IN THE HIGH COURT OF NEW ZEALAND
WELLINGTON REGISTRY

CIV-2015-485-235

UNDER	The Declaratory Judgments Act 1908 and the New Zealand Bill of Rights Act 1990
BETWEEN	LECRETIA SEALES Plaintiff
AND	ATTORNEY-GENERAL Defendant

AFFIDAVIT OF DR HARVEY CHOCHINOV ON BEHALF OF THE DEFENDANT

May 2015

Judicial Officer: Justice Collins
Next Event Date: Hearing commencing 25 May 2015

CROWN LAW
TE TARI TURE O TE KARAUNA
PO Box 2858
WELLINGTON 6140
Tel: 04 472 1719
Fax: 04 473 3482

Contact Person:
Paul Rishworth QC
Email: paul.rishworth@crownlaw.govt.nz

I, HARVEY MAX CHOCHINOV, of Winnipeg, Manitoba, Canada, Professor of Psychiatry and Director of the Manitoba Palliative Care Research Unit, solemnly and sincerely affirm:

1. I am a Distinguished Professor of Psychiatry at the University of Manitoba and Director of the Manitoba Palliative Care Research Unit, CancerCare Manitoba.

2. My publications addressing psychosocial dimensions of palliation have helped define core-competencies and standards of end-of-life care. I hold the only Canada Research Chair in Palliative Care.

3. I completed my undergraduate medical training and Psychiatric Residency at the University of Manitoba and completed a Fellowship in Psychiatric Oncology at Memorial Sloan-Kettering Cancer Centre, New York, New York. In 1998, I completed a PhD in the Faculty of Community Health Sciences, University of Manitoba.

4. I have been doing palliative care research since 1990 with funding support from local, provincial and national granting agencies. I have been a grantee of the Canadian Institutes of Health Research, the National Cancer Institute of Canada and the National Institute of Health. My work has explored various psychiatric dimensions of palliative medicine, such as depression, desire for death, will to live and dignity at the end of life.

5. I have been a guest lecturer in most major academic institutions throughout Canada and United States; I have also lectured in South America, New Zealand, Australia, Europe, Cuba, Israel, China, Singapore, Taiwan and Japan. I am the only psychiatrist in Canada to be designated as a Soros Faculty Scholar, Project on Death in America.

6. I am a recipient of the Queen's Golden Jubilee Medal, the Order of Manitoba; and am an Officer in the Order of Canada. I am the Chair for the Canadian Virtual Hospice, a Fellow of the Royal Society of Canada and a Fellow of the Canadian Academy of Health Sciences. I received the 2008 National Cancer Institute and Canadian Cancer Society O. Harold Warwick Prize. In 2009, I received the University of Manitoba's highest research honor, the Dr. John M. Bowman RH Institute Foundation Award. I am the 2010 recipient of the

Lifetime Achievement Award from the Canadian Association of Psychosocial Oncology and the International Psycho-Oncology Society's Bernard Fox Memorial Award, which recognizes an individual's outstanding contribution in education, research or leadership to the field of psycho-oncology. In 2012, I received the FNG Starr Award, which is the highest honor the Canadian Medical Association can bestow on one of its members in recognition of outstanding achievement. In addition to over 200 publications, I am the Co-Editor of the *Handbook of Psychiatry in Palliative Medicine*, published by Oxford University Press, and the Journal *Palliative and Support Care,* published by Cambridge University Press. My most recent book, *Dignity Therapy: Final Words for Final Days* (Oxford University Press) was the 2012 winner of the American Publishing Association Prose award for clinical medicine.

7. My *curriculum vitae* is annexed as exhibit **"HMC-1"** to this report.

8. In this affidavit I address:

    8.1 The importance of understanding dignity in the context of end of life care and requests for physician hastened death.

    8.2 Some specific comments regarding Ms Seales case

    8.3 Some comments on the issue of rational suicide

    8.4 A detailed commentary regarding the trial judgement in the Carter Case

9. I acknowledge that I have read and understood the Code of Conduct for Expert Witnesses and I agree to comply with it. Any views or opinions I express in this affidavit are within my area of expertise and experience. These are personal views and do not represent the view of any hospital, university or any other organisation with which I am affiliated.

10. Some of the documents attached to this report are authored or contributed to by myself and are based upon my own empirical research and experience. Where I refer to these materials I adopt them as part of my expert opinion in this affidavit.

11. Some of the documents referenced and attached to this report are not authored or contributed to by myself. Where I am not the author or contributor, I have reviewed the material and consider the conclusions drawn to be authoritative in my area of expertise, reasonable and in accordance with my own experience and work in this field.

Dignity and a Wish to Die

12. Study after study confirm a strong association between a loss of sense of dignity and a wish to die, variably expressed as a desire for death, loss of will to live, interest in physician hastened death or a request for physician hastened death.[1] That is why the examination of dignity and its complexities within the context of end of life and death hastening requests is of critical importance.

What factors affect personal dignity and can these factors be quantitatively and qualitatively tracked?

13. Our research team at CancerCare Manitoba is one of the few that has actually looked at the notion of dignity at end of life from an empirical vantage point. The term "dignity" is often cited within the medical literature and used in ways that are highly politicised.

14. Dignity is frequently used as the penultimate argument supporting various contentious issues in end-of-life care, including assisted suicide and euthanasia. Dignity arguments invoked by those who support assisted dying are usually framed in terms of the importance and the centrality of autonomy and self-determination. Those on the opposite side of this political fence would argue that the taking of human life is an affront to human dignity.

15. Until our work on this issue, what was missing from the medical literature was a detailed, objective examination of how dying patients understood dignity and how that might shape the way they are cared for. That was the primary

---

[1] See for example: Kouwenhoven PS, van Thiel GJ, Raijmakers NJ, Rietjens JA, van der Heide A, van Delden JJ. "Euthanasia or physician-assisted suicide? A survey from the Netherlands". Eur J Gen Pract. 2014 Mar;20(1):25-31; Rietjens JA, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. "Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making". Palliat Med. 2006 Oct;20(7):685-92; Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. "Physicians' experiences with the Oregon Death with Dignity Act." N Engl J Med. 2000 Feb 24;342(8):557-63; Ganzini L, Goy ER, Dobscha SK. "Oregonians' reasons for requesting physician aid in dying". Arch Intern Med. 2009;169:489-92: Loggers ET, Starks H, Shannon-Dudley M, Back AL, Appelbaum FR, Stewart FM. "Implementing a Death with Dignity program at a comprehensive cancer center." N Engl J Med. 2013;368:1417-24.

motivation behind our team launching a series of studies focused on dignity and the terminally ill.

16. We discovered that it was indeed possible to study a notion as seemingly nebulous as dignity; and that both qualitative and quantitative methods can be used to explore this issue in the context of palliative care. The primary publications based on this effort include the following articles:

    16.1 Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. *Dignity in the terminally ill: a cross-sectional, cohort study.* Lancet. 2002:360:2026-30. A copy of this article is annexed to this affidavit as exhibit **"HMC-2"**.

    16.2 Chochinov HM. *Dignity-Conserving Care: A New Model for Palliative Care.* JAMA. 2002;287:2253-2260. A copy of this article is annexed to this affidavit as exhibit **"HMC-3"**.

    16.3 Chochinov HM, Hack T, McClement S, Harlos M, Kristjanson L. *Dignity in the Terminally Ill: A Developing Empirical Model.* Social Science and Medicine. 2002;54:433-443. A copy of this article is annexed to this affidavit as exhibit **"HMC-4"**.

17. In *Dignity in the Terminally Ill* (exhibit **"HMC-2"**), we reported that patients were able to respond to a brief questionnaire, which simply asked them to rate their sense of dignity. In this way, patients were able to indicate the extent to which they felt their dignity was intact or fractured. Within a sample of 213 patients receiving palliative care (for whom the life expectancy was less than six months), seven percent reported a moderate to strong sense of lost dignity i.e. they reported this to be a significant problem; or a feeling that was experienced most of the time.

18. This rather low prevalence of fractured sense of dignity might have at least two possible explanations:

    18.1 patients may identify dignity as something that is internally held and resilient. That being the case, there is little that might cause it to shift; or

18.2 patients who receive state-of-the-art palliative care (as was the case with this study sample) are less vulnerable to assaults on their sense of dignity.

19. When we divided the study sample between those whose dignity was intact versus those whose dignity was fractured, we found there were significant differences between these groups. Patients whose dignity was fractured were significantly more likely to report a desire for death, a loss of will to live, depression, hopelessness and anxiety. As such, these appear to be the constellation of psychological symptoms that go hand in hand with a fractured sense of dignity. In terms of physical factors, we found that pain, difficulty with bowel function and physical appearance, were associated with a fractured or undermined sense of dignity.

20. We also reported on what we called the *intimate dependencies* – bathing, dressing and toileting. Needing assistance of this kind is often invoked as the epitome of lost autonomy. Patients with a fractured sense of dignity were significantly more likely to report difficulties within the realm of intimate dependencies i.e. that dependency in these areas was more prominent within this subgroup of patients. Patients with a fractured sense of dignity were much more likely to report their quality of life ratings were poor and their overall satisfaction with quality of life was less.

21. We also tried to discern which of these many factors might be most important in terms of predicting sense of dignity. The answer that emerged was *appearance* or the perception of how one is seen or appreciated. See Chochinov HM. *Dignity and the Eye of the Beholder.* Journal of Clinical Oncology. 2004;22: 1336-40. A copy of this article is annexed to this affidavit as exhibit **"HMC-5"**. That particular article makes the point that good end-of-life care is not just about what you do to a patient or what you do with a patient, but is mediated by how you see the patient. In brief, health care providers have the opportunity to affirm or disaffirm the worth of a person by virtue of their attitude towards that individual.

22. We also applied qualitative methods to the study of dignity in the terminally ill. The details of our findings are summarized in the publications noted above and appended as *Dignity Conserving Care: A New Model for Palliative Care* (exhibit

"HMC-3") and *Dignity in the Terminally Ill: A Developing Empirical Model. Social Science and Medicine*, (exhibit **"HMC-4"**). The most significant thing reported in those papers is an empirical model of dignity in the terminally ill.

23. This model revealed that there are three primary domains of influence on a dying person's sense of dignity. These include:

    23.1 Illness-related concerns i.e. issues or experiences that are directly mediated by the illness itself. These include level of independence, cognitive acuity, functional capacity; symptom distress, psychological distress, medical uncertainty and death anxiety;

    23.2 Social dignity inventory, referring to things within the social realm that can influence on their sense of dignity. These included privacy boundaries, social support; care tenor (or the tone of care; i.e. the nuances that allow health care providers to acknowledge personhood and provide patients with a sense of value and worth); burden to others (which has been identified prominently within the literature for its association with desire for death, assisted suicide, and interest in hastened death); and aftermath concerns (referring to the burden patients fear their death will impose on those they leave behind);

    23.3 Dignity conserving repertoire, referring to a constellation of issues having to do with the patient's psychological makeup, coping style, spiritual outlook, and life experiences.

24. The model of dignity in the terminally ill has many implications. For certain, the model tells us that what shapes dignity varies from one person to the next; and what influences dying with dignity is complex and highly diverse. Given the association between dignity and the wish to die, it is a fair extrapolation to say that understanding the experiential landscape of a request for hastened death requires due consideration be given to anything and everything that might influence dignity towards the end of life.

25. The complexity of the Model of Dignity in the Terminally Ill speaks to the multitude of variables that can influence dignity, and the various interventional strategies that can be invoked to mitigate a loss of sense of dignity. Those

strategies include everything from good pain and symptom management, to providing psychological and spiritual support; supports for families to ease the care load; ensuring a tone of clinical care in which patients feel valued, respected and known for who they are as whole persons. Pursuing ways of finding meaning and purpose, either through formal interventions, such as dignity therapy or meaning centred therapy, or informally by way of dealing with unfinished business or legacy making, can help to safeguard patients' sense of dignity.

26. Sense of dignity is vulnerable to fluctuation, depending on the current status of factors included within the model of dignity in the terminally ill. So, for example, poorly controlled pain that leaves the patient in distress, feeling vulnerable and out of control can assault one's sense of dignity. On the other hand, once pain is well controlled, dignity can be recovered. Not being included in decision-making might cause a patient to feel that they are not being respected, that their opinions no longer matter and that their lives no longer have value. Including patients in determining various facets of their care can heighten feelings of autonomy, even in the presence of marked reduction of functional capacity.

Is there evidence to suggest that patients, family members and health care professionals perceive the suffering in patients differently? What does the evidence show about correlations between a patient's perception of pain, personal dignity and their will to live?

27. My work has not directly looked at differentiating perceptions of suffering amongst patients, family members and health care providers. However, I am aware that there have been studies that have looked at this. My understanding is that the synchronicity between these perceptions is not always very good. For instance, it is not atypical that family members might ascribe higher degrees of suffering to patient experience than might their health care provider. Certainly clinical experience tells me that perceptions of patient suffering and family suffering are often inseparable i.e. what families see is often filtered through and modulated by their own sense of loss, fear; and in some instances guilt or remorse.

28. My response to the question pertaining to correlations between patient's perception of pain, personal dignity and will to live is largely based on findings from the following three studies:

28.1 Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. *Dignity in the terminally ill: a cross-sectional, cohort study.* Lancet. 2002;360:2026-30. (exhibit **"HMC-2"**);

28.2 Chochinov HM, Wilson KG, Enns M, Mowchun N, Lander S, Levitt M, Clinch JJ. *Desire for death in the terminally ill.* Am J Psychiatry. 1995;152:1185-91 (since being published, this article has periodically been included within the top ten most cited articles in the history of the American Journal of Psychiatry) . A copy of this article is annexed to this affidavit as exhibit **"HMC-6"**; and

28.3 Chochinov HM, Tataryn D, Dudgeon D, Clinch J. *Will to Live in the Terminally Ill*, The Lancet. 1999;354:816-19. A copy of this article is annexed to this affidavit as exhibit **"HMC-7"**.

29. "*Dignity in the terminally ill: a cross-sectional, cohort study*" (exhibit **"HMC-2"**) shows a clear and highly significant association between sense of dignity and pain.

30. "*Desire for death in the terminally ill*", published in The American Journal of Psychiatry (1995) (exhibit **"HMC-6"**) shows that patients who desire death are significantly more likely to experience depression, much more likely to experience pain (eighty percent of moderate severity or greater) and less likely to report optimal social support compared to those who do not endorse a desire for early death. This particular study also showed that when you follow people with desire for death over time, such desire can fluctuate i.e. of 17 patients who initially experienced a significant desire for death, 11 were unavailable for follow-up because of death, deterioration or discharge. Of the remaining 6 patients, two thirds or 4 of them no longer expressed a significant wish to die when seen for their two-week follow-up evaluation.

31. "*Will to Live in the Terminally Ill*", published in The Lancet (1999) (exhibit **"HMC-7"**) examined the relationship between pain and the construct of will to live in the terminally ill. Patients were evaluated twice daily; from the time

they entered the study to the time they were no longer able to give meaningful data. Besides the significant association between will to live and pain, we also reported that influences on will to live vary as proximity to death deceases. Initially, when patients were transitioning from community-based care to palliative care, anxiety accounted for most of the variance in will to live. Later into the course of hospital stay, depression was the most ardent predictor of will to live. Towards the time of death, physical factors, specifically shortness of breath, accounted for most of the variance in will to live. In summary, will to live can be influenced by a multitude of factors, all of which need to be explored in order to truly understand a wish to die in the context of terminal illness.

32. The clinical implications of these studies are as follows: 1) experiencing pain and distress can assault one's sense of dignity, while treating these symptoms can enable the recovering of dignity; 2) loss of dignity can express itself in a multitude of ways, including a desire for death and loss of will to live; and 3) given the temporal instability of will to live and desire for death, dignity can be understood as being vulnerable to change over time.

What are the best predictors for patients who are seriously injured, near the end of life and/or in palliative care and who are at risk for experiencing a fractured sense of dignity, and what has the literature, including your research, revealed about how to assess and maintain an intact sense of dignity in these patients?

33. The model of dignity in the terminally ill, referenced earlier, provides a good framework for trying to understand the various influences on sense of dignity. The model is not hierarchical, meaning that no variable is assumed to be more or less important than another. One variable, or a multitude of variables, may factor into how any one person perceives their dignity during the course of a terminal condition.

34. The model also reveals that dignity should not be treated as a monolith, but rather as a construct based on a diverse range of considerations. This realisation led to our team developing a novel psychometric instrument called The Patient Dignity Inventory ("PDI"), as reported in:

34.1 Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson L, Harlos M, Sinclair S, Murray A. *The Patient Dignity Inventory: A novel way of measuring dignity related distress in Palliative Care.* Journal of Pain and

Symptom Management. 2008: Dec. 36(6): 559 – 57. A copy of this article is annexed to this affidavit as exhibit **"HMC-8"**.

35. The PDI, which is based on the model of dignity in the terminally ill, has been translated into nearly a dozen languages and is being used in various programs and research initiatives around the world. It provides a way of assessing 25 possible domains of influence on sense of dignity. These items, like the model itself, covers psychological, physical, existential and spiritual domains of end of life experience. We have also used this instrument to determine the prevalence of various sources of distress near the end of life and published our findings. (See Chochinov, HM, Hack, T., Hassard, T., McClement, S., Kristjanson, L., Harlos, M., Murray, A. & Sinclair, S. *The Landscape of Distress in the Terminally Ill*, Journal of Pain and Symptom Management. 2009. 38, 641-649. A copy of this article is annexed to this affidavit as exhibit **"HMC-9"**).

36. To answer the question of maintaining dignity, I turn to several studies our group has published, all of which form part of my expert opinion evidence in this proceeding:

36.1 Chochinov HM, Kristjanson L, Hack T, Hassard T, McClement S, Harlos M. *Dignity in the terminally ill: revisited.* Journal of Palliative Medicine. 2006;9(3):666-672 . A copy of this article is annexed to this affidavit as exhibit **"HMC-10"**;

36.2 Chochinov HM. *Dignity and the essence of medicine: The A, B, C and D of Dignity Conserving Care.* British Medical Journal. 2007;335(7612):184-187. A copy of this article is annexed to this affidavit as exhibit **"HMC-11"**;

36.3 Chochinov HM, Hack T, Hassard T, Kristjanson L, McClement S, Harlos M. *Dignity Therapy: A novel psychotherapeutic intervention for patients near the end of life.* Journal of Clinical Oncology. 2005;23:5520-5525. A copy of this article is annexed to this affidavit as exhibit **"HMC-12"**; and

36.4 Chochinov HM, Kristjanson LJ, Breitbart W, McClement S, Hack TF, Hassard T, Harlos M. *Effect of dignity therapy on distress and end-of-life* *experience in terminally ill patients: a randomised controlled trial.* Lancet Oncol. 2011 August;12(8): 753-62. A copy of this article is annexed to this affidavit as exhibit **"HMC-13"**.

