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Elizabeth A. Lobb

University of Notre Dame Australia, Elizabeth.Lobb@nd.edu.au

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Elizabeth A. Lobb

PhD, MAppSci, BEdEd

Professor of Palliative Care
(Allied Health)
Calvary Health Care Sydney
Cunningham Centre for
Palliative Care

Adjunct Professor
School of Medicine
The University of Notre Dame
Sydney

Address
Calvary Health Care Sydney
Kogarah NSW 2217
Australia

Phone
(02) 9553 3093

Fax
(02) 9553 3159

Email
Liz.Lobb@easton.nahm.
nsw.gov.au

How Do Patients With Advanced Cancer Cope With an Uncertain Disease Trajectory? Implications for Grief Counselling

Abstract

A growing number of cancer patients are living longer with incurable disease. This paper describes strategies that patients use to cope with the uncertain trajectory of their disease. Twenty-seven patients with a prognosis of 12 months were recruited from the oncology and palliative care service in three metropolitan Sydney hospitals. A semi-structured face-to-face interview was conducted, which was audiotaped and transcribed verbatim. The patients coped with the uncertain trajectory of their disease through avoidance, maintaining a normal life, comparing themselves favourably to others in a similar situation and remaining positive. Participants indicated that they did not wish referral for psychological support. The implications of these findings and the influence of grief counselling are explored.

Strategies to Support Patients With Incurable Cancer and an Uncertain Disease Trajectory

Optimal care of patients with a cancer that indicates a limited prognosis must extend beyond conventional symptom management. It must begin to address the broader sources of suffering that can arise and identify strategies that allow patients to cope with the uncertain trajectory of their disease. Research has produced some important insights into the needs and experiences of patients with advanced cancer with various interventions being trialled. These include dignity conserving care (Chochinov et al., 2002a, 2002b) and integrated approaches including narrative, cognitive, existential and social therapies (Lethborg, Aranda, & Kissane, 2008). Further important research includes the understanding and prevalence of suffering, hope and hopelessness, spirituality, demoralisation and the role of healing connections in advanced cancer. (Chochinov & Cann, 2005; McClement & Chochinov, 2008; Mystakidou, Tsilika, Parpa et al., 2008 and Mystakidou, Tsilika, Athanasouli et al., 2008; Blindermann & Cherny 2005; Grant et al., 2004; Kissane, Clarke, & Street, 2001; Mount, Boston & Cohen, 2007).

These studies have almost exclusively been carried out in the population with advanced cancer who are receiving palliative care and are at the end stage of their disease. But what of those who have received a new diagnosis of an incurable cancer that has a limited prognosis but may live for months and, in some cases, for years? With treatment advances, many patients whose prognosis is limited are living longer. For example, women with advanced breast cancer can live for extended periods of time and with new treatments being developed and introduced, life expectancy continues to improve. In fact, living longer with poor prognosis for their disease is now becoming

a recognised reality for more patients (Ruiterkamp et al., 2011). This presents health professionals with the challenge of supporting patients who are faced with a diagnosis of incurable cancer, and who whilst living longer, will inevitably face a shortened life span.

Emotional distress represents a major psychological challenge for people living with advancing disease. Mitchell and colleagues (2011) estimated that the pooled prevalence of depression was 16.5% in palliative care settings and 38.2% for any mood disorder (including anxiety, depression and adjustment disorders). The association between depression and hopelessness has been well demonstrated to heighten suicidal ideation, and desire for death. (Breitbart et al., 2000; Breitbart & Rosenfeld, 1999; Chochinov, Wilson, Enns, & Lander, 1994, 1998; Chochinov, Wilson, Enns, & Lander, 1995).

Depression clearly contributes to suffering (Block, 2000), diminishes quality of life (Grassi et al., 1996) and places a huge psychological burden on the family (Cassileth et al., 1985). Kissane and colleagues have described "Demoralization Syndrome" in the terminally ill, consisting of a triad of hopelessness, loss of meaning, and desire for death. (Kissane, Clarke, & Street, 2001). Breitbart and colleagues demonstrated that spiritual wellbeing and meaning serve as a buffer against depression, hopelessness and desire for hastened death among terminally ill cancer patients. (Breitbart & Rosenfeld, 1999; Breitbart et al., 2000). Clearly, this data suggests that psychotherapeutic interventions targeting patients with advancing cancer, who face the real possibility of succumbing to their illness, must attempt to engender meaning and purpose, improve quality of life and help them cope with uncertainty.

