Is there hope in palliative care?

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Patients receiving bad news that they have a serious life threatening illness will ask *'What hope is there for me?'* Many feelings surge through the person, their family, friends and their medical carers. One response to the illness is a search between hope and hopelessness. An understanding evolves and changes at times and over time during the course of the illness. Change is the critical process. Hope is no longer a single or concrete phenomenon when one is dying; this is a fundamental in understanding for the patient, their family and the doctor.

This paper explores hope within the context of terminal illness and palliative care, defining its essential influences and effects. Hope does not only apply to the patient but applies to all of those involved, each of whom is searching for their own meanings. Hope is discussed from its origins to effects on the patient, family and their doctor. It appears there are stages of hope similar to the stages of dying. A dynamic understanding of hope can be used to beneficial effect when faced with despair caused by a diagnosis of terminal disease.

Hope?

Hope may be defined in several ways: *'A feeling of desire for something and confidence in the possibility of its fulfilment'*, *'to have a wish'*, *'to trust, expect or believe'*.[1] It is a *'multidimensional dynamic lifeforce characterised by a confident yet uncertain expectation of achieving good, which is realistically possible and personally significant'*.[2] The opposite of hope, hopelessness, is *'having or offering no hope'*, *'impossible to analyse or solve'*, *'unable to learn, function'*, *'without skill or ability'*.[1] Hopelessness in the context of serious illness embodies *'negative expectations about the occurrence of highly valued outcomes'*, e.g. return to full function and prior roles or cure, and also expectation that there will be no way of effecting cure.[2] Hope imparts a sense of future, an expectancy of future good.[3] This plays an important role in coping with the illness, and improves the individual's quality of life. Hope can exist even when time is limited. This is where it evolves to embody all the person's expectations, not simply cure alone. It is the appreciation of their values, family relationships, the control of symptoms, and exploration of spirituality.[3]

Essential elements of hope are:

- **Experience** – accepting what happens as an inevitable part of being,
- **Spirituality** – a higher sense of being,
- **Rational thought** – acknowledging past, present and future life, and
- **Relational** – experience of connectedness with other people.[2]

Sources of hope include family, friends, health carers, and a god or spiritual entity.[3] These are all external sources and we must acknowledge individuals' internal resources of optimism,[4] character and personality.[5]

Hope has sources as well as enemies. Diagnostic gravity may be the first cause of disintegration of hope, driven by a sense of overwhelming powerlessness, denial of possibilities, fear (of dying, powerlessness, psychological and physical pain and personal disintegration) and social withdrawal.[6] A spiritual struggle ensues where existing beliefs are now questioned. Hope is diminished by the loss of important life roles of the person and relationships that go with these.[5] Three factors jeopardise patients' sense of hope:

- Abandonment / isolation
- Uncontrolled pain, and
- Devaluation of oneself as a person.[3]

Hope and the patient

It begins with bad news. Breaking and receiving news that one has a potentially fatal disease is, without overstating it, the most difficult experience for doctor, patient and family. The way in which the news is relayed to the patient can leave a lasting impression. It can support or damage the person's hope and must be handled carefully. At the outset there may be a gap between the person's hopes, expectations and reality of life they are confronting. The person must carefully ease themselves from their existing conceptions, with possibilities of more concrete hopes and expectations, to the reality of the situation, requiring more flexible ideas, to adapt to the disease and illness.[7] Simultaneously it is important to acknowledge there is no way of turn-

ing bad into good news. Initially there will be an unreality about the news with uncertainty created, through which the patient is unable to fully comprehend the entire meaning of the news. Faced with this the doctor and consultation become central to the patient's focus, and a great source of hope in itself. During the consultation there is conflict within the patient regarding wanting and needing to know more but at the same time not wanting certain knowledge. Information assists the patient in differentiating between the disease process and the illness centred on their experience and precipitates various concerns, including:

- Change to functional ability;
- Change in roles;
- Symptoms, especially pain;
- Stress of the illness/disease on the family;
- Loss of control;
- Financial concern and
- Ambivalence regarding the need to know more about the disease and illness process and fearing further bad news.[8]

Initially bad news could produce unrealistic hope or hopelessness, before the person acquires and processes enough information in understandable chunks. Initially the diagnosis of terminal illness removes from the patient a sense of future. Hopelessness may take hold and if sustained may lead to giving up on any future, leading to resignation, despair and passivity. Alternatively a feeling of hope gives people energy and courage to continue.[2] When bad news is communicated it can almost always be done with a hopeful element woven into it.[3] Loss of hope may lead to depression which in itself is a predictor of morbidity and mortality and has been observed to increase the patient's wish for a hastened death fourfold over similar patients who were not depressed.[14] Many patients initially relate hope with successful treatment and cure of their disease, which may not be realistic.[3] A redefinition of hope is needed to re-conceptualise this changing and uncertain future. Indeed uncertainty may be important in the development of illusion, allowing the person to adapt positively to the news by creating an optimistic outlook.

The adaptive process does not start when diagnosed, but is the summation of affective and cognitive states that have been evolving within the person over their lifetime, having roots in their understanding of well-being.[4] Fundamental to this is the persons underlying personality and character.[5] Well-being is a state of feeling contented, healthy or successful,[1] and whilst it is a summation of life experience it is also a major contributor to how one feels about one's own life. Therefore those with positive life experiences often feel good about life. Those who feel good often feel positive about life. Well-being attempts to remain constant in the face of change. Adaptation occurs when a diagnosis is received in order to normalise or maintain as much as possible their sense of well-being.[4] This in association with the personality and character of the individual influences their response to the bad news by deploying optimism. It is more likely that a person with positive attitudes and previous achievements to be optimistic compared to an individual with poor expectation and a series of failures in the past.[5] One's ability to adapt to illness may be explained by expectation and a sense that things will be better in the future. Optimists are more adaptable.[4] However adaptation implies that expectations are dynamic and therefore the sort of things that will be better in the future also can change, rather than remaining fixed, possibly leading to disappointment.

Optimism is a stable personality characteristic, predicting a person's ability to cope with life events. Optimists are said to have a higher level of well-being and are more likely to possess a problem focused ability to cope than pessimists. An individual's optimism is a predictor of their expectation, and therefore future well-being. Likewise expectations are major predictors of motivation to act in the interest of achieving desired outcomes. A person's ability to act is affected by their beliefs about likely outcome of their actions. When desired outcomes become unlikely the person may cease to strive for them. Interestingly, when a situation appears uncontrollable an optimist is more likely to accept this, expressing their adaptability, and willingness to change their expectations in concert with their reality. This is advantageous for the person's coping, as denial or adherence to false expectations is often associated with poor coping. Optimism can therefore affect expectations and behaviours[4] and is a major determinant of hope in the face of suffering.

News of terminal disease creates threat to the well-being and integrity of the person in a physical, psychological, social and spiritual sense. The result of diagnosis and changes that occur as a consequence of disease is illness and suffering. Cassell defines suffering as *'a state of severe distress associated with events that threaten the intactness of the person'.* Suffering will prevail until threat has passed or the person has adapted, thus maintaining his or her own bio-psychosocial and spiritual integrity, or well-being. It follows that a determinant of hope in the face of disintegration and suffering is transcendence utilising internal resources such as one's personality and character, one's past and its associated experiences. Personal meaning is something the patient strives for in their quest for hope whilst suffering.[5] Achievement in the past may allow self-confidence and optimism giving rise to new hope. Ability to transcend is buried within one's personal life meaning.

People attempt to find meaning beyond their suffering, allowing them to make sense out of things. This in essence is spirituality. In search for meaning, transcendence from suffering may be achieved. Two elements of transcendence exist. Firstly, when one is faced with disintegration, situational transcendence is the immediate reaction. Important challenges here are hope, purpose, meaning, mutuality, connectedness and social presence.