37. In "*Dignity in the terminally ill: revisited*" (exhibit **"HMC-10"**) we reported that, within a large cohort of dying patients, feeling a burden to others and not feeling treated with respect were most highly associated with sense of dignity (87.5% in both instances). The therapeutic implications of these findings point to the importance of trying to assuage feelings of being a burden to others (by way of fostering family engagement; providing support and respite to mitigate feelings of being a burden to others, and avoid role distortions), and ensuring that patients feel that they are treated with respect, valued, and affirmed (i.e. delivering a dignity conserving tone of care).

38. "*Dignity and the essence of medicine: The A, B, C and D of Dignity Conserving Care*" (exhibit **"HMC-11"**) outlines core efficiencies of providing dignity-conserving care. It describes how care providers' attitudes, behaviour, compassion and dialogue (that acknowledges personhood) can help them achieve care that safeguards dignity, thereby shaping patient experience.

39. Our team has also developed a specific psychotherapeutic intervention, based on the model of dignity in the terminally ill, called Dignity Therapy. See on this point, *Dignity Therapy: A novel psychotherapeutic intervention for patients nearing death* (exhibit **"HMC-12"**) and *Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial* (exhibit **"HMC-13"**).

40. *Dignity Therapy: A novel psychotherapeutic intervention for patients nearing death* (exhibit **"HMC-12"**), which was our first study of Dignity Therapy, reported that the vast majority of terminally ill participants experienced it as helpful (86%), indicated that it enhanced their sense of dignity (76%), enhanced their sense of meaning (67%), purpose (68%), will to live (47%) and was an important source of providing comfort to their families (81%).

41. *Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial* (exhibit **"HMC-13"**) which reports on the randomised control trial of Dignity Therapy demonstrated that although it did not influence measures of distress across the three study conditions (Dignity

Therapy, a non-intervention support arm and a control group), patients randomised to Dignity Therapy were significantly more likely to report that the intervention had been helpful, increased their sense of dignity, changed how their family saw and appreciated them, and was helpful to their family. Dignity Therapy outperformed at least one other study arm on lessening feelings of sadness and depression and improving spiritual well-being.

42. A recent Portuguese randomised control trial study of Dignity Therapy demonstrated its ability not only to enhance end of life experience, but to decrease depression and anxiety (Julião M, Oliveira F, Nunes B, Vaz Carneiro A, Barbosa Efficacy of dignity therapy on depression and anxiety in Portuguese terminally ill patients: a phase II randomized controlled trial A. J Palliat Med.. 2014 Jun;17(6):688-95).

43. There have now been multiple trials of dignity therapy, in a variety of care settings (terminally ill, frail elderly, cognitively impaired personal care home residents, degenerative neuromuscular disorders) in various countries around the world (Canada, Australia, USA, Denmark, Portugal, UK, etc.). These studies demonstrate that, for some patients approaching end of life, opportunities to find meaning, purpose, address unfinished business and to provide guidance and comfort for soon-to-be-bereft loved ones can mitigate distress and enhance sense of dignity.

Are there ways to protect patient autonomy and an intact sense of dignity other than legalising physician-assisted suicide or intentional death by medical practitioner?

44. There are certainly ways of protecting patient autonomy and a sense of dignity aside from physician-assisted suicide or euthanasia. The paper, *Dignity Conserving Care: A New Model for Palliative Care.* JAMA 2002, (exhibit **"HMC-3"**), includes a table labelled A Model of Dignity and Dignity-Converting Interventions for Patients Nearing Death. This table offers therapeutic options corresponding to each of the dignity model themes and sub-themes. These options range from being more vigilant and attentive to physical domains of suffering to addressing psychological and spiritual discomfort that might undermine or influence a dying patient's sense of dignity.

45. It is worth noting that distinct from functional capacity (physical limitations imposed by illness), autonomy is determined by way of the ability to maintain some semblance of being in control (e.g. being included in decision making, directing care; being offered choices). This suggests that marked physical limitations and preserving autonomy are not mutually exclusive.

46. That said, in spite of outstanding palliative care, there will always be individuals who in the course of approaching death, will want the option of assisted suicide or euthanasia. When the paper on the Dignity Model was released, Faye Girsh, the one-time Executive Director and President of the Hemlock Society USA published a letter to the editor making that very point. However, another statement she made is also noteworthy: "if most individuals with a terminal illness were treated this way, the incentive to end their lives would be greatly reduced" (Letters, July 10, 2002 JAMA). A copy of this letter is annexed to this affidavit as exhibit **"HMC-14"**.

47. Health care providers must also be mindful that their outlook towards patients has a profound influence on sense of dignity and patient experience. As medicine has become more focused on technology, core efficiencies of medical professionalism - *The A, B, C and D of Dignity Conserving Care* - are often overlooked or are relegated to secondary importance (exhibit **"HMC-11"**).

48. When a clinician shares a patient's sense of hopelessness, this collusion can lead to assisted dying being perceived as the only viable option. While this dynamic is experienced by both parties as beneficent and even mutually comforting ("neither of us need feel helpless any longer"), it precludes continued efforts to address underlying sources of suffering rather than eliminating the person who is suffering. Clinicians who are less well-versed and less experienced in palliative medical approaches are more vulnerable to being caught up in this particular dynamic.

Are there risks for family members associated with medical aid in dying?

49. Yes there are. To begin, each member of a patient's family or support network will have their own feelings about a decision as profound as physician hastened death. Those who agree with the patient's wishes are more likely to come to terms with this approach, while those who do not agree are more likely to struggle. Both in Oregon's Death with Dignity Act and more recently

proposed in Bill 52 in Quebec, Canada, respect for patient autonomy dictates that patients can refuse to have their families involved in the decision for assisted dying entirely. In Oregon, about 10% of patients refuse to have their family members brought into these discussions. The fallout for these families (likely eliciting feelings of guilt, anger; betrayal, depression) have not been formally studied.

50. One study of families of patients who die as a result of euthanasia indicated that there was no evidence of higher rates of complicated grief. (Swarte NB, vanderLee ML, vanderBom JG ,vandenBout J, Heintz APM. Effects of euthanasia on the bereaved family and friends: a cross sectional study. Br Med J 2003;327(7408):189.) However, the results of the study have been questioned, given that the distribution of kinship relations between the two groups (those whose loved ones died as a result of euthanasia, versus those whose loved one died a natural death) were not comparable. Another study of family responses to the assisted suicide of their relative reported a 20% rate of full or sub-threshold post-traumatic stress disorder (Wagner B, Müller J, Maercker A. Death by request in Switzerland: posttraumatic stress disorder and complicated grief after witnessing assisted suicide. Eur Psychiatry. 2012 Oct;27(7):542-6. doi: 10.1016/j.eurpsy.2010.12.003. Epub 2011 Feb 11).

Is the legalisation of physician-assisted suicide or intentional death by medical practitioner or hastened death required to achieve good outcomes in palliative care?

51. Even in the absence of death hastening practices, good outcomes in palliative care are regularly achieved. Palliative care has made great gains over the last few decades and can now attend to most sources of symptom distress. In some instances, managing physical distress may involve having to sacrifice conscious awareness. This approach, known as proportionate palliative sedation, provides the patient with sufficient sedation so as to help them achieve comfort. This can be time limited, continuously re-evaluated and administered proportionate to patients' needs. As previously discussed, there are aspects of psychological and spiritual distress that are much better understood over the past decade and even amenable to treatment.

52. Palliative care will never be the perfect foil to suffering, as suffering is embedded within the fabric of human experience. Suffering is by no means

confined to end of life; and while physical aspects of suffering are more amenable to interventions, psychological and spiritual suffering as a result of loss of health, loss of function and grief require an approach on the part of care providers that is imbued with sensitivity, empathy, humility and a commitment to non-abandonment.

What are your professional and ethical obligations to a patient who expresses a desire for hastened death, regardless of whether they are seriously ill or injured?

53. Some clinicians fear that engaging in a conversation about patients' wishes to die will find them caught between not being drawn into a crime on the one hand, versus staving off feelings of impotence and helplessness because of an unwillingness to hasten their death. In these circumstances, the role of the medical professional includes:

    53.1 being willing to have the conversation;

    53.2 having the skill set and sensitivity to explore the underpinnings of a wish to die;

    53.3 being clear about what is and is not within one's professional mandate (e.g. offer care; obey the law); and

    53.4 assuring commitment to ongoing care (i.e. they need not fear abandonment).

54. Patients need to be put at ease and given permission to express anything and everything they might be feeling. Feelings are not dictated by rules, logic or laws, but rather by where an experience happens to move them. Having the conversation does not require one to be supportive of death hastening or being willing to be involved in that way. However, having the conversation provides an important outlet for patients and can be experienced as therapeutic.

Is a change in the law prohibiting assisted suicide necessary in order for you to provide appropriate care for seriously ill and injured patients? And further, do you believe that it would be a violation of your professional or ethical obligations to participate in a scheme that permitted physician-assisted suicide or intentional death by medical practitioner?

55. The answer to the first part of this question is no. Paragraphs 50-51 above discuss how palliative care can provide appropriate care for seriously ill and injured patients.

56. At this point in time, I would not be prepared to participate in a scheme permitting physician-assisted or intentional death by medical practitioner. My reasons for holding this position are as follows:

56.1 Health System Concerns: Provisions for physician assisted dying presume that doctors are competent and well trained in the areas of pain and symptom management; that they are experienced in having end of life conversations; that they are well versed in understanding the complexities of the physical, psychological, existential and spiritual antecedents of a wish to die; that they are capable of separating their own feelings of hopeless and helplessness from that of their patients. These are by no means easy skills to acquire and are generally not part of the therapeutic armoury of most generalist practitioners.

56.2 Potential Harms: While various safeguards have been described for current and prospective euthanasia/assisted suicide legislation, the data is not convincing that these safeguards can protect against various harms or that they are being enforced.

56.3 Subjectivity in Evaluation: While it would be reassuring to believe that requests for physician assisted suicide or euthanasia are, or could be, evaluated on the basis of objective criteria, there is evidence to suggest that that is simply not the case. For example, a study by Ganzini et al entitled *Attitudes of Oregon Psychiatrists Towards Physician-Assisted Suicide* (American Journal of Psychiatry 1996; 153:1469-1475) confirmed that the ethical views of psychiatrists influence their clinical opinions regarding patient competence to consent to assisted suicide. Specifically, those who supported Oregon's Death with Dignity Act were significantly more confident that they could adequately assess the patient (in the context of both a single evaluation and a long-term relationship with the patient) than those who did not support it.

56.4 A study by Portenoy et al (*Determinants of the willingness to support assisted suicide: a survey of physicians, nurses and social workers* Psychosomatics 1997;38:277-287) also provides evidence that health care providers' willingness to provide assisted suicide is mediated by way of various personal factors, including religious beliefs, concerns about analgesic toxicity, diminished empathy (using a subscale of a measure of professional burnout) and lesser knowledge of symptom management. Another study by Bachman et al (*Attitudes of Michigan physicians and the public toward legalizing physician-assisted suicide and voluntary euthanasia* New England Journal of Medicine. 1996;334:303-309) reported that doctors who had the least contact with terminally ill patients were the most likely to support the legalisation of assisted. Another survey by Cohen et al. (*Attitudes toward assisted suicide and euthanasia among physicians in Washington State.* New England Journal of Medicine. 1994;331:89-94) reported very similar findings i.e. physicians with the most contact and experience with terminally ill patients were least in favour of euthanasia or assisted suicide.

56.5 Unknown Changes in the Health Care Provider-patient Dynamic: As stated by Portenoy et al, "it is troubling to consider the potential influence of inadequate knowledge on the decision to assist a patient in dying".[2] No one likes to feel helpless or impotent. The literature indicates that those who are least experienced and least knowledgeable in care for the terminally ill are most likely to reach for a death hastening option. Could doing so be a way of dealing with a sense of therapeutic ineffectiveness? Whose sense of helplessness and wanting to give up would lead to the acquiescence for death hastening, the health care provider's or the patient's? Little is known about how this dynamic would change the patient-health care provider dynamic and to what extent the taking of a pro-death hastening stance would heighten or further entrench a patient's wish to die. If affirmation of worth can mitigate suffering and enhance sense of dignity, is it possible that supporting a patients wish to die—perhaps a form of collusion with the patient's sense of having run out of options—might unwittingly undermine the patient's sense of worth and dignity, moving both patient and health care provider

---

[2] Portenoy et al *Determinants of the willingness to support assisted suicide: a survey of physicians, nurses and social workers* Psychosomatics 1997;38:277, at 285.

inexorably down a narrowing pathway towards hastened death? At this time, we simply do not know enough about these issues.

56.6 Unwavering commitment and non-abandonment: These are longstanding, fundamental approaches within the practice of medicine to suffering. In dealing with patients who episodically or persistently experience a loss of will to live in the context of medical challenges of various sorts, this stance is the most powerful therapeutic tool that any clinician can wield. How this will change, and has changed, in the context of the availability of physician assisted suicide and euthanasia has simply not been well studied or documented.

Ms Seales's case

57. The plaintiff is concerned that as her illness develops, palliative care (a) will not be able to address all of her physical symptoms; (b) may not be able to manage her pain; (c) may not be able to address psychological, emotional and other forms of non-pain suffering she experiences; and (d) may require medication in doses, and with side effects, that are intolerable to her.

58. Pain associated with brain tumours is typically managed with a combination of opioids, steroids and/or radiation therapy. Ironically the most prominent side effect, somnolence, mimics the primary effect of the tumour itself. Other side effects such as constipation or opioid toxicity are routinely addressed by physicians who are competent in palliative approaches. Pain can always be managed, but in some instances this may mean a decreased level of conscious awareness.

59. The challenges to a patient's sense of dignity are usually related to feelings of their personhood being under assault. Dealing with these challenges requires ongoing involvement of family, social support networks, expert psychosocial, existential and spiritual supports; and of course, the unwavering commitment of healthcare providers well versed in palliative approaches, who will offer the best palliation possible and a commitment to non-abandonment.

Rational Suicide and Medical Aid in Dying

60. Rational suicide is a contentious issue in the psychiatric literature, particularly when it pertains to terminal illness and a request for physician-hastened death. The following points are worth considering:

60.1 The vast majority of suicides take place in the context of mood and substance abuse disorders i.e. in a minority of terminally ill people, an expression of a wish for death or interest in assisted suicide can arise in the absence of syndromal depression.

60.2 While mental illness can influence rationality and mental capacity, it does not necessarily do so i.e. one can be depressed, for instance, and still maintain decision-making capacity.

60.3 Judging rationality in these circumstances can be difficult for physicians, in that their judgment can become entangled in their own feelings regarding how they would anticipate coping in the patient's circumstances. As such, they may deem an expression of suicide rational, based on imagining themselves unable to cope in these circumstances, rather than on whether the request is truly rational and informed.

60.4 The notion of rational suicide in death hastening decisions raises the issue of what role physicians ought to play in these instances. Those who argue rational suicide as justification for physician-assisted suicide would describe the physician's role as evaluating mental capacity; that is, seeing if the patient meets specific eligibility criteria. Those who argue against assisted suicide state that the essence of a physician's role is to try to understand the nature of the patient's suffering and to provide care in order to assuage that distress.

60.5 As a case example, imagine an elderly woman, end stage metastatic breast cancer, requesting physician-assisted suicide. She describes her reasons as follows: 1) she is afraid that her pain medications will eventually wear off, given that she is on high doses of morphine and fears that she will become tolerant; 2) she feels like she has become a burden to her family; and 3) she no longer feels that she is valued, or that her life has any value. It is conceivable that she may not be depressed, that her thinking is rational and that she has decision-making capacity. Each of those are things that can be determined by a physician i.e. ensuring that she meets set criteria for assisted (rational) suicide.

60.6 A very different role for the physician is to address the source of her suffering and to commit to helping her until she dies. That would mean educating her about pain management (that opioids do not have a ceiling effect in terms of maintaining their efficacy; and that many other options are available to manage her pain should that become necessary); assuring her that you are qualified and prepared to keep her pain under good control; arranging to meet with her and her family to explore her feelings of being a burden and offer necessary supports, such as home care, respite care, hospitalisation, if and when needed; and to provide psychological and spiritual support, helping her to explore, cope, and perhaps even overcome feelings of worthlessness and despair.

60.7 There have been some attempts to obfuscate the language pertaining to rational suicide, assisted suicide, and euthanasia, so as to sanitize anything that might be considered unsavory or distasteful. The term "Medical Aid in Dying" (MAD) is a typical example. Introducing this term serves two purposes: 1) it provides a euphemism that eliminates the words "suicide" and "euthanasia"; this allows people to use clinical language that sounds safe, medically sanctioned, without having to explicitly use those more emotionally jarring terms; 2) there is a political purpose in using the term Medical Aid in Dying, and that is a) it is easier to garner support for something that sounds medical rather than something that sounds sinister, and b) Medical Aid in Dying sounds like it is regular care and can be conceived as part of that spectrum of care.

60.8 Supporters of Bill 52 in Quebec used the term "Medical Aid in Dying" to great effect; and accomplished their purpose in doing so, by way of garnering support and making the argument that euthanasia (another word they avoid using) is actually Medical Aid in Dying.

60.9 The term Medical Aid in Dying is conceptually unclear and lacks definitional specificity. Some have used it to refer to euthanasia exclusively, while others say it means assisted suicide. By using sanitized medical language, it also is meant to imply that it is part of the continuum of palliative care. However, it is not; according to the World Health Organization definition, palliative care "intends neither to hasten nor postpone death".

Response to the Carter Judgment

61. What follows are my responses to the decision of the trial Judge, The Honourable Madam Justice Lynn Smith in *Carter v Canada (Attorney-General)* 2012 BCSC 886. I provide specific critique of the way Her Honour addressed the evidence that was put before her in that case. Each comment is referenced to the corresponding numbered paragraph in *Carter v. Canada.* Excerpts from the judgment are in italics:

62. [4] The judge refers to palliative sedation as *"sedation to the point of persistent unconsciousness".*

62.1 This is not accurate. Palliative sedation is a proportionate response i.e. it can be time limited, re-evaluated and titrated to the patient's degree of expressed need. This misinterpretation is dangerous as it more easily conflates palliative sedation with euthanasia, suggesting that if one is ethical, so too is the other. Yet proportionate palliative sedation is not provided with the intent of hastening death, nor does the evidence support that it does hasten death. In fact, it appears that patients whose pain is well controlled seem to live longer.

