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Josephine M. Clayton
Phyllis N. Butow
Robert M. Arnold
Martin H. N. Tattersall

Discussing life expectancy with terminally ill cancer patients and their carers: a qualitative study

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J. M. Clayton (✉) · P. N. Butow ·
M. H. N. Tattersall
Medical Psychology Research Unit,
University of Sydney,
Blackburn Building D06,
Sydney, NSW, 2006, Australia
e-mail: josephine@student.usyd.edu.au
Tel.: +61-2-90365289
Fax: +61-2-90365292

J. M. Clayton
Sacred Heart Palliative Care Service
St Vincent's Hospital,
Darlinghurst, Sydney,
NSW, 2010, Australia

P. N. Butow
School of Psychology
University of Sydney,
Griffith Taylor Building A19,
Sydney, NSW, 2006, Australia

R. M. Arnold
Institute for Doctor-Patient
Communication and Section of
Palliative Care and Medical Ethics,
Department of Medicine
University of Pittsburgh,
Pittsburgh, PA, USA

M. H. N. Tattersall
Department of Cancer Medicine,
University of Sydney,
Blackburn Building D06,
Sydney, NSW, 2006, Australia

Abstract *Goals of work:* There is uncertainty regarding the preferred content and phrasing of information when discussing life expectancy with terminally ill cancer patients and their carers. The objective of this study was to explore the various stakeholders' perceptions about these issues. *Subjects and methods:* We conducted focus groups and individual interviews with 19 patients with advanced cancer and 24 carers from three different palliative care (PC) services in Sydney and 22 PC health professionals (HPs) from ten different sites in Australia. The focus groups and individual interviews were audiotaped and fully transcribed. Further focus groups and/or individual interviews were conducted until no additional topics were raised. Participants' narratives were analysed using qualitative methodology. *Main results:* Participants' suggestions regarding the content of prognostic discussions included: explaining uncertainty and limitations, explaining the process involved with making survival predictions, and avoiding being too exact. Those patients and carers who wanted to be given a time frame mostly wanted to know how long the average person with their condition would live and/or be given a rough range. HPs had various views regarding ways to phrase life expectancy: days versus weeks versus months, likelihood of the patients being alive for certain events, a rough quantitative range and probabilities (e.g. 10% and 50% survival). However, most HPs said they would rarely if ever give statistical information to patients. *Conclusions:* This paper provides some potential strategies, words and phrases which may inform discussions about life expectancy. Further research is needed to determine the generalizability of these findings.

Keywords Advanced cancer · Terminally ill · Palliative care · Prognosis · Communication

Introduction

Terminally ill cancer patients often ask health professionals (HPs) "How long have I got?". This information may be very important for them in order to set goals and priorities and make decisions about their care. Likewise, families need an indication of time frames in order to organize practical support and time off work. Clinicians need to respond to this question in a way that assists patients and their families to make appropriate decisions, be informed to the level that they wish and cope with their situation.

Whilst it is now well established that most oncologists tell patients the diagnosis, information about prognosis is less commonly presented even when patients indicate a preference for this information [5]. Similarly physicians may not provide their best estimate of survival even when asked by terminally ill cancer patients [12]. Furthermore, misunderstanding in cancer patients about their prognosis is common [5]. Patient anxiety and denial are likely to contribute to this misunderstanding. However, it may be caused at least to some extent by a lack of or poorly presented information. Reticence to provide information may be in part due to doctors' uncertainty about their predictions. Doctors' survival estimates in terminally ill cancer patients are often wrong and are usually over-optimistic [7]. However, doctors may also lack confidence in knowing how to communicate survival predictions to patients. When patients with advanced cancer are not adequately informed of their prognosis they are more likely to choose aggressive treatments that will probably not extend their life and may compromise its quality [25]. The et al. [24] reported that cancer patients may subsequently regret such decisions.

Very few empirical data exist concerning the preferred content of prognostic discussions or of terminally ill cancer patients' and their carers' preferences for discussing prognosis. Likewise, there is a lack of data regarding expert clinicians' views on communicating prognostic information to terminally ill cancer patients. Palliative care (PC) HPs have particular interest and experience in this arena, in part due to the centrality of this issue 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 for their own setting, but also for general oncology. The views of patients and carers, who are the target of such discussions, should arguably have the greatest influence on clinical practice. To our knowledge no previous studies have systematically examined terminally ill cancer patients', their carers' and PC HPs' views on how to phrase and discuss life expectancy. In the current study we aimed to explore the views of these stakeholders regarding these topics.

