Living with advanced cancer and an uncertain disease trajectory: An emerging population in palliative care?

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ABSTRACT

Objective This study explored how patients diagnosed with advanced cancer cope with an uncertain disease trajectory.

Subjects 27 patients with advanced cancer and with a prognosis of 12 months or more were recruited from the medical/radiation oncology and palliative care service at three metropolitan hospitals.

Methods A semistructured face-to-face interview was conducted. Interviews were audio-taped and transcribed verbatim. Data analysis was based on Grounded Theory using the constant comparison method.

Results Results indicate that patients cope by avoidance, remaining positive, maintaining as normal a life as possible, minimising the impact of the disease on their daily lives, comparing themselves favourably with others in a similar situation and focusing on the outcome of treatment to control disease progression. Most did not wish to discuss prognosis or have detailed information on disease progression.

Conclusions Participants in this study represent an emerging cancer patient population who are receiving palliative therapies. While they have incurable cancer, they self-report as clinically well, they describe a good quality of life and the trajectory of their disease, while unpredictable, may extend over many months to years. Our study suggests that a flexible model of care is needed to support the needs of people who may still be receiving some form of chemotherapy and/or radiotherapy, and remain well. This model may need to take more of an intermittent approach, that is, as required for specific symptom management, rather than patients being linked continuously to a palliative care service for long periods of time.
**METHODS**

Patients diagnosed with incurable cancer and with a prognosis of at least 12 months were recruited by referral from medical/radiation oncologists and palliative care specialists. All of those interviewed had recently been diagnosed with advanced cancer and told that the focus of any subsequent treatment was not with the intent of cure. Some had been diagnosed with cancer previously and this represented a recurrence; others had advanced cancer at diagnosis. Eligibility criteria: (a) at least 18 years of age; (b) have a diagnosis of incurable cancer; (c) have been informed by their clinician that their cancer was not curable; (d) be able to read and speak English; and (e) be able to provide valid, informed consent.

The study employed an emergent qualitative design, using theoretical and procedural direction from Grounded Theory research. Grounded Theory uses theoretical sampling to demonstrate the representativeness and variations of concepts inductively derived as interviews are undertaken, leading to the construction of a theoretical explanation for these similar or varying concepts. Semistructured face-to-face interviews were used to elicit information about patients’ coping strategies (see box 1). Interviews were tape-recorded and transcribed verbatim. The transcripts were uploaded to the software program QSR NVivo, V8 (2007).

**Data analysis**

Data analysis was conducted using the constant comparative method. It was iterative, commenced after the first interview and was ongoing throughout the study until saturation was reached; saturation was deemed to have occurred when the themes recurred and no new information emerged from subsequent interviews. In Grounded Theory, confidence in the theoretical scheme is high when saturation is achieved, ideas are well developed, and there is both repetition and variation in the data patterns. A sample of transcripts were read and coded independently by three members of the multidisciplinary team where disagreements around themes were discussed and resolved.

**Recruitment**

A sample size of 40 was considered sufficient to achieve informational redundancy. In all, 38 patients were invited to participate in the interview; of these, two declined; two were unwell; two were considered cognitively impaired; and five originally agreed to the interview but subsequently changed their minds. Participants who declined variably reported they were ‘too busy’, ‘were getting on with their lives’ or were feeling well and ‘did not want to focus on the negatives’. In all, 27 interviews were conducted (see Table 1) and data saturation was achieved.

Potential patients meeting eligibility criteria were identified by medical/radiation oncologists and palliative care specialists and given a letter of invitation and an information sheet. After the clinician obtained permission from the patient, his or her name and contact information was released to the research nurse. Those expressing an interest in the study were contacted by the research nurse who discussed the purpose of the study and obtained verbal and written consent. Patients needed to have sufficient physical and mental capacity to be able to relate their personal experience of illness and sufficient resources to participate in an interview of approximately 60 min. Ethics approval was obtained from the Human Ethics Committee of