63. [5] "*Some of these currently accepted practices* [administering medications even in in dosages that may hasten death, and to administer palliative sedation] *bear similarities to physician-assisted death, but opinions differ as to whether they are ethically on a different footing.*"

63.1 Using opioids to treat pain does not hasten death; nor does proportionate palliative sedation. Even the principle of double effect acknowledges that death is not a primary or targeted outcome. If a patient is taken off a ventilator and goes on to live days, weeks, months or years, there is no obligation to take action to hasten that person's death.

64. [9] "*No evidence of inordinate impact on vulnerable populations appears in the research.*"

64.1 In Oregon we do not know who administers the medicine once prescribed; there is no obligation to re-evaluate competence; there is no mechanism to reconcile differing opinions; there is no evidence to indicate what palliative interventions these patients are receiving and what degree of distress they are in when they take their lives. Most of these assisted suicides are arranged through an assisted suicide advocacy group who register all the patients in hospice care. As such, while they can claim these patients are on hospice, they cannot specify what palliative options they in fact access.

65. [9] "*Finally, the research does not clearly show either a negative or a positive impact in permissive jurisdictions on the availability of palliative care or on the physician-patient relationship.*"

65.1 Unwavering commitment and non-abandonment are the mainstay of addressing suffering in medicine and in psychiatry, this approach is the most powerful tool we have to help sustain patients through suffering and mental anguish. It is, therefore, not known how a death hastening option would taint or undermine this dynamic.

66. [9] In referring to safeguards, the judge says, "*second opinions and reporting requirements are followed.*"

66.1 The rate of referral for psychiatric evaluation is very low, and in the 2013 report was zero.

67. [10] "*The defendants identify a number of areas of risk for patients if physician-assisted death is permitted, for example relating to the patients' ability to make well-informed decisions and their freedom from coercion or undue influence, and to physicians' ability to*

assess patients' capacity and voluntariness. The evidence shows that risks exist, but that they can be very largely avoided through carefully-designed, well-monitored safeguards."

67.1 This over estimates the ability of physicians to make these determinations. The Ganzini studies indicate that only a minority of psychiatrists are able to make evaluations for competency to commit suicide in the context of an ongoing relationship. How, then, do we expect clinicians - even those lacking psychiatric expertise - to so readily make these determinations? While the judgment assumes it is easy to determine lack of coercion or undue influence, these issues can be very complex. In Oregon, patients can refuse to have their families engaged in the conversation. So how does one exclude the possibility of coercion when those who potentially might be the source of such coercion can be disqualified from the conversation?

68. [17] *"In addition, the legislation affects her right to life because it may shorten her life. Ms. Taylor's reduced lifespan would occur if she concludes that she needs to take her own life while she is still physically able to do so, at an earlier date than she would find necessary if she could be assisted."* See also [1277], [1322] and [1325].

68.1 Is there evidence to show that death-hastening lowers suicide rates? The suicide rate in Oregon is highest in the United States and has increased since the passage of the death with dignity act. If the availability of physician assisted suicide was designed to eliminate the need for people taking their own lives, one would expect that the suicide rates would have decreased. That has not happened.

69. [24(2.)] *"A "medical condition" means an illness, disease or disability, and includes a disability arising from traumatic injury."*

69.1 The suicide rate amongst people with traumatic injuries, such as spinal cord injuries, is about 7-10%. When these patients are followed over time, within two years, about 70% renege on their suicidal intent. This takes place by way of unwavering support, assurances of non-abandonment by the medical professional, along with whatever treatment is required. How will these dynamics change in the context of death hastening legislation? Will clinicians be obliged to impose protracted waiting periods, or will patients be able to insist that their autonomy allows them to have their lives ended, in spite of an anticipated albeit gradually acquired psychological recovery?

70. [42] *"The phrase "terminal sedation" is occasionally used synonymously with palliative sedation."*

70.1 This term should not be used; as it does not include the notion of proportionality. This has the unfortunate secondary effect of conflating terminal sedation with euthanasia, implying that if the former is justifiable then so too is the later.

71. [315(d)] *"Failing to respect an autonomous choice to die risks paternalism."*

71.1 But yielding to such a choice may deprive physicians of their most potent tool in being able to address suffering - unwavering commitment to providing continuous care.

72. [315(f)] *"If a patient's decision to hasten her own death by suicide is ethical, it may be ethical to provide assistance to that patient."*

72.1 The ethical issues in suicide implicate only the patient. In assisted suicide, both the patient and the healthcare provider are implicated. While the outcome for the former may be identical and therefore appear ethically indistinguishable, for the latter, he or she becomes a moral agent in bringing about the patient's death and hence responsible for their actions.

73. [315(g)] *"Medical ethics already permit practices that amount to assisting with hastened death (refraining from administering or discontinuing life-sustaining treatment, administering medication in doses which may hasten death and palliative sedation). The difference between those practices and physician-assisted suicide or voluntary euthanasia is ethically insignificant."*

73.1 This is simply wrong. When treatment is refused or withdrawn the force bringing about death is the underlying illness. If in spite of refusal or withdrawal of treatment the patient goes on living (and there are certainly instances where that occurs) the goal and obligation of the physician is not to end the patient's life. The use of opioids to treat pain does not bring about the death of patients, nor does palliative sedation. On the other hand, assisted suicide and euthanasia are carried out with the explicit purpose of ending or helping the patient to end their lives. The ethical difference could not be any clearer; that is, so long as intent is considered an important mediator of responsibility for ones actions.

74. [315(h)] *"Some patients may find death while under palliative sedation repugnant or unacceptable, and may find other forms of palliative care unacceptable. Patients should not be required to submit to treatment against their wishes."*

74.1 What is being referred to as repugnant is the process by which all humans die (with the exception of those who die suddenly). As people approach death they usually become more somnolent, they may stop eating and drinking, spend increasing amounts of time sleeping, and can be dependent on others for care until they die. Palliative care is very well versed on being sure that people can be kept entirely comfortable and pain free throughout this course until death ensues.

75. [315(l)] *"It is unethical to refuse to relieve the suffering of a patient who requests and requires such relief, simply in order to protect other hypothetical patients from hypothetical harm."*

75.1 Suffering towards the end of life derives from multiple sources. Suffering, especially physical suffering, can almost always be assuaged (always if consciousness can be sacrificed). Further the consequences of complying with a patients request for assisted suicide or euthanasia could impose suffering on others.

76. [339] *"The physician provides the means for the patient to do something which is itself ethically permissible. It is unclear, therefore, how it could be ethically impermissible for the physician to play this role."*

76.1 While the witness in the *Carter* case argued that suicide is ethical (and therefore remains ethical, even when assistance to carry out the act is provided), one must underscore that suicide only implicates the action of the person committing suicide. However, assisted suicide introduces an entirely new player; so the ethical calculus regarding that new player needs to be considered separate and apart from the scenario of self-inflicted death. In assisted suicide, the role of the physician has changed; he or she becomes the agent of death; a role that has never been a part of medicine. He or she is no longer able to commit, without ambivalence, to non-abandonment and continued care, given that physician assisted suicide will redefine what that dynamic looks like and how it plays out.

77. [347] *"Public opinion polls provide some indication as to societal values overall, and the polling evidence suggests that 63% of Canadians are supportive of physician-assisted death in some circumstances."*

77.1 This means that people are afraid of dying and in the absence of adequate competence on the part of healthcare providers and the lack of availability of quality palliative care, their fears may be increased. It also suggests that people are poor at predicting what they would want in circumstances that have yet to unfold. In Oregon, despite the popular support for physician assisted suicide when it was introduced, less than 0.5% of dying patients avail themselves of it.

78. [360] *"In contrast, the plaintiffs say that it is possible to screen out people who should not be assisted to die. They say that empirical evidence collected in jurisdictions that permit assisted dying demonstrates that the safeguards in those jurisdictions are generally effective in preventing the deaths of persons who are incompetent, subject to undue influence or unsettled in their desire to end their lives."*

78.1 It is hard to rule out undue influence when there is no obligation to meet with families and patients can prohibit families being brought into the discussion.

79. [394] It is worth noting that in reviewing the safeguards in place for the Oregon Death With Dignity Act ("ODDA"), there is nothing that addresses

any obligation on the part of the physician to explore the source of the patient's suffering, nor an obligation to try to mitigate such suffering. This essentially changes the role of the physician i.e. they are no longer serving a role as a healer, but rather, are providing a technical service comprised of being sure the patient meets particular entry criteria, and providing a means by which the patient can end their life.

80. [394(b)(v)] "*recommend that the patient notify next of kin of his or her request for medication (though a patient who declines will not have his or her request denied for that reason);*"

80.1 How does one rule out undue influence under those circumstances. In 10% of cases in Oregon, patients refuse to have their families brought into the discussion. This same stipulation regarding families has been embedded within the proposed Bill 52 in Quebec.

81. [394(b)(vi)] "*counsel the patient about the importance of having another person present when the patient takes the prescribed medication and of not taking the medication in a public place;*"

81.1 Notice that this 'other person' need not be the physician. Physicians are in attendance at the time of medication consumption in only about 10% of instances. This means there is no re-evaluation of competence, nor a determination of who is administering the medication, no ability to reassess the issue of coercion; no opportunity to determine if at the time they plan to commit suicide, the patient is suffering from remediable symptoms such as pain, nausea, depression, anxiety, etc.

82. [394(c)] "*If either the attending or consulting physician is of the view that the patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment, he or she must refer the patient for counselling. No medication will be prescribed until the individual prescribing the counselling determines that the patient is not suffering from such impaired judgment.*"

82.1 Almost no referrals for psychological/psychiatric evaluation are made; in 2013 in Oregon, none of the patients who received a lethal prescription were referred for psychiatric evaluation.

83. [394(d)] *"No less than 48 hours must elapse between the patient's written request and the writing of a prescription under the ODDA."*

83.1 In the Canadian Palliative Care Survey (Wilson KG, Chochinov HM, McPherson CJ, et al. Desire for euthanasia or physician-assisted suicide in palliative cancer care. Health Psychol. 2007;26:314-23), 5.8% of terminally ill respondents said they would currently want physician hastened death if it was available. On the other hand, 9.5% of respondents said that at some point during the course of their terminal condition they had wanted physician hastened death, but no longer held that position. In other words, the temporal stability of these requests is something that needs to be carefully considered and understood.

84. [397] *"The Oregon Health Division ("OHD") monitors compliance with the Act. All physicians who prescribe under the ODDA are required to notify the OHD and provide documentation that legal requirements are met."*

84.1 There is no obligation for physicians who have refused to report; no obligation for discussion or reconciliation process between supporting and opposing clinicians; no obligation to be present to witness the event; no obligation to re-evaluate competence; no obligation to evaluate the clinical state of the patient at the time and to provide palliation.

85. [400] Regarding this table from the OHD, notice that the majority of patients who die under the act are over the age of 65; they are white (groups that are marginalized or have a history of being marginalized tend to be distrusting of medicine e.g. notice how few African Americans avail themselves of this option; they are significantly also less likely to forgo life sustaining treatment); while they are nearly all enrolled in hospice, the vast majority of these patients have their death hastening arrange through a pro assisted suicide organization Compassion & Choices, who routinely register all potential candidates on

hospice. While such registration creates the illusion of good end of life care, there is no data indicating what level care or expertise is brought to bear in understanding or attempting to mitigate their distress.

86. While the majority, according to the table, have health insurance, the precarious nature of many of these insurance plans is well known in terms of its variability and limitations on costs it will cover. There is certainly ample evidence demonstrating the financial demands and hardships—including out of pocket expenses—incurred by patients and families facing catastrophic illness. While financial implications of treatment are not indicated as a motivation for death hastening, doctors are not well versed in evaluating these issues; and affirming a financial motivation would disincline clinicians from providing patients the service based on that rationale i.e. there are reasons to understate the financial motivation, knowing that it might preclude their access to a hastened death.

87. The table affirms how few psychiatric referrals are made (none in the most recent report). These patients are for the most part well educated, which implies they also have likely held reasonably paying jobs. So the cumulative picture is older, white people with some financial means and resources, who may or may not have underlying remediable sources of suffering, who may or may not receive adequate palliative care, whose wish to die is responded to with a lethal prescription, written by a physician whose relationship to the patient is short term (median ~4 months); taken 15 to 692 days post prescription (2013 data); in most instances unwitnessed by said physician (in 2013, 8% of physicians and 3% of other healthcare providers), under circumstances where the person administering the medication, the patient's current competence and the patient's current status in terms of suffering remediable distress is not evaluated and thus unknown.

88. [416] Reference is here made to improvement in end of life care since the passage of ODDA. One cannot conclude cause and effect. In fact, end of life care has improved significantly throughout the United States and Canada over the last 10 to 15 years; and such improvement is independent of hastened death legislation. While Oregon has scored well on national palliative care report cards (Report Card: America's Care of Serious Illness. A State-by-State

Report Card on Access to Palliative Care in Our Nation's Hospitals, Center to Advance Palliative Care. 2011), several studies suggest problems with how pain is managed in certain settings (see comments re paragraph 710) [Fromme EK, Tilden VP, Drach LL, Tolle SW. Increased family reports of pain or distress in dying Oregonians: 1996 to 2002. Journal of Palliative Medicine 2004;7:431-42; Wagner AM. Goodwin M, Campbell B et al. Pain prevalence and pain treatment for residents in Oregon nursing homes. Geriatric Nursing. 1997;18:268-72; Hickman SE1, Tolle SW, Tilden VP. Physicians' and nurses' perspectives on increased family reports of pain in dying hospitalized patients. J Palliat Med. 2000 Winter;3:413-8].

89. [425] While Ganzini reports that 30% of patients requesting PAS had depression in her study, it is again noteworthy that very few to no patients are referred for psychiatric assessment amongst those who receive a lethal prescription.

90. [429] This paragraph indicates that in some instances, depressed patients are not being diagnosed and are receiving lethal prescriptions they use to end their lives.

91. [431] This underscores the fact that evaluating competency to consent to assisted suicide is not so straight forward; only 6% of psychiatrists were very confident that they could do so within the context of a single evaluation. If that is the case, how will none specialists manage to take on this task?

92. [432] *"Psychiatrists who favoured the ODDA were significantly more confident of their ability to adequately assess the patient in the context of both a single evaluation and a long-term relationship than those who were opposed to the legislation."*

    92.1 This statement underscores that the ability to evaluate competence, and the presence of a psychiatric disorder in the context of a death-hastening request, is vulnerable to the physician's personal views and opinions on the practice of PAS.

93. [635] While this and preceding paragraphs argue that there is no slippery slope, there is no question that autonomy is hard to draw a circle around. While PAS was conceived as being a means of helping terminally adult patients hasten

their death, the practice of PAS has extended to non-terminally ill cohorts (e.g. mental suffering; children; chronic illness; tiredness of life). While the argument has been made that PAS will allow people to extend their lives, given they will not have to commit suicide prematurely in order to avoid an existence that they feel will be intolerable, current practices do not allow patients who are not competent to receive PAS. Therefore, excluding these patients e.g. patients with early dementia—and not being able to request PAS in an advanced directive—will place these patients in exactly in the position of the plaintiff i.e. having to end life sooner than had they been eligible for PAS by advance directive.

94. [645] and [667] While these studies claim that 'vulnerable populations' have not been disproportionately affected by death hastening acts, every bit as relevant a question is whether these groups feel more vulnerable in the context of seeking healthcare.

95. [688] One cannot assume that there is a cause and effect between death hastening legislation and improvements in palliative care. In fact, according to a report entitled 'The Quality of Death. Ranking End of life care across the world' produced by the Economist Intelligence Unit (2010) - UK, Australia, New Zealand, Hungary, Canada, Ireland, US and Hong Kong all rank higher than European countries with death hastening options: Belgium (ranked 9th), Netherlands (17th), Denmark (20th), Luxembourg (23rd); and Switzerland (30th).

96. [710] This paragraph cites an article that makes the case that palliative care has improved in Oregon since the ODDA.

96.1 This does not establish cause and effect. (The suicide rates in Oregon have also increased since the ODDA and are the highest in the United States; however, any cause and effect are only speculative). Palliative care has improved in most parts of the United States and Canada over the past 2 decades.

96.2 Several studies from Oregon indicate high degrees of pain and distress in the last weeks of life, as reported by decedents of people who have died in private homes, nursing homes and other community based sittings (Fromme EK, Tilden VP, Drach LL, Tolle

SW. Increased family reports of pain or distress in dying Oregonians: 1996 to 2002. Journal of Palliative Medicine 2004;7:431-42; Wagner AM. Goodwin M, Campbell B et al. Pain prevalence and pain treatments for residents in Oregon nursing homes. Geriatric Nursing. 1997;18:268-72; Hickman SE1, Tolle SW, Tilden VP. Physicians' and nurses' perspectives on increased family reports of pain in dying hospitalized patients. J Palliat Med. 2000 Winter;3:413-8).

96.3 The more important consideration is not so much if palliative care is better or worse, but rather, what palliative care is actually being offered to patients making death-hastening requests. Being registered with hospice is not an accurate proxy for what services are and are not being received.

97. [714] and [715] Compassion and Choices Washington actually enrol PAS candidates in hospice; again, while this creates a favourable optic, it does not convey what services are provided.

98. [720] This paragraph makes the case that *"the Dutch level and practice of palliative are stand well in comparison to other European states."*

98.1 Comparisons between countries regarding delivery of palliative care are difficult. According to the 'The Quality of Death. Ranking End of life care across the world' produced by the Economist Intelligence Unit (2010), the Netherlands stands 17th in terms of quality of End of Life Care.

99. [741] This paragraph states that, *"the existing prohibition against physician-assisted death interferes with the physician-patient relationship because it precludes an important treatment option and creates a climate of secrecy and fear."*

99.1 Good palliative care should include an openness to discussing a loss of will to live, desire for death, and interest in PAS. These conversations are a critical part of understanding patients and being able to respond to their suffering. While this may not prevent every suicide – whether patients are terminally ill or not – the ability to commit to supporting patients, addressing their distress, assurances of non-abandonment, and offering excellent medical care is the mainstay of how these patients should be managed and prevents the vast majority of suicides.

100. [742] This paragraph address the potential effect of legalized physician assisted dying on the physician-patients relationship and trust in physicians. A study that sheds some light on this topic was published by Ganzini et al (Oregon Physicians' Attitudes About and Experiences With End of Life Care Since Passage of the Oregon Death with Dignity Act. JAMA. 2001;285:2363-2369). The data do not clearly indicate that a position in support of PAS improves the physician-patient relationship. According to the physicians surveyed, 4% reported patients being concerned about their supportive PAS stance, compared to 11% reporting patients concerned about an opposed stance to PAS. 1% reported patients leaving their practice because of a supportive stance, compared to 4% who reported patients leaving their practice for an opposed PAS stance. However, 21% who were supportive of PAS reported their patients felt more positive about care after knowing the physician's position, compared to 28% amongst physicians who opposed PAS.