Subjects and methods

Sample

Specialist PC services are well established in Australia [16]; they are composed of teams with a range of medical, nursing, and allied HPs and volunteers. Each 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. Patients are referred any time from diagnosis and many are still receiving antineoplastic treatment with palliative intent [3]. 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 was approximately 8–12 weeks.

Three groups felt to have important input were sampled: (1) PC patients, (2) carers of PC patients, and (3) HPs working in PC. Patients and carers were eligible to take part if they were: (1) over 18 years of age, (2) English speaking, (3) well enough to take part in a focus group or interview, (4) able to give informed consent, and (5) referred to a specialist PC service and diagnosed with an incurable and progressive illness, or the carer 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 carers were recruited from these services via hospitals, PC units and the community.

PC doctors and community nurses identified suitable patients and carers and sought their approval to be contacted by a researcher. Patients and carers were then telephoned 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 centres to ensure that relevant views were represented. A snowballing technique was used [23], whereby the initial participants were asked to suggest other HPs who would possibly be willing to participate in an interview. Eligible HPs were contacted by an investigator and invited to participate. All participants received an information sheet and gave written consent.

Data collection and analysis

Focus groups of four to eight participants, supplemented by individual interviews with those unable to attend a focus group, were held separately with patients and carers 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 discussion format for the interviews and focus groups is outlined in Appendix 1. In this paper we report participants' views regarding the optimal content, process and phrasing of information given about life expectancy. The results of the other discussion items outlined in Appendix 1 will be reported elsewhere. Sociodemographic data about 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 [20]. The transcripts were read and individual points identified by the facilitators, using the participants' own language where possible. These were discussed by both facilitators to ensure consistency of interpretation and were organized into mutually exclusive categories. Further 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

A total of 24 carers took part in three focus groups (21 participants) and three individual telephone interviews. Three additional carers declined to participate in either an interview or a focus group (all said they were too busy). A total of 19 patients took part in three focus groups (14 participants) and five individual telephone interviews. Four additional patients declined to participate in either an interview or a focus group (either too unwell or unstated reasons). The demographic characteristics of patients and carer participants are shown in Table 1 (demographic details of patients and carers who refused participation are unavailable, because consent for this information was not obtained).

Of 22 PC HPs interviewed, 13 were doctors (7 specialist physicians and 6 senior registrars in training), 4 nurses and 5 allied health staff (an occupational therapist, physiotherapist, social worker, bereavement counsellor, and pastoral care worker). One additional PC HP (a specialist physician) was invited to participate, but declined for unstated reasons. The HPs worked at ten different PC services in two states of Australia in a variety of settings including teaching hospital, community and inpatient PC units (many mixed). All HP participants were working full time in clinical PC practice. There was a range of PC experience amongst the HPs with seven (32%) having more than 10 years experience (mean 8.3 years, SD 4.9 years). Their ages ranged from 31 to 70 years (mean 41.5 years, SD 10.4 years). Only five participants (23%) were male (all doctors), but this is representative of the sex distribution of palliative care HPs in Australia.

Table 1 Demographic and disease characteristics of patient and carer participants

Characteristic	Carers participating in focus group/individual interviews (*n*=24)	Patients participating in focus group/individual interviews (*n*=19)
Age (years)		
Median	53	68
Range	23–71	36–83
Sex		
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
Underlying diagnosis of patient		
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
Time since referral of patient to palliative care		
Median	14 weeks	12 weeks
Range	2 weeks to 2.5 years	3 weeks to 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
Carer'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 of one of the carers was both advanced cancer and motor neurone disease

Results

Process

Participants had many suggestions regarding the preferred process or style of discussing life expectancy with PC patients, as outlined in Table 2. These are similar to published recommendations regarding breaking bad news [1, 6, 18, 21] and discussing prognosis with early-stage cancer patients [14]. All participant groups said that the manner in which the information is given is often more important than what is actually said. All participant groups emphasized the importance of honesty, and no patients or carers said that they did not want to be told the truth. Nevertheless patients, carers and HPs all stated that it is important not to be too blunt or give a lot of detailed information that the patient does not want to hear.

Roles of health professionals

The allied HPs stated that giving prognostic information is not part of their perceived role. If the patient asked them about prognosis they may explore the patient's concerns about the future but then suggest they discuss it with their doctor. One nurse said that it was not her area of expertise but that she was comfortable to discuss it with the family if the patient was obviously dying imminently. The other nurses and all of the doctors said they were frequently asked to provide predictions of life expectancy and felt it was their role to discuss this with patients, whether or not they would actually provide a time frame. Patients and carers reported having discussions about prognosis with their physician(s) (e.g. PC physician and/or oncologist) and their PC nurse.

