PM GLYNN
INSTITUTE

The re-framing of hope in palliative care

ACU
AUSTRALIAN CATHOLIC UNIVERSITY

The re-framing of hope in palliative care

Dr. Cris Abbu

PM Glynn Institute
Australian Catholic University

Abstract

Hope plays a pivotal role in difficult times. Often sickness or ill health has hopelessness associated with it. Sustaining hope is part of caring for people with life-limiting illness. But what is hope? Hope is a "multidimensional dynamic life force characterised by a confident yet uncertain expectation of achieving future good, which, to the hoping person is realistically possible, and personally significant" (Dufault and Martocchio, 1985, p.360). Its effects on patients at end-of-life are well known. At its essence, it is closely connected with quality of life.

This paper delves into the role of hope in patient care. It discusses the need to adopt a more holistic approach to palliative care provision - one that incorporates and recognises the incredible significance of sustaining and nurturing hope in patients with life-limiting illness. In particular, this paper suggests the need to re-frame hope as an essential component of quality palliative care. It is envisioned that this paper will induce further discussion on the role of hope in palliative care and will act as a stimulus for the adoption of hope-engendering initiatives for palliative care patients in Australia.

Introduction

In December 2018, the PM Glynn Institute conducted a survey on hope, trust and belonging. It attempted to investigate underlying attitudes and concerns that shape responses to current political, social and ethical issues in Australia. The survey involved 3000 randomly selected respondents aged 16 years and above. One of the questions posed in the survey concerned the respondents' stance on palliative care as a human right, specifically stated as:

"Where do you stand on the following human rights issue? Protecting the rights of the terminally ill people to receive high quality palliative care and pain control, in preference to legalising assisted suicide or a 'right to die'".

The following were the results:

	(N)	(%)
Support	1758	58.60%
Neutral	723	24.10%
Oppose	519	17.30%
Total (N)	**3000**	**100.00%**

Nearly 60% of respondents supported high quality palliative care for people with a life-limiting illness. Only 17% of respondents opposed it while 24% were neutral. If a significant number of respondents supported high quality palliative care, the question that begs asking is: What is quality palliative care?

The role of hope in quality palliative care

According the World Health Organisation (2019), palliative care is the prevention and relief of suffering by means of early identification and exemplary assessment and treatment of pain and other problems, including physical, psycho-social and spiritual. The WHO outlines some its key characteristics:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if needed;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Crucial to this definition is the integration of the psycho-social and spiritual aspects of patient care. Psycho-social aspects of care refer to care for the patient's distress and pain over loss of independence, loss of relationships and loss of faith (Casey and Doyle, 2021; Best et al., 2015; Monforte-Roy et al., 2010). People with life limiting illness often describe their worst pain as psycho-social pain. They also deal with this pain by maintaining hope (Duggleby, 2000). Hope is a psycho-social need.

Hope has been described by patients, particularly those at the end of life, as an inner resource, a coping mechanism for their quality of life. According to Duggleby and Wright (2005, p.76), patients associate hope with "not suffering anymore", "living life to the fullest in the time they had left", peaceful death, life after death, and a better future for their families. Moreover, as noted by Olsman and Duggleby (2014), hope is related to patients' psycho-spiritual wellbeing and can be defined as finding meaning in life, finding future-oriented goals or having a positive perspective in life. Dufault and Martocchio (1985, p.360) note that hope is a "multidimensional dynamic life force characterised by a confident yet uncertain expectation of achieving future good, which, to the hoping person is realistically possible, and personally significant".

The effects of hope

The effects of hope are well known. Various studies have recognised its importance particularly to those with life-limiting conditions. It is positively correlated with quality of life (Esbensen et al., 2007; Vellone et al., 2006; Duggleby and Wright, 2005). For example, in a study of patients with cancer, hope was positively correlated with quality of life (Vellone et al., 2006). Hope was also considered a resource, a coping strategy for people living with cardiovascular diseases, Parkinson's disease, and other diseases (Arrnaert et al., 2006).

