

Death awareness, feelings of uncertainty, and hope in advanced lung cancer patients: can they coexist?

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Patients with advanced lung cancer may experience both uncertainty and hope. Patient statements such as ‘I don’t know how long this chemo is going to work’ and ‘denial gives me hope’ should prompt clinicians to question whether they really understand what the patient is communicating. It is important to pay attention to the real meaning behind patients’ words. With the ever-narrowing time frame allotted to patients, clinicians may be too quick to label patients as being in denial when they say they are hoping for healing. Many patients hope for healing because they are uncertain about their future.

A natural coping tendency for patients facing uncertainty is to want a positive treatment outcome. If health professionals conduct business as usual, they try to reduce the patient’s uncertainty by improving their understanding of the facts. But if they reduce or suppress the patient’s feelings of uncertainty, they may also risk extinguishing a flicker of hope, and hope that accompanies uncertainty may be positive. This paper aims to provide a deeper understanding of how the seemingly antithetical emotions of death awareness, uncertainty, and hope can coexist to the benefit of the patient, and to provide clinicians with practical considerations for supporting patients’ hope throughout their terminal illness.

Case report

Mrs S was 47 years old when she was diagnosed with advanced lung cancer. She was happily married with two daughters and four young grandchildren. She had undergone a kidney transplant 5 years earlier and almost died. Having survived these many years post-transplant, she and her husband were devastated on learning that she had not only lung cancer but also bone and brain metastases. She was informed that this was incurable but that receiving palliative therapy could prolong her life and provide her with the best quality of life possible. Mrs S felt confused and, once again, uncertain about life.

Abstract

Patients diagnosed with stage-IV lung cancer are forced to quickly transition from a cancer-free and perhaps healthy life to one of serious illness, uncertainty, and anticipation of a premature death. Health professionals may be too quick to label the patient as being in denial if they hope for healing. Hope may not be lost when reality is accepted. Studies have investigated what it is like to live with awareness of impending death. Using a patient case study this paper discusses the concepts of death awareness, uncertainty, and hope. The aim is to provide a deeper understanding of how these seemingly antithetical emotions can coexist to the benefit of the patient, and to provide clinicians with practical considerations for supporting patients’ hope throughout their terminal illness.

Key words: Death awareness ● Uncertainty ● Hope ● Lung cancer

She felt an overwhelming sense of disbelief because she thought that surviving a kidney transplant would have increased her overall chances for survival. She struggled with her diagnosis and stated that it was like a black hole full of questions but offering no answers—at least no acceptable answers. Treatment options were discussed and initiated. After learning how to control the side effects of chemotherapy, she described her life as beginning to feel a bit more normal. She spent time with her grandchildren, enjoyed gardening, went on trips with her husband, and overall felt very hopeful that she might yet ‘beat this thing’.

Mrs S enjoyed almost a full year of stable disease with minimal side effects before the computerised tomography (CT) scan showed progressive disease. The news of progression was almost as devastating as the initial diagnosis, and Mrs S and her husband found it difficult to comprehend. The physician explained that targeted chemotherapy was available but that Mrs S first needed to be evaluated by the radiation oncologist for potential treatment regarding brain metastases that had enlarged. Mrs S asked how successful the radiation and chemotherapy would

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Box 1. Levels of death awareness

Glaser and Strauss's (1965) Theory of Death Awareness:

- Level 1: Closed awareness—patient is unaware, but others are aware
- Level 2: Suspicion awareness—patient suspects impending death and attempts to get confirmation from others
- Level 3: Mutual-pretense awareness—everyone knows but no one talks about it
- Level 4: Open awareness—everyone knows and openly talks about it

Timmermans' (1994) Contexts of Open Awareness:

- Context of suspended open awareness—explicit diagnosis and prognosis are disregarded
- Context of uncertain open awareness—negative information is disregarded and the possibility of a good outcome is held on to
- Context of active open awareness—the patient and family accept the information and respond accordingly

be for her and how long the treatments would work. She stated that facing the unknown was very difficult, and the uncertainty of whether the treatments would help and for how long made her feel very vulnerable. This uncertainty was also very difficult for her family, especially her husband. Mrs S had spent many hours on the internet obtaining information on survival statistics, treatments, and nutrition. After the physician provided information on radiation and targeted therapy, Mrs S was reminded that the overall goal of treatment was to lengthen her life with the best quality of life possible, for however long that would be. The goal was not cure.