Table 2 Participants views on the optimal process of prognostic discussions

Feature recommended	Raised by whom		
	HPs	Patients	Carers
Conversation rather than question/answer	Yes	Yes	Yes
Allow adequate time	Yes	No	Yes
Describe in every-day terms	Yes	Yes	Yes
Honesty	Yes	Yes	Yes
Not too much information at once	Yes	No	Yes
Exploring the patient's or carer's emotional reaction to the information and responding to this	Yes	Yes	Yes
Opportunity to ask questions and revisit the topic	Yes	Yes	Yes
Check understanding and that the patient or carer has received the information that they want	Yes	No	No

Content

A range of themes were raised regarding the content of discussions. Summaries of these themes are presented below; participants' quotes are shown in Figs. 1 and 2.

Whether to provide a time frame

There was a wide variation regarding how to phrase life expectancy, ranging from not giving a time frame at all to provision of specific probabilistic information. Regardless, most HPs, patients and carers stated that it was important that patients be informed that their lifespan was limited by their disease so they could make plans for the future.

General indication, not a time frame

A few doctors said they rarely give patients or carers predictions of life expectancy, even if this is requested. They would tell patients that their lifespan is limited by their illness, but that it is impossible to predict how long an individual will live. Many patients and carers said they did not want to be given a time frame, but wanted a general indication of what to expect in the future.

A time frame if requested

Most doctors and some nurses stated that after explaining the limitations they would give a time frame if requested. Some patients and carers said that it was important to them to be given a survival time frame. A few patients and carers expressed frustration that they had not been given this information. Some carers said their reasons for needing a time frame were different to those of the patient; for example, knowing how much time to take off work and whether to call other family members to share the care-giving burden.

Explain uncertainty and limitations involved

All HPs said it was important to explain the uncertainty and limitations involved with predictions of life expectancy. Some doctors explicitly acknowledged that doctors are not good at predicting life expectancy, but worried this would be interpreted as an unwillingness to disclose. They therefore unambiguously told patients they were willing to talk about prognosis if the patient wished. Other HPs felt it was important to acknowledge how frustrating and difficult prognostic uncertainty is. Most patients and carers were aware of the uncertainty involved in predicting a person's life expectancy. A few patients even said that it was unfair to ask doctors how long they might live because the doctor cannot possibly know the answer.

Fig. 1 Participants' quotes regarding the content of prognostic discussions

Whether to provide a time frame

General indication, not a time frame

"I wouldn't want a time put on it, I just like to know which hill and valley are we going, downhill and up… is the way I'd describe it. So that you know exactly, well you can't know exactly but you know what road you're travelling down and whether it's going to be a long rocky road" (carer from focus group 4)

"I wonder whether any kind of time frame would be useful…from very short to a bit longer. If you go beyond that longer, after that it is just waiting for it to happen, that is what I find …But if there is anything that the person still wants to do in their life, if they have unfinished business, they should start thinking about it, but not a time frame"(carer from focus group 6)

A time frame if requested

"As I said no-one's god and no-one can say your time's going to be up in 6 months, but I think if you've got some idea…you can put your life in order and get your family and that prepared a bit. I think that's good." (patient individual interview 1)

"Initially they (carers) would like to know what the periods involved are, and I'm talking about people who may be working, who really haven't got unlimited time and it may help them make a decision about how to care for the person, whether to care at home or whether to have it done at the hospital. Because if you've got other things, and everybody does have other things, you can't put your life on hold for an unlimited period. So I would think they'd need to have some idea of time frames, a rough time frame anyway." (carer individual interview 1)

Explain uncertainty and limitations involved

"I would start off by … stating the uncertainty of any prognostication and saying that anyone who tells them with any measure of certainty, invariably gets it wrong .. Acknowledge how very difficult the uncertainty (is)." (doctor 8)

"I think it is an embarrassment for the patient to ask the professional how long have I got. I mean they have got no way of divining, you know the future. And I have never asked." (patient from focus group 1)