101. [743] *"That evidence, they say, is to the effect that addressing such requests with their patients has improved their relationship with those individuals."*

101.1 The statement that acquiescing to the patient's request improves the relationship between the physician and the patient is highly problematic. Doing what patients ask of physicians can improve the sense of connectedness and having a common purpose – at least in the short term – but that does not make it an appropriate interaction. Providing a drug addict with narcotics might improve the relationships, but it does not imply good or appropriate care.

102. [745] This paragraph describes a physician who felt frustrated that she did not have a death hastening option to provide her dying patients. Yet palliative care clinicians have treated patients for decades in the absence of such frustration; and tend to offer least support for this death hastening approach.

103. [746] and [1271] I think it is inaccurate to speculate that PAS will promote enhanced trust resulting from more open communication. Physicians have

almost no training in end of life conversations; their communication skills training is limited. They need to be taught that an expression of a wish to die is an expression of human suffering; and that illness, disease and acquired disability can impose suffering. To respond appropriately, they need to be taught how to be comfortable discussing these issues opening and honestly. To suggest that the way of enhancing trust and more open communication is by legalising assisted suicide is, in my opinion, misguided and misses the point entirely.

104. [775] It is interesting and noteworthy that witnesses who are in favour of PAS (that is Dr. Ganzini's position) indicate the evaluation of competence is easy; those who are disinclined state the opposite. While Dr. Ganzini may state the cognitive demands are straight forward, the underlying emotion demands and complexities that belie such decisions are far from straight forward.

105. [815] While the court concludes that coercion can be determined as part of a capacity assessment, in Quebec and Oregon patients can refuse to have their family members engaged in the discussion altogether.

106. [824] As stated previously, being enrolled in hospice (which is routinely done by the pro euthanasia organization who arrange logistics around PAS) does not address what services are and are not provided to patients.

107. [827] While I testified that hypothetical scenarios may differ from what people would actually do when presented with options, this was to make the point that while many people support PAS from the vantage point of good health, only a tiny minority would choose to avail themselves of such options should they find themselves in these circumstances. In other words, people are very poor at anticipating what they would actually want under circumstances that have not as yet unfolded.

108. [831] While the court says that a *"range of treatment options described would have to encompass all reasonable palliative care interventions, including those aimed at loss of personal dignity"*, these options are not readily available. Palliative care is an approach, not a singular intervention, which must provide continuous support for patients and families, community based alternatives, respite, and palliative care expertise. The availability of a consultation is hardly synonymous with

this kind of comprehensive end of life care. And the further one expends beyond tertiary care, urban centres, the more palliative care services and supports become scares.

109. [837] *"I agree with the evidence of the plaintiffs' experts that it would be incorrect to draw the inference from the Oregon data that there is widespread ambivalence."*

109.1 While the court does not agree that the evidence suggests ambivalence, psychiatric literature confirms that ambivalence is a part of all expressions of suicidality and an expressed wish to die.

110. [839] *"Dr. Downing testified that patients change their minds and often adapt as their circumstances change while under palliative care."*

110.1 As previously stated, there is evidence that the majority of people who are suicidal in the context of acute traumatic injuries renege on their suicidal intent over the course of months to years. For dying patients, the Canadian National Palliative Care Survey indicated that 9.5% of patients who were terminally ill indicated that during the course of their illness, they at one time would have wanted a hastened death but had now changed their mind.

111. [852] It is important to note that the conclusion about disabled persons not being overly represented in the Belgium data was gleaned from death certificates (i.e. it was not specifically asked about otherwise). This is a highly unreliable approach to determine the presence of chronic concurrent disabilities.

112. [856] Dr. Librach states that the context of PAS should include the following: *"We also need to ensure that access to quality palliative care and effective assessment is available to all persons."* This is far from the current status quo.

113. [1070] While stopping nutrition and hydration is often described in macabre terms, it is part of a normal pathway preceding death. In a study on the topic (Jacobs S. Death by Voluntary Dehydration — What the Caregivers Say. N Engl J Med 349:325, July 24, 2003), 94% of nurses reported that patients who no longer were receiving nutrition or hydration towards the end of life experienced a peaceful death. They indicated that patients typically did not

experience hunger or thirst, and that mouth dryness was alleviated by moistening to lessen any discomfort. When death by voluntarily stopping of eating and drinking was compared with death resulting from physician-assisted suicide, nurses reported that patients in the former group had less suffering, less pain, and were more at peace than the latter group.

114. [1071] the description of a *"gruesome and macabre"* 7 to 10 days of dying is inflammatory and would reflect the absence of appropriate palliation. That kind of suffering is anathema to proper palliation and should never be tolerated, nor is it necessary; if required to achieve symptom relief, patients can receive proportionate palliative sedation. As well, increasing somnolence, not eating, not drinking are a normal common pathway that leads to death. That is neither macabre nor gruesome; it is simply how human beings die.

115. [1159] A total loss of independence at the end of life is universal, expect for people who die suddenly. If this is a rationale for PAS, everyone can argue that how humans die is intolerable and PAS should be provided.

116. [1273] The association between PAS legislation and improved palliative care is tenuous.

117. [1274] The paucity of palliative care as a rationale for not supporting PAS is not 'hostage-taking'; rather, it addresses the reality that if such care is not available, patients will not have a real choice between good care and death hastening options.

118. [1328] I know of no circumstances that would preclude the effective use of proportionate palliative sedation; just as there is no instance in which a surgery is so invasive that proper analgesia cannot be achieved. All patients who do not die suddenly gradually lose consciousness; and that process of dying is something that all families bear witness to. While it is surely hard to watch a loved one die, the most marked suffering that people experience is when they sense their loved one is in pain (this can be controlled) and the suffering of losing a loved one to death. Addressing future fears and being pre-emptive around issues of pain and symptom distress is embedded within and part of the essence of palliative care.

AFFIRMED)
at this)
day of 2015
)
before me:)

Harvey Max Chochinov

A person duly authorised to take oaths by the law of Canada

"HMC-1"

Curriculum Vitae

Dr. Harvey Max Chochinov

O.C., O.M., M.D., Ph.D., F.R.C.P.C., F.R.S.C., F.C.A.H.S.

This is the exhibit marked "**HMC-1**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at
this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

Contact Information

3017-675 McDermot Avenue
675 McDermot Avenue
Winnipeg, Manitoba, Canada R3E 0V9
Office Phone: (204) 787-4923
Fax: (204) 787-4937
Email: hchochinov@cancercare.mb.ca

Current Academic Appointments

2008 -	Distinguished Professor, Department of Psychiatry, University of Manitoba, Winnipeg, MB Canada
2002 - 2017	Canada Research Chair in Palliative Care (Tier 1), Department of Psychiatry, Faculty of Medicine, University of Manitoba, Winnipeg, MB Canada
2002 -	Director of the Manitoba Palliative Care Research Unit, Faculty of Medicine, University of Manitoba, Winnipeg, MB Canada
1998 -	Professor, Division of Palliative Care, Department of Family Medicine, Faculty of Medicine, University of Manitoba, Winnipeg, MB Canada
1998 -	Professor, Department of Community Health Sciences, Faculty of Medicine, University of Manitoba, Winnipeg, MB Canada
1996 -	Co-Director, Psycho-Social Oncology Research Group, Faculty of Medicine, University of Manitoba, Winnipeg, MB Canada

Dual/Joint Appointments

2014-2017	Adjunct Professor, Swinburne University of Technology, Faculty of Health, Arts and Design, Victoria, Australia.
2012 – 2013	Adjunct Professor, Western Australia Centre for Cancer and Palliative Care Curtin University, Faculty of Health Sciences, Perth, Australia
2007 – 2016	Riverview Health Centre Research Affiliate, Winnipeg, MB Canada
2001 -	Adjunct Professor, School of Nursing and Public health, Edith Cowan University, Perth, Australia
2001 -	Chair Canadian Virtual Hospice, Winnipeg, MB Canada
1993 -	Head, Clinical Services and Academic Affairs, Department of Psychosocial Oncology, CancerCare Manitoba, Winnipeg, MB Canada

Previous Appointments

1999 – 2000	Medical Research Council of Canada Scientist (Regional Partnership Program)
1998 – 2008	Professor, Department of Psychiatry, Faculty of Medicine, University of Manitoba, Winnipeg, MB Canada

1993 – 1998	Associate Professor, Department of Psychiatry, Faculty of Medicine, University of Manitoba, Winnipeg, MB Canada
1987 – 1993	Assistant Professor, Department of Psychiatry, Faculty of Medicine, University of Manitoba, Winnipeg, MB Canada
1987 – 2010	Psychiatric Consultant, The Pas Mental Health Care, The Pas, MB Canada

Credentials

2007	Fellow (Academy of Health Sciences), Canadian Academy of Health Sciences, Canada
2006	Fellow of the Royal Society of Canada, Royal Society of Canada
1996	Fellow, Academy of Psychosomatic Medicine
1987	Fellow of the Royal College of Physicians of Canada (Psychiatry)

Education

1994 - 1996	Doctor of Philosophy, Community Health Sciences, University of Manitoba
1990 - 1993	Bachelor of Arts, English, University of Winnipeg
1986 - 1987	Clinical Fellowship, Psycho-oncology, Memorial Sloan Kettering Cancer Centre. New York, New York
1986 - 1987	Fellowship, Psychiatry, New York Hospital. New York, New York
1986 - 1987	Fellowship, Psychiatry, Cornell Medical College. New York, New York
1978 - 1983	Doctor of Medicine, University of Manitoba

Awards and Honours

2015	Eduardo Bruera Award in Palliative Medicine, Canadian Society of Palliative Care Physicians
2014	Officer of the Order of Canada
2014	Carmelita Lawlor Lectureship in Palliative Care. Hospice Palliative Care Ontario
2013	Patient Dignity Question Study: One of Top Canadian Cancer Society funded research stories of 2013.
2013	Dignity Therapy: Final Words for Final Days received the 2012 Prose Award for Clinical Medicine (The Prose Awards are the American Publisher's Awards for Professional and Scholarly Excellence).
2012	Canadian Medical Association's Frederic Newton Gisborne Starr Award
2012	Scholastic Award, Doctors Manitoba

2011	San Diego Hospice and the Institute for Palliative Medicine, Visiting Professorship Program Scholarship, Sponsored by the Academy of Psychosomatic Medicine
2011	American Association for Hospice and Palliative Medicine Award for Excellence in Scientific Research
2010	Health and Science Communications Association, Boston, MS, Silver Award, for the Canadian Virtual Hospice
2010	Canadian Association of Psychosocial Oncology Lifetime Achievement Award
2010	International Psycho-Oncology Society Bernard Fox Memorial Award
2009 – 2016	Honorary Professor in the Centre on Behavioral Health, The University of Hong Kong (Renewal 2013)
2009	The Dr. John M. Bowman Memorial Award Winnipeg RH Institute Foundation
2008	Distinguished Professor, University of Manitoba
2008	O. Harold Warwick Prize, National Cancer Institute of Canada
2007	Fellow, Canadian Academy of Health Sciences
2007 - 2010	Honorary Professorship in the School of Nursing, The Hong Kong Polytechnic University
2006	Fellow of the Royal Society of Canada
2006	J.M. Cleghorn Award for Excellence and Leadership in Clinical Research, Canadian Psychiatric Association
2005	Balfour M. Mount Visiting Professorship in Palliative Medicine, Royal College of Physicians and Surgeons, Canada
2004	Order of Manitoba
2004	Research Award Recipient, Academy of Psychosomatic Medicine
2002	Visiting Professorship, Academy of Psychosomatic Medicine, Laval University, Quebec City, PQ Canada
2002 -	Tier I Canada Research Chair in Palliative Care
2002	Queen's Golden Jubilee Anniversary Medal
2000 - 2002	Canadian Institutes of Health Research Investigator
1999	The Academy of Psychosomatic Medicine 1999 Dorfman Journal Paper Award [Best paper published in the Journal of Psychosomatics in 1999]; Honourable Mention for "Depression, Hopelessness, and Suicidal Ideation in the Terminally Ill"
1999	Nominee, Canadian Palliative Care Award of Excellence
1998 -	Official representative of the Education for Physicians on End of Life Care Project American Medical Association
1998	Hoffman LaRoche Inc. Award for Population based Research, University of Manitoba, Faculty of Medicine, Graduate Studies
1996 -	Canadian Who's Who
1996 - 1999	Soros Faculty Scholar, Project on Death in America, Open Society Institute
1996 - 1998	Portney Research Scientist Award, Manitoba Cancer Treatment and Research Foundation

1996	RH Award for Outstanding Contributions to Scholarship Research $2500.00, University of Manitoba
1995	Professional Development Scholar ($10,000), Health Sciences Research Foundation, Canada
1995	Detweiler Scholarship, Royal College of Physicians and Surgeons of Canada
1986	Dr. R.A. Macbeth Travelling Fellowship, Canadian Cancer Society
1976	Staff Alumni Award, Garden City Collegiate

Student Supervision
Post Doctoral

2013 – 2018	Dr. Lori Montross (Co-Supervisor) University of California, San Diego Funding: Amercian Cancer Society; Mentored Research Scholar Grant Study: Positive outcomes in cancer care: Emphasizing quality of life and legacy Current position: Assistant Professor, Department of Family and Preventative Medicine, University of California, San Diego
2015 – 2017	Dr. Qiaohong Guo (Principal Supervisor) University of Manitoba MHRC/CancerCare Manitoba Postdoctoral Fellowship Award, $36,750.00/year for 2 years Study: Dignity Management in Palliative Care and the Development of the Dignity Caregiving Assessment Scale (DCAS)
2010 – 2012	Dr. Shane Sinclair (Principal Supervisor) University of Manitoba Wyeth Fellowship/CIHR Study: Spiritual Dimensions of End of Life Care Current position: Assistant Professor, Faculty of Nursing, University of Calgary
2007 - 2009	Dr. Genevieve Thompson (Principal Supervisor) University of Manitoba Study: Palliative Care in the Institutionalized Elderly Current position: Assistant Professor, College of Nursing, University of Manitoba; Research Associate, Manitoba Palliative Care Research Unit

2004 - 2009 Dr. Heidi Janz (Co-Supervisor)
University of Manitoba
CIHR funded Vulnerable Persons and End-of-Life Care NET grant
Study: Vulnerable Persons and End of Life Care
Current position: Adjunct Professor, John Dossetor Health Ethics Center, University of Alberta

2004 - 2006 Dr. Kerstin Roger (Principal Supervisor)
University of Manitoba
Health Sciences Centre Post Doctoral Fellowship Award
Study: Dementia and Palliative Care
Current position: Associate Professor, Department of Family Social Sciences, University of Manitoba

Doctoral

2012 - 2016 Maia Kredentser (Co-supervisor with Dr. Corey Mackenzie, Psychology)
Clinical Psychology, University of Manitoba
Study: Personality, coping, and burden in patients and caregivers in four non-cancer populations at the end-of-life
Current position: PhD Candidate, University of Manitoba

2013 – 2015 Heather Campbell-Enns (Academic Advisor)
Interdisciplinary Cancer Control Program, University of Manitoba
Study: Decision-making across the adult lifespan in the context of breast cancer
Current position: PhD Candidate, University of Manitoba

2010 – 2014 Miguel Julião (Academic Advisor)
Faculdade de Medicina da universidade de Lisboa
Study: Eficácia da terapia da dignidade na patologia psicossocial de doentes em fim de vida seguidos em cuidados paliativos: ensaio clínico aleatorizado e controlado
Current position: Professor auxiliar da faculdade de Medicina da universidade de Lisboa

2010 - 2013 Victor Cellarius (Academic Advisor)
Dalla Lana School of Public Health, University of Toronto
Study: A conceptual analysis of Canadian Palliative Care Ethics
Current position: Assistant Professor, Family & Community Medicine, University of Toronto

2010 – 2013	Andy Ho (Academic Advisor) University of Hong Kong Study: Living and Dying with Dignity: An Interpretive-Systemic Framework in Hong Kong Current position: Research Assistant Professor, Sau Po Centre on Ageing, University of Hong Kong
2007 - 2013	MacKinnon, Christopher (Academic Advisor) Counselling Psychology, Psychology Intern Palliative Care McGill University and Montreal General Hospital Study: The Development and Pilot Testing of the Meaning-Based Group Counselling Intervention for Bereavement Current position: Faculty Lecturer ,Department of Oncology, Faculty of Medicine, McGill University, Montreal, QC; Counselling Psychologist, Private Practice, Monkland Professional and Medical Center, Montreal, QC
2008 - 2012	Lai Cheung Wong (Academic Advisor) Hong Kong Polytechnique University, Hong Kong Study: A study of forgiveness and reconciliation of married couples in the Chinese context: Development of a clinical intervention model Current position: Honorary Lecture at the Department of Social Work and Social Administration; Honorary Clinical Associate at Center on Behavioral Health in The University of Hong Kong; the Honorary Advisor for Serena's Heart Centre - Counseling & Training Service, Hong Kong
2005 – 2010	Lise Jul Houmann (Academic Advisor) Copenhagen University Study: A prospective evaluation of Dignity Therapy in advanced cancer patients admitted to palliative care Current position: Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark
2004 – 2009	Carla Ens (Principal Supervisor) Community Health Sciences, College of Medicine, Faculty of Health Sciences, University of Manitoba Study: Palliative and Hospice Care in South Africa: The Confluence of Context and Education Current position: Director, Epidemiology and Surveillance Unit, Public Health Branch, Government of Manitoba

2004 - 2009	Ann-Louise Ellwood University of Calgary Study: The desire for hastened death among cancer patients near the end of life: Are hopelessness, depression, and quality of life mediated by the valuation of life construct Current position: Unknown
2003 - 2007	Genevieve Thompson (Co-Supervisor) Community Health Sciences, College of Medicine, Faculty of Health Sciences, University of Manitoba Study: Family Perceptions and Satisfaction with end of life care at long term care facilities Current position: Assistant Professor of Nursing, University of Manitoba Research Associate, Manitoba Palliative Care Research Unit

Master's

2010 - 2015	Priscillah Makuchete (Academic Advisor) Faculty of Social Work, University of Manitoba Study: Dealing with childhood parental bereavement: The narratives of senior undergraduate students Current position: Counsellor at Norwest Coop Community Health Centre
2000 - 2005	Patricia Prosen (Co-Supervisor) Department of Sociology, University of Manitoba Study: Public opinions of physician-assisted suicide: The role of ageism in acceptance Current position: PhD Student, University of Manitoba
2002 - 2003	Bruce Martin (Academic Advisor) Community Health Sciences, College of Medicine, Faculty of Health Sciences, University of Manitoba Study: Palliative Care and the Kivalliq Region of Nunavut: Determinants of Programme Development and Implementation Current position: Associate Dean, College of Medicine, Faculty of Health Sciences, University of Manitoba; Physician Consultant, Palliative Care Program, Winnipeg Regional Health Authority
1999 - 1999	Brenda Peters Watrell (Academic Advisor for Comprehensive Exam) College of Nursing, Faculty of Health Sciences, University of Manitoba Current position: PhD Student, College of Nursing, Faculty of Health Sciences, University of Manitoba