Mrs S completed whole-brain radiation followed by targeted chemotherapy. She did well on the new treatment with minimal side effects, CT scans showed stable disease, and the doctor was very positive. She again began to feel hopeful and enjoy life. Several months of good news provided her with the confidence to enquire about making plans to travel. When asked about her optimistic outlook, she acknowledged that things were difficult, but she had decided to be positive because to be otherwise was self-defeating. Rather than thinking about having lung cancer all of the time, she decided to put her emotions and energies into hoping for a cure. Focusing on the negative outcome was not helpful. She put cancer out of her mind and expectantly hoped for improvement each time she saw the doctor. Mrs S stated that she believed God would provide healing but that she did not live in a bubble of faith. She was 'not walking in a Pollyanna path without looking at reality' and she stated that 'denial gives me hope'.

Two months later, Mrs S began to get progressively short of breath and underwent several thoracenteses to palliate the symptom.

The time interval between procedures became shorter and she eventually required oxygen. She also experienced excruciating multifactorial pain, for which she was placed on an intravenous infusion pump in addition to oral pain medications. Over the period of a month, she became oxygen-dependent and virtually non-ambulatory, required assistance to go to the bathroom, and was admitted to the hospital three times for pain control. Aware that she was rapidly deteriorating, she reluctantly consented to hospice care but still maintained hope that there would be another treatment to prolong her life. Mrs S held on to that hope until she died at home 1 month later.

Death awareness, uncertainty, and hope

When patients are diagnosed with stage-IV lung cancer, the transition from a normal life to unwanted anticipation of a premature death is very difficult. It can lead to feelings of uncertainty, hope, and denial. Some of the more difficult situations are when patients experience positive or negative fluctuations in the illness trajectory as a result of treatment or disease progression. For those few who outlive their prognosis, life is lived in a state of limbo or uncertainty, and the illness becomes what Bern-Klug (2004, p58) described as a 'stuttering dying trajectory' instead of the usual downward illness trajectory experienced by so many patients with advanced lung cancer. Hutchings (2012, p50) further described this as living with the 'twin mysteries of prognostication and death awareness in the face of ambiguous dying'. The longer one lives beyond the prognosis, the more awareness of death becomes tangential. Life becomes ambiguous and uncertain.

The pioneering work by Glaser and Strauss (1965) in the area of death awareness is important for understanding the foundation of uncertainty and hope. Prompted by personal experiences, Glaser and Strauss studied the dying process in six hospitals in northern California. They learnt that patients knew very little about their impending death even though the staff were usually aware. The goal of the study was to gain a clear understanding of how people manage and negotiate social change in the structural context of the hospital. From their research, Glaser and Strauss proposed four levels of death awareness: closed awareness, suspicion awareness, mutual-pretense awareness, and open awareness (*Box 1*).

Closed awareness is when the patient is unaware of his or her impending death, but others are aware. Suspicion awareness occurs

when patients suspect they are dying and try to get confirmation from others. With mutual pretence, all involved know that the patient is dying but no one talks about it, pretending that everything is normal. In open awareness, the patient and others know and talk about the patient's impending death.

Timmermans (1994) believed that Glaser and Strauss's work neglected the emotional characteristics of the patient's behaviour. He maintained that understanding and emotional reactions vary between patients at different points in time, based on their interpretation of the information received. Timmermans further delineated three gradations of open awareness: suspended, uncertain, and active (*Box 1*). He pointed out that patients will shift back and forth between these gradations based on their interpretations of the information provided.

Suspended open awareness

According to Timmermans (1994), in the context of suspended open awareness the patient openly disregards the information regarding diagnosis and possibly prognosis in spite of being told several times. There is no talking about impending death. There are three circumstances in which this occurs. The first is after hearing that their condition is terminal; the patient cannot assimilate the consequences of the information and there is a sense of disbelief. The second circumstance is when disbelief becomes permanent: the patient questions the veracity of the information that their condition is terminal and may begin to make long-term plans or use alternative methods of treatment. The final circumstance is when the patient's health status progressively improves or deteriorates beyond expectations: this can cause the patient to doubt the final outcome of the disease.

Mishel (1984) defined uncertainty in illness as an inability on the part of the patient to create meaning around illness-related events. Subjective interpretation of the illness determines whether the uncertainty is a threat or an opportunity, and because the situation may change so may the interpretation. This is especially hard for those patients who have outlived their prognosis and are in what Bern-Klug (2004) termed the stuttering dying trajectory. When experiencing the ebb and flow of impending death and hope, a family member stated: 'Occasionally, the resurgence of a symptom reminds us that somewhere nearby [...] mortality lurks in the shadows ... We briefly revisit our end-of-life preparations and then park our death awareness once again' (Hutchings, 2012, p50).

