

MAKING SENSE OF A DIAGNOSIS OF INCURABLE CANCER: THE IMPORTANCE OF COMMUNICATION

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ABSTRACT

Purpose: *Patients diagnosed with incurable cancer may experience existential distress and difficulty in re-appraising their lives because of uncertainty about the future.*

Objectives: *This study sought to understand how patients living with incurable cancer made sense of their diagnosis, how they prepared for the future and what support they wanted from their health professionals.*

Subjects: *Twenty-seven patients were recruited from the oncology and palliative care service at three metropolitan hospitals in Sydney, Australia.*

Methods: *A qualitative research approach was used. Semi-structured face-to-face interviews were conducted. Interviews were audio-taped and transcribed verbatim. Data were analyzed using the constant-comparative method.*

Results: *Participants did not express a need to make sense of their diagnosis nor always ascribe to a particular religious belief; rather, many relied on a personal spirituality or philosophy to bring meaning to their experience. Importance was placed on their doctor keeping up with technology, being honest, being confident and positive.*

Conclusion: *Participants in this study had incurable cancer but making sense of their current situation was not a conscious priority. For these patients, uncertainty was a positive, as certainty for them indicates death is approaching. What these interviews suggest, from the patient's perspective, is that there is an implied contract between doctor and patient during this period which involves the doctor managing the flow of difficult information so that the patient can maintain normality for as long as possible. Understanding this helps to explain the difficulty of having advance care planning conversations within this setting, despite the many opportunities that a longer disease trajectory would seem to offer.*

BACKGROUND

Following the diagnosis of incurable cancer, patients often can experience a number of physical and psychological stressors, including challenges to spiritual beliefs, denial, grief over multiple losses, and difficulty planning life in the context of uncertainty about the future.¹ From studies it has been found that many people diagnosed with incurable cancer will often engage in a number of activities in an attempt to make sense of what has happened to them². Meaning making, the restoration of meaning in the context of highly stressful situations,³ is seen as being crucial to the task of 'making the most' of the circumstances of living with a life-limiting illness.⁴ Failure to bring meaning to the interpretation of a life-limiting prognosis is reported to be highly associated with feeling hopeless, a sense of suffering, depression, anxiety and desire for hastened death.⁴⁻¹¹ For some cultural groups, engaging in religious rituals and activities and/or a personal spirituality have frequently been reported as playing a fundamental role in maintaining well-being in the face of an uncertain future;^{12,13} however, the manner and extent to which this occurs for individuals may vary markedly.^{8(pp14-16)} Spiritual beliefs and a clear sense of meaning have often been identified as significant issues influencing acceptance, with patients describing the role of faith, prayer, and belief in an after-life as helping them to accept their situation.^{7(pp.57-60)} Feelings of inner peace have also been attributed to acceptance; those patients identified as having peaceful acceptance

demonstrate lower levels of psychological distress than those patients who were not peacefully aware.^{17,18}

With treatment advances, for many patients with incurable cancer the trajectory of their disease, while unpredictable, may extend over many months and often to years.¹⁹ Therefore the cancer journey is increasingly developing characteristics in common with a number of chronic, life-limiting non-malignant diseases. This study sought to understand how patients living with incurable cancer made sense of their diagnosis, how they prepared for the future and what support they wanted from their health professional. Few studies have reported on how patients with incurable cancer, who are not yet in the last months of life, make sense of a shortened lifespan and an uncertain disease trajectory.

METHODS

Participants

The sample comprised of patients with a diagnosis of incurable cancer with clinician-estimated prognosis of at least 12 months. They were recruited by referral from medical/radiation oncologists and palliative care specialists at three major metropolitan hospitals in New South Wales, Australia. Eligibility criteria were: (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.