<table>
<thead>
<tr>
<th>Box 1 Interview schedule</th>
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<tbody>
<tr>
<td><strong>Introduction:</strong> We are interested in understanding how you are managing with the experience of being diagnosed and living with advanced cancer. Would you like to tell me about some of your experiences?</td>
</tr>
<tr>
<td>▶ What information have you been given about your cancer?</td>
</tr>
<tr>
<td>▶ Do you have any thoughts about why this has happened to you?</td>
</tr>
<tr>
<td>▶ How did you feel when you were told you had advanced cancer?</td>
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<tr>
<td>▶ How do you see yourself and your life since your diagnosis?</td>
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<tr>
<td>▶ How prepared do you feel for what is likely to happen in the future?</td>
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<tr>
<td>▶ What do you think is going to happen in the future?</td>
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<td>▶ What helps you cope with your cancer PROMPT your spiritual beliefs, your friends and your family?</td>
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<tr>
<td>▶ How do you cope with uncertainty?</td>
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<td>▶ How have you been able to make sense of what has happened to you?</td>
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<td>▶ How has your diagnosis of advanced cancer affected you physically or emotionally?</td>
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<td>▶ How would you describe your quality of life?</td>
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<tr>
<td>▶ Are you concerned about anything? If so what is/are your major concerns?</td>
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<tr>
<td>▶ Have any good things come from your diagnosis?</td>
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<td>▶ How can health professionals best support you at this time?</td>
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**Table 1** Demographics of the sample (n=27)

<table>
<thead>
<tr>
<th>Gender</th>
<th>n=11</th>
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<tbody>
<tr>
<td>Male</td>
<td>11</td>
</tr>
<tr>
<td>Female</td>
<td>16</td>
</tr>
<tr>
<td>Age</td>
<td>Median 63 (range age 21–88)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married or partnered 65%</td>
</tr>
<tr>
<td>Employment</td>
<td>Retired or unable to work 73%</td>
</tr>
<tr>
<td>Occupation</td>
<td>Business owners, trades, emergency services, secretarial and retail 27%</td>
</tr>
<tr>
<td>Education</td>
<td>Year 10 42%</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Technical and further education 50%</td>
</tr>
<tr>
<td>University</td>
<td>8%</td>
</tr>
</tbody>
</table>

Breast 23% 
Lung 19% 
Prostate 8% 
Other 12%
South East Sydney Illawarra Area Health Service and Calvary Health Care Sydney.

RESULTS

Avoidance (n=21)
The majority of participants interviewed reported that after the initial shock of the diagnosis they avoided thinking about what the future may hold by keeping busy or distracting themselves from their thoughts:

I might just get in the car and go and do my shopping and it’s gone (thoughts) and I don’t—I just put it away and I don’t want to think about it anymore until something else comes up ...I seem to be able to do that. P028

For some this distraction worked for them during the day, but in the silence of the night worrying thoughts would enter their minds and they would then distract themselves by turning on the radio or the television. They avoided talking about their illness with friends and when asked about their health gave minimal information. They proposed that the constant reference to their illness acted as a reminder of their cancer diagnosis, a reminder which many wanted to avoid as they did not want it to pervade all aspects of their lives:

I try to avoid talking about it as much as possible because you’ve got to focus on other things. And as much as friends and people say ‘How are you?’ (I say) ‘I’m all right’.... you’re going, no, I don’t want to talk about this again. P008

Maintain normality (n=21)
Participants described how they actively sought to maintain a sense of normality and independence in their lives by ‘taking it from day to day or week to week’, not dwelling on their cancer and by trying to create ‘just a normal balance’ claiming ‘I’ll cope with it as long as there’s normality’. Remaining in the workforce gave many a sense of purpose, structure and routine. Some chose not to tell many people as ‘I thought I’d be treated differently’ and they wanted ‘to be treated the same as before at work’.

After the radiotherapy when the pain started to ease, I found I could pick up my grandchildren, it was such a special feeling – so it’s all about that, about getting back to my normal life and to do the things that are important to me in life. P011

I’ll just keep going and don’t sit around and feel sorry for myself. I don’t want to think like a sick person. P003

And just a normal balance in my life, I’ll cope with it that way as long as there’s normality. I’ll just cope with it that way and just hit it on the head when it comes. P014

The prospect of a shortened lifespan did not deter patients from achieving goals, even if these goals required modification. For some life took on a slower pace, others described a ‘sense of urgency’ to ‘live each day as fully as possible’ with a narrower focus of spending time with friends and family:

There’s really not many things, like I don’t want to climb Everest or you know—I just want to be with my family or just experiencing the life I have, the normal things that happen...so rather than rushing around—like a bucket list I suppose...yeah, it’s just nice to be around family and friends and enjoy life. P028

I have goals for my life and so, and I had short term goals and long term goals, and I don’t know now if I’ll ever be able to make those long term goals but I don’t want to give up on them either because then I think I’m just giving up on life, so I don’t want to lose sight of those goals. P011

Many of those interviewed adopted an attitude of inevitability at ‘not being able to change anything’ and often expressed more concern for how other family members would cope without them rather than concern for what might happen to them:

I don’t have as much fear as I probably have before, but what can you do if someone tells you you’re going to die? You can’t do much about it you can only just keep going on and I’d probably feel more concerned about probably not so much myself but probably preparing the kids and preparing my husband, and you know and I think that will be my biggest job that would be—the worst thing for me. P014

Minimising impact of disease (n=20)
Patients did not engage in self-pity or rumination, but rather attempted to minimise the impact of their disease by comparing themselves favourably with others, cultivating a desire to help others and attempting to make a meaningful contribution to their family and the community.