1994 - 1996
Lorraine Avery (Co-Supervisor)
College of Nursing, Faculty of Health Sciences, University of Manitoba
Study: The dying trajectory: Family members' perceptions of care during terminal cancer patients' last 24 hours of life
Current position: Regional Clinical Nurse Specialist, WRHA Cardiac Sciences Program

1993 - 1995
Harback, Joan (Co-Supervisor)
College of Nursing, Faculty of Health Sciences, University of Manitoba
Study: Critical Nursing Behaviors in Care for the Dying in Adult Medical Units
Current position: Retired

Other

2014 - 2015
Linda Pan (Principal Supervisor)
BSc Med Student, College of Medicine, Faculty of Health Sciences, University of Manitoba
Study: The TIME Questionnaire: Personhood and Residence Living in Nursing Homes
Current position: Undergraduate medicine student

2011
Bridget Johnston (Academic Advisor)
University of Dundee
As visiting researcher to the Manitoba Palliative Care Research Unit, Dr. Johnston was able to outline a program of research following up directly upon our prior research. Her work includs the development of a dignity-conserving pathway; a trial of the patient dignity question in acute palliative care settings; and a pilot study of Dignity Therapy in patients with early cognitive decline. This program has produce seven peer reviewed publications in the last 3 years directly related to this work.
Current position: Research Associate, University of Dundee

2010 – 2010
Olav Lindqvist and Carol Tishelman (Academic Advisor)
Karonlinska Institute, Stockholm Sweden
Visited the Manitoba Palliative Care Research Unit to consult on research, with a particular focus on Dignity Therapy. Received individualized training, including patient simulations, and assistance and advice regarding protocol development. This resulted in conducting Dignity Therapy research at the Karolinska Institute, funded by the Swedish Cancer Society.
Current positions: Researchers, Karonlinska Institute, Stockholm, Sweden

2003 - 2003	Alia Norman (Academic Advisor) B.Sc.(Med.), University of Manitoba Study: Relationships Between Palliative Oncology Patients and Their Family Physicians: The Patient's Perspective Current position: Radiation Oncologist, Memorial University, Newfoundland

Research Funding

Funds Requested

2015 – 2019	Thompson, G., Chochinov, HM., McClement, S., Hack, T., Doupe, M. A RCT of a Dignity Conserving Intervention for Residents Nearing End of Life. NIH1, $113,793.62 (US dollar).
2014-2015	Bhar, S., Michael, N., Fisher, J., Ugalde, A., Abbott, J., Burney, S., O'Callaghan, C., Fletcher, J., Brooker, J., Thomas, N., Kristjanson, L., Chochinov, HM. Dignity Therapy Online: A Feasibility Study. Bethlehem Griffiths Research Foundation, Melbourne, Australia, $49,957.72 (Australian dollars).
2014 -	CIHR Foundation Grant

Currently Held Funds

2014 – 2018	Thompson, G., McClement, S., Chochinov, HM. Hack, T., Harlos, M., Funk, L., Pereira, A., Labun, N. (Collaborators Klaasen, K. & Derksen, J.) Excellence in delivering person-centered intimate care: What makes the difference. CIHR $725,309.
2013 – 2017	Chochinov, HM., Cory, S. et al. Knowledge Tools (CVH--KT): Addressing National Gaps. Canadian Partnership Against Cancer. $1,000,000
2013 – 2017	Montross, L. Primary Mentor: Chochinov, HM. Co-Mentor: Jeste, D. Consultants: von Gunten, C., Zisook, S., Golshan, S., Steinhauser, K., Irwin, S. Positive Outcomes of a Psychotherapy for End-of-Life Care, American Cancer Society, Career Development Award, $714,000. (Chochinov, HM. Primary Mentor $10,000)
2010 - 2017	Chochinov H. Canada Research Chair in Palliative Care, Canada Research Chair, $200,000/per annum for 7 years (total 1.4 million dollars)

2014 – 2016	McClement, S., Chochinov, HM., Thompson, G., Hack, T., Harlos, M., Lobchuk, M. Explanatory Models of Cancer-Anorexia Cachexia. CIHR $113, 859.
2012 – 2016	Thompson, G., McClement, S., Chochinov, H., Hack, T., Roger, K., St. John, P. Development & Testing of a Question Prompt Sheet for Family Caregivers of Older Adults with Dementia in Long-term Care. CIHR/MHRC Regional Partnership Program. $152,054.
2014 – 2015	Chochinov, HM. Infrastructure Funding Request. CancerCare Manitoba Foundation. $90,000
2013 - 2015	Sinclair, S., Chochinov, HM., Hagen, N., McClement, S., Hack, T., Raffin- Bouchal, S. CIHR Understanding Compassion: An empirical approach to cancer patients' perspectives and experiences of compassion at the end of life. $88,410. (01/04/13 – 31/10/14)
2012 – 2015	Chochinov, HM, McClement, SE, Hack, TF, Lobchuk, M., Thompson, G., Harlos, M. Dignity Talk: a novel palliative care intervention for patients and their families, CIHR, $200,383.
2008 - 2015	Chochinov HM. Canadian Virtual Hospice, Winnipeg Regional Health Authority, $500,000/per annum.
2013 – 2014	Thompson, G., Doupe, M., (Co-Pi) Chochinov, H. Developing Dignity in Care Quality Indicators for Personal Care Homes. Manitoba Health. $70,000.
2013 - 2014	Johnson, B., Chochinov, HM., Buchanan, D. Using the Dignity Patient Question (PDQ) as an intervention to enhance dignity and person-centered care for people with palliative care needs in the acute hospital setting. University of Dundee. £50,000.
2013 – 2014	Chochinov, HM. Infrastructure Funding Request. CancerCare Manitoba Foundation. $100,000
2004 – ongoing	Chochinov, HM. Manitoba Palliative Care Research Unit Funding. Winnipeg Regional Health Authority. $50,000/per annum.

Previously Held Funds

2012 - 2013	Chochinov HM Co-applicants: Damant R, Davison S, Enns, M, Hack T, Harlos M, Johnston W, McClement S, Ramsey C, Strang D, Zacharias J.,

	Milke, D. Personhood and Dignity at End-of-Life within Non-Cancer Populations, CIHR Planning Grants Competition $22,700.
2012 - 2013	Zacharias, J., Dart, A., Chochinov, HM. Quality of Care Indicators in End Stage Renal Disease, Dr. Paul H.T. Thorlakson Foundation Fund, $33,963.25. (August)
2012 - 2013	Chochinov HM, McClement S, Hack T, Harlos. Keep in Touch (KIT): A means of using technology to enhance connectedness for terminally ill patients and their support network. Riverview Health Centre Foundation, $100,000.
2012 - 2013	Chochinov, HM. International Center for Dignity and Palliative Care Business Plan. Manitoba Health, $50,000.
2012 – 2013	Chochinov, HM. Infrastructure funding for the Manitoba Palliative Care Research Unit, CancerCare Manitoba Foundation, $100,000.
2010 – 2013	Chochinov, HM, McClement, SE, Hack, TF, Hassard, T, Thompson, G, Harlos, M. The Patient Dignity Questionnaire (PDQ): A Novel Approach to Enhancing Care for Patients near the End-of-Life. Canadian Cancer Society Research Institute. $136,698.
2009 – 2013	Aoun, C, Oldham, L, Kristjanson, L, Chochinov, H. Dignity Therapy: A Novel Psychotherapeutic Intervention for Motor Neurone Disease Patients near the End of Life. Linkage project LP0991305 Motor Neurone Disease Association of Western Australia. $78,420.
2008 – 2013	Chochinov, HM. Canadian Virtual Hospice, Canadian Partnerships Against Cancer, $300,000/per annum (total $1,500,000).
2011 –2012	Hohl, C., Stenekes, S., Harlos, M., Chochinov, HM., McClement, S. The use of Methotrimeprazine for the management of nausea, dyspnea, sleep disturbance and agitation at the end of life in children. Manitoba Institute of Child Health, $1,145.
2011 – 2012	Chochinov, HM. Partial Salary Support. CancerCare Manitoba Foundation, $13,500.
2011 – 2012	Chochinov, HM. Infrastructure funding for the Manitoba Palliative Care Research Unit, CancerCare Manitoba Foundation, $85,000.
2011-2012	Chochinov, H., Stienstra, D., Derksen, J.Towards Inclusive Palliative Care and Cancer Care, Canadian Institutes of Health Research: Meetings,

	Planning and Dissemination Grants: Knowledge Translation Supplement, $35,850.
2010 – 2012	Chochinov HM. Wyeth Fellowship Program 2009, Wyeth Pharmaceuticals, $90,000.
2009- 2012	Chochinov HM, McClement S, Hack T, Hassard T, Harlos M, Johnston W, Davison S, Damant R, Enns M, Strang D, Ramsey C, Richman-Eisenstat J, Zacharias J, Milke D. Dignity and Distress across End-of-Life Populations, CIHR, $532,908.00 over 3 years.
2008 - 2012	Chochinov HM. The ABCD's of Dignity Conserving Care: A Pilot Dissemination Project, Winnipeg Regional Health Authority, $500,000.
2011	Stenning, A. & Chochinov, HM. Caregiver Video Project, The Winnipeg Foundation Board of Directors, Grant # 20111623, $30,000.
2011	McClement, S., Chochinov, H. The 2nd Annual Dignity Therapy Educational Workshop. Meetings, Planning and Dissemination Grant: Knowledge Translation Events. Canadian Institutes of Health Research, $20,000.
2010 – 2011	Chochinov, HM., Taylor-Brown, J, Benoit, T., Jardine, C., Cory, S. Implementing a Dignity Conserving Care Approach to Improve the Quality of Patient Centred Care at CancerCare Manitoba. CancerCare Manitoba Foundation, $30,000.
2010 – 2011	Chochinov, HM. Partial Salary Support, CancerCare Manitoba Foundation, $13,500.
2010 – 2011	Chochinov, HM. Infrastructure funding for the Manitoba Palliative Care Research Unit, CancerCare Manitoba Foundation, $85,000.
2009 – 2011	Lindqvist, O, Tishelman, C, Rasmussen, B, Furst, C, Salander, P, Olsson, M, Josephsson, S, Chochinov, H, Groenvold, M. To support the individual's sense of dignity, meaning and well-being at the end-of-life: an intervention for patients and their relatives. Cancer and Traffic Injury Fund, $15,000 & Cancer Research Foundation in Northern Sweden, $15,000.

2009 – 2011	McClement, S., Chochinov, HM., Hack, T., Hassard, T., Harlos, M., Thompson, G., Murray, A, Hagen, N., Sinclair, S., Stiles, C. Assessing the Relevance of the Patient Dignity Inventory in Identifying Distress and Influencing Clinical Care in Palliative Care, CIHR's Institute of Cancer Research. $100,000 (+ $50,000 from MHRC).
2008 - 2011	Dumont S, Jacobs P, Villeneuve P, Burge F, Johnston G, Chochinov HM. Palliative Care in Canada II: The economic perspective in rural areas, CIHR, $339,666.
2008 - 2011	Gagnon, P., Fillion, L., Blais, M-C., Aubin, M., Chochinov H, Creating Meaning Following a Cancer. National Cancer Institute of Canada, $908,229.
2008 - 2011	Chochinov H, Hack T, Harlos M, Hassard T, McClement S. The National Patient Dignity Inventory study, National Cancer Institute of Canada, $446,050.
2010	McClement, S., Chochinov, H Dignity Therapy Educational Workshop Meetings, Planning and Dissemination Grant: Knowledge Translation Events May 14-16, 2010. Canadian Institutes of Health Research, $15,000.
2009 – 2010	Stenekes, S., Ens, C., Harlos, M., Chochinov, HM., Mytopher, K. Perinatal Palliative Care Study: The View of Health Care Providers, Innovation Fund in Children's Palliative Care Research through TRAC-PG at SickKids, $4,015.
2009 – 2010	Harlos, M., Stenekes, S., Lambert, D., Hohl, C., Chochinov, HM., Ens, C. Use of Intranasal and Buccal Transcmucosal Fentanyl in Palliative Care of Newborns and Infants, Manitoba Institute of Child Health, $500.
2009 – 2010	Chan, CL, Chochinov, HM, Pang, SM, Tse, DMW, Leung, PPY, Ho, AHY, Living and Dying with Dignity: Development of an Empirical Model, University Grants Committee of the Hong Kong Special Administrative Region - General Research Fund. $321,784.
2009 – 2010	Chochinov,HM. Manitoba Palliative Care Research Unit. CancerCare Manitoba Foundation, $78,500.
2009 – 2010	Chochinov, HM. Manitoba Palliative Care Research Unit, CancerCare Manitoba Foundation, $13,500.

2009 – 2010	Stenekes, S., Harlos, M., Ens, C., Brown, D., Chochinov, HM., Kuling, S. Perinatal Palliative Care: Measuring the Impact of Manitoba's Pediatric Symptom Management and Palliative Care Service (PPCS), Innovation Fund in Children's Palliative Care Research Competition 2009, $4,015.
2008 - 2010	Hall S, Higginson I, Murray S, Chochinov HM, Harding R, Richardson A. Dignity Therapy for older people in care homes: assessing potential effectiveness, feasibility and acceptability, Dunhill Medical Trust (UK), $208,566.00.
2007 - 2010	Adler S, Burns B, Chochinov HM. Underserved Women with Breast Cancer at End of Life, California Breast Cancer Research Program over 3 years. (Consultant), $540,330.
2004 - 2010	Chochinov HM, Steinstra D, Kaufert JM, Lutfiyya ZM. Vulnerable Populations in End of Life Care, Canadian Institutes of Health Research, $1,395,000 over 5 years. {1 year extension}
2004 - 2010	Gagnon P, Aubin M, Chochinov HM, Dumont S, Fillion L, Pereira JL. Developing, evaluating, and implementing new interventions in palliative care, Canadian Institutes of Health Research, $1,395,000 over 5 years. {1 year extension}
2004 - 2010	Chochinov HM, Breitbart W, Kristjanson L, Hack T, McClement S, Hassard T, Harlos M. Dignity Intervention for Terminally Ill Cancer Patients, National Institute of Health, $2,070,293 over 4 years. {1 year extension}
2003 - 2010	Chochinov HM. Canada Research Chair in Palliative Care (Tier I), Canadian Institutes of Health Research, $200,000 over 7 years (total $1,400,000).
2008 - 2009	Willison, KB, Porteous, I., Woods, A., Kington, C., Chochinov, HM. Mental Health Nursing/Palliative Care Cross-Training, The Registered Nurses Association of Ontario $13,000.
2008 - 2009	Hall S, Edmonds P, Harding R, Higginson I, Chochinov HM. Dignity Therapy for people with advanced cancer: assessing feasibility, acceptability and potential effectiveness, Dimbleby Cancer Care (UK), $160,143.
2008 – 2009	Stienstra, D., Chochinov, HM. Addressing Disability in Cancer Care, CPAC, $291,000
2008 - 2009	Chochinov HM. Manitoba Palliative Care Research Unit, CancerCare Manitoba Foundation, $64,500..

2008 - 2009	Chochinov HM. Partial Salary Support Manitoba Palliative Care Research Unit, CancerCare Manitoba Foundation, $13,500.
2004 - 2009	Ens, C. & Chochinov HM. SSHRC, South African Physicians and the provision of palliative end of life care: An evaluation. $50,000.
2008	Chochinov, HM., O Warwick Prize, NCIC & Canadian Cancer Society, $20,000.
2007 - 2008	McClement S, Chochinov H, Dean R, Lobchuk M. A phenomenological study of health care aides' "Experiences of the ethical" in caring for dying patients in a personal care home', Canadian Institutes of Health Research, $39,538.
2007 - 2008	Chochinov HM. Manitoba Palliative Care Research Unit Infrastructure Support, CancerCare Manitoba Foundation, $48,000.
2005 – 2008	Ens, C., Chochinov, HM., Berard, J., Harlos, M., Stenekes, S., Wowchuk, S. Pediatric Palliative Care Online: The Views of Health Care Providers. Manitoba Palliative Care Research Unit. $30,000.
2006 - 2007	Chochinov HM. Manitoba Palliative Care Research Unit Infrastructure Support, CancerCare Manitoba Foundation, $48,000.
2005 - 2007	Chochinov HM. Manitoba Health, for ongoing operating requirements, Canadian Virtual Hospice, $500,000.00. $225,000 per year.
2005 - 2006	McClement S, Myers C, Chochinov HM. Reliance on tube-feeding: a grounded theory study of dysphagic head and neck cancer patients' experience, CancerCare Manitoba Foundation, $13,500.00.
2005 - 2006	Groenvold M, Kristjanson L, Chochinov HM. A Danish Language feasibility study of Dignity Therapy, Danish Cancer Society, $110,000.00. Funds in USD
2004 - 2005	McClement SE, Woodgate R, Chochinov HM. Involuntary weight loss in advanced cancer: patient and family perspectives, CancerCare Manitoba Foundation, $14,335.
2004 - 2005	Kristjanson LJ, Toye C, Almeida O, Chochinov HM, Oldham L, Hassard T. A study to pilot a clinical trial to test dignity psychotherapy for the frail elderly, National Health Medical Research Council (Australia), $25,000.