Explaining the process involved with making survival predictions

"If they want to talk about their life expectancy … I'll give them two choices, one is the short answer and one is the long answer, and I tend very firmly to offer them the long answer so that they know what I'm thinking and the sort of changes they can see in their own life, in their own level of function which will help them to determine how things are going. So that's the next area on which I would place some emphasis… I go through 5 things with them, the disease itself, is it small cell lung cancer, is it Ca pancreas, whatever. Secondly how their body is coping with the disease, has it been creeping up on them, has it been changing rapidly. Their comorbidities, you know is their heart disease actually going to take them off the face of this planet, long before their cancer ever does. How their level of function, weight, systemic things have changed, and over what time period…and fifthly I ask them how they think things are, and I preface that by saying I think this has a lot of importance that we can't necessarily measure at the moment and I will give you my honest answer without modifying it to what you say, but what are your thoughts." (doctor 10)

"Sometimes I'll also use the information that the patient sometimes has more control over how long they've got depending on their will to fight and what their personality's been like." (doctor 4)

Avoid being too exact with time frames unless time is obviously short i.e. days

"The danger is that if you put a time on it, that person will believe you…the closer it gets the more freaked out they get. That happened to my wife, that is the median, she believed it and was almost counting the weeks away."(carer from focus group 6)

Explaining the process involved with making survival predictions

Some doctors and one nurse said they explained to patients and/or carers how predictions of life expectancy are determined prior to providing them with a time frame. These HPs asked how things have been going over certain periods of time, what changes they have noticed (for example, in their appetite, energy levels and level of function) and then used this information to explain how things may go in the future. One doctor said that he asked patients their own estimation of their life expectancy, as this influenced his prediction. Other HPs mentioned that they explained to patients and their families how various factors not related to the person's disease

Fig. 2 Participants' quotes regarding the content of prognostic discussions

Various ways to phrase time frames

"I think an average would probably be the best, rather than the how long and how short. I think on average how long people live with the illness, because there will always be people out of the average won't there."(patient individual interview 5)

"I expect the time frames should be expressed in months, generally speaking I guess we're talking months or… if someone is going to live for some months, you can indicate that it won't be a year, and then they know that it's within that guide line … so … a parameter which they can think about." (carer individual interview 2)

Days versus weeks versus months

"I'll give them a time, but I never put numbers, I'll always say I believe your life is probably measured in … days to weeks, or weeks to months or months to year, but I'll go back and say I can't say how many days.." (doctor 5)

Likelihood of making it to Christmas or other events

"I … talk about things in the future which they may or may not … achieve … I'll use the analogies of Christmas or birthdays or anniversaries so that's … will they live to Christmas, will they live till Easter, will they live to their anniversary … the odds are that you will make your birthday, but I can't promise … so I often approach it that way and then have a general chat about things in between" (doctor 7)

Rough quantitative range

"The best thing that I can tell you is that your time is limited, you haven't got 5 years, you haven't got 12 months. It's somewhere less than 6 months and over the next few weeks or the next couple of months we will have an idea of how quickly things are accelerating to get a closer picture of the answer." (doctor 8)

Probabilistic (eg 10% survival and 50% survival)

"I think a lot of us have been taught to focus it in terms of a time frame that might be useful to a patient like in terms of whether it's hours, days, weeks, months, years … but I think that information's a bit meaningless … What I try to do now is talk in terms of more straight probabilities … I would try to give what I think is the median survival and the probably 10% survival, don't talk so much about the 90% survival … What I'd say to a patient would be that it's not possible to be certain in an individual case but based on other people I've seen in your situation, if you took a large group of them I'd say that half of them would still be alive let's say for the sake of argument in 6 weeks time and that maybe 10% of them would still be alive in say 9 months time. So that's how I say it to people I basically try and tell them what I think their median survival is and what their …90% chance of being dead is… So I try to be as specific as possible. Scientifically accurate, … and I give it in terms of probability"(doctor 11)

"I think it's important to highlight … everyone is an individual, that everyone's experience is different, everyone's illness is different, and everyone's prognosis is different."(patient individual interview 5)

Use of graphs or other aids

"I think in the palliative setting you've got someone whose disease is now manifesting itself. Either it's incredibly stable … or it is progressing. And if their ECOG or Karnofsky is changing at a rate that you and the patient can determine then unless there's something you can do to influence that rate, you're getting a pretty clear graph, and I so I suppose I draw a graph in the air occasionally and say this is the change that you've seen and this is continuing, so that's all I would do." (doctor 10)

can influence their lifespan. The HPs said that this practice, of explaining the process involved with making predictions, helps to demystify the time frame and to assist patients in understanding its limitations. In addition, the HPs felt that it gives power to patients to make their own prediction and helps them to feel involved. Other doctors and nurses said they explained that with observation over time, it is easier to predict how long the patient will live. Patients and carers did not express a preference about whether or not it would be helpful to be informed how HPs predict patients' life expectancy.

