

Palliative Medicine Grand Round

# Understanding Dignity in the Light of Chochinov

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**ABSTRACT**

Professor Chochinov should be appraised for the current understanding of dignity in palliative care. The dignity model in the terminally ill provides us with a useful framework to approach patients suffering from dignity and existential problems. This article reviews Chochinov's work on dignity, dignity therapy and the Patient Dignity Inventory (PDI).

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Respecting and preserving dignity is one of the core values in modern palliative care<sup>1,2</sup>. However, a request to die with dignity, is often a quoted reason for euthanasia<sup>3</sup>.

In a landmark qualitative study published in 2002, Chochinov et al. studied 50 terminal cancer patients using a semi-structured interview, exploring their perception of dignity<sup>4</sup>. Three major categories, including Illness Related Concerns, Dignity Conserving Repertoire and Social Dignity Inventory were identified. Under each category were different themes and subthemes, as shown in Fig. 1. These form the foundation of the Dignity Model in the Terminally Ill.

The relationship between dignity and the will to live was established in the same year in an article published in the Lancet. Chochinov et al.

performed a cross-sectional study in a cohort of 213 terminally ill cancer patients. Patients were asked to rate their sense of dignity on a 7-point sense of dignity item scale. Sixteen out of 213 (7.5%) patients indicated that loss of dignity was of great concern. Patients who indicated that their sense of dignity was fractured, were more likely to have more psychological and symptom distress, and were more likely to have loss of will to live<sup>5</sup>. It provided the empirical data to suggest that compromised dignity correlated with higher desire for death.

Based on the dignity model, Chochinov et al. established the dignity psychotherapy<sup>6</sup>. Using a standard framework of questions, the therapist allowed the client to discuss the issues that mattered most or that they would most want remembered. With the cues provided, the therapist would restructure and reorganize the clients' thoughts. The interview would be audio-taped and the recorded dialogue was reshaped with transcript. In a pilot study with 100 patients under palliative care (50 from Australia and 50 from Canada, 3 had non-malignant condition), 91 patients felt satisfied with the intervention. Seventy-six patients out of 100 reported a heightened sense of dignity. There was significant improvement in the measurement of suffering ( $p=0.023$ ) and depressive symptoms ( $p=0.05$ ). There was also improvement in the sense of dignity but it was statistically insignificant ( $p=0.085$ ).

**Fig. 1: The Dignity Model in Terminally Ill, and its corresponding PDI item numbers correlated with the individual theme and subthemes<sup>8</sup>.**

Dignity Model in Terminally Ill

Illness-related concerns	Dignity Conserving Repertoire	Social Dignity Inventory
<b>Level of independence (1,2)</b>	<b>Dignity conserving perspectives</b>	Privacy boundaries (20)
Cognitive acuity (9)	Self continuity (4, 11)	Social Support (21, 22)
Functional Capacity (8)	Role preservation (13)	Care Tenor (25)
<b>Symptoms distress</b>	Generativity/ legacy (15, 16)	Burden to others (18)
Physical distress (3)	Maintenance of pride (12)	Aftermath concerns
Psychological distress (5,6)	Hopefulness (14)	
Medical uncertainty (7)	Autonomy / control (19)	
Death anxiety (8)	Acceptance (24)	
	Resilience / fighting spirit (23)	
	<b>Dignity conserving practices</b>	
	Living in the moment (10)	
	Maintaining normalcy (10)	
	Seeking spiritual comfort (17)	

Here we come to face a practical problem: Can dignity be measured? If yes, how can we measure dignity? A validated measurement becomes essential if we want to show that dignity intervention is successful. At least, we have to consider which components of dignity should be measured.

There are 22 items in the Dignity model. Chochinov et al. interviewed 211 palliative care patients and asked them to decide which items were related to their sense of dignity<sup>7</sup>. All but 1 out of the 22 items were endorsed as dignity-related by over half of the subjects. The most important issues were “not being treated with respect or understanding”, and “feeling a burden to the others”. These findings established the importance of every single item in the Dignity model to help construct a measurement scale. This forms the background of Patient Dignity Inventory (PDI)<sup>8</sup>.

### **Patient Dignity Inventory**

The PDI consists of 25 self-report items rated on a 5-point scale. Patient are asked to rate how

much each of the specific items or issues posed a problem to their sense of dignity. The 5-point scale was rated as: (1) not a problem, (2) a slight problem, (3) a problem, (4) a major problem and (5) an overwhelming problem. (Table 1)

During the validation, the researchers administered the PDI to 253 patients receiving palliative care, 8% of whom had non-cancer advanced diseases. The mean duration of survival from the time of interview to the time of death was 78 days. The test-retest reliability was tested by asking the patient to complete PDI again 24 hours later if they agreed. The Pearson  $r$  was 0.85 for the full PDI. Cronbach's coefficient alpha, which reflects the internal consistency, was 0.93.