Methods

A semi-structured interview guide was used during interviews with each participant (see Appendix A). The interviews were conducted by one of two skilled senior palliative care nurses who had over 25 years of experience in palliative care individually and who were trained in research interviewing techniques. Interviewer AM completed 7 interviews before moving to another research position, and interviewer LW completed the remaining 20 interviews. The average length of each interview was 45 minutes and all were held in the participants' homes. Interviews were tape recorded with verbal and written permission and transcribed verbatim by a professional transcribing company. A confidentiality contract was signed and transcripts were transcribed to remove all identifying name of individuals and places. Vocal inflections were included where noted, including pauses, expressions of distress and laughter. The semi-structured interview format gave a pre-existing structure to the thematic responses.

Recruitment

Thirty-six patients were invited to participate in the interview and twenty-seven interviews were conducted (Table 1) with data saturation achieved. Of the nine patients not interviewed four were male and five were female. Six were referred from radiation oncology; two from medical oncology and one from palliative care. Reasons for refusal included that they were too busy with medical appointments; going overseas; not interested and one was unwell.

Gender	
Male	n=11
Female	n=16
Age	Median 63 (range age 21-88)
Marital Status	
Married or partnered	65%
Employment	
Retired or unable to work	73%
Employed	27%
Occupation	Business owners, Trades, Emergency Services, Secretarial and Retail
Education	
Year 10	42%
Technical & Further Education	50%
University	8%
Diagnosis	
Bowel	38%
Breast	23%
Lung	19%
Prostate	8%
Other	12%

Table 1 Demographics of the sample (n=27)

The methodology has been described elsewhere.²⁰ Given the potential for the interviews to trigger distress participants were given the contact details of health professionals to obtain support (e.g. social workers, pastoral care workers, and a clinical psychologist). Ethics approval was obtained from the Human Ethics Committee of South East Sydney Local Health District and Calvary Health Care Sydney.

Data Analysis

This descriptive qualitative study employed a constant comparative technique which began with verbatim transcription, then reading and re-reading of transcripts. Analysis began as soon as possible after each interview to inform sampling of subsequent participants.²¹ The first author supervised the collection of data and led the data analysis. Co-authors LW and AH each participated in the analysis and interpretations of data, with preliminary analyses of transcripts circulated between and discussed among the research team until agreement was reached, thus contributing to the dependability of the findings.²¹ Data collection and analysis were conducted concurrently until saturation was reached; i.e., when the themes recurred and no new information emerged from subsequent interviews.²¹

RESULTS

Making sense of the diagnosis

When asked if they had been able to make sense of what had happened to them the majority of participants reflected that *“it can happen to anyone”* and there is *“nothing I can do about it.”*

“How have I been able to make sense of it? I haven’t. I’ve just accepted the fact that these things happen. I don’t know, it’s a random thing. (It) can happen to anyone.” P020

They reported that they did not spend time thinking about what may have caused their cancer:

“Not really no. I don’t dwell on it. I just think well I don’t know why it happened because I don’t – it must have been a chemical or something I’ve come in contact with. it doesn’t seem to be genetic or rife in my family. I don’t know. Might be a weak gene, I haven’t thought about it too much” P002

Others gave varied responses, including finding a cause or reason for their diagnosis in terms of genetics, stress, smoking, and as this respondent explained, to home renovations:

“Oh. I know why it’s happened so it’s no mystery. Oh well its exposure to asbestos that I experienced when I was doing some home building.” P026

Several participants reported that when they were first diagnosed with cancer that they initially asked *“Why me?”* but in time had accepted what had happened:

“Well I’ve come to learn that it’s....you know things like this are non-selective, it could happen to anyone, which it has. You know, but I haven’t gone back to why me sort of thing.” P009

Participants described a number of positive benefits which could be attributed to post-traumatic growth coming from the diagnosis including stronger family ties, a shift of focus, a renewed appreciation for life and a prioritization of what was important to them:

"I think I've quietened down a lot. I look at life differently I think now. Just, I think you start off trying to get a house and fend for your family and then it turns into a hierarchy of needs. It's like that. I'm not like that now I think it really doesn't matter. It doesn't matter, possessions, you don't take them with you." P003

Role of religion/spirituality in acceptance

When asked if religious or spiritual beliefs played a role in accepting a diagnosis of incurable cancer, over half of the participants interviewed (n=15) indicated that they did not ascribe to any strong religious beliefs, although some admitted:

"I would probably start praying when I knew my number was up." P014

*"No really no, I'm the world's worst for that. I just always believe we're here and now and when we die, we get buried and that's it. I'm terrible like that but that's just my belief."
P004*

Whilst not all professed to any particular religious beliefs, many of those interviewed did identify with having a belief system that had developed over a lifetime and upon which they drew to see them through difficult times:

"I'm not a religious person, but I do have my own spiritual beliefs, there's not one spiritual thought like Buddhism or anything like that, I don't follow anything like that, it's just my own spiritual beliefs that I guess I've developed with life experiences." P011

The language describing belief systems varied with some preferring to call it a personal philosophy:

"So I mean, you know we'll, we'll just keep on, you know, our kind of philosophy is a kind of Buddhist thing ... before enlightenment carry water and you know you've still got to do the same thing after enlightenment, you go to the well - carry water – so that's our philosophy around it." P007

Those who expressed a belief in God or a strong faith found "comfort" "strength" and "peace" in prayer, reading the Bible, attending church and in the church community:

"That really helped a lot like with my faith in God and stuff. I don't know I probably would have thought about it differently if I didn't have that faith like, so yeah just reading the

bible and being around all the people at the church and stuff it's really helped, I've kept a good attitude about it." P018

Many expressed gratitude for those who prayed for them and they prayed for those who took care of them, and some bargained:

"Oh well, I believe in God, I said if you can get me to my daughter's 16th birthday, I'll never ask you anything again. In fact I call God a she...and she has, and that's fine by me, and I won't ask for anything else." P005

Preparation for the future

The majority of those interviewed were either not concerned about the future, or chose not to think about it, with some expressing an acceptance for what may lie ahead:

"You know...you've got to die sometime, it's as good time as any but maybe, you know, I prefer not to, I'd like a few more years...so I just have to live as long as I'm allowed and make the best of it." P026

Thinking about the future was couched in terms of trying to remain living in the present and maintaining normality in their lives (n=21):

"The quest is to go on living rather than, you know, rather than to go on dying...that's been my intention, and that's what we've done, we've got on with things." P007

Establishing a time frame was elusive for most:

"I feel like I've been resigned to, to not being around for a long time, since it came back in my lungs, my impression was that I certainly wasn't going to live to a ripe old age but I didn't have a kind of time frame." P007

With uncertainty a key feature:

"At the moment it feels a bit, um, I'm unsure – I don't know about being prepared, I don't have a vision of how it finishes if you like....Intellectually I feel like I'm OK about not being here." P007

and establishing goals elusive:

"I've always been a person with a goal or a dream that I want to meet and I work hard to get it, so now, I don't know." P003

Whilst acknowledging that their quality of life was good at present, and indeed in some cases better than before their diagnosis, they did acknowledge that this may change in the future, especially if physical symptoms were to increase:

“My quality of life at present is good. But, as I say, because I haven’t felt anything... 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

Health professional support

Participants (n = 14) were clear that they wanted their doctor to be supportive, have “a good bedside manner”, “give them advice”, “guidance and honesty.” Keeping up with “the latest medications” and technology was a key element:

“By giving me right advice, guidance, and honesty. That’s very important. Bedside manner, that’s about it. I think that is it in a nutshell.” P004

The role of health professionals in generating hope which in turn facilitated coping was identified. For example, they expressed a wish for clinicians to control their cancer in the hope of new treatments being developed was also a common response:

“If they can keep it under control I’ve always got faith with all the studies that are going on around the world that new treatments are coming out, better treatments, eventual cure. All right it may be years down the track, fair enough, but as long as they can keep you going” P010

“How can they support me? Well support me hopefully by giving me the right chemo to kill off the cancer or keep it at bay, that’s about it. I mean, you can’t, what else can you do?” P032

Many of those interviewed wanted their doctor to remain positive (n=19) because “if they’re confident, they’re the ones that know what they’re doing – you know, then that gives me confidence.”

