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Hope in advanced cancer patients

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ABSTRACT

Individuals diagnosed with advanced cancer frequently experience physical and psychological distress. Hope has been identified as an essential resource in the lives of people with cancer, helping them to cope during times of suffering and uncertainty. Therefore, in order to help bolster hope, health care providers require an understanding of its meaning from the perspective of advanced cancer patients and an awareness of those interventions demonstrated empirically to foster hope in this patient population. This paper summarises salient evidence pertaining to hope in advanced cancer patients and their families or informal caregivers. We examine the challenging issue of how to define hope, discuss the issue of measuring hope and review the state of evidence addressing interventions that may enhance or bolster hope in the face of advanced disease.

1. Introduction

Roman author, orator and politician Cicero observed, 'to the sick, whilst there life is there is hope'.[1] Hope in the field of cancer care is often conflated with hope for a cure.[2] When a person is diagnosed with advanced cancer, however, cure is not possible, prolonged survival is doubtful and life may seem anything but hopeful. Individuals living with a terminal illness often experience physical and psychological distress, as well as loss of meaning, purpose and a fractured sense of dignity.[3–7] How then is hope to be understood within the context of terminal illness? Of what does it consist? What interventions might clinicians and researchers implement to bolster hope in the terminally ill and their families and how might these interventions be evaluated? This paper summarises salient evidence pertaining to hope in advanced cancer patients and their families or informal caregivers. We examine the challenging issue of how to define hope, discuss the issue of measuring hope and review the state of evidence addressing interventions that may enhance or bolster hope in the face of advanced disease.

2. The importance of hope in advanced cancer

The concept of hope figures prominently in end-of-life care discourse.[8–10] The empirical literature demonstrates both the importance of hope to terminally ill patients and the integral role hope appears to play in advanced cancer patients' psychosocial well-being. Ninety-nine percent of terminally ill patients ($N = 120$) interviewed by Geisinger and colleagues[11] identified having a sense of hope as a salient existential concern. An integrative literature review conducted by Lin and Bauer-Wu[12] identified that living with meaning and hope is a major component of psycho-spiritual well-being in the terminally ill and that those patients with an enhanced sense of psycho-spiritual well-being are able to cope more effectively with the terminal illness experience.

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The findings of many studies demonstrate that living with hope is a significant factor that assists individuals to adjust to their cancer illness, reduce their psychological distress and enhance their psychosocial well-being and quality of life.[13–18] Conversely, hopelessness – defined as experiencing an insurmountable situation wherein no goal attainment is expected[19,20] is associated with depression and the desire for hastened death and is correlated with suicidal ideation and suicidal intent.[21–23] Therefore, an understanding of what hope is and how it may be fostered in those with advanced cancer is clearly warranted, as it constitutes an important part of the therapeutic landscape of end-of-life care.

3. Conceptual challenges: defining hope

Despite both its ubiquitous nature and putative role in dealing with end-of-life concerns, a clear understanding of the term has yet to be realised.[24,25] Dictionary definitions provide a starting point from which to glean an understanding of what hope means. Etymologically, hope is derived from the Old English 'hapian' which means 'to wish, expect and look forward to'.[26] When used as a noun, The Oxford English Dictionary[27] defines hope as a feeling of expectation and desire for something to happen; and a person or thing that gives cause for hope. Hope can also function as a verb, wherein a person expects and wants something to happen (e.g. I hope). Defined in these ways, hope contains notions of an individualised, future orientation, implies active participation on the part of an individual and references the possibility of a positive outcome.[8]

Various definitions of hope have been advanced in medical, nursing, theological, psychological and philosophical literature[28–31] and its components have been examined from the perspectives of children,[32] adolescents[33] and the elderly.[34,35] Whilst no universal definition of hope exists in the literature,[36] what is apparent is that any conceptualisation of hope must reflect its complex, process-oriented, multidimensional, dynamic, individualised and future-oriented nature.[25,37]