2004 - 2005	Chochinov HM. Manitoba Palliative Care Research Unit, CancerCare Manitoba Foundation, $78,000.
2003 - 2005	Chochinov HM. Manitoba Health, Canadian Virtual Hospice, $450,000 over 2 years.
2002 - 2005	Chochinov HM. Western Economic Diversification, Canadian Virtual Hospice, $500,000over 3 years.
2000 - 2005	Cohen SR, Deschamps M, Chochinov HM, Band P, Blood P, Daneault S, Fournier L, Gratton J, Marchand R, Poirier LR, Wilson KG, Gagnon P, Allard P, Fiset V, Kristjanson L, Neron S, Courneya K, Fyles G, Graham I, Lawlor P, Leis A, Logan J, Poulson J, Nikoletti S. Improving quality of life and informing social policy in palliative care, National Cancer Institute of Canada, $444,000 over 5 years.
2003 - 2004	Cohen R, Chochinov HM, Deschamps M, Wilson K, Allard P, Viola R, Fiset V, Lachance J, Gagnon P, McClement S, Daeninck P, Stajuhr K. Improving Quality of Life and Informing Social Policy in Palliative care, National Cancer Institute of Canada, $88,000).
2003 - 2004	Chochinov HM. Palliative Care Research Unit, Canadian Foundation for Innovation, $305,881.
2001 - 2004	Daeninck P, Chochinov HM, Marr H, Harlos M. Sublinguinal Sufentanil for the Management of Incident Pain, Riverview Health Centre Foundation, $6,000.
2003	Chochinov HM, Steinstra D. Vulnerable Populations in End of Life Care, CIHR, $5,000.
2002 - 2003	Chochinov HM. Riverview Health Centre, Canadian Virtual Hospice, $150,000.
2002 - 2003	Chochinov HM. Health Canada, Office of Health and the Information Highway, Canadian Virtual Hospice Funding, $120,000.
2001 - 2003	Wilson K, Chochinov HM, Graham ID, Viola R, Vigano A, Chary S, O'Shea F, Gagnon PR, Kuhl DR, De Luca M, Clinch JJ. National Palliative Care Survey, Medical Research Council of Canada, $613,338 over 2 years.
2001 - 2003	Chochinov HM, Kristjanson L, Kuhl D. Dignity Psychotherapy: An Intervention for Suffering in the Terminally Ill, American Foundation of Suicide Prevention, $100,000 over 2 years. (Funds in USD)

2000 - 2003	Chochinov HM, Hack T, McClement S, Harlos M, Kristjanson L. The Palliative Care Dignity Inventory, National Cancer Institute of Canada/ Canadian Nurses Foundation (CNF), $139,209 over 3 years.
2000 - 2003	Chochinov HM, Degner L. Satellite Research Centre, National Cancer Institute of Canada, $45,000 over 3 years.
1999 - 2003	Chochinov, HM, McClement, S., Tatryn, D., Hack, T., Harlos, M. Psychiatric Dimensions of Palliative Medicine, Canadian Institutes of Health Research, $130,000 over 5 years.
1999 - 2003	Chochinov HM. Canadian Institutes for Health Research Investigator (RPP), $280,000 over 4 years.
1999 - 2002	Cohen R, Chochinov HM, Deschamps M. Improving quality of life and informing social policy in palliative care, Sociobehavioral Cancer Research Network Team. Centre for Behavioral Research and Program Evaluation, Canadian Cancer Society / National Cancer Institute of Canada, $180,000 over 3 years.
2001	Chochinov HM. Western Economic Diversification Fund, Canadian Virtual Hospice, $20,000.
1997 - 2001	Chochinov HM, Hack T, Kristjanson L, Harlos M. Explicating the Construct of Dignity in the Terminally Ill, National Cancer Institute of Canada, $89,668 over 4 years.
1999 - 2000	Degner L, Kirk P, Chochinov HM. Primary Research Satellite Centre: Patients in Treatment, People Living with Cancer, Family Physicians, National Cancer Institute of Canada, $15,650.
1997 - 2000	Cohen R, Kristjanson L, Carriere KC, Leis A, Koop P, Laizner A, Chochinov HM, Mount B. Predictors of the health, family functioning and care satisfaction of family members of advanced cancer patients, Medical Research Council of Canada, $185,853 over 3 years.
1999	Chochinov HM. Canadian Palliative Care Association Research Agenda, Health Canada, $100,000.
1999	Goodwin P, Leszcz M, Arnold A, Chochinov HM, Doll R, Navarro M, Prichard K. Breast Expressive-Supportive Therapy Study, Canadian Breast Cancer Research Initiative, $118,810.

1997 - 1999	Hack T, Harlos M, Sisler J, Chochinov HM. Explicating the role of family physicians in the care of cancer patients, Manitoba Health Research Council, $31,000 over 2 years.
1996 - 1999	Chochinov HM. Project on Death in America, Open Society Institute, $229,500.00 over 3 years. Soros Faculty Scholar. $76,500 U.S. annually.
1996 - 1997	Chochinov HM. Portney Research Scientist Award, Manitoba Cancer Treatment and Research Foundation, $100,000.
1996 - 1997	Chochinov HM, Kirk P, Degner L. Sanjay Khandelwal - Factors that Influence Family Practitioners in Screening for Colorectal Cancer, B.Sc. Med. Program, Faculty of Medicine, University of Manitoba.
1995 - 1997	Chochinov HM, Degner L, Kirk P. Sociobehavioral Cancer Research Network, National Cancer Institute of Canada.
1994 - 1997	Chochinov HM, Dudgeon D, Clinch J. The Influence of Symptom Evaluation Feedback Upon Palliative Patient Care, National Cancer Institute of Canada, $127,557.
1995 - 1996	Chochinov HM. Professional Development Scholarship, Health Sciences Centre Research Foundation, $10,000 (Recipient).
1995	Chochinov HM, Dudgeon D, Clinch J, Tataryn D. Patient Symptom and Intervention Monitoring System (PSIMS) Orthobiotech, $10,000.
1992 - 1995	Chochinov HM, Brown P, et al. A Randomized Trial of Group Psychosocial Support in Metastatic Breast Cancer, Medical Research Council of Canada.
1992 - 1993	Chochinov HM, Kroft CDL, Wilson KG. Stimulants for Depression in the Terminally Ill, Manitoba Health Research Council, $35,950.
1990 - 1993	Chochinov HM, Wilson KG, Enns M, Mowchun N, Levitt M. Depression and the Desire for Death Among the Terminally Ill, Manitoba Cancer Treatment and Research Foundation, $10,910.
1991 - 1992	Chochinov HM, Wilson KG, Enns M, Mowchun N, Levitt M. Depression and the Desire for Death Among the Terminally Ill, Manitoba Mental Health Research Foundation, $9,350.

Awards to Trainees

Dr. Qiaohong Guo:

2014 – 2016	MHRC/CancerCare Manitoba Postdoctoral Fellowship Award, $36,750/year for 2 years

Maia Kredenster:

2014-2015	Jack MacDonell Scholarship for Research on Aging, Centre on Aging, University of Manitoba ($4,000)
2014-2017	Canadian Institutes of Health Research (CIHR) Frederick Banting and Charles Best Canada Graduate Scholarships – Doctoral Award ($105,000)
2014-2015	Blouw, M., Kredentser, M.S., Ryu, J., Sareen, J., Olafson, K., Bienvenu, O.J., & Logsetty, S. Preventing post-traumatic stress in ICU survivors: A pilot randomized controlled trial of ICU diaries. Manitoba Medical Service Foundation (MMSF) Operating Grant ($25,000).
2013-2017	University of Manitoba Graduate Fellowship (UMGF) ($64,000)
2013-2014	Sheu L. Lee Family Scholarship in Oncology Research ($3000)
2013-2014	Esther and Samuel Milmot Scholarship, Centre on Aging, University of Manitoba ($650)
2012-2013	Esther and Samuel Milmot Scholarship, Centre on Aging, University of Manitoba ($500)
2014	Dept of Psychology Conference Travel Award, University of Manitoba ($100)
2013-2014	Eli Ross Bursary, Jewish Foundation of Manitoba ($387)
2013-2014	Patty & Jack Sherman Memorial Scholarship, Jewish Foundation of MB ($1,613)
2013	Financial Support Award, Dept of Psychology, University of Manitoba ($6,000)
2013	Graduate Students' Association Travel Award, University of Manitoba ($575)
2013	Faculty of Arts Conference Travel Award, University of Manitoba ($350)
2013	Faculty of Arts Endowment Fund Conference Travel Award, University of Manitoba ($750)
2013	Dept of Psychology Conference Travel Award, University of Manitoba ($100)
2012-2013	Faculty of Graduate Studies Awards, University of Manitoba ($1,000)
2012-2013	Jewish Foundation of Manitoba Academic Award ($625.54)
2012-2013	Israel and Babs Asper Scholarship, Jewish Foundation of Manitoba ($1374.46)

Heather Campbell-Enns:

2013-2015	Canadian Institutes of Health Research (CIHR) Frederick Banting and Charles Best Canada Graduate Scholarships – Doctoral Award ($70,000).

2013-2015	Psychosocial Oncology Research Training (PORT) fellowship, CIHR ($10,000).
2014	Sheu L. Lee Family Scholarship in Oncology Research ($3,000).
2014	Graduate Student Research Poster Competition Silver Award ($300).
2011-2013	Manitoba Health Research Council PhD Studentship ($35,700).
2013	Finalist, 3 Minute Thesis Competition, University of Manitoba ($700).
2011	Nancie J. Mauro Graduate Scholarship in Oncology Research, University of Manitoba ($4,600).
2011	Sheu L. Lee Family Scholarship in Oncology Research ($3,000).
2011	DeWiele-Topshee Award for Excellence in Oncology Research, Health Sciences Foundation, Winnipeg, MB ($1,500).
2010	Graduate Studies Research Allocation, University of Manitoba ($800).

Genevieve Thompson:

June, 2006	Canadian Institutes for Health Research (CIHR) Clinical Research Fellowship (tenure – 1 year; Award Amount: $50,000)
June, 2006	Canadian Nurses Foundation Certification Award – Hospice Palliative Care Nursing (Award Amount – certification cost)
May, 2006	Centre on Aging Betty Havens Memorial Graduate Fellowship (award amount: $4,000)
June, 2005	Manitoba Health Research Council (MHRC) Studentship Award- Renewal (Award Amount: $17,850 for one year)
2004 - 2008	Thompson G. Family perceptions and satisfaction with end-of life care at long term care facilities, Manitoba Health Research Council, $17,000 (Supervisor).
2004 - 2008	Thompson G. Family perceptions and satisfaction with end-of-life care at long term care facilities Centre on Aging, Betty Havens Memorial Graduate Fellowship, $4,000 (Supervisor).
2004 - 2008	Thompson G. Family perceptions and satisfaction with end-of-life care at long term care facilities, CIHR Clinical Research Fellowship, $50,000 (Supervisor).
2004 - 2007	Thompson G. Family perceptions and satisfaction with end-of-life care at long term care facilities, Western Regional Training Centre, $20,000 over 3 years (Supervisor).

Shane Sinclair:

2010 – 2012	Sinclair, S. CIHR-Wyeth pharmaceuticals post-doctoral fellowship $45,000/year (Co-Supervisor).

Carla Ens:

2007 - 2008	Ens C. South African physicians and the provision of palliative end-of-life care: An evaluation of perceived roles, competencies and the influence of distance education in addressing these needs, Manitoba Health Research Council, $5,000 (Supervisor).
2004 – 2009	Ens, C. Ph.D. Community Health Sciences, Social Sciences and Humanities Doctoral Fellowship $40,000 (Supervisor).

Kerstin Rogers:

2004 - 2006	Health Sciences Centre Post Doctoral Fellowship Funding, $76,000 over 2 years (Supervisor).
2004	Cognitive Impairment and the Terminally Ill, Health Sciences Centre, $38,000 (Supervisor).

Expert Witness

1. 26/01/12 LeBlanc vs Government of Canada, Quebec Supreme Court
2. 20/11/11 Taylor vs Government of Canada, BC Supreme Court

Publications

Referred Journals

In Press

1. MacKinnon, CJ., Smith, NG., Henry, M., Milman, E., Berish, M., Farrace, A., Korner, A., Chochinov, HM. & Cohen, SR. A pilot study of meaning-based group counseling for bereavement. Omega: Journal of Death and Dying (in press).

Published

1. Mowll, J., Lobb, EA., Lane, L., Lacey, J., Chochinov, HM, Kelly, B. Agar, M., Links, M., Kearsley, JH, (2015). A preliminary study to develop an intervention to facilitate communication between couples in advanced cancer. Palliative & Supportive Care. Feb.6 , p.1-10 [epub ahead of print]. PMID: 25655763
2. MacKinnon, CJ., Smith, NG., Henry, M., Milman, E., Chochinov, HM., Korner, A., Berish, M. Farrace, A., Liarikos, N. & Cohen, RS, (2015). Reconstructing meaning with others in loss: A feasibility pilot randomized controlled trial of a bereavement group. Death Studies. Feb.12 [epub ahead of print]. PMID: 25674830
3. 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, Journal of Pain and Symptom Management (2015), doi: 10.1016/j.jpainsymman.2014.11.291.
4. Aoun SM, Chochinov, HM, Kristjanson, LJ, (2014). Dignity Therapy for People with Motor Neurone Disease and their Family Caregivers: A Feasibility Study. Journal of Palliative Medicine. 18(1): 31-37. doi:10.1089/jpm.2014.0213.

5. Stenekes, S., Ens, C., Harlos, M., Chochinov, HM., Mytopher, K. (2014). A descriptive study evaluating perinatal health care providers' perspectives of palliative programming in 3 Canadian Institutions. The Journal of Perinatal and Neonatal Nursing, Oct-Dec; 28(4): 280-9; quiz E1-2. doi: 10.1097/JPN.0000000000000020.
6. Stenekes, S., Ens, C., Harlos, M., Chochinov, HM., Mytopher, K. (2014). A descriptive study evaluating perinatal health care providers' perspectives of palliative programming. The Journal of Perinatal and Palliative Care Nursing.
7. Chochinov HM. (2014). Health Care, health caring, and the culture of medicine. Current Oncology. Oct;21(5):e668-9 diuL 10.3747/co.21.2239. PMID: 25302036.
8. Kredentser, M.S., Martens, P.J., Chochinov, H.M., Prior, H.J. (2014). Cause and rate of death in people with schizophrenia across the lifespan: A population-based study in Manitoba, Canada. Journal of Clinical Psychiatry. 75(2): 154-161.
9. Chochinov, HM. (2014).The secret is out: Patients are people with feelings that matter. Palliative and Supportive Care. Aug;11(4):287-8. doi: 10.1017/S1478951513000503. PMID: 24650506
10. Wilson, K., Dalgleish, T., Chochinov, HM., Chary, S., Gagnon, P., MacMillan, K., DeLuca, M., O'Shea, F., Kuhl, D., Fainsinger, R. (2014). Mental Disorders and the Desire for Death in Patients Receiving Palliative Care for Cancer. BMJ Supportive and Palliative Care 2014;0:1–8. doi:10.1136/bmjspcare-2013-000604. PMID: 24644212
11. Chochinov, HM. Is It Time to Get MAD? HealthcarePapers, 14(1) April 2014: 50-57.doi:10.12927/hcpap.2014.23971
12. MacKinnon, C.J., Smith, N.G., Henry, M., Milman, E., Berish, M.,Körner, A., Copeland, L., Chochinov, H.M., & Cohen, S.R. (2014). Bridging theory with emerging trends in intervention research: Meaning-based group counseling for bereavement. Death Studies, 38(3). 137-144. DOI: 10.1080/07481187.2012.738768.
13. MacKinnon, C.J., Milman, E., Smith, N.G., Henry, M., Berish, M.,Copeland, L., Körner, A., Chochinov, H.M., & Cohen, S.R. (2013)Means to meaning in cancer-related bereavement: Identifying clinical implications for counseling psychologists. The Counseling Psychologist. 41(2), 216-239. DOI: 10.1177/0011000012459969
14. Chochinov, H.M. (2013). Dignity in Care: Time to Take Action. Journal of Pain and Symptom Management.Nov; 46(50: 756-9. doi: 10.1016/j.jpainsymman.2013.08.004. Epub 2013 Oct 5.
15. Houmann, LJ., Chochinov, HM., Kristjanson, L., Petersen, MA., Groenvold, M. (2013). A prospective evaluation of Dignity Therapy in advanced cancer patients admitted to palliative care. Palliative Medicine. Dec 5 PMID: 24311296.
16. Hohl, C., Stenekes, S., Harlos, M., Shepherd, E., McClement, S., Chochinov, H. (2013). Methotrimeprazine for the management of end-of-life symptoms in infants and children. Journal of Palliative Care. 29(3). 178 – 185. PMID: 24380217
17. Sinclair, S. & Chochinov, HM. (2012). Communicating with patients about existential and spiritual issues: SACR-D work. Progress in Palliative Care; 20(2): 72-78.

18. Martens PJ, Chochinov HM, Prior HJ. (2013). Where and how people with schizophrenia die: a population-based, matched cohort study in Manitoba, Canada. J Clin Psychiatry;74(6):e551-7.
19. Chochinov, HM. (2013). Palliative care: Secobarbital in Seattle—why lose sleep? Nature Reviews Clinical Oncology **10**, 369-370 |doi:10.1038/nrclinonc.2013.88
20. Ho, Andy HY., Chan, C.L.W., Chochinov, HM., Neimeyer, RA., Pang, SMC., Tse, DMW., Leung, PPY. (2013). Living and dying with dignity in Chinese society: Perspectives of older palliative care patients in Hong Kong. Age and Aging. 2013 Feb 25. [Epub ahead of print] PMID 23443510
21. Chochinov, HM, McClement, SE., Hack, TF., McKeen, NA., Rach, AM., Gagnon, P., Sinclair, S., Taylor-Brown, J. (2013). Healthcare provider communication: An empirical model of therapeutic effectiveness. Cancer. 2013 Jan 22. doi: 10.1002/cncr.27949. [Epub ahead of print] PMID: 23341092
22. Sinclair, S, Raffin, S., Chochinov, H., Hagen, N., & McClement, S.E. (2012). Spiritual care: How to do it. British Medical Journal (BMJ) Supportive & Palliative Care. BMJ Supportive & Palliative Care,2:319-327.
23. Chan, S., Ho, AHY., Leung, P., Chochinov, HM., Neimeyer, R., Pang, S., Tse, D. (2012).The Blessings and the Curses of Filial Piety on Dignity at the End of Life: Lived Experience of Caregivers. Journal of Ethnic & Cultural Diversity in Social Work, 21:277–296.
24. Thompson, GN., McClement, SE., Menec, VH., Chochinov, HM. (2012). Understanding Bereaved Family Members' Dissatisfaction with End-of-Life Care in Nursing Homes. Journal of Gerentological Nursing, 38(10): 49-60.
25. Bentley, B., Aoun, S., O'Connor, M., Breen, LJ., Chochinov, HM. (2012). Is dignity therapy feasible to enhance the end of life experience for people with motor neurone disease and their family carers? BMC Palliative Care. Sept 20;11(1):18.
26. Harlos, M., Stenekes, S., Lambert, D., Hohl, C., Chochinov, HM. (2012) Intranasal Fentanyl In The Palliative Care Of Newborns and Infants. Journal of Pain and Symptom Management. 2012 Sep 24. doi:pii: S0885-3924(12)00374-0. 10.1016/j.jpainsymman.2012.07.009
27. Chochinov, HM., McClement, S., Hack, T., McKeen, N., Rach, A., Gagnon, P., Sinclair, S., Taylor-Brown, J. (2012). The Patient Dignity Inventory: Applications in the oncology setting. Journal of Palliative Medicine, Vol. 15(9): 998-1005.
28. Chochinov HM, Martens PJ, Prior HJ, Kredentser MS. (2012). Comparative health care use patterns of people with schizophrenia near the end of life: A population-based study in Manitoba, Canada. Schizophrenia Research; 141(2-3):241-246. August 20.
29. Corn, BW., Chochinov, HMC., Vachon, M. (2012). Integrating spiritual care into the practice of oncology. Current Opinions in Supportive Care. Jun; 6(2):226-7.
30. Pilkey, J., Demers, C., Chochinov, HM., Venkatesan, N. (2012). Does gynaecologic malignancy predict likelihood of a tertiary palliative care unit hospital admission? A comparison of local, provincial and national death rates. Palliative and Supportive Care. May 22: 1-6.