And they were clear that they only wanted to be given “good news” (n=13):

“Just whoever I went to see, whoever doctor, whatever it was, just for them to give me the most positive news that they could possibly give me and that was all I ask for and now I’m just going to fight and do the rest, and do whatever they tell me.” P014

Participants (n=16) did not ask questions or seek further information, particularly about disease progression:

"I didn't really ask a lot of questions. I didn't really want to know everything. I just want, you know to take medicine." P018

Empathy and compassion were important qualities from health professional communication, even if they were qualities that could not be articulated by the patient, but when "something" was missing from the consultation, this was noted, especially at time of disclosing bad news:

"I just thought at that stage [being given bad news] I should have got a little bit more you know, doctor-patient thing." P009

DISCUSSION

This study explored how patients with incurable cancer, who were not imminently dying, made sense of their diagnosis, and coped with their uncertain future. What is significant in our findings is that the majority of those patients interviewed (n=21) did not express significant distress, nor did they consider there was "sense" to be made of their diagnosis. The latter finding, found in 14 of 21 responses, may be in how the question in the interview was framed. We note that our interview asked participants if they had "made sense" of their diagnosis. This may have resulted in a cognitive response rather than an emotional response as illustrated by references to practical explanations such as "genetics", "family history", "smoking" or "asbestos." In view of the responses, the use of language such as "meaning making" may not have elicited further information as participants may have been reluctant to invite the interviewer in to a more private aspect of their reasoning such as this terminology suggests.

In this context, it is relevant to review the previously-reported components of meaning-making, as summarized by Park.³ These tenets include the following: "(a) people possess orienting systems (global meaning) that provide them with cognitive frameworks with which to interpret their experiences and with motivation; (b) when encountering situations that have the potential to challenge or stress their global meaning, individuals appraise the situations and assign meaning to them; (c) the extent to which that appraised meaning is discrepant with their global meaning determines the extent to which they experience distress; (d) the distress caused by discrepancy initiates a process of meaning-making; (e) through meaning-making efforts, individuals attempt to restore a sense of the world as meaningful and their own lives as worthwhile and (f) this process, when successful leads to better adjustment to the stressful event".^{3(p257)}

Our finding that few patients (n=3) reported existential distress suggests that either our patients did not embark on a search for meaning in their experience of advanced cancer or they used several other, more subtle processes, such as acceptance, reappraisal of their diagnosis, or a change in worldview in order to adjust to their new situation. Several of these processes may have been automatic, or even unconscious in nature. Our findings may also reflect some of the cultural differences between Australia and other

countries where these issues have previously been studied. Given that broader global goals are internal representations of desired processes, events or outcomes,²² our participants sought to maintain normality, to remain as well as they could, to go on living, to strengthen relationships with loved ones and friends, and to adjust their goals. If global meaning is constructed in early life^{22,23} then perhaps many of the “philosophies” attributed by our participants such as “*making the best of the situation*” and “*getting on with it*”, represent a resilient and culturally specific way in which Australians view life events, and are able to draw upon these attitudes in times of stress.

Meaning-making can also result in identifying goals that are not attainable, abandoning them, or substituting alternative goals. As one of our participants reported “*I look at life differently now. It doesn't matter, possessions, you don't take them with you.*” Of interest, it appears to us that many patients have reappraised the meaning of their life-limiting illness by transferring responsibility to their doctor to not only manage the physical aspects of their illness but to filter the information about their disease progression and convey it only as and when needed or requested. This apparent “gate-keeping” of information fulfils the role of rendering it less fearful and final. They perceive that their doctor's role is to manage the situation whilst having achieved some level of acceptance or of having come to terms with the incurability of their disease. They expect positivity from their doctor, to be informed of potential new treatments and to approach the next phase of their illness with a degree of certainty in terms of a treatment plan. Whilst the participants in our study did not use language around survivorship, rather their views support those of Sand et al. 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”.^{2(p14)}

However, the importance they place on their doctor filtering information on disease progression to some extent mirrors the concept of “fear of recurrence” which is reported in the cancer survivorship literature.²⁴ Our participants were aware that their disease has recurred/advanced, but rather than fear of recurrence itself, they feared that their doctor would tell them that they are no longer able to control that recurrence.