An important strategy used to clarify the meaning of words is the process of concept analysis. This formal linguistic strategy facilitates the examination of the defining characteristics or attributes of a concept.[38] Concept analyses of the term hope have been conducted,[39–41] though minimal attention has been directed towards explicating the essential attributes of hope from the perspective of the terminally ill. A notable exception is the work conducted by Johnson[41] who used concept analysis methodology to delineate 10 attributes of hope in this patient population. They included: (i) positive expectation – establishing a positive outlook with hopes for a better tomorrow despite a grim prognosis; (ii) personal qualities – an inner strength and problem solving approach to life and the attainment of important goals; (iii) spirituality – connections to a higher being; hope of an afterlife and reunion with loved ones and finding purpose in the remainder of life to be lived; (iv) goals – the setting and attainment of short-term goals; (v) comfort – being pain free and comfortable; (vi) help/caring – behaviours of others such as touch, listening humour and the provision of honest information; (vii) interpersonal relationships – loving relationships with friends and family; honest relationships with health care providers; (viii) control – some degree of input and choice regarding care decisions; (ix) legacy – leaving behind something of value to others and (x) life review – acknowledgements of past achievements and contributions to the lives of others.

Though Johnson's work does not reflect a culturally diverse understanding of hope and is limited to the perspective of adults, it nonetheless provides direction about the kinds of strategies and interventions that may be effective in supporting hope in those with advanced disease. The attributes Johnson identified appear to be congruent with the findings of qualitative studies examining the strategies initiated by patients themselves to maintain hope in the face of advanced cancer, thereby supporting the rigour of her conceptual analysis of hope.[17,42,43] Though the sample sizes are small and the findings cannot be generalised, taken as a whole, the research suggests that the strategies patients most commonly used included religion and prayer; living in the present; relationships with others; control of symptoms; situational control; positive thinking and focusing on positive memories.[44]

Health care providers and researchers can use their knowledge of the attributes of hope to develop and test interventions aimed at maintaining and bolstering hope in patients with advanced cancer. For example, pain is recognised as impacting on all dimensions of cancer patients' quality of life.[45] Underlying reasons for hopelessness may be related to fears of a painful death and poor symptom management.[46] That comfort is related to hope in advanced cancer patients underlines the need for clinicians to ensure meticulous pain management and symptom control by assessing routinely for symptoms and initiating evidence-based treatments.[47]

Whether secular in nature or religiously framed, spirituality has also been identified as an important component of hope[48] and The Institute of Medicine (IOM) identifies spiritual well-being as an important domain of quality supportive care of the dying.[49] Spiritual pain and suffering that attack the social and psychological intactness of a person may manifest as physical symptoms, psychological distress, a crisis of faith or disintegration of social relationships.[48,50] Thus interventions aimed at mitigating spiritual suffering and existential pain, whilst supporting patients' hope, have the potential to impact positively on multiple facets of the illness experience. Both general and specific spiritual care approaches used in end-of-life care have been reported in the literature.[48]

Legacy and life review activities were identified by Johnson[41] as contributing to patients' hope. Such activities may help terminally ill individuals to feel that their life has order and purpose, thereby negating the existential challenges created by a terminal diagnosis.[51–53] Chochinov and colleagues[54–57] have developed and tested a brief, individualised, empirically based psychotherapeutic intervention, known as dignity therapy, aimed at alleviating suffering and engendering a sense of meaning and purpose in patients with advanced disease. Dignity therapy facilitates review of one's life and provides the opportunity for the dying to reflect upon issues that matter most to them or speak of things they would most want remembered as death draws near. Dignity therapy sessions are tape-recorded, transcribed and edited, with a final version being returned to the patient who can bequeath it to an individual(s) of her/his choice. Specific details about the dignity therapy protocol have been published elsewhere.[54]

