future and around the time of death. Many HPs said that patients might be frightened to talk about this issue, so if appropriate it is important for the HP to bring this topic into the conversation. The value of reassuring patients who did not currently have pain that they may never get it, and that several options to control pain are available, also was emphasized by all participant groups.

Emotional support, care, and dignity

Patients, caregivers, and HPs all said that it is vital for the HP to convey the sense that they care about the patient and to show compassion. The value of listening and acknowledging the emotional concerns of the individuals involved also was highlighted. All participant groups emphasized that patients need to know that their physician and other HPs are doing their utmost to help them, and that they will not be abandoned, they will have plenty of support, and they will be well cared for in the terminal phase.

The importance of reassuring patients that their dignity will be respected and that the person is made to feel valuable was also emphasized by HPs and patients, although caregivers did not raise the latter specifically.

Some HPs believed that it is important to reassure caregivers that they are doing a good job of looking after the dying person and occasionally to reassure even the patient themselves, when they reach the terminal phase (final days) of their illness, that they are doing a good job of dying. Patients and caregivers did not mention this.

Practical support

Patients, caregivers, and HPs all commented that it was reassuring for both patients and caregivers to be told that the patient can be admitted to the PC unit if needed, to be informed about equipment and resources that are available for the person to be cared for at home, and about the possibility of respite care for caregivers.

Explore realistic goals

Several HPs commented that when discussing prognosis it is very important to enquire about the patients' concerns and priorities for the future. Exploring realistic goals and helping patients when possible to achieve these goals was seen, by many HPs, as a significant way to help patients to cope with their limited life expectancy. However, one physician commented that he did not believe it was the role of an HP to be exploring goals, but rather this was a deeply personal issue for the patient that we should not assume we can address.

Some patients and caregivers said that the PC team had helped them to achieve some small goals, such as going on a special outing, and that this was very helpful and made them feel supported and gave them hope.

Act now rather than later

Some HPs suggested posing a hypothetical question to explore the patient's goals and priorities if the patient did not appear ready to discuss their prognosis or if there was an element of denial or unrealistic expectations (e.g., "while we are hoping that things will go well with the chemotherapy, if by some chance you didn't get better, what would be the most important things that you would want to do while you are able to?") Several physicians and nurses and some allied health staff said it

Emphasize what can be done

Control of physical symptoms

"I am not frightened of dying, that doesn't worry me at all, … I just don't want to die in agony. You know you would like to… (be told) they have got good palliative care workers here, don't worry about that. If you… were in pain, well they have got something to fix it… I wouldn't want to …be hanging on, you know, week after week if you were that bad." (Patient from Focus Group 5)

Emotional support, care, and dignity

"We're going to be there with you. We're going to be watching your condition, we're going to be monitoring how you are, we can change things if they're not good. We can try and support the family and you and we're going to be beside you with this. So while I don't know exactly what's going to happen we're going to be watching and assisting you with every twist in the road sort of thing, and I guess that's probably what they're wanting to know more than anything else." (Nurse 1)

"An analogy … I occasionally use … for people… I say dying is a bit like doing an absail. Absailing is a pretty frightening thing to do and to sort of go off the edge of a cliff with just a rope between you and life and death is very frightening, and …there are several things that help you and that is trust…you wouldn't do it unless you trusted the people there with you…and this means the doctors and nurses. You wouldn't do it unless you've got the support of people like your family and friends, but the other thing that helps you do it and carry on is when people say yes, you're doing it right, you're putting your foot in the right place, you're in the right angle, those things help." (Doctor 9)

"It's very good to know that there is a place like this were you can be received and … you retain your dignity. You have love and care surrounding you, and brave compassion and if … the cards fall against you are somewhere where you can … be let down … softly softly with great dignity and loving care…So they give you back your human identity rather than a bed number" (Patient from Focus Group 1)

"From the purely point of view of moral support, they told me that they would be with me through the whole of the time, and that was what they initially said, they said we will walk through this with you and we don't want you to feel that you're left alone … You need to know that you will not be left, because none of us have generally been through this and we have no idea what to expect." (Caregiver Individual Interview 2)