Avoid being too exact with time frames unless time is obviously short, i.e. days

Most doctors and nurses, several carers and some patients stressed that it is important not to be too restrictive or definite with time frames, because patients may fixate on this. There were several reports of patients marking a particular date on the calendar, believing literally that they had a particular amount of time to live. The exception is when the time frame is likely to be very short, for example hours to days. Then HPs felt that it was important for at least the family to be informed about this and possibly the patient if they were mentally clear enough and wanted this information.

Various ways to phrase time frames

Those patients and carers who wanted to be given a time frame mostly said they would like to know how long the average person with their condition would live and/or be given a rough range. A few said they would like to know the longest possible time that they might live. The doctor and nurse participants, on the other hand, had various views regarding how to phrase time frames (see below). Some used more than one way of explaining it with the same patient.

Days versus weeks versus months

The most common way that doctors and nurses said they expressed life expectancy to patients was in broad time frames such as days versus weeks versus months. Most said that they would not give a specific number of months but would tell patients that they are likely to live for several months but not years, or they are likely to live for several weeks rather than months etc. A few doctors said they had tried giving patients more precise time frames but had been proven wrong, which had then made them cautious about giving a more specific range than in the order of weeks or months.

Likelihood of making it to Christmas or other events

Several doctors and one nurse said they discussed life expectancy in terms of whether the patient is likely to be alive for certain dates that are important for the particular patient. For example dates such as Christmas, birthdays, anniversaries or the birth of a child in the family.

Rough quantitative range

Some doctors said they gave a more specific time frame than months versus weeks or days. For example, they would say it is likely to be less than 12 months and more than 3 months. One doctor said if there were survival data available regarding the patient's particular situation (e.g. new diagnosis of cerebral metastases) then they may give this information to the patient.

Probabilistic (e.g. 10% and 50% survival)

Most doctors said that they would rarely if ever give statistical information to patients. Many doctors admitted that they did not remember these statistics and did not trust their accuracy for PC patients. One doctor said patients in palliative care have already failed the statistics regarding survival and the likelihood of response to treatment. Only one doctor said that he would regularly discuss life expectancy with patients and their families in terms of the specific probability that they will be alive for certain time periods. This doctor told patients their median and 10% survival based on palliative prognostic tools, such as the palliative prognostic score [19] because he believed this information is more accurate, scientific and meaningful for patients than using words such as months or weeks or saying whether they are likely to be alive for a particular date. Doctors, nurses and allied HPs all said that it is important to explain the limitations of statistics if this information is given to patients. Patients and carers also said that it is important to explain that statistics apply to a group so they can only be used as a guide. Patients and carers wanted their HPs to highlight that every person is an individual and that people's experiences are different even with the same disease. However, patients and carers did not clearly state a preference for either receiving statistics or not.

Use of graphs or other aids

Nearly all HPs said they would not usually use graphs or other aids to illustrate life expectancy. Some doctors remarked that this would be too clinical; others said that such aids are not available for PC patients. A few doctors said that they would occasionally describe or draw a bell shaped curve and use this to explain the limitations regarding predicting life expectancy. Patients and carers did not express a preference for this, although they were not specifically asked.

Discussion

This is the first study to explore in detail how patients, their caregivers and health care providers with extensive experience believe life expectancy should be discussed with terminally ill cancer patients. Another unique contribution of this study is that it allows comparison of patients', carers' and HPs' views regarding these matters.

While most patients and carers said it was very important to be informed that their illness would limit their lifespan, not all wanted to be told detailed information about their life expectancy. This finding is consistent with those of two previous patient surveys. Kaplowitz et al. [10] found that although 80% of heterogeneous cancer patients wanted a qualitative prognosis only half wanted a quantitative one. Kutner et al. [11] found that 59% of 56 terminally ill patients surveyed wanted to be told how long they were expected to live.

One of the few studies [14] examining patients' preferences for phrasing life expectancy was conducted in the early stage breast cancer setting. In that study most patients wanted to be told the average survival but only half wanted to know the longest and fewer than half wanted to know the shortest time people in their situation had lived. The relevance of this finding for patients with advanced cancer is unknown. The potential average survival for patients with early cancer is years, while the average survival of patients referred to PC is weeks to months. No studies to our knowledge have examined how terminally ill patients would like prognostic information to be phrased, for example numbers versus words, and preferred phrases. We asked patients generally how they thought prognosis should be discussed, but did not ask patients to rate the different ways for describing time frames reported by HPs. Therefore it is difficult to reach a firm conclusion.