Research conducted with palliative care patients from Canada ($N = 50$) and Australia ($N = 50$) has demonstrated the feasibility of dignity therapy and determined its impact on various measures of psychosocial and existential distress including depression suffering, hopelessness, sense of purpose, sense of meaning, desire for death, will to live and suicidality.[5] Study findings indicate that dignity therapy shows promise as a potent intervention for ameliorating suffering and distress at the end of life. Participants in the study reported an increased sense of purpose (68%); a heightened sense of meaning (67%) and increased will to live (47%). Following dignity therapy, measures of suffering showed significant improvement ($P = 0.023$) and depressive symptoms were reduced ($P = 0.05$). Results also indicated that participants believed that dignity therapy had helped or would be of help to their family members. This belief correlated significantly with life feeling more meaningful ($r = 0.480$; $P < 0.0001$); having an increased sense of purpose ($r = 0.562$; $P < 0.0001$); lessened sense of suffering ($r = 0.327$; $P = 0.001$) and increased will to live ($r = 0.387$; $P < 0.0001$). Data collected from bereaved family members of terminally ill patients who had taken part in dignity therapy ($N = 60$), also endorsed it as an intervention that heightened the patient's sense of purpose (78%); reported that it helped the patient prepare for death (65%) and reduced the patient's suffering (43%).[58]

Duggleby and colleagues[59] used a concurrent nested experimental design to evaluate the impact of a psychosocial supportive intervention called the 'Living with Hope Program' (LWHP) on the outcome variables of hope and quality of life in a sample of 60 terminally ill cancer patients with a mean age of 74.9 years. Patients in the intervention group watched a film about hope and were asked to work on their choice of a hope activity (e.g. writing a letter; beginning a hope collection and beginning an 'about me' over a period of one week). Compared to controls, patients receiving the intervention had statistically significant higher hope ($U = 255$, $P = 0.005$) and quality-of-life scores ($U = 294.5$, $P = 0.027$). Ongoing research is needed to determine the efficacy of this intervention in younger cancer patients; those from varied cultures and amongst in-patients who may have a poorer functional status.

4. Family caregivers' perspectives on hope

The unit of care in advanced cancer care is the patient and family.[60] Therefore, any discussion of hope in advanced cancer must also include family caregiver perspectives.[61] Research examining the experience of hope for family caregivers of critically and terminally ill patients though limited, reveals several important findings. First, hope within family caregivers appears to have a reciprocal role in the maintenance of patient hope,[31,62] suggesting that interventions designed to bolster family member hope will have a salutatory effect on patients' experience of hope. Second, caring for a terminally ill loved one, whilst rewarding, is also stressful and demanding.[61,63] Research demonstrates that family caregivers experience negative changes in their own physical and mental health, both during the illness and in the bereavement period.[64] To prevent family caregivers from becoming our future patients, health care providers must be prepared to assess hope in family members and intervene with them in ways that help them shore up hope.

Qualitative research findings provide guidance as to what interventions might foster hope in family caregivers. Herth[31] conducted a longitudinal study exploring the meaning of hope, the influence of specific background characteristics on hope and strategies used to foster hope in a convenience sample of caregivers of terminally ill patients ($N = 25$). Strategies emerging from content analysis of interview transcripts revealed strategies that served to foster hope. They included: (i) involvement in relationships perceived to be warm and nurturing; (ii) cognitive reframing of threatening perceptions into a more positive frame through the use of positive self talk, meditation and humour; (iii) living in the moment; (iv) holding attainable expectations and focusing on a sense of 'being with' as opposed to 'doing' as death draws near and (v) practising spiritual beliefs and balancing available energy. In contrast, factors identified as interfering with hope included a sense of isolation; feeling overwhelmed due to concurrent cumulative losses and the patient's symptoms being poorly controlled. Future research is needed to develop and evaluate the effect of specific interventions aimed at developing and maintaining hope in family caregivers.

Holtslander and Duggleby[65] conducted a grounded theory study of hope with a sample of family caregivers of palliative patients ($N = 10$). They identified difficulty in communicating with health care professionals, which consisted of feeling depersonalised and receiving too many negative messages, as eroding caregiver hope. The importance of hope in communication between health care providers and family members was also identified by Kirk and colleagues in a qualitative study of 21 palliative care patient–family member dyads. They examined their experiences about the process of diagnostic disclosure and their satisfaction with the ways information was shared with them during the illness trajectory.[66] Content analysis of interviews revealed that even when patients were aware and accepting the terminal stage of disease, they still needed to hear hopeful messages from health care providers, including the possibility of a miracle.