Explore realistic goals

"You try and elicit what were the things that were most meaningful to the person and maybe help them try and address some of those things… Focus on what's important to them, and try and give them a sense of hope that maybe some of those things actually were achievable, even though in the bigger picture yes they're dying, but there's things that they can still do while they're alive that can help them feel better or help them get a sense of fulfilment or a sense of completion or something." (Physiotherapist)

"I was asked one day what I would like to do and I said I used to love to walk down to (the beach) and immediately the palliative care sister said to me well that can be arranged, we can organise you a wheelchair. And just somebody saying yes …we can do this. Just because you haven't got the energy to walk from A to B, doesn't mean you're cut off from the world, and you can still do the things you like to do, within reason, and it's no trouble for them to help you."(Patient Individual Interview 1)

Act now rather than later

"I might say something along the lines of we… hope that we're going to live a long time or whatever but … it might be as well for them to sort out all the practicalities and not have to think about it any more." (Doctor 1)

"What might happen, and whilst I don't remember anybody saying this, they may have. I'm not even sure whether it's palliative care's job, but somebody should mention to both the carer and the patient that if they have things that need to be done, things like accounts, bills, anything that needs to be sorted out, it's wise to do that in the initial stages. But … it's probably not a bad idea to generally say to them, if you have things that you want to sort out, do it now or do it while you both want to talk about it, because in the latter stages it becomes extremely difficult to talk about these things with some clarity." (Caregiver Individual Interview 2)

Discuss day-to-day living

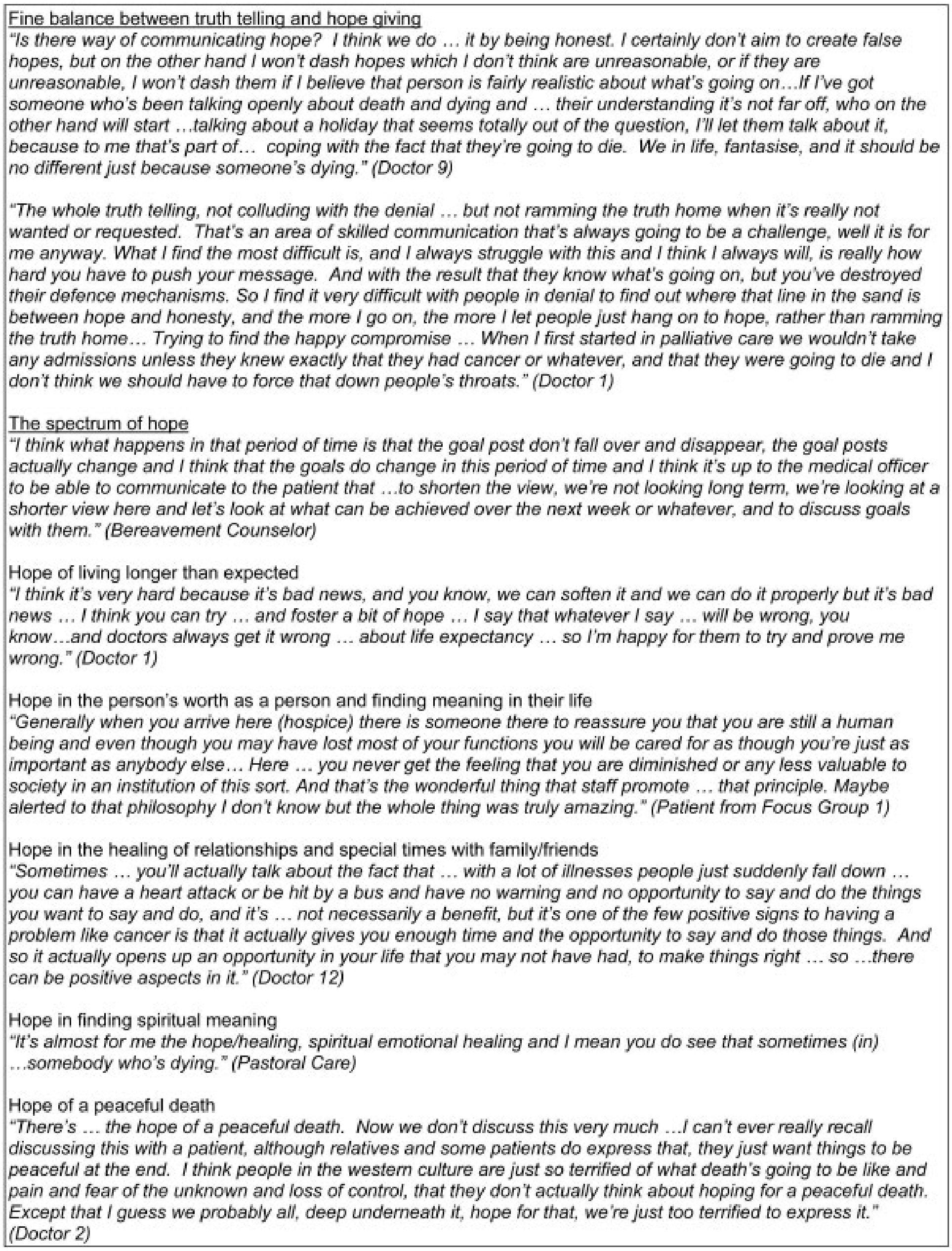
"It has been good for me to get information in terms as of what to expect… They are not just saying you can expect this and this is going to get worse, they are also saying … that there will be some really good days and some ups and downs … and that is really helpful and very true." (Caregiver from Focus Group 6)