Focus is on the immediate physical disease threat. Secondly, a moral and biographical transcendence comes into play. This less immediate response becomes more important once situational needs are met. Focus then shifts to more spiritual needs of the person.[9] The concept of transcendence appears integral to the person's establishment and maintenance of hope.

Stages of Hope

In 1969 Elizabeth Kubler-Ross published her book '*On Death and Dying*'[10] in which she described five stages of dying:

1. Denial and isolation
2. Anger
3. Bargaining
4. Depression
5. Acceptance

This was the first discourse on the change in the dying process and spoke of adaptations required by patients during the terminal phase of illness. Adaptation, cognitively and affectively, as stated is an important determinant of the person's maintenance of well-being, by adjustment to disease and normalisation of their existence.[4] It is suggested that there are likewise five stages of hope facilitating adaptation throughout the terminal illness that determine the person's well-being. These stages also allude to change and resolution within the patient over time, in much the same way as the five stages of dying do. However the Kubler-Ross stages are less linear as one moves to and fro between stages during the time-course of an illness. The Hope concept is espoused by an Australian survivor of osteosarcoma, Ian Gawler, who facilitates workshops for medical professionals and patients at the Yarra Valley Living Centre in Victoria Australia. A veterinarian surgeon by training, he later set up the Gawler Foundation for support of people with cancer. The five stages of hope are:

1. Hopelessness
2. Hope for survival
3. Hope for a better future
4. Hope for spiritual realisation and or enlightenment
5. Hope for fulfilment in this present moment.[6]

A patient moves through each stage sequentially, accomplishing each task prior to moving up to the next. As with Kubler-Ross's paradigm there is no guarantee every patient necessarily reaches the fifth stage, owing to individual response to illness and the time course of the terminal phase. Given reality of terminal illness, however, it is important to evolve as disease inevitably progresses, otherwise hopes and expectations may become unrealistic, with subsequent passivity and helplessness adversely casting the patient in despair. The journey from hopelessness to fulfilment in the present moment is not an insignificant one. Achievement, however, may well be the key to passing hope on to all those around, as it defines profound realisation and contentment equating with the final stage of acceptance, proving that one can face inevitable death with hope intact.

Hope and the doctor

Ideas regarding hope in patients with terminal illness equally apply to doctors. Doctors are uniquely placed to help patients realise their hope. From the outset they can either assist or damage the patient and family as a result of their own interpretation and projection. Central to all medical practice, including palliative care, are the four principals of ethics, autonomy, beneficence, justice and non-maleficence. A doctor must respect a patient as an individual, investigate, inform and treat for the benefit and not to the detriment of the patient and provides access equitably to all appropriate care available at the time and place. Doctors must ethically assist patients in their realisation of hopes, help to maintain or restore their sense of being, and help the person come to terms with eventual death. By being aware of the importance of hope doctors can encourage patients to see past their immediate situation and help to sustain them.[11] A doctor should attempt to approach a patient with an understanding of the complex and changing nature of hope, and how it evolves in the dying person. It is unfortunate that doctors may, either consciously or unconsciously, misrepresent hope as cure. Terminal illness and hope are, sadly, often not considered mutual in this context.

Doctors may also misrepresent hope by delivering bad news with an exaggerated and misguided promise of potentially curative treatments that can promote false optimism in the patient, creating false expectations of investigations, treatment and cure.[3] This is not to say that a pessimistic approach is correct. Appropriate establishment of hope assists the person moving on from initial bad news to cope with what follows. By appropriately phrasing hope, the patient can gently adjust to the diagnosis.[2] This may motivate the person to continue with appropriate and useful beliefs and activities.

