

# The Importance of Patient Dignity in Care at the End of Life

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## PREFACE

James Alexander Logan, a second-year medical student at the Barts and The London School of Medicine and Dentistry, died in February 2001 after a painful illness. A Trust was set up in his name in 2003 to promote education in the recognition and treatment of cancer pain and it provided funds for an annual essay prize, open to those undergraduate medical students of Queen's University, Belfast, who had completed their fourth year palliative care teaching. The first competition took place in 2010 and the winning entry appeared in the Ulster Medical Journal in 2011.

The Trust itself was dissolved in 2014 but the essay prize continues and the Trust's website can still be accessed at <http://www.jameslogantrust.org.uk/>

## INTRODUCTION

When one hears the words 'patient dignity', one tends to think of showing the patient that they are, in a sense, worthy of honour and respect. While no-one is likely to dispute that patient dignity is an important concept, it is much more difficult to translate this abstract concept into the clinical setting. Maintaining patient dignity is something we often hear mentioned when discussing the principles of palliative care; however it is possible that this almost becomes a phrase of vain repetition with little relevance to the quality of care the patient actually receives.

The purpose of this essay is to consider why dignity is important in palliative care and how the concept of dignity can affect one's day-to-day practice.

## DEFINITION

Firstly, one may ask the question 'What is dignity'? The word dignity originates from two Latin words, *dignitus* (merit) and *dignus* (worth). The International Council for Nurses Code of Ethics 2012 instructs that the observance of dignity should not be limited by the individual's age, colour, creed, culture, gender, sex, nationality, race, social status, or health status. However, while dignity is accepted as a universal need which is fundamental to the well-being of every individual in all societies, the actual 'practical' meaning of dignity remains complex and unclear because it is a multidimensional concept<sup>1</sup>.

The concepts of *respect*, *autonomy*, *empowerment* and *communication* have been identified within the literature

as being key defining attributes of dignity. In turn, each of these attributes is multidimensional, further contributing to the complex, ambiguous nature of the concept. For example, *respect* may involve self-respect, respect for others, and respect for people's privacy; *autonomy* may involve having choice, giving choice, making decisions, competence and independence; *empowerment* may involve self-esteem, self-worth, modesty and pride; and *communication* may involve explaining and understanding information using verbal and non-verbal modalities<sup>2</sup>.

## NEEDS OF THE PATIENT

Secondly, one may ask 'What practical implications will this abstract, multidimensional concept have for patients requiring end-of-life care?' Two key factors which influence the preservation of dignity at the end of life are promoting self-respect and treating the patient with respect<sup>3</sup>; but how are these translated in practice into palliative care? Most end-of-life interventions focus predominantly on symptom control, rather than holistic care<sup>4</sup>. Therefore it may be helpful to consider the *physical*, *emotional* and *spiritual* needs of patients in palliative care settings.

Regarding *physical* needs, when trying to enhance and preserve dignity, a systematic review found that symptom control and being placed in the correct environment are important in delivering dignified end-of-life care<sup>5</sup>. Good management of physical symptoms such as pain, dyspnoea, constipation, nausea, and respiratory secretions may allow for opportunities to work through unfinished emotional, psychological and spiritual issues, and promote a sense of closure towards the end of life<sup>6</sup>. However, invasive and inappropriate investigations should be avoided<sup>7</sup>.

Regarding *emotional* needs, a review found that important actions for healthcare professionals providing end-of-life care include communicating, listening, conveying empathy, and involving patients in decision-making<sup>8</sup>. Furthermore, good communication between the patient and their partner about their feelings should be promoted<sup>9</sup>.

*Spiritual* needs should also be addressed<sup>7</sup>. An observational study evaluated the spiritual needs of patients with terminal

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cancer. The two most relevant needs were the need to be recognised as a person until the end of life without losing their identity, and the need to know the truth about their illness. Less importance was placed on concerns for the past and future, and for religious matters<sup>10</sup>. It would appear that, as spiritual care goes beyond the scope of religion, it involves more than facilitating access to the relevant chaplains. Any healthcare professional can be involved in spiritual care by being present, understanding the patient's perspective, and creating with the patient a holistic care plan which considers dignity issues<sup>11</sup>.

Other measures found to promote dignity include enabling of the management of finances, facilitating activities such as reading or watching television, allowing the patient to spend time with their family, providing choices regarding the place of death, remembering the dignity of the family after the death of the individual, and offering emotional support<sup>7</sup>. In addition, life storytelling has been shown to help individuals with dementia maintain their dignity of identity. This may be helpful in end-of-life care also, and may help carers better understand the patient's needs<sup>12</sup>.