FIGURE 1. Participant quotes regarding helping patients and their families to cope with a poor prognosis.

is important to suggest that patients think about settling out their affairs and doing the things that they want or need to do now while they are still well enough (e.g., spending time with family and sorting out any unfinished business). Other HPs said it is not something that they would discuss out of the blue and they would only do so with certain patients or in specific circumstances, such as if the patient was planning a trip for a distant time in the future when their condition obviously was deteriorating or if it became obvious that they had not made arrangements for their young children. Some patients and caregivers emphasized that it was helpful and/or important for HPs to recommend that they get their affairs in order. However, one patient was upset that a PC physician had suggested that he think about writing his will. It was the first time that he had come into contact with the PC team and he was not ready to think about dying.

Discuss Day-to-Day Living

Some patients and several caregivers commented that sensitive and well timed advice from PC HPs concerning how to cope on a daily basis was helpful. Within the



Fine balance between truth telling and hope giving

"Is there way of communicating hope? I think we do … it by being honest. I certainly don't aim to create false hopes, but on the other hand I won't dash hopes which I don't think are unreasonable, or if they are unreasonable, I won't dash them if I believe that person is fairly realistic about what's going on…If I've got someone who's been talking openly about death and dying and … their understanding it's not far off, who on the other hand will start …talking about a holiday that seems totally out of the question, I'll let them talk about it, because to me that's part of… coping with the fact that they're going to die. We in life, fantasise, and it should be no different just because someone's dying." (Doctor 9)

"The whole truth telling, not colluding with the denial … but not ramming the truth home when it's really not wanted or requested. That's an area of skilled communication that's always going to be a challenge, well it is for me anyway. What I find the most difficult is, and I always struggle with this and I think I always will, is really how hard you have to push your message. And with the result that they know what's going on, but you've destroyed their defence mechanisms. So I find it very difficult with people in denial to find out where that line in the sand is between hope and honesty, and the more I go on, the more I let people just hang on to hope, rather than ramming the truth home… Trying to find the happy compromise … When I first started in palliative care we wouldn't take any admissions unless they knew exactly that they had cancer or whatever, and that they were going to die and I don't think we should have to force that down people's throats." (Doctor 1)

The spectrum of hope

"I think what happens in that period of time is that the goal post don't fall over and disappear, the goal posts actually change and I think that the goals do change in this period of time and I think it's up to the medical officer to be able to communicate to the patient that …to shorten the view, we're not looking long term, we're looking at a shorter view here and let's look at what can be achieved over the next week or whatever, and to discuss goals with them." (Bereavement Counselor)

Hope of living longer than expected

"I think it's very hard because it's bad news, and you know, we can soften it and we can do it properly but it's bad news … I think you can try … and foster a bit of hope … I say that whatever I say … will be wrong, you know…and doctors always get it wrong … about life expectancy … so I'm happy for them to try and prove me wrong." (Doctor 1)