Bonnano et al. (2005) have argued that meaning-making efforts represent unproductive rumination, reflecting distress rather than adaptive processes.²⁵ Several researchers have argued that those who do not attempt to make meaning are as well off, if not better off, than those who do.^{25,26} The seeming lack of existential distress as reported during these interviews suggests some level of assimilation (perhaps at an unconscious level) has occurred in our participants with their “*quest to go on living*” rather than “*go on dying*”. Alternatively, some of our patients may not ever have embarked upon a search for meaning. These issues, and suggestions for more extensive research, are discussed fully by Park.³

Spiritual beliefs (where identified) were described mainly in secular terms as a personal philosophy rather than a religious belief. The reported lesser role of spirituality in bringing meaning to a diagnosis of

advanced cancer is contrary to the results of studies which suggest that existential concerns and religious/spiritual activities play a prominent role for many patients in coping with incurable malignancy.^{5,7,14,15} Our results are similar to a study of patients newly diagnosed with advanced gastrointestinal cancer where almost half expressed a belief in God, a higher power or a divine power²⁷, and in contrast with studies in patients with more advanced disease from other settings in the USA and UK.¹⁴⁻¹⁷ Despite the conflicting research results as to whether appraised meaning, and the results of meaning-making, change over time, it is possible that the role of spirituality and/or religion will become a more relevant influence in our patients as they become more symptomatic and progress towards a terminal state.

Alternatively, it may reflect real cultural differences between Australia and other countries where these issues have been studied previously in palliative care populations. Australia has held a deep spiritual history for thousands of years, as observed by the Aboriginal people as well as the Torres Strait Islanders. However, the number of people reporting no religion in Australia has increased substantially over the past hundred years, from one in 250 people to one in five in 2011.²⁸ Similar declines were reported from the settings of the studies reported above. For example, reported rates of “no religion” in England and Wales went from 15% in 2001 to 25% in 2011; Canadian rates rose from 16% to 24% over the same time. While the United States do not have a question on religion in their Census, the General Social Survey showed the rate of American adults reporting no religion was 20% in 2012 compared with 14% in 2000.²⁸

The participants in our study made the distinction between “religion” and “spirituality” specifying, for example *“I am not a religious person but I have my own spiritual beliefs.”* In the literature, “some definitions emphasise differences between spirituality and religion, others stress their overlapping dimensions and still others favour the concept of religion over spirituality because the latter is more difficult to measure”^{29(p281)} Authors have recognised that psycho-spiritual needs vary across cultures and call for qualitative studies to understand more fully psycho-spiritual well-being among those patients in populations and countries where little is known.³⁰ Our study provides further insight by highlighting the importance of the framing, language and perhaps timing in asking religious and/or spirituality-related questions in a palliative care population.

The finding in our study that the majority of participants described a good quality of life has been reported in another study of cancer patients with active disease who described themselves a “fairly healthy” and “very healthy”, even though 12 of the 50 patients interviewed died during the study.³¹ Other studies report disparity between measures of health and the patient’s own subjective evaluation.^{32,33} The key issue is how the person identifies their situation – living versus dying, implying that subjective self-assessment that does not always correlate with more objective markers of disease activity. Perhaps also, the

appraised meaning of their situation has been modified by reappraisal of the meaning of their diagnosis, and selectively focussing on the positive attributes, thereby lessening its noxious nature.³³

Limitations

Some patients had been diagnosed with cancer previously and had developed recurrence, while other patients had incurable cancer at the time of presentation and diagnosis. Thus, the former may have had a longer period of time to develop coping strategies and to adjust to an uncertain future. As the interview was conducted in English we did not include participants from non-English speaking backgrounds. Additionally, our study was conducted in a major city with access to a major cancer treatment center. Participants from rural or remote areas may not have had the option of travelling long distances for continuing palliative chemotherapy or radiotherapy. Additionally, this study did not specifically focus on spiritual beliefs and it might be that in the Australian context, patients are less likely to discuss these with others, even when they hold them, than other cultures.