The age of the patient may influence how one thinks of dignity in end-of-life care. For example, a study to explore the characteristics of a 'good death' for children with cancer highlighted the importance of maintaining 'normality' as far as possible. Thus the child should be offered sufficient opportunities to play freely, access to their usual activities and relationships, a sense that others acknowledge and respect the patient's childhood, and symptomatic care. There should also be less emphasis on the prospect of impending death<sup>13</sup>.

Religious and cultural factors may also influence how one thinks of dignity in end-of-life care. As dignity is a value- and culture-laden concept that encompasses a wide spectrum of physical, psychosocial, spiritual, familial and cultural issues, an awareness of ethnic diversity is required for all healthcare professionals<sup>4</sup>. For example, Muslims may view a 'dignified death' as one where the individual dies facing Makkah and has someone present to recite the Qur'an<sup>14</sup>. A Hindu may accept or reject certain treatments based on their interpretation of suffering in relation to beliefs about Karma<sup>15</sup>.

### LOSS OF DIGNITY

Thirdly, let us consider 'What is loss of dignity?' I would propose that there is no clear distinction between dignity being present or lost in end-of-life care; rather loss of dignity is a spectrum and is subjectively experienced. A case report highlighted aspects of losing one's dignity as 'insults'; in this example the lady was most bothered by junior members of staff addressing her by her forename and having to wear poorly-fitting hospital gowns<sup>16</sup>. A longitudinal study found that a downward trend in the sense of dignity following admission to a nursing home was associated with the feeling of a loss of control and a loss of self-worth<sup>17</sup>.

Considerations of patient dignity may also be set aside unintentionally due to time constraints and heavy workloads,

for example in the Emergency Department<sup>2</sup>. Lack of feeling empathy or the inability to emotionally engage with patients may indicate healthcare provider burnout<sup>18</sup>. Spiritual care has been shown to be hindered by a lack of privacy and discontinuity in care<sup>11</sup>. Furthermore, the concept of dignity may be forsaken due to the pressures of modern medicine, where the emphasis is on providing *care* (i.e. evidence-based practices) rather than actually *caring* (i.e. developing a relationship with the patient and understanding what matters to them) – two concepts which ought to be inseparable<sup>18</sup>.

### IMPORTANCE OF DIGNITY

Fourthly, 'Why is dignity in end-of-life care important?' Unsurprisingly, no-one appears to have studied whether or not patients and/or healthcare professionals believe dignity in end-of-life care is important, nor have they tried to quantify 'how much' dignity is required. "The secret of the care of the patient is in caring for the patient" are words which were delivered by Dr. Francis Peabody in his famous address to Harvard medical students in 1925<sup>18</sup>. Why? It is no surprise that patients and families are less satisfied with medical encounters when the 'caring' aspect of care is lacking. A lack of caring may result in the patient being less forthcoming with concerns – leading to missed treatment opportunities, medical errors, and ultimately compromised patient safety. Furthermore, studies consistently show that most complaints against healthcare professionals derive, not from medical errors, but from a failure to communicate and the absence of caring – in other words, compromised patient dignity<sup>18</sup>.

### PROMOTION OF DIGNITY

Fifthly, 'how can dignity be promoted?' As touched on previously, dignity can be upheld by measures such as symptom control<sup>5</sup>; promoting independence, privacy, social support and a positive tone of care<sup>8</sup>; listening, giving appropriate information, having a caring bedside manner<sup>19</sup>; and showing respect, empathy and companionship<sup>16</sup>. Spiritual care has been shown to be facilitated by having sufficient time, employing effective communication, and reflecting on one's personal experiences<sup>11</sup>.

It is clear that involvement of the palliative care team encourages a sense of dignity as the emphasis is less on the disease and more on the person<sup>16</sup>. Measures such as getting acquainted with new living structures or involvement with staff and other residents have been shown to encourage a sense of dignity among nursing home residents – measures which may be transferred to palliative care units<sup>17</sup>.

A sense of depersonalisation reduces the perception of patient dignity<sup>10</sup>; thus getting to know the patient as a person is likely to help promote dignity. The Patient Dignity Question (PDQ) 'What do I need to know about you as a person to take the best care of you that I can?' was devised for patients with palliative care needs by Chochinov to combat this depersonalisation associated with modern medicine<sup>20</sup>.