Hope in the person's worth as a person and finding meaning in their life

"Generally when you arrive here (hospice) there is someone there to reassure you that you are still a human being and even though you may have lost most of your functions you will be cared for as though you're just as important as anybody else… Here … you never get the feeling that you are diminished or any less valuable to society in an institution of this sort. And that's the wonderful thing that staff promote … that principle. Maybe alerted to that philosophy I don't know but the whole thing was truly amazing." (Patient from Focus Group 1)

Hope in the healing of relationships and special times with family/friends

"Sometimes … you'll actually talk about the fact that … with a lot of illnesses people just suddenly fall down … you can have a heart attack or be hit by a bus and have no warning and no opportunity to say and do the things you want to say and do, and it's … not necessarily a benefit, but it's one of the few positive signs to having a problem like cancer is that it actually gives you enough time and the opportunity to say and do those things. And so it actually opens up an opportunity in your life that you may not have had, to make things right … so …there can be positive aspects in it." (Doctor 12)

Hope in finding spiritual meaning

"It's almost for me the hope/healing, spiritual emotional healing and I mean you do see that sometimes (in) …somebody who's dying." (Pastoral Care)

Hope of a peaceful death

"There's … the hope of a peaceful death. Now we don't discuss this very much …I can't ever really recall discussing this with a patient, although relatives and some patients do express that, they just want things to be peaceful at the end. I think people in the western culture are just so terrified of what death's going to be like and pain and fear of the unknown and loss of control, that they don't actually think about hoping for a peaceful death. Except that I guess we probably all, deep underneath it, hope for that, we're just too terrified to express it." (Doctor 2)

FIGURE 2. Participant quotes regarding fostering hope when discussing prognosis and end-of-life issues.

context of exploring a patient's concerns and priorities, if distress is clear and the patient and/or caregiver is seeking guidance, many HP participants suggest helpful strategies. Ways of thinking about and coping with the reality of the illness that were discussed spontaneously by patient and caregiver participants as being helpful are outlined in Table 3. These coping strategies also were raised independently by HP participants.

Nurturing Hope When Discussing Prognosis and EOL Issues

The Fine Balance between Truth Telling and Nurturing Hope

All HPs and several patients and caregivers said that it is important to be honest with patients when discussing the future. None of the patients and caregivers indicated that they did not want their HP to be honest. Some participants even said that it gave them hope when the HP was honest. Nevertheless, patients, caregivers, and HPs all stated that it is important not to be too blunt or provide a great deal of detailed information that the patient does not want to hear.

The need to maintain hope was emphasized by all the participant groups. Several HPs found the balance between honesty and hope to often be very challenging and difficult to achieve. Many HPs commented that it was important not to offer unrealistic hope or to collude with patients' unrealistic expectations. The

TABLE 3
Ways of Coping That Were Independently Reported to be Helpful by Patient, Caregiver, and Health Professional Participants

Ways of coping with a terminal prognosis
Take each day at a time
Focusing on the present
Knowing that there will be good days and bad days
Making the most of good days when they feel well
Learning to get through the bad days
Trying not to anticipate too many awful things that may or may not happen
Incorporating the things they enjoy into their life
Trying to continue "living" because life does not stop when you are dying
Trying to maintain some sense of normality and routine
Not focusing only on dying

reasons given for this belief by some HPs was to avoid harm to the patient and their family if patients were not doing things that needed to be done or having the opportunity to prepare for their death. One physician spoke of the difference between hope and wishing: hope is grounded in reality whereas wishing is about fairy tales. Conversely, many HPs said that they respected denial as a coping mechanism and do not compel people to hear the truth. These HPs pointed out that you can not make someone hear what they do not want to hear. Several physicians said they would allow patients to fantasize or dream about unlikely possibilities if they appeared to be otherwise realistic and prepared. Some patients and caregivers said that it is important for HPs not to give false hope but any positive aspects should be emphasized. A few patients said they found it hard to think about their future and the reality of their diagnosis, let alone talk about it. Therefore, as a way of coping, they pushed it aside and tried to get on with living their everyday lives.

The Spectrum of Hope

The HPs spoke about different types of hope and how there is a change in the focus of hope over time as the person's illness progresses, and as the patient and their family come to terms with this deterioration. The challenge for HPs is to help patients refocus their goals and hopes onto those things that can be realistically achieved. Several patients and some caregivers also spoke about a range of ways to find hope in their situation. The different forms of hope, as described by the participants, are outlined in Table 4. These types of hope were not seen as being mutually exclusive or necessarily progressing in a stepwise direction. For example, some patients simultaneously hoped to live longer than expected as well to be free of pain and to have a peaceful death.