Uncertain open awareness

According to Timmermans (1994), uncertain open awareness occurs when the physician or nurse explains the diagnosis or prognosis in a manner that leaves just enough room for uncertainty and therefore hope. Creen (2002, p17) defined hope as having 'the capacity to embrace the reality of the individual's suffering without escaping from it (false hope) or being suffocated by it (despair, helplessness, hopelessness)'. McIntosh (1977) connected uncertainty with hope in that patients would rather endure uncertainty than know the truth, because with uncertainty there could be hope. There is a difference between suspecting the truth and knowing the truth. Suspecting the truth preserves hope whereas knowing the truth may cause hope to be lost. Timmermans (1994) suggested that it is this linkage of uncertainty to hope that is at the heart of uncertain open awareness. Patients will use strategies to find hope such as selectively looking for and rationalising clues, asking questions for which the answers remove any sense of hopelessness, and comparing their situation with another patient who is worse off. In their interviews with 27 patients who had advanced cancer, Lobb et al (2013) found that patients minimised the impact of the disease by comparing themselves with other patients with advanced cancer.

Williams et al (2013) conducted research with rural female caregivers in Canada caring for family members with advanced cancer. A qualitative aspect of the study included analysis of 342 journal entries from 24 participants over 3 years. One of the topics participants were asked to write journal entries about was what gave them hope each day. A key comment made was 'to hope against hope' even when there is no hope for a cure. Hope is a choice. The authors suggested that the phrase 'hope against hope' illustrates how caregivers persevere in finding hope even when there are no substantiating facts to support it. In line with Creen (2002) and McIntosh (1977), Williams et al's (2013) study also showed how seemingly paradoxical emotions can coexist.

Devik et al (2013) interviewed five patients aged ≥ 75 to better understand their lived experience of having incurable cancer and living alone. One of the subthemes that emerged was coping with conflicting feelings. A female patient described her life as living in constant tension that came from trying to suppress doubts while also trying to focus on the positives. This left her neither happy nor sad, but she still persevered. Copp (1997) also observed coexisting emotions in 12 patients and their nurses dealing with

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impending death in a hospice. She learnt that denial and acceptance of the patient’s health condition fluctuated and were used as coping strategies to both avoid threats and protect relationships. Copp saw acceptance and denial as interdependent strategies rather than independent strategies.

Active open awareness

Returning to Timmermans (1994), the third form of open awareness is active open awareness. This occurs when the patient and all those involved no longer hope for a cure. It does not mean that the patient has no hope, but rather that there can be peace of mind spiritually or in simply reflecting on their own lives. There is open dialogue about the impending death and death-related matters. However, Timmermans pointed out that the disclosure of terminal information does not automatically lead to active open awareness: it is how patients emotionally cope with that information that determines the context of open awareness.

Discussion

According to Timmermans (1994), when a patient receives a diagnosis of a life-threatening illness, definitions of self and identity are undermined by this emotional crisis. In the authors’ experience, certainty does not need to be real: it just needs to feel real to the patient. Neither does certainty have to be logical or make sense to anyone else for it to feel real to the patient. Below, Mrs S’s case is discussed in light of Timmermans’ contexts of open awareness.

Mrs S experienced all of Timmermans’ (1994) three contexts of open awareness. When she was first told that she had advanced lung cancer and that it was incurable, she not only felt uncertain but also felt an overwhelming sense of disbelief. Subsequently, after her side effects were controlled and life seemed more normal, she began to feel hopeful that she would beat the disease. This is what Timmermans (1994) termed suspended open awareness. Mrs S’s initial disbelief was normal and it is understandable that full comprehension of the disclosure was unattainable at that time. Once Mrs S moved beyond the initial disbelief, the improvement in her health facilitated living her life as fully as possible. Timmermans (1994) suggested that some patients begin to doubt the outcome of their disease when improvement in their health is experienced. Mrs S never indicated that this was the case for her either verbally or through her behaviour. However, neither did she talk about her impending death, which also aligns with this context. Suspended open awareness is usually transitory:

patients gradually move on to another kind of open awareness (Timmermans, 1994).