31. Sinclair, S. & Chochinov, HM. (2012). The role of chaplains within interdisciplinary oncology teams. Current Opinions in Supportive and Palliative Care, 6:259-268.
32. Steinstra, D. & Chochinov, HM. (2012). Palliative Care for Vulnerable Populations. Palliative and Supportive Care, 10(1): 37-42
33. Chochinov HM, Cann B, Cullihall K, Kristjanson K, Harlos M, McClement SE, Hack T, Hassard H. (2012). Dignity Therapy: A Feasibility Study of Elders in Long-term Care. Journal of Palliative and Supportive Care, 10: 3-15.
34. Chochinov HM, Stienstra D. (2012). Vulnerability and Palliative Care. Journal of Palliative and Supportive Care, 10: 37-42.
35. Chochinov, HM. (2012). Relatively speaking. Journal of Pain and Symptom Management. March;43(3): e6-7.
36. Thompson, G., McClement, S., Chochinov, HM. (2011). How respect and kindness are experienced at the end-of-life by nursing home residents. CJNR, 43(3) pp96-118.
37. Chochinov HM, Kristjanson LJ, Breitbart W, McClement S, Hack TF, Hassard T, Harlos M. (2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. Lancet Oncol. August;12(8): 753-62, Jul 6
38. Chochinov, HM. (2011). Death, time and the theory of relativity. Journal of Pain and Symptom Management. Sept;42(3):460-3
39. Ens, Carla, Chochinov, HM, Gwyther, E, Moses, S, Jackson, C, Thompson, G Harding, R. (2011). Postgraduate palliative care education: Evaluation of a South African programme. South African Medical Journal, 101(1): pg 42-44.
40. McClement, SE., Lobchuk, M., Chochinov, HM, Dean, R. (2010). Broken Covenant : Healthcare Aides' Experience of the Ethical in Caring for Dying Seniors in a Personal Care Home. The Journal of Clinical Ethics. Fall;21(3):201-11.
41. Chochinov, HM. (2010). Humility and the Practice of Medicine. Canadian Medical Association Journal. Aug 10;182(11); 1217-8..
42. Gagnon, P., Chochinov, HM., Cochrane, J-P., le Moignan Moreau, J., Fontaine, R., Croteau, L. (2010). Psychothérapie de la dignité: une intervention pour réduire la détresse psychologique chez les personnes en soins palliatifs. Psycho-Onoclogy, 4 :169-175.
43. J Houmann, L., Rydahl-Hansen, S., Chochinov, HM., Kristjanson, L., Groenvold, M. (2010). Testing the feasibility of the Dignity Therapy interview: adaptation for the Danish culture. BMC Palliative Care, Sept 22 9(1): 21.
44. Hack, TF., McClement S., Chochinov, HM., Cann, BJ., Hassard, TH., Kristjanson, LJ., Harlos, M. (2010). Learning from dying patients during their final days: life reflections gleaned from dignity therapy. Palliative Medicine, July 6. 24(7); 715-723.
45. Thompson, G. & Chochinov HM. (2010). Reducing the potential for suffering in older adults with cancer. Palliative & Supportive Care. Feb 18:1-11
46. Thompson, G., Chochinov, H., Wilson, K., McPherson, C., Gagnon, P., Kuhl, D., O'Shea, F., Fainsinger, R. (2009). Prognostic acceptance and the well-being of patients receiving palliative care for cancer. Journal of Clinical Oncology. October 13

47. Puchalski, C, Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., Chochinov, H., Handzo, G., Nelson-Becker, H., Prince-Paul, M., Pugliese, K., Sulmasy, D. (2009). Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. Journal of Palliative Medicine. Oct;12(10): 885-904.
48. Chochinov, HM, Hack, T., Hassard, T., McClement, S., Kristjanson, L., Harlos, M., Murray, A. & Sinclair, S. (2009). The Landscape of Distress in the Terminally Ill, Journal of Pain and Symptom Management. 38, 641-649.
49. Wowchuk, S., Wilson, E., Embleton, L., Garcia, M., Harlos, M., Chochinov, HM. (2009). The Palliative Medication Kit: An effective way of extending care in the home for patients nearing death. Journal of Palliative Medicine. Sep;12(9):797-803.
50. Wilson, K., Chochinov, H., Allard, P., Chary, S., R., Gagnon, MacMillan, K.,P., Luca, M., O'Shea, F., Kuhl, D., Fainsinger, RL. (2009). Prevalence and correlates of pain in the Canadian National Palliative Care Survey. (special series on cancer pain) Pain and Research Management. Sept-Oct 14(5): 365-70
51. Hall, S. Edmonds, P., Harding, R., Chochinov, H. & Higginson, I. (2009). Assessing the feasibility, acceptability and potential effectiveness of Dignity Therapy for people with advanced cancer referred to a hospital-based palliative care team: Study protocol, BMC Cancer Palliative Care, May 16: 8:5
52. Martens, P., Chochinov, HM., Prior, HJ., Fransoo, R., Burland, E. (2009). Are cervical cancer screening rates different for women with schizophrenia? A Manitoba population-based study. Schizophrenia Research. Aug;113(1): 101-6.
53. Chochinov, HM., Martens, P., Prior, HJ., Fransoo, R., Burland, E. (2009). Does a diagnosis of schizophrenia reduce rates of mammography screening? A Manitoba population-based study. Schizophrenia Research. Aug; 113(1): 95-100.
54. Thompson, GN, Menec, VH, Chochinov, HM, McClement, SE. (2009). Family satisfaction with care of a dying loved on in nursing homes: What makes the difference? The Exchange. Available at: www.virtualhospice.ca
55. Thompson, G, Ens, C, Chochinov, H. (2009). Patient centred supportive and palliative care. The Exchange. Available at: www.virtualhospice.ca
56. Chochinov, HM. (2009). Dignidad y la esencia de la medicina: el A, B, C y D del cuidado centrado en la dignidad. (translated into Spanish by Carolina Casañas i Comabella) Medicina Palliativa. 16:2.
57. Hall, S, Chochinov, HM, Harding, R., Murray, S, Richardson, A, Higginson, I. (2009). A Phase II randomized control trial assessing the acceptability and potential effectiveness of Dignity Therapy for older people in care homes: Study protocol, BMC Geriatrics. 2009, 9;924 Mar.
58. Chochinov HM. (2009). The Culture of Research in Palliative Care: You Probably Think this Song is About You. Journal of Palliative Medicine. March 12(3): 215-7.

59. Chochinov HM. (2008). Psychiatry and palliative care: 2 sides of the same coin. Journal of Psychiatry. 53(11):711-712.
60. Chochinov (2008). HM. Dignity. Dignity? Dignity! Journal of Palliative Medicine. 11(5):674-5.
61. Ens CD, Gwyther L, Moses S, Chochinov HM, Jackson C, Harding R. (2008). Access to hospice care: multi-professional specialist perspectives in South Africa. International Journal of Palliative Nursing. 14(4):169-74.
62. Thompson G, Chochinov HM. (2008). Dignity based approaches in the care of the terminally ill. Current Opinion in Supportive and Palliative Care. 1751-4258.
63. Thompson G, Chochinov HM, Menec V, McClement S. (2008). Family satisfaction with care of a dying loved one in nursing homes: What makes the difference. Journal of Gerontological Nursing. 34(12):37-44.
64. McClement S, Chochinov HM. (2008). Hope in advanced cancer patients. European Journal of Cancer. 44(8):1169-74.
65. Rasic, DT., Belik, SL., Bolton, JM., Chochinov, HM., Sareen, J. (2008). Cancer, mental disorders, suicidal ideation and attempts in a large community sample. Psychoonology. Jul; 1797: 660-7.
66. Ens C, Berard J, Harlos M, Chochinov HM, Stenekes S, Wowchuk S. (2008). Pediatric palliative care online: the views of health care professonals. Journal of Palliative Care. 24(1):41-8.
67. Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson L, Harlos M, Sinclair S, Murray A. (2008). The Patient Dignity Inventory: A novel way of measuring dignity related distress in Palliative Care. Journal of Pain and Symptom Management. Dec. 36(6): 559 – 571
68. Chochinov HM, Kristjanson L, Hack T, Hassard T, McClement S, Harlos M. (2007). Burden to others and the terminally ill. Journal of Pain and Symptom Management. 34(5):463-71.
69. McClement S, Hack T, Chochinov HM, Hassard T, Kristjanson L, Harlos M. (2007). Dignity Therapy: Family Member Perspectives. Journal of Palliative Medicine. 10(5):1076-82.
70. Chochinov, HM. (2007). The five research C's. Palliative and Supportive Care. Sept;5(3): 203-5.
71. Wilson K, Chochinov HM, McPherson C, Skirko M, Allard P, Chary S, Gagnon P, Macmillan K, DeLuca M, O'Shea F, Kuhl D, Fainsinger R, Karan A, Clinch J. (2007).Desire for euthanasia or physician-assisted suicide in palliative cancer care. Health Psychology. 26(3):314-323.
72. Wilson K, Chochinov HM, McPherson C, LeMay K, Allard P, Chary S, Gagnon P, Macmillan K, De Luca M, O'Shea F, Kuhl D, Fainsinger R. (2007). Suffering with advanced cancer. Journal of Clinical Oncology. 25(13):1691-7.
73. Wilson KG, Chochinov HM, Graham M, Allard P, Chary S, Gagnon PR, Macmillan K, DeLuca M, O'Shea F, Kuhl D, Fainsinger RL, Clinch JJ. (2007). Depression and anxiety

disorders in palliative cancer care. Journal of Pain and Symptom Management. 33(2):118-129.

74. Chochinov HM. (2007). Dignity and the essence of medicine: The A, B, C and D of Dignity Conserving Care. British Medical Journal. 335(7612):184-187.

75. Kelly B, McClement SE, Chochinov HM. (2006). Measurement of psychological distress in palliative care. Palliative Medicine. 20(8):779-789.

76. Thompson G, Chochinov H. (2006). Methodological Challenges in Measuring Quality Care at the End of Life in the Long-term Care Environment. Journal of Pain and Symptom Management. 32(4):378-91.

77. Chochinov HM, Kristjanson L, Hack T, Hassard T, McClement S, Harlos M. (2006). Personality, Neuroticism and End-of-Life Care. Journal of Pain and Symptom Management. 32(4):332-341.

78. Chochinov HM. (2006). Barney's Version: Observations from the Edge. Palliative and Supportive Care. 4(3):217-218.

79. Chochinov HM, Kristjanson L, Hack T, Hassard T, McClement S, Harlos M. (2006). Dignity in the terminally ill: revisited. Journal of Palliative Medicine. 9(3):666-672.

80. Chochinov HM., Derksen, J. (2006). Disability and end-of-life care: let the conversation begin. Journal of Palliative Care. 22(3):175-182. Interview by Harvey Max Chochinov.

81. Chochinov HM. (2006). Dying, Dignity and new Horizons in Palliative End-of-Life care. CA: A Cancer Journal for Clinicians. 56(2):84-103.

82. Stienstra D, Chochinov HM. (2006). Vulnerability, disability and palliative end-of-life care. Journal of Palliative Care. 22(3):166-74.

83. Chochinov HM. & Sneiderman, B. 2005). Dying with dignity: the doctor's perspective, the lawyers perspective. Canadian Healthcare Manager. 12(8):23-24.

84. Chochinov HM. (2005). Cruising for a bruising. Palliative and Supportive Care. 3(3):171.

85. Menzies H, Chochinov HM, Breitbart C. (2005). Cytokines, Cancer and Depression: Connecting the Dots. Journal of Supportive Oncology. 3:55-7.

86. Chochinov HM, Hack T, Hassard T, Kristjanson L, McClement S, Harlos M. (2005). Dignity Therapy: A novel psychotherapeutic intervention for patients nearing death. Journal of Clinical Oncology. 23:5520-5525. *This lead article in the JCO outlined results on a novel therapeutic intervention to address end of life distress; a major contribution to advancing care for the terminally ill [Betty Farrell. JCO. 2005;23:5427-5428].*

87. Chochinov HM. (2005). Global Sorrow Following Catastrophic Loss. Journal of Palliative Care. 21:136-138.

88. Chochinov HM, Cann B. (2005). Interventions to enhance the spiritual aspects of dying. Journal of Palliative Medicine. 8(Supp 1).

89. Chochinov HM, Hack T, Hassard T, Kristjanson L, McClement S, Harlos M. (2005). Understanding Will to Live in Patients nearing Death. Psychosomatics. 46:7-10.

90. Chochinov HM. (2005). Vicarious Grief and Response to Global Disasters. The Lancet. 366:697-698.

91. McClement SE, Chochinov HM, Hack TF, Kristjanson LJ, Harlos MS.)2004). Dignity conserving care: Application of Research findings to practice. International Journal of Palliative Nursing. 10:173-9.
92. Chochinov HM, Stern A. (2004). Canadian Virtual Hospice. Journal of Palliative Care. 20(1):5-6. www.virtualhospice.ca
93. Chochinov HM. (2004). Defending Dignity. Journal of Supportive and Palliative Care. 1:307-308.
94. Hack T, Chochinov H, Hassard H, Kristjanson L, McClement S, Harlos M. (2004). Defining Dignity in Terminally Ill Cancer Patients: A Factor-analytic Approach. Psycho-Oncology. 13:700-708.
95. Chochinov HM, Hack T, Hassard T, Kristjanson L, McClement S, Harlos M. (2004). Dignity and Psychotherapeutic Considerations in End of Life Care. Journal of Palliative Care. 20:142-143.
96. Chochinov HM. (2004). Dignity and the Eye of the Beholder. Journal of Clinical Oncology. 22:1336-40. An article articulating the importance of 'how one perceives oneself' to be seen as an important mediator of dignity at the end of life.
97. Chochinov HM. (2004). Palliative Care: An Opportunity for Mental Health Professionals. Canadian Journal of Psychiatry.49:347-349.
98. Chochinov HM. (2003). Thinking outside the box: Depression, hope, and meaning at the end of life. Innovations in End-of-Life Care. 4(6):973-7. www.edc.org/lastacts
99. Bordeleau L, Szalai JP, Ennis M, Leszcz M, Speca M, Sela R, Doll R, Chochinov HM, Navarro M, Arnold A, Pritchard KI, Bezjak A, Llewellyn-Thomas HA, Sawka CA, Goodwin PJ. (2003). Journal of Clinical Oncology. 21:1944-51.
100. Chochinov HM. (2003). Reflections of losing a friend. Journal of Palliative and Supportive Care. 1:109.
101. Schwartz L, Lander M, Chochinov HM. (2002). Current management of depression in cancer patients. Oncology. 16:1102-1110.
102. Cohen LM, Halls KC, Morris JE, Pekow PS, Chochinov HM. (2002). Depression and suicidal ideation in patients who discontinue the life-support treatment of dialysis. Psychosomatic Medicine. 64:889-96.
103. Chochinov HM. (2002). Dignity Conserving Care: A New Model for Palliative Care. JAMA. 287:2253-2260. A paper introducing the concept of Dignity Conserving care into the palliative care literature.
104. Chochinov HM, Hack T, McClement S, Harlos M, Kristjanson L. (2002). Dignity in the Terminally Ill: A Developing Empirical Model. Social Science and Medicine. 54:433-443. *The first empirical study, using a qualitative approach, to address the issue of dignity in the terminally ill.*
105. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. (2002). Dignity in the terminally ill: a cross-sectional, cohort study. Lancet. 360:2026-30. *The first empirical study, using a quantitative approach, to address the issue of dignity in the terminally ill.*

106. Tataryn D, Chochinov HM. (2002). Predicting the Trajectory of Will to Live in the Terminally. Psychosomatics. 43:370-377.
107. Wilson KG, Chochinov HM, Allard P, Chary S, DeLuca M, Gagnon PR. (2002). The Canadian National Palliative Care Survey. J Palliat Care. 18:232.
108. Chochinov HM. (2001). Interventions in end-of-life care. Archives of Internal Medicine. 161(8):1117-8.
109. Chochinov HM. (2001).Depression in Cancer Patients. Lancet Oncology. 2:499-505.
110. Carstairs S, Chochinov HM. (2001). Politics, Palliation and Progress in Canadian End of Life Care. The Journal of Palliative Medicine. 3:395-400.
111. Goodwin PJ, Leszcz M, Ennis M, Koopmans J, Vincent L, Guther H, Drysdale E, Hundleby M, Chochinov HM, Navarro M, Speca M, Masterson J, Dohan L, Sela R, Warren B, Paterson A, Pritchard KI, Arnold A, Doll R, O'Reilly SE, Quirt G, Hood N, Hunter J. (2001). The Effect of Group Psychosocial Support on Survival in Metastatic Breast Cancer. N Engl J Med. 345:1719-1726.
112. Lander M, K W, Chochinov HM. (2000). Depression and the older dying patient. Clinical Geriatric Medicine. 16(2):335-56.
113. Chochinov HM. (2000). A second primary. Palliative Medicine. 3:335-336.
114. Lander M, Chochinov HM, Wilson K. (2000). Depression and the Dying Older Patient. Clin Geriatr Med. 16:335-356.
115. Goodwin PJ, Leszcz M, Quirt G, Koopmans J, Arnold A, Dohan E, Hundleby M, Chochinov HM, Navarro M. (2000). Lessons learned from enrolment in the BEST study : a multicenter, randomized trial of group psychosocial support in metastatic breast cancer. J Clin Epidemiol. 53(1):47-55.
116. Chochinov HM, Tataryn DJ, Wilson KG, Ennis M, Lander S. (2000). Prognostic awareness and the terminally ill. Psychosomatics. 41:500-504.
117. Chochinov HM. (2000). Psychiatry and Terminal Illness. Canadian Journal of Psychiatry. 45:143-150.
118. Daeninck PJ, Honer J, Harlos MS, Chochinov HM. (2000).The Changing Nature Of Utilization Of A Tertiary Palliative Care Unit (TCPU) Over The Last Decade. J Palliat Care. 16(3)
119. Chochinov HM, Hack T, McClement S, Kristjanson L. (2000). The Palliative Care Dignity Inventory. Psychosomatics. 41:160.
120. Chochinov HM. (2000). The Senate Report on End of Life Care: The Ball is in Our Court. Canadian Medical Association Journal. 164:794-795.
121. Chochinov HM, Wilson, K W. (1999). Patients with amyotrophic lateral sclerosis and physican-assisted suicide. New England Journal of Medicine. 340(10):817.
122. Chochinov HM, Kristjanson L. (1999). Dying to pay: the cost of end of life care. Journal of Palliative Medicine. 14:5-15.