Future directions

With improved treatments for patients with incurable cancer a significant number of our patients may continue to live for many months and often years.³⁴ Our results have important practical implications for the optimum management of patients with incurable cancer who are clinically well and who report a good quality of life. It has been previously recommended that these patients represent an emerging palliative care population which requires a more flexible model of care with an intermittent approach.²⁰ That is, as required for specific symptom management by a specialist palliative care service, rather being linked continuously to a palliative care service for long periods of time.²⁰ The participants in our study wanted their doctor to keep up with technology, give advice and guidance and be honest, but most of all to be confident and positive in their future medical care.

In considering the psychosocial support that would be appropriate and acceptable to this patient population, discussion of existential concerns or use of language such as “meaning-making” may be unwelcome, and will require sensitivity and a mirroring of the language used by patients to describe their personal philosophy and its role in coping with an uncertain future. A take home message from this study is that clinicians and allied health professionals cannot necessarily generalize findings from other countries or cultures on the role of religion or spirituality in coping with advanced disease to their own patient population. Given our variance in findings, the importance of religion and spirituality for patients facing incurable disease in the Australian context needs to be further explored. Healthcare professionals need to be aware of patients’ expressed desires to continue activities of daily living, which may well be compromised as cancer treatments are not only often associated with a significant treatment-related

burden in the form of time and resource commitments, but also are frequent physical reminders of the disease.

This study provides a valuable insight into the dynamics of the doctor-patient relationship during the sometimes prolonged period before any explicit transition to end of life care. What these interviews suggest, from the patient's perspective, is that there is an implied contract between doctor and patient during this period which involves the doctor managing the flow of difficult information so that the patient can maintain normality for as long as possible. Understanding this helps to explain the difficulty of having advance care planning conversations within this setting, despite the many opportunities that a longer disease trajectory would seem to offer. Furthermore we can hypothesize that when both doctors and patients are focused on the tasks of living well, it may be possible to introduce the idea of a plan for dying well when the time comes without significantly disrupting that relationship. Understanding the complexity of the communications between doctor and patient in the cancer setting better may lead to more effective strategies to promote advance care planning at an earlier point in these patients' illness.

CONCLUSIONS

Our findings suggest that patients with relatively asymptomatic incurable cancer do not draw on formal religious beliefs to cope but find meaning through connections with others and "getting on with things." Whilst finding meaning in activities of daily life is not a new finding,³⁵ the apparent lack of existential distress invites alternative communication strategies.

The challenge is for clinicians to adapt communication skills to address the multifaceted needs of this emerging palliative care population who are living longer with cancer. Psychological interventions may be initiated when disease progression is noted and management options are limited. Such interventions could involve referral for supportive care and /or specialist palliative care and appropriate allied health support services for optimal symptom management to achieve the patient's goal of keeping life as normal as possible.■

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CONFLICT OF INTEREST

The authors have no financial relationship with St George Hospital Cancer Care Centre. They have full control of all primary data and agree to allow the journal to review their data if requested.

DISCLOSURES

None.

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APPENDIX 1

Interview Schedule

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?

- What information have you been given about your cancer?
- Do you have any thoughts about why this has happened to you?
- How did you feel when you were told you had advanced cancer?
- How do you see yourself and your life since your diagnosis?
- How prepared do you feel for what is likely to happen in the future?
- What do you think is going to happen in the future?
- What helps you cope with your cancer?
- Is there uncertainty in your life?
- Does this cause you distress?
- How do you cope with uncertainty? PROMPT family/religion/spirituality.
- How have you been able to make sense of what has happened to you?
- How has your diagnosis of advanced cancer affected you physically or emotionally?
- How would you describe your quality of life?
- Are you concerned about anything? If so what is/are your major concerns?
- Have any good things come from your diagnosis?
- Are there any sources of support missing from your life?
- How can health professionals best support you at this time?