The next context, uncertain open awareness, is when patients tend to ignore negative information and hold on to the possibility of a good outcome. They are selective about what information they hold on to. When clinicians provide clinical information to patients, they may unintentionally leave enough uncertainty to make the patient perceive that there is some reason for hope. This context is where Mrs S spent the majority of her time. In returning to a ‘normal’ life afforded by her improved and stable health, Mrs S was able to set aside the negative information and prefer hope to the certainty of death. Hope is both essentially human and essential to human existence (Elliott and Olver, 2009). In interviewing dying patients with cancer, Elliott and Olver (2009) learnt that hope for a cure did not preclude awareness and knowledge of death. Patients receive treatment because they believe in the potential of medical science. As medical science promises potential cures for cancer, it is perhaps not surprising that patients hope for a cure even if the chance is vanishingly small. To view a patient’s hope as denial is to ‘challenge or negate the accumulative weight and legitimacy of dominant representations of cancer, medical science, and hope’ (Elliott and Olver, 2009, p619).

McIntosh (1977, p94) also connected feelings of uncertainty to hope. He stated:

‘The proposition that patients would attempt to cope with uncertainty by seeking to find out about their condition presupposed that they would want to know what they had and what the outlook was likely to be. Many did not. They would rather suffer from uncertainty than know the truth. They did so because for them, to suffer the uncertainty was preferable to the risk of losing their hope. Suspecting and knowing are entirely different things. So long as a patient did not know, he could always retain the hope that he might not have cancer. In other words, with uncertainty there was hope. Those patients who did not seek a true assessment of their prognosis did so for the same reason that patients did not seek confirmation of their diagnosis. As long as they were uncertain, there was hope of a favorable outcome.’

Mrs S was hoping for a cure or anything that would prolong her life. Engaging in activities with her husband and family gave her great joy, so using ‘denial’ to give her hope was not an act of denying death, but rather an act of affirming life and what was important to her. If this kind

Box 2. Clinical practice considerations for supporting hope

Suggested clinician probes for assessing patient hope*:

- What is your understanding of your lung cancer and the course of your illness?
- In light of what you know about your illness, can you share with me how hopeful you are?
- What gives you hope?
- Does that source of hope help you to cope? Has this source given you hope in the past?
- Do you have someone to talk to?
- What gives you meaning in life? What sustains you?
- Do you feel a sense of purpose in your life?
- Are you uncertain about anything? What is your tolerance for uncertainty?
- How do you normally cope with uncertainty?

Suggested clinician considerations for supporting hope (as appropriate)[†]:

- Normalise the patient's feelings
- Affirm values, do not deny hope
- Acknowledge hopes that have changed but also affirm that prior hopes are not worthless
- As health status declines, support the patient's hopes for an acceptable death
- Facilitate the patient's desire to leave a legacy
- Look for hope-giving clues, e.g. rationalising information, selective hearing of facts
- Facilitate navigation of the health-care system
- 'Presence' conveys true caring and support
- Provide clear and accurate information to the patient and team members
- Assist the patient in managing uncertainty
- Tailor amount of information, approach to hope, and prognosis needs to match the patient's wishes
- Support the patient's goals as appropriate
- Reinforce information provided to the patient by the physician
- Help the patient to assimilate medical information into their lives

*Nekolaichuk and Bruera (1998), Ersek and Cotter (2010), Reinke et al (2010), Stephenson and Berry (2014).

[†]Timmermans (1994), Mishel (1999), Bern-Klug (2004), Curtis et al (2008), Chochinov et al (2009), Elliott and Olver (2009), Maguire and Weiner (2009), Reinke et al (2010), Hansen et al (2012), Lobb et al (2013).

of hope is deemed unrealistic by clinicians or others, there is a risk of devaluing what the person holds dear.

As Mrs S transitioned into the third context, active open awareness, she did not relinquish the hope for more time, but she did sign on to hospice (albeit grudgingly) and open talk about things that needed to be done while she was still here. Mrs S's decision to enrol in hospice while maintaining hope exemplifies what Copp (1997) termed 'interdependent strategies', Williams et al (2013) called 'hope against hope', and Creen (2002) defined as embracing reality without escaping from it. Mrs S wanted to live until she died. In 11 narrative interviews with patients with cancer, Benzein et al (2001) learnt that there was a difference between hoping for something, such as a cure, and living in hope, which reconciles life and death. Until that reconciliation occurred, patients stated that they were both

doomed to live and doomed to die. They belonged to both life and death, but felt they had to live for as long as they were alive. Cassell (2013, pxiv) stated that 'Wellbeing is not just quality of life [... it] is related to feelings of being oneself (with oneself and in relation to others), being able to live life as desired, and feeling able to accomplish what is considered important.' Until the very end, Mrs S's balancing protected her powerful need to be fully engaged in life while preparing for the inevitable dying. She provided living and, in the end, dying proof that feelings of uncertainty and hope can indeed coexist in patients with lung cancer in the midst of death awareness.