The hope given must be realistic and information should be kept open ended and given in small amounts repeatedly over time so that the person can digest what they have been told and affectively and cognitively adjust to it.[7] Good communication underlies the doctor's effectiveness in providing the patient information that is relevant to them and can be clearly understood. Doctors' abilities in communicating information influences patient behaviour and outcomes such as symptomatic and functional status, satisfaction with care and ongoing engagement with treatment plans. Effective communication may be impaired by values, expectations, goals and knowledge differences between doctor and patient.[8] Other essential elements include age, cultural and religious factors, and the underlying cognitive and affective makeup of the person.

At the outset, doctors attempt to bring more certainty and stability into the patients' lives by providing small goals in investigations and treatments. This 'medical activism' is probably the result of a strong need for control and giving hope. Dividing information and activities into smaller amounts with optimistic and attainable goals inevi-

tably improves the patient optimism in the short term. However, failure to provide essential information to the patient may lead them to a cascade of treatments without realistic insight. Then the patient lives completely within the medicalised moment, which is full of medical activity and hope, without due regard for the likelihood of unpleasant outcomes and their own mortality. This may well produce false optimism about their recovery.[12]

Unrealistically optimistic approaches may lead to the patient making counterproductive choices and high expectation that treatment will provide cure, rather than opting for more appropriate and timely palliative approaches.[13] Establishing unrealistic hope may paradoxically increase suffering by encouraging futile investigation and treatments causing possible harm and betraying hope already established. In much the same way the patient may become stuck at an inappropriate treatment stage, caste at a point in the evolution of hope that denies them timely and successful progress to the following stage.[6] If a person remains at stage two, 'Hope for survival', it may be too late for them to realistically adjust to their situation, denying them the subsequent quality of life they could have achieved during their terminal stages.

A fine line exists in the care of a patient with terminal illness between giving hope, whilst not raising false optimism. Doctors do not wish to pronounce a death sentence and patients do not want to hear this pronouncement, and so the doctor is led into goal oriented 'medical activism' and the patient into focused adherence in a treatment and recovery plan that probably cannot be realised.[12] It might be better for the patient to realise earlier the likely reality, which gives them more time to appropriately adjust to the new demands and achieve more personal goals rather than spending time and energy on medical interventions alone. It is the doctor's role to maintain an open view for the patient so they do not become bio-medically entrapped and miss out not only on their primary hope for a cure but also the chance to transcend through the stages of hope to more appropriately manage their own last months, weeks, days or hours alive.

Hope in palliative care?

When confronted by apparently pointless, seemingly endless suffering, how is hope maintained? When a person's entire self is altered by disease and there is little they appear to be able to do to restore their biological, psychological and social integrity, they have lost control and life feels as if it has lost meaning. An important factor in restoring hope is to re-establish meaning in their life. Suffering incorporates two concepts, a sense that it has no end, and a sense of helplessness. Giving endpoints to suffering establishes a sense of control and restores hope in life. Control is an antidote for helplessness, which is closely aligned to hopelessness. A patient with a sense of control will express more hopefulness.

An important message for patients and their family is that hope is a changing entity. Initially they will swing between the extremes of hope and hopelessness. As time goes by and realisation sets in there is a redefinition of the meaning of hope. Much like travelling through a funnel, as death comes closer, the definition of one's hopes sharpen, becoming focused on more attainable goals. Hope remains important for the person to maintain momentum in their life and so ought to be fully supported up until the end. Doctors must understand the importance of hope, its determinants within and outside the person and the main detractors to the sustenance of hope, and should be willing to help patients readjust to the challenges they face and tap into their internal resources so they might transcend, reaching appropriate goals. It is helpful to understand why some people give up, why some fight and why others accept. Appreciation of the person's life, their previous experiences, successes and failures, their social interconnections, their personality and character are important in restoring well-being at some level. Hope and optimism are intertwined with well-being. Optimists have a more adaptable nature and at no time like during terminal illness is adaptability important. Even when a person is dying, hope is indispensable.

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