Increasing hope and quality of life for patients with life-limiting illness has been the focus of psycho-social, hope-fostering strategies and interventions. These interventions include the following: the application of self-awareness and reflection activities by nurses and other palliative care health professionals; positive communication strategies so that the worth and value of patients are affirmed; collaborating with the patients in all aspects of care (e.g., creating a partnership, taking time to listen and talk to the patient); adopting a holistic approach to care (e.g., helping the patient to focus on everyday life in the present moment, assisting in maintaining interest in their hobbies, helping them participate in creative arts projects); giving emotional support (e.g., being optimistic, focusing on the positive aspects, having a sense of humour); supporting the patient's hopes and wishes (e.g., showing of video interviews with other palliative care patients describing their hope and how they maintain hope); helping patients with their relationships; and, facilitating their expression of spiritual beliefs (Kylma et al., 2009).

Studies point to the positive impacts of these hope-engendering interventions. In a study on cancer patients in three palliative care services in Sydney, the importance of strategies to nurture and maintain hope was emphasised by patients, caregivers and their palliative care team. Patients linked hope to positive feelings of self-worth and value as an individual, including finding meaning in their situation (Clayton et al., 2005). In another study, interventions to nurture hope were cited as important because they helped patients deal with an uncertain future (Rittman et al., 1997). Using a randomised trial on older palliative care home care patients, Duggleby et al. (2007a; 2007b) initiated an award-winning intervention - a video on hope and a hope activity to work on over a period of one week. Patients who received the intervention, called "Living with Hope Program", had statistically significant higher hope and quality of life scores after the intervention compared to the control group with no intervention. These impacts are also highlighted in other hope engendering studies (Buckley and Herth, 2004; Kennett, 2000; Koopmeiners et al., 1997).

Re-framing palliative care provision

Surprisingly, the role of hope and the importance of maintaining it is not usually considered in palliative care provision (Caresearch Australia, 2017). As Feudtner (2015) cites, hope is like water because it is part of human nature, existing in different states, with different properties. In end-of-life contexts, hope of patients and that of their families changes as the end-of-life journey progresses. Hope changes from hope of being cured to hope about having a better quality of life despite the prognosis, such as not having distressing symptoms, having the chance to tie-up loose ends, reconciling relationships or re-establishing connections, and leaving behind some kind of legacy. Hope also changes to hope in life after death (Caresearch Australia, 2017). Hence, there is a need for increased awareness of the importance of hope for people with life-limiting illness. Given that people at end-of-life have a variety of needs that are linked to all aspects of their personhood, a holistic approach that places significance to the role of hope in the provision of palliative care is crucial. As Miller (2007) argues, hope is a central concept in caring for patients at end-of-life. They need to be nurtured, respected, affirmed and valued. This puts an incredible importance on sustaining hope as a significant aspect of a holistic approach to palliative care.

Conclusion

Strong support for protecting the internationally-recognised human right of people with life-limiting illness to receive quality palliative care in preference to legalising assisted suicide or a ‘right to die’ was one of the important findings of the PM Glynn Survey on hope, trust and belonging. The central idea of this paper rests on the premise that quality palliative care integrates interventions that support and maintain hope for these patients. Given the evidence pointing to the correlation of hope with better quality of life even at the end-of-life of a person, understanding and recognising the significant role of hope is a first step towards a more holistic approach to palliative care provision. Needless to say, hope is a very important component of palliative care. Overall, it is envisioned that this paper will encourage further discussion on the role of hope, including the adoption of strategies and interventions that sustain it for palliative care patients. This paper can also provide a starting point for a more focused study on hope engendering initiatives for palliative care patients in Australian contexts.

Bibliography

Arrnaert, A., Filteau, N., Sourial, R. (2006), *Stroke patients in the acute care phase: Role of hope in self-healing,* Holistic Nursing Practice, 20, 137-146.

Best, M.C., Aldridge, L., Butow, P.N., Olver, I.N., Webster, F. (2015), *Conceptual analysis of suffering in cancer: A systematic review*, Psycho-oncology, 24(9), 977-86.