The PDQ was found to be acceptable to patients with

palliative care needs<sup>21</sup>. Asking this question was found to make improvements to a person-centred environment and levels of empathy perceived by patients, and also supported disclosure of information previously unknown to healthcare professionals<sup>22</sup>.

In one study, 93% of patients felt that the information they disclosed was important for healthcare professionals to know, whilst 99% said they would recommend the PDQ for others. Furthermore, 64% of healthcare professionals studied claimed to be emotionally affected by the response they received, and 59% said it influenced their sense of empathy<sup>20</sup>.

Encouraging life review can also promote patient dignity<sup>16</sup>. In a formal sense, this may involve dignity therapy, a psychotherapeutic intervention proposed by Chochinov. Dignity therapy focuses on dignity conservation tasks such as settling relationships, sharing words of love, and preparing a legacy document for loved ones. Patients have reported high satisfaction and benefits for themselves and their families including an increased sense of meaning and purpose<sup>23</sup>. Compared with standard palliative care, patients undergoing dignity therapy reported that it improved their quality of life, increased their sense of dignity, changed how their family saw and appreciated them, was helpful to their family, and was superior to standard care in lessening sadness or depression<sup>24</sup>. Hospice staff also rated dignity therapy as worthwhile, felt it reduced pain and suffering, and felt it enabled a greater connection with patients. They also reported increased job satisfaction<sup>25</sup>. Commonly discussed topics during dignity therapy were autobiographical information, love, lessons learned in life, defining roles in vocations or hobbies, accomplishments, character traits, unfinished business, hopes and dreams, and guidance for others<sup>26</sup>.

### HEALTH CARE PROFESSIONAL

Sixthly, 'can healthcare professionals be taught how to promote patient dignity or does it come with experience?' This is difficult to say. It has been suggested that there is actually a decline in the level of empathy shown by medical students as they progress through medical school, perhaps driven by the greater emphasis placed upon technology and innovation than on individual patient's needs<sup>27</sup>. There appears to be nothing in the literature relating to dignity in the Objective Structured Clinical Examinations; however it has been suggested that the subject of dignity should be incorporated in its own right within the curriculum for those studying to become healthcare professionals, perhaps in an inter-professional education setting<sup>28</sup>. In developing a 'culture of caring', caregivers are recommended to look at what shapes their 'tone of care', including their own attitudes, vulnerabilities, and fears<sup>18</sup>.

### CONCLUSION

In conclusion, despite being viewed as an abstract concept, the importance of patient dignity in end-of life-care cannot be denied. I propose that the concept of dignity may be likened to that of love – important, widely understood, difficult to

define, and cannot be taught in a black-or-white manner. As dignity is subjectively experienced and each patient is unique in their requirements, it is important that healthcare professionals use an open approach to assess each patient's needs and aim to meet these accordingly, using discretion as to what is appropriate when providing care for patients of different ages, cultures and religions. Simple measures such as the PDQ and life storytelling can help healthcare professionals view the patient receiving end-of-life care as a person; thereby helping them to promote patient dignity and address needs which would otherwise not be known.