We found no other studies examining the different words HPs actually use to describe life expectancy with terminally ill cancer patients. However, there are a variety of recommendations in the literature regarding words to use. Christakis [2] stated the opinion that the use of phrases such as ‘days to weeks’ or ‘weeks to months’ is the most common way doctors describe likely survival to patients with a limited life expectancy. It is also the method recommended by Quill [22].

More recently Lamont and Christakis [13] have recommended phrasing life expectancy to patients with incurable cancer in terms of probabilities. For example, they suggest saying to a patient with advanced gastric cancer that “on average patients with stage IV gastric cancer live 4 months. One-quarter of patients will live 1.5 months or less and one-quarter will live 8 months or more. While I do not know for sure where you are in this group, the fact that you are feeling so poorly right now and in bed most of the time makes me concerned that you may not live longer than the average 4 months”. This approach is similar, although not exactly the same as the way one physician in our qualitative study discussed life expectancy. Most medical participants were reluctant to use statistics to determine or communicate patients’ life expectancy. This is consistent with the empirical literature [8]. Finally, Loprinzi et al. [15] report telling patients the likelihood of being alive for certain events as one of the methods of discussing life expectancy although the overall recommendation in their paper is to foretell a ‘general, realistic time frame’.

A small number of HP participants in the current study said they would not normally give patients a numerical survival estimate, even if the patient requested this information. This practice has been recommended by some authors previously [4, 17, 26]. Physicians’ concerns about giving patients time frames when they specifically request this information appear to be decreasing in the recent literature. Many of our patients really want this information and/or say that they need it in order to make an informed choice about treatment options and make decisions for their remaining life and death.

Explaining the uncertainty and limitations in survival predictions and trying not to be too exact with time frames has also been suggested previously [2, 8, 9]. On the other hand, we could find no previous recommendations for HPs to explain the process involved with making survival predictions.

Limitations and applicability of findings

The aim of qualitative techniques such as those used in the current study is to describe the breadth and depth of responses. To allow more detailed data collection, the sample size is usually small and therefore not representative of the total population. The use of qualitative methods is common in exploratory studies and can generate hypotheses and provide rich descriptive information about a phenomenon. However, it is difficult to make assumptions about the generalizability of data obtained using such methodology.

The sample in this study was limited to English speaking patients and carers (some of the carers were caring for patients from non-English speaking backgrounds) from three different PC services in an urban setting in Sydney with an underlying illness of advanced cancer. The patient and carer participants may therefore not have been representative of Australia’s culturally diverse population. The educational background of the carer group was higher than the general population. All patients and carers 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 12–14 weeks, range 2 weeks to 2.5 years). Thus participants may have been more accepting of a palliative approach to their illness and therefore have different views on discussing life expectancy than those patients with incurable cancer outside a PC setting.

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

Implications and future research

There was no consensus amongst participants in the current study to enable the recommendation of a particular way of phrasing life expectancy with terminally ill cancer patients. However, a variety of ways were proposed by HPs. There may not be one right or wrong way of expressing time frames to terminally ill cancer patients. Rather it may be appropriate to use different ways at different times depending on the situation or to start generally and then check with the patient whether they want more details. Further research is needed to more explicitly elicit terminally ill cancer patients’ and their carers’ preferences for the different approaches proposed by HPs.

The results of this study will be useful for informing clinicians and further research regarding communication about prognosis with terminally ill cancer patients and in turn the development of communication training interventions for HPs in discussing this difficult topic.

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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 carers of palliative care patients?

How do you think information about the future should be portrayed during a palliative care consultation?

Do you ever initiate discussion about the future during a palliative care consultation? In what circumstances do you think this is appropriate?

When discussing the future with a palliative care patient or with his or her carer, is there any way of communicating hope?

If a palliative care patient (or his or her carer) 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 carers

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 consultation) What information do you think is important for a palliative care doctor to tell carers about the prognosis of the person they care for?

How do you think information about prognosis should be portrayed during a palliative care consultation?

Who should initiate discussion about prognosis during a palliative care consultation?

Should palliative care doctors offer to discuss prognosis with you (for carers: or the person you care for or with you the carer) at certain times?

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