In a recent study we sought the views of people with incurable cancer on how they coped with the uncertainty of their illness. (Lobb et al., 2013). The themes that emerged from our interviews were that they 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 focusing on the outcome of palliative treatment aimed at controlling their disease and by comparing themselves to others who they perceived to be in a worse situation. (Lobb et al., 2013).

All of the participants in our study talked of the initial shock and distress of being told that they had advanced cancer and that they were avoiding thinking about what the future may hold. They avoided talking about their illness with friends and when asked about their health they gave minimal information. They proposed that the

constant reference to their illness acted as reminder of their cancer diagnosis, a reminder that many wanted to avoid as they did not want it to pervade all aspects of their lives.

Avoidance has been seen as a subtype of denial and is defined as “a knowing effort to shun any circumstances that bring stressful material to the forefront” (Wool & Goldberg, 1986, p. 3). Such denial could be seen as positive coping mechanism for patients; however, it may also lead to isolation, either of themselves or of family members and friends who may wish to discuss what is happening or offer support but are receiving messages from the patients that such discussions are not welcome. Other avoidance strategies cited included minimising the reality of incurable disease and hoping for disease progression to be stabilised.

Participants in our study talked about “*keeping busy*”, “*watching television*” or “*listening to the radio*” to avoid thinking about their situation. Other studies report similar findings of patients trying to gain control over uncertainty by keeping busy, either through their working lives or other activities such as caring for their family in order to distract themselves from thinking about what might happen in the future. (Turner, Kelly, Swanson, Allison, & Wetzig, 2005; Svensson, Brandenberg, Einbeigi, & Ahlberg, 2009). In studies of advanced breast cancer, women spoke of consciously suppressing thoughts related to their uncertain future in order to control the overwhelming range of emotions that uncertainty elicited. (Burnet & Robinson, 2000; Davies & Sque, 2002; Wiseman & Worden, 1986).

While patients who were interviewed were aware that their cancer was incurable, nonetheless, they made an active choice to maintain a “positive attitude” by focusing on the “smaller, achievable” aspects of their lives. One aspect of remaining positive was the reluctance for patients to have information about their prognosis and a preference to have limited information about their disease progression. Some reported that they were unaware of their disease status, thinking perhaps they were in “remission”, perhaps they were “stable”, but they did not want to ask in case they were given information they did not want to hear. Participants’ reports of wanting to remain positive could be defined as dispositional optimism, that is, the tendency to expect positive versus negative life outcomes (Scheier & Carver, 1985). Optimism may act as a buffer against stress by influencing the types of coping strategies individuals choose to employ (Scheier, Weintraub, & Carver, 1986). The wish to remain positive may also be related to fear – fear of what may happen in the future, fear of pain or of when or how they may die. What is not clear from our data, which was captured at one point in time in the illness trajectory, is whether such optimism could be sustained in the face of increasing physical decline.

Participants 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*”. Participants acknowledged that their lives had changed and would never be the same but there was a “*new normal*” to adjust to.

All of those interviewed considered themselves to be “living” with their cancer not “dying” with it. They perceived their quality of life to be good at the time of the interview, and in some cases better than before they were diagnosed with their cancer. Many were receiving palliative chemotherapy or radiation therapy and most had a prognosis of six months or more. They acknowledged that their disease may shorten their life but the prospect of a shortened life span did not deter them from achieving goals, even if these goals required modification. Goals took on a slower pace with a narrower focus of spending time with friends and family. A renewed appreciation of relationships or a change in relationships, which were distant but now are closer, was seen as one positive aspect of the disease.

Patients did not engage in self-pity or rumination but, rather, attempted to minimise the impact of their disease by comparing themselves favourably to others, cultivating a desire to help others and attempting to make a meaningful contribution to their family and the community. This finding, that participants compared themselves to others who were in a similar situation, may 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 (Molleman, Pruyn, & Van Knippenberg, 1986; Van der Zee et al., 1996). The participants in our study chose downward comparisons, that is, evaluation against less fortunate others as this can lead to self-enhancement or more positive views of oneself, one’s situation, and one’s mood. An alternative view could be that a diagnosis of an incurable cancer may produce a profound philosophical shift in people to a connection with a reservoir of compassion for self and others.