### REFERENCES

1. Adib-Hajbaghery M, Aghajani M. Patients dignity in nursing. *Nurs Midwifery Stud.* 2015;**4**(1):e22809.
2. Griffin-Heslin VL. An analysis of the concept dignity. *Accid Emerg Nurs.* 2005;**13**(4):251-7.
3. Periyakoil VS, Noda AM, Kraemer HC. Assessment of factors influencing preservation of dignity at life's end: creation and the cross-cultural validation of the preservation of dignity card-sort tool. *J Palliat Med.* 2010;**13**(5):495-500.
4. Ho AH, Chan CL, Leung PP, Chochinov HM, Neimeyer RA, Pang SM, et al. Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. *Age Ageing.* 2013;**42**(4):455-61.
5. Pringle J, Johnston B, Buchanan D. Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: a systematic review. *Palliat Med.* 2015;**29**(8):675-94.
6. Clary PL, Lawson P. Pharmacologic pearls for end-of-life care. *Am Fam Physician.* 2009;**79**(12):1059-65.
7. Sridhar P, Renuka PK, Bonanathaya R. End of Life and Life After Death - Issues to be Addressed. *Indian J Palliat Care.* 2012;**18**(3):226-9.
8. Johnston B, Larkin P, Connolly M, Barry C, Narayanasamy M, Östlund U, et al. Dignity-conserving care in palliative care settings: an integrative review. *J Clin Nurs.* 2015;**24**(13-14):1743-72.
9. Mowll J, Lobb EA, Lane L, Lacey J, Chochinov HM, Kelly B, et al. A preliminary study to develop an intervention to facilitate communication between couples in advanced cancer. *Palliat Support Care.* 2015 Oct;**13**(5):1381-90.
10. Vilalta A, Valls J, Porta J, Viñas J. Evaluation of spiritual needs of patients with advanced cancer in a palliative care unit. *J Palliat Med.* 2014;**17**(5):592-600.
11. Daaleman TP, Usher BM, Williams SW, Rawlings J, Hanson LC. An exploratory study of spiritual care at the end of life. *Ann Fam Med.* 2008;**6**(5):406-11.
12. Heggstad AK, Slettebø ÅJ. How individuals with dementia in nursing homes maintain their dignity through life storytelling - a case study. *J Clin Nurs.* 2015;**24**(15-16):2323-30.
13. Ito Y, Okuyama T, Ito Y, Kamei M, Nakaguchi T, Sugano K., et al. Good death for children with cancer: a qualitative study. *Jpn J Clin Oncol.* 2015;**45**(4):349-55.
14. Tayeb MA, Al-Zamel E, Fareed MM, Abouellail HA. A "good death": perspectives of Muslim patients and health care providers. *Ann Saudi Med.* 2010;**30**(3):215-21.
15. Dewar R, Cahners N, Mitchell C, Forrow L. Hinduism and death with dignity: historic and contemporary case examples. *J Clin Ethics.* 2015;**26**(1):40-7.
16. Rajagopal M. Disease, dignity and palliative care. *Indian J Palliat Care.* 2010;**16**(2):59-60.

17. Oosterveld-Vlug MG, Pasman HR, van Gennip IE, Willems DL, Onwuteaka-Philipsen BD. Changes in the personal dignity of nursing home residents: a longitudinal qualitative interview study. *PLoS One*. 2013;**8(9)**:e73822.
18. Chochinov HM. Dignity in care: time to take action. *J Pain Symptom Manage*. 2013;**46(5)**:756-9.
19. Beach MC, Forbes L, Branyon E, Aboumatar H, Carrese J, Sugarman J, et al. Patient and family perspectives on respect and dignity in the intensive care unit. *Narrat Inq Bioeth*. 2015;**5(1A)**:15A-25A.
20. Chochinov HM, McClement S, Hack T, Thompson G, Dufault B, Harlos M. Eliciting personhood within clinical practice: effects on patients, families, and health care providers. *J Pain Symptom Manage*. 2015;**49(6)**:974-980.
21. Johnston B, Gaffney M, Pringle J, Buchanan D. The person behind the patient: a feasibility study using the Patient Dignity Question for patients with palliative care needs in hospital. *Int J Palliat Nurs*. 2015;**21(2)**:71-7.
22. Johnston B, Pringle J, Gaffney M, Narayanasamy M, McGuire M, Buchanan D. The dignified approach to care: a pilot study using the patient dignity question as an intervention to enhance dignity and person-centred care for people with palliative care needs in the acute hospital setting. *BMC Palliat Care*. 2015 Apr 9;14:9.
23. Fitchett G, Emanuel L, Handzo G, Boyken L, Wilkie DJ. Care of the human spirit and the role of dignity therapy: a systematic review of dignity therapy research. *BMC Palliat Care*. 2015 Mar 21;14:8.
24. Chochinov HM, Kristjanson LJ, Breitbart W, McClement S, Hack TF, Hassard T, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncol*. 2011;**12(8)**:753-62.
25. Montross LP, Meier EA, De Cervantes-Monteith K, Vashistha V, Irwin SA. Hospice staff perspectives on Dignity Therapy. *J Palliat Med*. 2013;**16(9)**:1118-20.
26. Montross L, Winters KD, Irwin SA. Dignity therapy implementation in a community-based hospice setting. *J Palliat Med*. 2011;**14(6)**:729-34.
27. Weisberg DF. Science in the service of patients: lessons from the past in the moral battle for the future of medical education. *Yale J Biol Med*. 2014;**87(1)**:79-89.
28. Matiti MR. Learning to promote patient dignity: an inter-professional approach. *Nurse Educ Pract*. 2015;**15(2)**:108-10.