Whilst research suggests that some patients and health care providers prefer to avoid detailed discussion of the patient's condition and prognosis in order to preserve hope, a recent systematic review conducted by Clayton and colleagues[2] about sustaining hope whilst communicating with terminally ill patients and their families suggests that patients and caregivers tend to prefer an exchange of honest and accurate information, delivered in an empathic and understanding manner. Exchanges that patients and families experience as hopeful with health care providers include such things as assurances about pain control; being knowledgeable about the patient's cancer and answering the patient's questions and using humour appropriately and supporting patient dignity. Conversely, poor communication with health care providers in the context of cancer care is associated with inadequate pain management, heightened anxiety and depression, ineffective coping, reduced quality of life and hopelessness.[67,68] Far from being merely a matter of bad manners or the absence of social graces, poor communication between patients, families and health care providers that diminishes hope has significant untoward psychosocial sequelae. Therefore, efforts aimed at improving honest patient–professional communication, in addition to enhancing the effectiveness of the clinical encounter, may help support patient hope as well.

Preliminary research using a mixed-method, concurrent triangulation, pre- and post-test design conducted by Duggleby and associates[69] has evaluated a potentially promising intervention aimed at fostering hope in family caregivers ($N = 10$) of advanced cancer patients. Based on theoretical foundations of hope identified in their previous qualitative research examining the process of hope in family caregivers, the intervention consists of having caregivers watch a video about hope and make 5 min daily journal entries reflecting on their caregiver challenges and what gave them hope that day. Findings from the pilot study, though limited by the small size, demonstrated increases in mean scores on the outcome variables of hope and quality of life.

5. Measuring hope

Interventions aimed at supporting hope in advanced cancer patients require evaluation. Any tool or instrument selected for this purpose needs to have both a strong theoretical base and be psychometrically sound.[61] The issue of subject burden must also be considered when working with those with advanced disease, many of whom may be weak and fatigue easily.[70]

Instruments designed to measure hope have been developed.[19] A full review and critique of these tools is beyond the scope of this article. The Herth hope index (HHI),[71] an instrument with demonstrated psychometric properties that has performed well when used in advanced cancer populations and their family members, warrants description.

The Herth hope index (HHI) is a brief, 12 item Likert scale designed to assess hope in adults in clinical settings and takes approximately five minutes to complete. Scores range from 1 to 4, where 1 is ‘strongly disagree’ and 4 is ‘strongly agree’. Total scores can range from 12 to 48, with higher scores being indicative of higher levels of hope. Psychometric properties of the HHI have been established, with Cronbach’s alpha coefficient of 0.91 and test–retest reliability at two weeks of 0.91 in a convenience sample of acutely, chronically and terminally ill adults ($N = 172$). Criterion-related validity of the HHI was established based on correlation coefficients with the longer parent scale from which it was derived ($r = 0.92$), the existential well-being scale ($r = 0.84$) and the Nowotny hope scale ($r = 0.81$). A robust negative correlation with the Beck hopelessness scale established divergent validity ($r = -0.73$). Construct validity was established by factor analysis, with three factors identified: (i) temporality and future; (ii) positive readiness and expectancy and (iii) interconnectedness, accounting for 41% of the total variance. The HHI has subsequently been used successfully with homeless families, older adults in community and institutionalised settings and has been translated into Swedish, where it has been used with adult palliative care patients.[72–74]

6. Summary

Hope plays a vital role in the experience of advanced cancer patients and their family members. Intimately bound with suffering, yet inextricably linked to coping, ‘hope serves as a buffer to stress, and is a significant factor in physical and mental well-being’.[31] Delineation of the essential attributes of hope has provided the foundation from which theoretically sound and empirically derived hope-fostering interventions can be mounted. The evaluation of such interventions is appearing in the palliative care literature. Future research is needed, which validates specific interventions aimed at supporting hope across the lifespan and in diverse ethnic populations. Longitudinal studies will contribute to an understanding of the temporal stability of hope over the course of the illness trajectory. In conjunction with extant works, findings from future studies will provide health care providers with a solid evidence base from which to support patients’ and families’ experiences of hope in the face of advanced disease.

Conflict of interest statement

None declared.

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