During the factor analysis, five factors were identified which accounted for 58% of the overall variation. They include Symptom Distress (items 3, 5-9), Existential Distress (items 4, 11-14, 18), Dependency (items 1, 2, 20), Peace of Mind (items 15-17) and Social Support (items 21, 22, 25). The concurrent validity of different factors was tested with different psychometric

**Table 1: The Patient Dignity Inventory questions<sup>8</sup>**

1. Not being able to carry out tasks associated with daily living (e.g. washing myself, getting dressed).
2. Not being able to attend to my bodily function independently (e.g. needing assistance with toileting-related activities).
3. Experiencing physically distressing symptoms (such as pain, shortness of breath, nausea).
4. Feeling that how I look to others have changed significantly.
5. Feeling depressed.
6. Feeling anxious.
7. Feeling uncertain about my illness and treatment.
8. Worrying about my future.
9. Not being able to think clearly.
10. Not being able to continue with my usual routines.
11. Feeling like I am no longer who I was.
12. Not feeling worthwhile or valued.
13. Not being able to carry out important roles (e.g. spouse, parent).
14. Feeling that life no longer has meaning or purpose.
15. Feeling that I have not made a meaningful and lasting contribution during my lifetime.
16. Feeling I have 'unfinished business' (e.g. things left unsaid, or incomplete).
17. Concern that my spiritual life is not meaningful.
18. Feeling that I am a burden to others.
19. Feeling that I don't have control over my life.
20. Feeling that my illness and care needs have reduced my privacy.
21. Not feeling supported by my community of friends and family.
22. Not feeling supported by my health care providers.
23. Feeling like I am no longer able to mentally 'fight' the challenges of my illness.
24. Not being able to accept the way things are.
25. Not being treated with respect or understanding by others.

instruments. The correlation of different factors with corresponding individual instruments were significant and obvious except in the factor Peace of Mind, which was not correlated with various measurement of psychological wellbeing except the current level of anxiety of measurement by the Edmonton Symptom Assessment Scale (ESAS) ( $r=0.152$ ,  $p=0.021$ ). Further analysis showed that Peace of Mind item was significantly correlated with the Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being (FACIT)-Inner Peace factor ( $r=-0.213$ ,  $p=0.002$ ), but not with the measurement of Spiritual factor nor Meaning and Purpose factor. It was noted that the factor Existential Distress correlated well with measures of suffering, well-being, depression, anxiety, and quality of life items. This may provide hints that Peace of Mind concept and Existential Distress are distinct entities. Furthermore, during the validation, the factor Existential Distress did not correlate significantly with either the sense of dignity or the will to live.

The authors claim that the PDI has excellent face validity. It can be completed by patients both in the in-patient and out-patient settings, requiring a few minutes time. It may serve a useful tool to screen or monitor dignity related problems in the palliative care setting. The tool may be used to study the differential distribution of distress among different populations or care settings. In their pilot study, patients reported an average of 5.74 problems<sup>9</sup>. However, “the impairment of dignity” was not defined, and there was no cut off values proposed to distinguish between intact or impaired dignity. The study of course has not been validated in Chinese palliative care setting.

#### **Upcoming research using PDI**

There are two upcoming studies to assess the effectiveness of dignity therapy using the Patient Dignity Inventory as the primary outcome measures. The first study plans to recruit 64 elderly home residents, (not necessarily suffering from a terminal illness or receiving palliative care), as the researchers regard living in elderly home as comparable to one’s end of life<sup>10</sup>. The same group is also planning another randomized controlled trial aiming to recruit 40 advanced care patients referred to a hospital-based palliative care team<sup>11</sup>. In both studies the participants will be allocated to either Intervention group receiving Dignity Therapy, or Control group receiving standard care. The primary outcome measures

will be the participants’ sense of dignity, as measured by the Patient Dignity Inventory.

#### **Conclusion**

While awaiting more scientific confirmation or even trans-cultural validation of dignity therapy and the Patient Dignity Inventory, the core values of medical professionalism – kindness, humanity and respect remain universal. Not everyone of us can be the dignity psychotherapists, nonetheless, every member in palliative care team can participate in providing dignity conserving care by using A, B, C and D<sup>12</sup>: ‘A’ stands for appropriate questions to be asked and actions to be taken, ‘B’ stands for the behavior during our contact with patients, clinical examination and subsequent communication, ‘C’ for compassion – we have to get in touch with patient’s own feeling in spoken and unspoken ways, and ‘D’ stands for the dialogue we use, by showing acknowledgement to personhood, as well as willingness to know the patient. Different psychotherapeutic interventions are available, however, let us not forget our therapeutic role.

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