I was listening and I thought well I’m not as bad as that person, they’ve got a tougher deal than I’ve got you know. So you start off dealing with it differently and you start to think, well I could be worse, you know. I could be that woman, I could be that man there. P008

You know like, whatever else happens to me, you know like I’ve been lucky in that respect you know. There’s always someone worst off than yourself. P014

Focus on positive aspects (n=19)
While patients who were interviewed were aware that their cancer was incurable, they made an active choice to maintain a ‘positive attitude’ in their lives by focusing on the ‘smaller and achievable’ aspects of their lives.

Like even small things, you go for a walk or go in the yard or do something other than...you know think, oh life’s not that bad really ...could be a lot worse, particularly when you come in [to the clinic] and see the other people. P031
The power of the mind, you know. And they tell you you’ve got to be really positive so I forget about everything until that Tuesday when I drive in there and then...here we go. P008

An aspect of remaining positive was the reluctance for patients to have information about their prognosis and, in particular, information about disease progression:

I don’t know the prognosis and I don’t think I want to know. I can remember saying to the doctor don’t tell me anything bad. P015

I just want to know what I need to know, because I think for me too much information is not going to help me it’s just going to make me more stressed. P028

Because I haven’t felt any symptoms from the disease and illness itself I don’t know what it will be like and I don’t really want to know. P008

Oh, no, no, no, look, I don’t want to know the truth, how long I’ve got, how long I don’t—that would kill me because really we don’t know. P010

They wanted their doctor to be confident and to emphasise the positive aspects of their illness.

You know I just have to be confident and you know that’s what I said to the doctor, I need to hear something that’s a bit confident, you know that gives me confidence, you know to keep going. P014

**Focus on outcome of current treatment (n=19)**

Many of those interviewed placed importance on the outcome of scans and tests which they hoped would indicate that their disease process was stabilised. They saw the role of their clinician as ‘keeping an eye on it’. Although the focus for such treatment was not with the intent of cure, patients felt a greater sense of control and hope if their cancer and their symptoms were being controlled:

Even if it just keeps it under control, that’s—I don’t expect miracles you know because my age. P030

I haven’t got any concerns because I’m only going along with whatever the doctors tell me to do. My only concern is that they keep track of it, that they keep an eye on it. P014

Patients reported that clinic appointments and treatments became part of the ‘normal routine’ in their lives and while these follow-up visits were stressful, they offered reassurance and comfort through regular contact with their doctor. This, in turn, increased their sense of security and continuity:

That’s one thing I hate, is when I have to go for a test and then I have to go and hear the report. That can be very, very, very daunting, believe me. If he tells me these pains are normal... well at least I’m reassured—I mean he’s an oncologist, he should know surely. P010

However, there were patients who wanted to be given information illustrating the importance of acknowledging differing patient preferences for information and decision-making:

He rang and said everything’s fine but like I say if there was something there I’d rather them tell me than not. You’ve got to prepare your mind for these things. P003

Many of those who participated in the interview did not wish to be referred to a psychologist to receive formal support. They expressed surprise at how helpful the interview was as it enabled them to voice their concerns, identify the positives in their experience and highlight how well they perceived they had coped with the process.

They asked us if we wanted counselling and, no we’re right. We’re the sort of people that always get on with our lives. P003

I know that’s not the reason for this [interview] but I just think it’s probably been quite good and cathartic for me to talk about this. P011

**DISCUSSION**

This study sought the views of people with incurable cancer on how they coped with an uncertain disease trajectory. The themes that emerged from our interviews were that patients avoided thinking about their situation; they preferred to remain positive and to keep their lives as normal as possible. They minimised the impact of the disease on their lives by comparing themselves with others who they perceived to be in a worse situation and focused on the outcome of treatment to control disease progression. Most did not want to know their prognosis or information on disease progression.

Similar to a study of palliative care patients with a prognosis of 6 months or less, participants in our study engaged in a range of both active and passive coping strategies. Avoidance strategies involved minimising the reality of incurable disease, hoping for disease progression to be stabilised and trying not to think about their illness. Several of those interviewed reported coming to acceptance by resigning themselves to the fact that they had no control over the outcome of the illness. None of those interviewed in our study discussed their impending death perhaps because the majority reported that they had a good quality of life; they were receiving palliative chemotherapy or radiation therapy; had good symptom control; and had a prognosis of 12 months or more.