There was overlap between the participants' views on the different forms of hope and ways to help the patient and their family cope with their illness. Some of the types of hope outlined in Table 4 have been discussed earlier in the section concerning helping patients and their families to cope with a poor prognosis. The hope of being well cared for and supported by HPs was the source of hope that was mentioned most frequently by patients and caregivers. Some further details regarding some of the forms of hope are provided.

TABLE 4
Views of the Participants Regarding the Different Forms of Hope as the Patient's Illness Progresses

	Raised by whom		
Type of hope	Health professionals	Patients	Caregivers
Hope of a miracle cure or spontaneous disease remission	Yes	Yes	Yes
Hope of living longer than expected	Yes	Yes	Yes
Hope of making it to certain events or achieving goals	Yes	Yes	Yes
Hope of every day living	Yes	Yes	Yes
Hope in the person's worth as an individual and finding meaning in their own life	Yes	Yes	No
Hope it the healing of relationships and having special times with family and friends	Yes	No	No
Hope of good pain and symptom control	Yes	Yes	Yes
Hope of being well cared for and supported	Yes	Yes	Yes
Hope in finding spiritual meaning	Yes	No	No
Hope of a peaceful death	Yes	Yes	No

Hope of a miracle cure or spontaneous disease remission

Whether to discourage patients to hope for a miracle cure was a contentious issue among the HP participants. A few allied HPs said that they would not discourage patients in their hope for a miracle cure, including the development of new treatments, alternative medicine, or a spontaneous disease remission. These participants argued that spontaneous disease remissions do occur rarely, and if it helps the patient to cope with their situation then why not allow them this hope and let the patient to come to terms with their limited life expectancy at their own pace. However, physicians particularly were concerned about allowing people to hope for something that ultimately will not occur and said they would discourage patients from investing their time and energy in futile treatments. Some patients and caregivers spoke about how initially their hope was focused on treatments to control the tumor and a few patients said they still hoped for a cure, although they knew the chances were small. A few patients found hope in knowing their HPs would help them "fight" the cancer as long as possible.

Hope of living longer than expected

Several HPs, but fewer patients and caregivers, spoke of the hope of beating the odds and being on the tail of the survival curve. The inaccuracy and uncertainty of the prediction of life expectancy were seen as potential causes for hope because the person may live longer than average.

Hope in the person's worth as a person and finding meaning in their life

Several HPs emphasized the person's worth as an individual as a source of hope. Encouraging the patient to talk about their life and showing interest in them as a person were seen as giving hope. Likewise, patients said it gave them hope when their HPs made them feel valuable and important. Caregivers did not mention this in the context of hope but they highlighted the importance of the patient's relationship with their HP.

Hope in the healing of relationships and special times with family/friends

Some HPs raised the hope that the person will become closer to their family, resolve issues, and/or heal relationships (e.g., by reconnecting with estranged family members). Some physicians tell patients that a diagnosis of a serious illness, such as cancer, is an opportunity to say and do things with important people in their lives that other people may never get around to doing. The patient and caregiver participants did not raise this form of hope.

Hope in finding spiritual meaning

A few HPs said spiritual and existential meaning can be an important source of hope for patients, but only a few said that they would regularly discuss this with patients. No patients or caregivers raised this form of hope.

Hope of a peaceful death

Some HPs spoke of the hope of a peaceful death, although they commented that it is not something that is often discussed with patients. A few patients mentioned the hope of a peaceful death, but no caregivers did so.

DISCUSSION

The current study has identified several ways of fostering coping and nurturing hope when discussing prognosis and EOL issues with terminally ill cancer patients and their families. A unique contribution of this study is that it allows a comparison of the views of patients, caregivers, and HPs on these topics. It is reassuring that, overall, the views of HPs were not dissimilar to those of patients and caregivers, suggesting that the methods some PC HPs currently use to promote hope and coping in this context are generally appreciated by patients.