Clinical practice considerations

Living with advanced lung cancer means living with uncertainty. However, patients cling to the hope circuitously provided by that uncertainty.

‘The clinician’s approach to providing hope and to disclosing the prognosis should match the wishes of the patient ...’

There are means by which clinicians can support the patient’s hope in the midst of their uncertainty (Box 2). Normalising the patient’s feelings by actively listening is very important (Bern-Klug, 2004). When patients realise that they are not an isolated case, it builds hope in the sense that they are not alone. Another way to support hope is to affirm the patient’s values (Elliott and Olver, 2009). Clinicians do not have to agree with a patient’s hopes in order to affirm what they value. The patient may be hoping for a cure that will never occur, but their valuing of life and family can be affirmed. It is also important to acknowledge patient hopes that may have changed to better align with their current situation while also affirming that their prior hopes are not worthless. Hopes may change not only with different stages of life but also as a result of changing circumstances. As the patient’s health status declines, clinicians can be instrumental in supporting the patient’s hopes for an acceptable death (Elliott and Olver, 2009).

A patient’s desire to leave a legacy is one of the more tangible expressions of maintaining hope as it affirms the patient’s presence and value in life (Borneman and Brown-Saltzman, 2010). Leaving a legacy provides hope in that it connects the past, present, and future, which will continue after the patient dies. It also provides a means for the patient to feel valued as part of humanity, having made a contribution from which others can learn (Elliott and Olver, 2009).

Timmermans (1994) mentioned three different strategies used by patients looking for hope. The first was using hope-giving clues such as rationalising information, selective hearing of facts, and looking for alternative explanations. The second was the polarity game, in which patients ask questions about life and death scenarios related to the illness that result in answers which provide hope. For example, a patient may ask how much time they have left to live, and the doctor may reply ambiguously that they do not know. The patient may take from this that they probably have more time than they thought. The third strategy is comparing oneself to others. When patients compare themselves to other patients who are worse off, this offers hope. Clinicians can be aware of these tactics and look for opportunities to support the patient’s hopes or affirm their values when appropriate.

Assisting patients to manage their uncertainty and reduce their anxiety can also support hope. Clinicians can help patients to navigate the health-care system by answering questions regarding treatment delays or waiting times for results and by being ‘present’ (Maguire and

Weiner, 2009; Hansen et al, 2012). Presence conveys true caring and support. Hansen et al (2012) found that supporting patients through relationships involves eye contact, supportive communication, and active listening. Patients need to share their uncertainties and have their experiences believed. Clinicians can support patients’ hopes by providing clear and accurate information and then regulating the flow of information and providing reassurance (Curtis et al, 2008; Hansen et al, 2012).

Patients can be helped to manage their uncertainty by reframing their situation (Reinke et al, 2010). Clinicians can encourage patients to live one day at a time, pace activities to match energy levels, and set boundaries on uncertainty to avoid it affecting every aspect of life (Mishel, 1999).

Given that patients vary in what and how much information they desire, it is helpful to ascertain what they would like to know. The clinician’s approach to providing hope and to disclosing the prognosis should match the wishes of the patient (Curtis et al, 2008). Curtis et al (2008) reported that patient recommendations for taking a more indirect approach to hope and prognosis included being aware of the patient’s emotional state, affirming non-abandonment, addressing the patient’s fears, providing a clear plan of action, and discussing prognosis outcomes in relation to groups instead of individuals. Recommendations to clinicians for taking a more direct approach to hope and prognosis included providing clear and full communication about the disease trajectory. Knowledge was power for these patients and gave them hope.

Reinke et al (2010) suggested that independent and interdependent nursing activities and provision of prognostic information can foster hope. Independent activities that can foster hope include assessing the patient’s meaning of hope, focusing on quality of life, building relationships, and assessing what the patient knows and following their lead in conversations to determine their needs. Interdependent strategies include knowing what the doctor has told the patient, feeding information from the patient back to the doctor, and continuing discussions with patients after disclosure of bad news. These strategies helped nurses to build a sense of trust with patients and support their hope.

Conclusion

Patients living with advanced lung cancer, as with many other advanced diseases, experience uncertainty and hope. Uncertainty and hope can coexist and, in fact, hope that comes from

uncertainty may be positive. When patients come to accept the ultimate outcome of their disease, hope is not necessarily lost but may be maintained. Clinicians have a vital role in supporting patients' hopes. 

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