Valuing life in the present was a goal articulated in previous interviews conducted with patients with advanced cancer conducted over a 2-year period. They also endorsed the strategy of making positive comparisons with those who they perceived had greater suffering than their own. The finding that participants compared themselves with others in a
similar situation can be explained by Social Comparison Theory. Many studies have shown that individuals confronted with health problems tend to compare their situation with that of others and that such comparisons may play a role in the coping process. In particular, because social comparisons occur when a person is under threat, cancer patients often use social comparison information to feel better about their situation. If palliative care may also provide a reference point for defining the change the outcome. The participants in our study chose downward comparisons, that is, evaluation against less fortunate others. It has been reported that this can lead to self-enhancement or a more positive view of oneself, one’s situation and one’s mood.

The finding that individuals wished to maintain normality may reflect a desire to feel healthy and also to be perceived as having a role in life other than the ‘sickness role.’ Maintaining perceptions of normality may also provide a reference point for defining the current state of living with dying. If palliative care patients cannot control the course of their disease, being in control of some of their mundane, normal, day-to-day problems may protect them from being overwhelmed by negative emotions.

Many of the patients on this study were receiving treatment with or without palliative care multidisciplinary support services. Cancer treatments often are associated with a significant treatment-related burden in the form of time and resource commitments but also frequent physical reminders of the disease. Those participants still receiving disease-modifying treatments described fitting these treatments around other aspects of their lives. However, while they could go about their lives and not think of their future, they reported they became anxious when they came into the clinic for treatment. In other studies, patients spoke about their lives revolving around treatment plans and waiting for test results, while treatment effectiveness, whether positive or negative, influenced their uncertainty and ability to control their lives.

Similar to the patient priorities in living with a terminal illness our participants acknowledged that restrictions on some activities meant goals needed to be modified and they acknowledged the importance of relationships with friends and family. Many of those interviewed spoke of how the interview, of itself, was helpful. This is reflected in studies in advanced breast cancer where simply talking about their uncertainty with another person contributed to women feeling better supported, even if this did not change the outcome.

There was no evidence from the interviews that participants were in denial of the seriousness of their illness; however, fewer wanted information about their prognosis or to know about disease progression. The concerns raised about discussing prognosis and disease progression suggest some potential strategies around language use with patients receiving treatment in this situation. Clinical practice guidelines recommend an open disclosure policy when discussing prognosis; however, our study highlights the importance of checking with the patient what type of information he/she wishes to know and at what level of detail, so that prognostic information can be tailored to the individual.

While the participants in our study expressed the need for their doctor to remain confident and positive, this relationship could also be perceived as threatening as highlighted by the rise in anxiety reported around the time of follow-up clinic appointments. As the doctor holds the knowledge of when disease status begins to change and further treatment may no longer be an option, this in turn may threaten their contract with the doctor whose role was seen to ‘keep an eye on their disease’ and ‘do their best to control it.’

Limitations of the study

The interview was conducted at one point in the disease trajectory and views of patients may have changed as they became more debilitated. We did not obtain data on when patients had been diagnosed with primary disease. Thus, some patients, for example, those with breast or prostate cancer, may have been living with metastatic disease for some time and may have developed adaptive coping strategies.

CONCLUSIONS

Contrary to our hypothesis, patients with advanced cancer do not report high levels of distress in coping with an uncertain disease trajectory. Such uncertainty actually gives them hope and acts as a buffer against the certainty of impending death. It has been noted that ‘there is a crucial difference between coping with a disseminated disease and focusing on living for as long as possible, and coping with one’s impending death in a situation when one realizes life will soon come to an end’ (p14). As long as their disease progression was being managed and they had confidence in their doctor, participants could cope with a potentially shortened lifespan. This theory was supported by one patient interviewed who exhibited high levels of existential distress having been told the day before our interview that his treatment was being stopped due to the progression of his disease.

Our study suggests that a flexible model of care is needed in future practice. This model may take a more intermittent approach. That is, as required for specific symptom management, rather than patients being linked continuously to a palliative care service for long periods of time. Alternatively, there may need to be a better integration of palliative care interventions within oncology services, as referral to a palliative care service is often distressing for patients and families, or may be refused if they do not perceive themselves as ‘dying’. Further research is needed to assess this model and to quantify the quality of life and psychological status of this emerging palliative care population.
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Collaborator Dr David Thomas.

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