The value of emphasizing what can be done in terms of the control of physical symptoms; emotional support, care, and dignity; and practical support was highlighted by all participant groups, and is consistent with the views of participants regarding the important aspects of EOL care.[20–22] The only point within this theme that was raised by HPs but not by patients or caregivers was the reassurance of caregivers and patients that they were doing a good job of caring for the person or, in the case of patients, dying. No patients or caregivers said that they would not appreciate such reassurance, and we believe further, more specific probing of this issue would be worthwhile in future research to determine whether it is of value to patients and caregivers.

Sensitive advice regarding how one can cope with a terminal prognosis on a day-to-day basis was valued by some patients and several caregivers and suggested by some HPs. Clearly, any advice if unsolicited may be unhelpful, but if offered in the context of exploring the needs of the patient, the ways of thinking about everyday living as outlined in Table 3 may be useful for some patients and caregivers. Likewise, exploring patients' priorities and needs with regard to what needs to be done while they are still well enough was valued by some patients and caregivers. Only one patient in the current study found it too confronting when it was suggested that they get their affairs in order. However, this may reflect our sample of terminally ill cancer patients who were willing to take part in this type of research.

To our knowledge, the majority of literature concerning the coping strategies of cancer patients has focused on patients with early-stage disease or those still receiving anticancer treatment.[4,23] To our knowledge, less is known regarding the coping strategies of patients in the terminal phase of their illness. However, the ways of coping with a terminal prognosis that are outlined in Table 3 are similar to some of the "dignity-conserving practices" reported by Chochinov et al.[24] In their study, 50 patients with advanced terminal cancer from a PC unit in Canada were interviewed regarding how they coped with their illness and their perceptions of dignity. "Living in the moment" and "maintaining normalcy" were among the subthemes identified. The attitudes described in Table 3, such as "taking each day as it comes" are distinct from "positive thinking" or having a "fighting spirit, " which are well described in the previous literature regarding the coping strategies of cancer patients.[4,23] "Taking each day as it comes" is perhaps a more realistic and sustainable approach for patients with far advanced disease for whom a cure is no longer possible and who want to maximize the quality of their remaining life. The burden of and pressure to be positive and present a "fighting spirit" to family, friends, and HPs has been voiced by cancer patients in recent studies.[25,26] As emphasized by participants in the current study, any advice given by HPs to patients and their families regarding ways of coping with the illness must be balanced with allowing them to express a full range of emotions, both positive and negative.

Exploring realistic goals with terminally ill patients as a way of promoting hope and coping has been reported frequently. This has been described mainly on the basis of the authors' clinical experience[7,27] and, to a lesser extent, studies of the views of HPs.[28] This is the first study that we are aware of to provide empiric data regarding the views of terminally ill cancer patients and caregivers to support this practice. The use of a hypothetical question by HP participants to explore patient goals when the patient had unrealistic expectations or was in denial is similar to the communication strategy of hoping for the best while preparing for the worst as described by Back et al.[7] and Von Roenn et al.[27] However, further research is required to assess whether patients and caregivers actually prefer realistic versus unrealistic goals.

The "fine balance" between telling the truth and nurturing hope when communicating with patients with advanced cancer has been reported previously in the theoretic medical and nursing literature.[9,29,30] The importance of being honest while at the same time not imposing the truth about a patient's prognosis when it was not wanted was emphasized by all participant groups. Similarly, pointing out the positive aspects while not encouraging the patient's false hopes also was raised by all participant groups. These findings are consistent with those of Kutner et al.[31] In this study, although all 56 terminally ill patients surveyed wanted their physician to be honest, 91% also wanted their physician to be optimistic.

Various different types of hope have been described in patients with advanced cancer and other terminal illnesses in previously published theoretic literature[9,27,32] and empiric literature of HPs', mainly nurses', views.[28,33–34] To our knowledge, fewer studies have been conducted with regard to the views of PC patients and their families on hope. Benzein et al.[15] interviewed 11 PC patients with cancer about their views on hope; the types of hope identified in their study included "a hope of being cured," "a hope of living as normally as possible," "a presence of confirmative relationships," and "reconciliation with life and death. " In a study with four PC patients as subjects, Flemming[35] reported the following types of hope: the hope of controlling disease progression, the existence and presence of family members and an anticipated future with them, and medical or nursing staff taking an interest in them.