Buckley, J., Herth, K. (2004), *Fostering hope in terminally ill patients*, Nursing Standard, 19, 33-41.

Caresearch Australia (2017), *Helping to maintain hope,* viewed 8 April 2021, http://www.caresearch.com.au/caresearch/tabid/2715/default.aspx

Casey, M., Doyle, J. (2021), *Speaking of Suffering: towards a conversation about death and dying,* PM Glynn Institute Occasional Paper No. 2.

Clayton, J., Butow, P., Arnold, R., Tattersall, M. (2005), *Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers,* Cancer 103 (9),1965-75.

Duggleby, W. (2000), *Elderly hospice cancer patients' descriptions of their pain experiences,* American Journal of Hospice Palliative Care, 17 (2), p. 111-117.

Duggleby, W., Wright, K. (2005), *Transforming hope: How elderly palliative care patients live with hope*, Canadian Journal of Nursing Research 37(2): 70-84.

Duggleby, W., Degner, L., Williams. A. et al. (2007a), *Living with hope: Initial evaluation of a psychosocial hope intervention for older palliative home care patients,* Journal of Pain and Symptom Management, 33, 247-257.

Duggleby, W., Wright, K., Williams, A. et al. (2007b), *Developing a living with hope program for caregivers of family members with advanced cancer,* Journal of Palliative Care, 23, 24-31.

Dufault, K., Martocchio, B.C. (1985), *Symposium on compassionate care and the dying experience. Hope: its spheres and dimensions,* Nursing Clinics of North America, 20(2): 360.

Esbensen, B.A., Osterlind, K., Rahm Hallberg, I, (2007), *Quality of life of elderly persons with cancer: A 6-month follow-up*, Scandinavian Journal of Caring Sciences, 21, 178-190.

Feudtner, C. (2015), *Responses from palliative care: Hope is like water,* Perspectives in Biology and Medicne, 57 (4), 555-557.

Kennett, C.E. (2000), *Participation in a creative arts project can foster hope in a hospice day centre,* Palliative Medicine, 14, 419-425.

Koopmeiners, L., Post-White, J., Gutknecht, S. et al. (1997), *How do health care professionals contribute to hope in patients with cancer,* Oncology Nursing Forum, 24, 1507-1513.

Kylma, J., Duggleby, W., Cooper, D., Molander, G. (2009), *Hope in palliative care: An integrated review*, Palliative and Supportive Care, 7, 365-377.

Miller, J.F. (2007), *Hope: A construct central to nursing,* Nursing Forum, 42, 12-19.

Monforte-Roy, C., Tomas-Sabado, J., Villavicencio-Chavez, C., Balaguer, A. (2010), *The wish to hasten death: A review of clinical studies*, Psycho-oncology, 20(8), 759-62.

Olsman, E., Duggleby, W. (2014), *Improving communications on hope in palliative care: A qualitative study of palliative care professionals' metaphors of hope: grip, source, tune and vision*, Journal of Pain and Symptom Management 48(5):831-838.

Rittman, M et al. (1997), *Phenomenonogical study of nurses caring for dying patients*, Cancer Nursing, 20, 115-119.

Vellone, E., Rega, M.L., Galletti, C. et al. (2006), *Hope and related variables in Italian cancer patients,* Cancer Nursing, 29, 356-366.

WHO (2021), *Palliative care,* viewed 2 April 2021, https://www.who.int/health-topics/palliative-care.

The PM Glynn Institute was established by Australian Catholic University (ACU) in 2016 as a public policy think tank to analyse issues of concern to the Catholic Church and the wider Australian community. Its focus is public policy for the common good.

pmg@acu.edu.au

pmglynn.acu.edu.au

This information has been researched and compiled by Dr. Cris Abbu, PM Glynn Institute.

Cover image: Robert Moore, *Red Table Vase*, 2016. Oil and enamel on board.
Australian Catholic University Art Collection.

ACU
AUSTRALIAN CATHOLIC UNIVERSITY