Implications for Psychological Support

The goals of counselling with clients facing incurable disease include: development of a therapeutic bond that alleviates the sense of isolation experienced with terminal illness; integration of the present illness into a continuum of life experiences; exploration of issues of separation, loss, and the unknown that lies ahead; and to help the client face death with a sense of dignity (Greenstein & Breitbart, 2000). As suggested previously, these patients represent an emerging palliative care population that may require a more flexible model of care. Many of those who participated in the interviews did not wish to be referred to a psychologist to receive formal support. They expressed surprise at how helpful our interview was as it enabled them to voice their concerns, identify the positives in their experience, and to highlight how well they perceived they had coped with the process. They

endorsed the response of one interviewee: "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" (Lobb et al., 2013). What strategies then could potentially benefit this group of patients?

Loss

When people are diagnosed with a life-threatening illness they can experience a number of losses. In this group of patients, loss of life expectancy, loss of control and loss of safety may be of particular relevance. Given that grief is a normal response to loss, there is a potential role for grief counselling. In the move from active treatment to palliative treatment they may experience a sense of loss of relationships with health professionals that were built up over time and struggle to form relationships with new members of the palliative care team. A referral to palliative care may in fact challenge some of the coping strategies they have identified and that have worked for them in the past.

They can report feeling a sense of abandonment and isolation, which can be explored in a neutral and supportive environment with a counsellor. The counsellor can help clients draw up a list of questions, explore expectations and validate and support concerns and strategies. There is also a role to support family members who may themselves be feeling isolated and who have not had an opportunity to express their distress for fear of distressing the patient or violating the patient's coping strategies.

Uncertainty

Based on our data, and the surprise expressed at the perceived helpfulness of our interview, counselling strategies to support patients cope with uncertainty may include a review of the trajectory of the illness to date. Depending on the time available and energy levels, most people welcome the opportunity to talk about their experiences from diagnosis, through treatment, perhaps during remission and to now dealing with recurrence. Such a review can elicit previously unvoiced feelings around the time of diagnosis, such as anger at the delay or perceived insensitivity in the disclosure of the diagnosis or the prognosis. It may also break down their active or passive self-protective coping system, so a careful exploration of what they wish to discuss will be needed.

Normality

Keeping their lives as normal as possible was a major concern of this group. Exploring the individual's definition of normality may be helpful as this can allow for short- and medium-term goals to be defined and planned. The importance placed on relationships with family members and community suggest an opportunity to identify existing services. This may also present an opportunity to ask how family members are coping, as some friends or family members may draw near at this time while others may pull away, often out of a sense of not knowing what to say or what to do.

Avoidance

As trust begins to build in the counselling relationship, opportunities can arise to address unrealistic goals,

beliefs and plans. Maintaining hope is a delicate balance and can begin by eliciting the client's innermost hopes for maintaining dignity, respect and control. Quality of life becomes a focus when cure is no longer an option. Helping clients clarify priorities can sharpen the attention on the remaining weeks or months. Some of those interviewed identified the quiet of the evening as a particularly difficult time when distraction with activity is minimal and protective avoidance may not sustain. Gently encouraging self-reflection by first identifying strengths and achievements can be supportive. If the counsellor is invited into this potentially frightening landscape, exploring fears for the future and individual concepts of a good death can be appropriate.

A range of practices is available to the counsellor to help their client manage the anxiety that can travel alongside uncertainty. These practices include mindfulness, meditation, relaxation and visualisation (Carlson, 2010). Creativity may be needed to modify practices and assist those who are experiencing physical pain and discomfort or whose attention may be distracted or dulled by medication. Other behavioural techniques, such as muscle relaxation and imagery, can be utilised to reduce distress in cases of mild anxiety and for pain control.

Conclusion

Our study has identified the coping behaviours of patients with nonacute, incurable cancer. For many patients with incurable cancer, the trajectory of their disease, while unpredictable, may extend over many months to years. Therefore, the cancer journey may have characteristics in common with a number of chronic (nonmalignant) diseases, such as cardiac, renal and respiratory failure. These interviews affirm that patients desire to live with cancer as normally as possible, and not to be reminded constantly of their incurability.

As highlighted in our study and contrary to our hypothesis, they 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. Carter, MacLeod, Brander and McPherson (2004) 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. (p. 14)

As long as their disease progression was being managed and they had confidence in their doctor, participants could cope with a potentially shortened life span (Lobb et al., 2013).

The transition points, such as when disease progression is noted and management options become more limited, may be the times when these reported adaptive coping strategies fail and counselling and psychological interventions may need to be initiated.

Such intervention should be targeted and, more importantly, initiated at a time when there is a readiness and willingness to explore existing strategies. The key question for the counsellor is whether the coping strategies identified in these interviews cause distress, either to the patient or their family and/or supporters.

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