In the current study, patients had wide-ranging hopes and some had several different concurrent hopes or fluctuated between the different types of hope. A few patients still were hoping for the impossible (a cure) for their cancer, even at this late stage of illness, and valued being a fighter even against slim odds. However, the majority of patient participants were hoping for other things within the spectrum of hope. This is in contrast to the findings of Sardell and Trierweiler,[36] who conducted a survey of patients with early-stage cancer and examined the factors influencing patient hopefulness when the cancer diagnosis is disclosed. In the study by Sardell and Trierweiler, the most highly ranked factors were those that instilled a sense of being able to fight the cancer. However, in the current study, several patients maintained a strong sense of hope despite having shifted their focus from fighting the disease to other types of hope within the spectrum.

The conflict among HP participants with regard to whether to support the hopes of terminally ill patients for a cure appears to reflect the tension between a professional responsibility to help patients refocus their hopes onto more realistically achievable things, and thereby avoid futile treatments, and respecting the patients' own coping strategies. However, Nuland[13] contended that hope for a cure is misguided in the context of a terminal illness, and that physicians and patients need to find hope in other ways. Likewise, Kodish and Post[9] argued that physicians need to do more than respond to the hopes of their patients and should actively participate in shaping realistic hopes when cancer recurs.

All the different types of hope within the spectrum of hope (see Table 4) were raised by HPs; however, some were not mentioned by the patient and/or caregiver participants. For example, the hope for the healing of relationships and finding spiritual meaning was not raised by either patients or caregivers, and the hope in the person's worth as an individual and the hope of a peaceful death were not raised by caregivers. In the current study, many patients and caregivers spontaneously volunteered their perspectives on hope; however, we did not specifically ask patients and caregivers about their views on the different types of hope raised by HPs. More specific probing of the views of patients and caregivers on the different types of hope would be of value in future research.

Limitations and Applicability of the Current Study Findings

Qualitative methodology dictates small sample sizes. The use of qualitative methods such as those used in the current study is common in exploratory studies and can generate hypotheses and provide rich descriptive information regarding a phenomenon. However, it is difficult to make assumptions about the generalizability of the data obtained using such methodology.

The sample in the current study is limited to English-speaking patients and caregivers (some of the caregivers were caring for patients from non-English-speaking backgrounds) from three different PC services in an urban setting in Sydney, Australia in cases in which there was an underlying illness of advanced cancer. Therefore, the patient and caregiver participants may not be representative of Australia's culturally diverse population. The educational background of the caregiver group was higher than that of the general population. All patients and caregivers had been referred to a PC service, were willing to receive ongoing follow-up from the PC team, and had been in contact with the PC service for a relatively long time (median of 12–14 weeks, with a range of 2 weeks–2.5 years). Therefore, participants may have been more accepting of a palliative approach to their illness and therefore had different views concerning coping and hope than those patients with incurable cancer who were being treated outside a PC setting. We obtained each patient's and caregiver's views on only one occasion. It is likely that views of the patient and caregiver regarding hope and coping strategies evolve over time.

The HP participants came from various disciplines and from several different PC centers in Australia servicing culturally diverse populations in mainly urban settings. However, the views of PC HPs may differ from those of providers caring for terminally ill patients in other settings.

Implications

The majority of participants in the current study believed there were ways of coping and maintaining hope, even at this late stage of illness, and that HPs can play a role in facilitating hope with terminally ill cancer patients and their caregivers. However, further research is needed to assess the generalizability of these findings and whether the suggestions made by participants are actually helpful for patients and caregivers in practice.

REFERENCES

1. Folkman S, Greer S. Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. *Psychooncology.* 2000;9:11-9.
2. Weisman A. Coping with cancer. New York: McGraw-Hill, 1979.
3. van der Molen B. Relating information needs to the cancer experience: 1. Information as a key coping strategy. *Eur J Cancer Care (Engl).* 1999;8:238–244.
4. Dunkel-Schetter C, Feinstein LG, Taylor SE, Falke RL. Patterns of coping with cancer. *Health Psychol.* 1992;11:79–87.
5. Leydon GM, Boulton M, Moynihan C, et al. Cancer patients' information needs and information seeking behaviour: in depth interview study. *BMJ.* 2000;320:909–913.
6. Hegarty M. The dynamic of hope: hoping in the face of death. *Prog Palliat Care.* 2001;9:42–46.
7. Back AL, Arnold RM, Quill TE. Hope for the best, and prepare for the worst. *Ann Intern Med.* 2003;138:439–443.
8. Johnston G, Abraham C. Managing awareness: negotiating and coping with a terminal prognosis. *Int J Palliat Nurs.* 2000;6:485–494.
9. Kodish E, Post SG. Oncology and hope. *J Clin Oncol.* 1995; 13:1817–1822.
10. Rustoen T. Hope and quality of life, two central issues for cancer patients: a theoretical analysis. *Cancer Nurs.* 1995;8: 355–361.
11. Fromm E. The revolution of hope: towards a humanized technology. New York: Harper & Row, 1968.
12. Dufault K, Martocchio BC. Symposium on compassionate care and the dying experience. Hope: its spheres and dimensions. *Nurs Clin North Am.* 1985;20:379–391.
13. Nuland SB. How we die: reflections on life's final chapter. New York: Knopf, 1994.
14. Oken D. What to tell cancer patients: a study of medical attitudes. *JAMA.* 1961;175:1120–1128.
15. Benzein E, Norberg A, Saveman BI. The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliat Med.* 2001;15:117–126.
16. Maddocks I. Palliative care in the 21st century. *Med J Aust.* 2003;179(6S):S4–S5.
17. Currow D. Australia: state of palliative service provision. *J Pain Symptom Manage.* 2002;24:170–172.
18. Rice PL, Ezzy D. Qualitative research methods: a health focus. Melbourne, Victoria, Australia: Oxford University Press, 1999.
19. Pope C, Mays N. Qualitative research in health care. 2nd edition. London: BMJ Books, 2000.
20. Curtis JR, Wenrich MD, Carline JD, Shannon SE, Ambrozy DM, Ramsey PG. Understanding physicians' skills at providing end-of-life care perspectives of patients, families, and health care workers. *J Gen Intern Med.* 2001;16:41–49.
21. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Ann Intern Med.* 2000; 132:825–832.
22. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA.* 2000;284:2476–2482.
23. Petticrew M, Bell R, Hunter D. Influence of psychological coping on survival and recurrence in people with cancer: systematic review. *BMJ.* 2002;325:1066–1076.

24. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med*. 2002;54:433–443.
25. McGrath P. The burden of the 'RA RA' positive: survivors' and hospice patients' reflections on maintaining a positive attitude to serious illness. *Support Care Cancer*. 2004;12:25–33.
26. Byrne A, Ellershaw J, Holcombe C, Salmon P. Patients' experience of cancer: evidence of the role of 'fighting' in collusive clinical communication. *Patient Educ Couns*. 2002;48:15–21.
27. Von Roenn JH, von Gunten CF. Setting goals to maintain hope. *J Clin Oncol*. 2003;21:570–574.
28. Owen DC. Nurses' perspectives on the meaning of hope in patients with cancer: a qualitative study. *Oncol Nurs Forum*. 1989;16:75–79.
29. Begley A, Blackwood B. Truth-telling versus hope: a dilemma in practice. *Int J Nurs Pract*. 2000;6:26–31.
30. Porter WG. Truth-telling and hope. The dilemma of modern medicine. *N C Med J*. 1999;60:142–148.
31. Kutner JS, Steiner JF, Corbett KK, Jahnigen DW, Barton PL. Information needs in terminal illness. *Soc Sci Med*. 1999;48:1341–1352.
32. Penson J. A hope is not a promise: fostering hope within palliative care. *Int J Palliat Nurs*. 2000;6:94–98.
33. Benzein E, Saveman BI. Nurses' perception of hope in patients with cancer: a palliative care perspective. *Cancer Nurs*. 1998;21:10–16.
34. Cutcliffe JR. How do nurses inspire and instil hope in terminally ill HIV patients? *J Adv Nurs*. 1995;22:888–895.
35. Flemming K. The imponderable: a search for meaning. The meaning of hope to palliative care cancer patients. *Int J Palliat Nurs*. 1997;3:14–18.
36. Sardell AN, Trierweiler SJ. Disclosing the cancer diagnosis. Procedures that influence patient hopefulness. *Cancer*. 1993;72:3355–3365.