123. Shuster JLJ, Breitbart W, Chochinov HM. (1999). Psychiatric aspects of excellent end-of-life care. Ad Hoc Committee on End-of-Life Care. The Academy of Psychosomatic Medicine. Psychosomatics. 40:1-4.
124. Chochinov HM, Tataryn D, Dudgeon D, Clinch J. (1999). Will to Live in the Terminally Ill. The Lancet. 354:816-19. The first empirical study to address the issue of will to live in the terminally ill.
125. Chochinov HM, Wilson KG, Enns M, Lander S. (1998). Depression, Hopelessness, and Suicidal Ideation in the Terminally Ill. Psychosomatics. 39:366-370. The first study to confirm the linkage between hopelessness and suicidal ideation in the terminally ill.
126. Breitbart W, Chochinov HM. (1998). Psycho-oncology research: the road traveled, the road ahead. Journal of Psychosomatic Research. 45:185-189.
127. Shuster J, Breitbart W, Chochinov HM. (1998). The APM's Ad HOC Committee on End of Life Care: A Position Statement of the Academy of Psychosomatic Medicine. Journal of Palliative Medicine. 1:113-115.
128. Chochinov HM, Wilson K. (1997). Assisted suicide for HIV patients. American Journal of Psychiatry. 154(2):294-5.
129. Chochinov HM, Wilson K, Enns M, Lander S. (1997). Are you depressed? Screening for depression in the terminally ill. American Journal of Psychiatry. 154:674-676. *This screening approach has received endorsements from the American College of Physicians - American Society of Internal Medicine and the American Association of Clinical Oncology.*
130. Chochinov HM. (1997). Euthanasia, Social Policy and Empirical Data. Policy Options. 18(10):5-9.
131. Wilson K, Chochinov HM. (1996). Physician Assisted Suicide. New England Journal of Medicine. 335(7):518-9.
132. Goodwin PJ, Leszcz M, Koopmans J, Arnold A, Doll R, Chochinov H, Navarro M, Butler K, Pritchard KO. (1996). Randomized trial of group psychosocial support in metastatic breast cancer: The BEST study. Cancer Treatment Reviews. 22(Supplement A):91-96.
133. Chochinov HM, Wilson K. (1996). The euthanasia debate: attitudes, practices and psychiatric considerations. The Canadian Journal of Psychiatry. 40(10):593-602.
134. Chochinov HM, Wilson K. (1995). The Euthanasia Debate: attitudes, practices and psychiatric considerations. Canadian Journal of Psychiatry. 40(10):593-602.
135. Chochinov HM, Wilson KG, Enns M, Mowchun N, Lander S, Levitt M, Clinch JJ. (1995). Desire for death in the terminally ill. Am J Psychiatry. 152:1185-91. *10th most highly cited article in the history of the American Journal of Psychiatry.*
136. Breitbart W, Bruera E, Chochinov HM, Lynch M. (1995). Neuropsychiatric Syndromes and Psychological Symptoms in Patients With Advanced Cancer. Journal of Pain and Symptom Management. 10(2).
137. Goodwin PJ, Leszcz M, Pritchard KO, Chochinov H, Navarro M, Koopmans J, Arnold A, Doll R. (1995). The BEST study: A multicentre randomized trial of group psychosocial

support in metastatic breast cancer. Journal of Psychosomatic Obstetrics and Gynecology. 16:47.

138. Chochinov HM. (1994). Psychiatric Care of the Cancer Patient. North American Medicine.
139. Chochinov HM, Enns M, Lander S. (1994). Correlates of Desire for Desire for Death Among the Terminally Ill. Journal of Palliative Care. 10:131.
140. Chochinov HM, Wilson KG, Enns M, Lander S. (1994). The Prevalence of Depression in the Terminally Ill: Effects of Diagnostic Criteria and Symptom Threshold Judgements. American Journal of Psychiatry. 151:4. First major epidemiological survey of psychiatric morbidity in palliative care.
141. Chochinov HM, Wilson KG, Enns MW, Mowchun N, Levitt M. (1992). Depression and Desire for Death in the Terminally Ill. Journal of Palliative Care. 8(3).
142. Chochinov HM. (1989). Bereavement: A review for oncology health professionals. Cancer Investigations. 7:593-600.

Abstracts Accepted

1. MacKinnon, CJ, Milman, E., Henry, M., Smith, N.G., Chochinov, H.M., Körner, A., & Cohen, S.R. (2015, April). Meaning-based group counseling: A novel intervention for cancer bereavement. Workshop to be presented at the Annual conference of the Canadian Association of Psychosocial Oncology, Montreal, QC.

Abstracts and Posters Published

1. MacKinnon, CJ., Milman, E., Smith, NG., Henry, M., Korner, A., Chochinov, HM., Cohen, SR. (2014 October). Meaning-based group counselling for bereavement: New developments in collective meaning-reconstruction after loss. Workshop to be presented at the 20th International Congress on Palliative Care, Montreal, QC.
2. Milman, E., Smith, N.G., Henry, M., Körner, A., Chochinov, H.M., & Cohen, S.R. (2014, September). *Meaning-based group counselling for bereavement: New developments in collective meaning-reconstruction after loss.* Workshop to be presented at the 20th International Congress on Palliative Care, Montreal, QC.
3. Kredentser, M.S., Chochinov, HM, Martens, PJ, Prior, HJ. (2014, September). How, Where and Why Patients with Schizophrenia Die: What We Know from Five Years of Epidemiological Research in Manitoba, Canada. Proffered paper to be presented at the International Congress on Palliative Care, Montreal QC.
4. Sinclair, S., Chochinov, HM., McClement, SE., Hack, T., Raffin, S., Hagen, N. (June 5-7, 2014) Compassion: Understandings from the literature and the bedside. 8th World Research Congress of the European Association of Palliative Care, Lleida, Spain. (presented by Dr. Sinclair)
5. Kredentser, M.S., Chochinov, HM, Martens, PJ, Prior, HJ. (2014, April). How, Where and Why Patients with Schizophrenia Die: What We Know from Five Years of Epidemiological

Research in Manitoba, Canada. Oral presentation to be presented at the Canadian Association of Psychosocial Oncology Annual Conference, Winnipeg, MB.

6. Thompson, G., Chochinov, H., & McClement, S. (October 17-20, 2013). Differences in Family Perceptions of End-of-Life Care for Long-Term Care Residents with and without dementia. Canadian Association on Gerontology (CAG) Conference, Halifax, N.S. (poster)
7. Martens PJ, Chochinov H, Prior H. The end-of-life experience for people living with schizophrenia: where do people die, and of what cause? A population-based comparative study in Manitoba, Canada. Accepted for oral presentation at the Canadian Public Health Association National Conference. Ottawa, ON. June 10-13, 2013.
8. MacKinnon, C., Smith,N., Henry, M., Milman, E., Berish, M., Farrace, A., Körner, A., Chochinov, HM., Cohen, R. Meaning-based group counseling for bereavement: results of a pilot study. October 9-12, 2012 19th International Congress on Palliative Care, Montreal, PQ.
9. MacKinnon, C., Smith,N., Henry, M., Milman, E., Berish, M., Farrace, A., Körner, A., Chochinov, HM., Cohen, R. (2012). Meaning-based group counseling for bereavement: results of a pilot study. Journal of Palliative Care, 28(3), 207-
10. MacKinnon, C.J., Smith, N.G., Henry, M., Berish, M., Milman, E., Copeland, L., Chochinov, H.M., Körner, A., & Cohen, S.R. (2012, March). Meaning-based group counseling for bereavement. 34th Annual Conference of the Association for Death Education and Counseling, Atlanta, GA, USA.
11. MacKinnon, C.J., Smith, N.G., Henry, M., Berish, M., Milman, E., Körner, A., Chochinov, H.M., Copeland, L., & Cohen, S.R. (2011, October). Development of a meaning-centered group counseling intervention for bereavement: Preliminary results. Psycho-Oncology, 20 (Suppl. 2), 85.
12. MacKinnon, C.J., Smith, N.G., Henry, M., Milman, E., Berish, M., Farrace, A. Körner, A., Chochinov, H.M., & Cohen, S.R. (2012). A pilot randomized controlled trial of the meaning-based group counselling intervention. *Proffered paper presented at the 19th International Congress on Palliative Care, Montreal, QC.*
13. Hall S, Goddard C, Opio D, Speck P, Chochinov HM, Higginson IJ. A novel approach to enhancing hope in patients with advanced cancer: a phase II RCT of Dignity Therapy,Poster Presentation, Marie Curie Conference 2011.
14. Chochinov, Harvey M., Johnston, Wendy, Strang, David G., Milke, Doris L., McClement, Susan, & Hack, Thomas, et al. Dignity and Distress Across End-of-Life Populations, Poster Presentation, Canadian Association on Gerontology Annual Scientific and Educational Meeting, Montreal December 1-4, 2010.
15. Hack, T., McClement, S., Chochinov, H., Cann, B., Hassard, T., Kristjanson, L., Harlos, M. (2010). What can we learn from cancer patients' reflections on life as death approaches? Analysis of dignity therapy transcripts. Journal of Palliative Care, 26, 223.
16. McClement, SE., Chochinov, HM., Dean, R., Lobchuk, MM. Health care aides 'experience of the ethical' in caring for dying seniors in a personal care home. Home Book of Abstracts: 3rd International in Sickness and in Health Conference: Government of the self in the clinic and the community A2-p.23. 2009.

17. Wilson K, Chochinov HM, Allard P, Chary S, Gagnon P, Macmillan K, DeLuca M, O'Shea M, Kuhl D, Fainsinger R. Prevalence and correlates of pain in the Canadian National Palliative Care Survey. 12th World Congress on Pain. Glasgow, Scotland. 2008.
18. Thompson G, Menec V, Chochinov HM. End-of-Life care for the elderly in long-term care: Family members' experiences and satisfaction with care. Journal of palliative care. 2008;24(3).
19. Thompson G, Menec V, Degner L, Chochinov HM. End-of-Life care for the elderly in long-term care: Family members' experiences and satisfaction with care. 18th Annual Provincial Hospice and Palliative Care Conference. Book of Abstracts. 2008.
20. Ens C, Chochinov HM. Evaluation of a distance education palliative care course in Cape Town, South Africa. Stem Cells: From Embryos to Ethics. Winnipeg. 2008.
21. Houmann L, Kristjanson L, Rydaho-Hansen L, Groenvold S, Chochinov HM. Implementaion of Dignity Therapy in Denmark: Experiences and cultural challenges. 5th Research Forum of the European Association of Palliative Care. May 29-31; Trondheim, Denmark. Palliative Medicine. 2008;22(4). p. 407.
22. Thompson G, Menec V, Chochinov HM. To transcribe or not to transcribe: Using digital-editing software in data analysis. International Journal of Qualitative Methods. 2008.
23. Rasic D, Belik S, Chochinov H, Sareen J. Mental disorders, and suicide in a large community sample. 57th annual conference for the Canadian Psychiatric Association. November 15-18, 2007; Montreal PQ. 2007.
24. Chochinov HM. Dignity in Palliative Care - History and New Developments. Palliativ Medicinsk Afdeling 10 ars Jubilaeums Symposium. May 11-12, 2007; Copenhagen, Denmark. 2007.
25. Ens C, Thompson G, Gwyther E, Chochinov HM. A Qualitative Exploration of Referral and Access to Hospice Care in South Africa: Multi-Professional Specialist Perspectives. Canadian Palliative Care Association Conference. Montreal. 2007.
26. Rasic D, Belik S, Bolton J, Sareen J, Chochinov HM. Cancer, Mental Disorders and Suicide in a large community sample. Psychooncology. 2007.
27. Chochinov HM. Dignity Therapy Symposium - Dying, Dignity and Quality of End-of-Life Care. CESPU. May 31-June 2; Porto, Portugal. 2007.
28. Poppito S, Pitrelli K, Berg A, Kristjanson, L., Breitbart W, Chochinov HM. In good hands: dignity therapy and a mother's legacy in end-of-life cancer care. American Psychosocial oncology society 4th annual conference. March 1-4, 2007.
29. Chochinov HM. Panic attacks in patients receiving palliative care for cancer. Annual Convention of the Canadian Psychological Assocation. June 7 - 9, 2007.
30. Rasic D, Pagura J, Belik SL, Cox B, Sareen J, Chochinov HM. The Psychological Impact of Cancer on Patients and their Relatives. Canadian Psychiatric Association Meeting. November 15-18; Montreal, PQ. 2007.
31. Ens C, Thompson G, Gwyther E, Chochinov HM. The University of Cape Town's Palliative Care Distance Education Program: An Evaluation from the Perspective of Graduates. Canadian Palliative Care Association Conference. Montreal. 2007.

32. Chochinov HM, Stienstra D, Lutifiyya Z, Kaufert J. Advancing the Dialogue: Disability and End-of-Life Care. 16th International Congress on Care of the Terminally Ill. September; Montreal, Quebec. 2006.
33. Wilson K, Chochinov HM, McPherson C, LeMay K, Allard P, Chary S, Gagnon P, Macmillan K, DeLuca M, O'Shea F, Fainsinger R. Suffering with advanced cancer. 16th International Congress on Care of the Terminally Ill. September; Montreal, Quebec. Journal of Palliative Care. 2006;22. p. 191.
34. Ens C, Berard J, Chochinov H, Harlos M, Peters-Watral B, Stenekes S, Stern A, Wowchuk S. Canadian Virtual Hospice and Children. A Needs Assessment. Canadian Student Health Research Forum 2006, University of Manitoba. 2006.
35. Chochinov HM. Desir de vivre, desir de mourir. INFO Kara Revue internationale francophone de soins palliatifs. 2006.
36. Chochinov HM. Dying with Dignity: Rhetoric, data and therapeutic opportunities. 8th World Congress of Psycho-Oncology. 2006.
37. Chochinov HM, Ens C, Stern A, Berard J, Harlos M, Stenekes S, Wowchuk S, Peters-Watral B. Health and Aging Conference Report. 2006.
38. Houmann J, Rydahl S, Kristjanson L, Chochinov HM, Groenvold M. Implementaion and evalluation of Dignity Therapy in Denmark: Experiences and cultural challenges. 8th World Congress of Psycho-Onocology. 2006.
39. Ens C, Stern A, Berard J, Harlos M, Chochinov H, Stenekes S, Wowchuk S, Peters-Watral, B. Online communication and pediatric palliative care: A needs assessment for the Canadian Virtual Hospice. European Association for Palliative Care. Venice, Italy. 2006.
40. Ens C, Harlos M, Stern A, Chochinov HM, Berard J. Online communication and pediatric palliative care: a needs assessment for the Canadian Virtual Hospice. Palliative Medicine. 2006;20(3). p. 283.
41. Chochinov HM. un traitement qui preserve la dignite. INFO Kara Revue internationale francophone de soins palliatifs. 2006.
42. Wilson KG, Chochinov HM, Graham M, Allard P, Cary S, DeLuca M, Gagnon PR, Kuhl D, Macmillan K, O'Shea F, Fainsinger R. Depression and anxiety disorders in palliative cancer care. 15th International Congress on Care of the Terminally Ill. September; Montreal, Quebec. Journal of Palliative Care. 2004;20. p. 229.
43. Chochinov HM, Buenger U, Wilson KG, Murray MM. Dignity psychotherapy for ALS patients. 14th International Symposium on ALS/MND. November; Milan, Italy. 2003.
44. Wilson KG, Chochinov HM, Allard P, Chary S, DeLuca M, Gagnon PR, O'Shea F, Macmillan K, Fainsinger RL, Kuhl D. The Canadian National Palliative Care Survey. 14th International Congress on Care of the Terminally Ill. October; Montreal, QC. Journal of Palliative Care. 2002;18. p. 232.
45. Kristjanson L, Chochinov HM, Yuen K, Oldham L, Hale H. Dignity Therapy: An Intervention for Suffering at the End-of-Life. Perth, Australia. 2002.

46. Wilson KG, Chochinov HM, Allard P, Chary S, De Luca K, Gagnon PR, O'Shea F, Macmillan K, Fainsinger R, Kuhl D. National Palliative Care Survey. International Congress of Care of the Terminally Ill. Montreal, Quebec. 2002.
47. Stern A, Chochinov HM, Fassbender K, Jadad A, Librach SL, Lynch J, Pereira JL, Weaver L, Weir R. The Canadian Virtual Hospice. International Congress of Care of the Terminally Ill. Montreal, Quebec. 2002.
48. Cohen SR, Deschamps M, Chochinov HM, Allard P, Fiset V, Fyles G, Gagnon P, McClement S, Néron S, Viola RA, Wilson KG. Networking to conduct palliative care research. Canadian Palliative Care Association Annual Meeting. October; Victoria, B.C. 2001.
49. Paul J, Daeninck J, Honer M, Harlos S, Chochinov HM. The Changing Nature Of Utilization Of A Tertiary Palliative Care Unit Over The Last Decade. 13th International Congress on the Care of the Terminally Ill. September; Montreal, Quebec. 2000. Poster Presentation.
50. Chochinov HM, Hack TF, Kristjanson LJ, McClement SE, Harlos MS. Development and Testing of the Palliative Care Dignity Inventory: Preliminary Data. Pan-American Congress of Psychosocial & Behavioural Oncology. New York, New York. 2000.
51. Chochinov HM, Hack TF, Kristjanson LJ, McClement SE, Harlos MS. Dignity in the Terminally Ill. Psychosocial Oncology 2000 and Beyond- Future Directions. Vancouver, BC. 2000.
52. Harlos M, Daeninck P, Chochinov HM. Characteristics of length of stay in a palliative care unit. Canadian Palliative Care Association. October; London, Ontario. 1999.
53. Hack TF, Norman A, Harlos MS, Sisler J, Chochinov HM, Woodgate RL, McClement SE. Health Care Team--Myth or Reality?: Patient Reports of Ambiguity and Abandonment. 5th National Conference on Cancer Nursing Research. Newport Beach, CA. 1999.
54. Chochinov HM, Hack TF, Kristjanson LJ, Harlos MS, McClement SE. Explicating the Construct of Dignity in Palliative Cancer Patients. 4th International Qualitative Health Research Conference. Vancouver, B.C. 1998. p. 116. Abstract No. PC8.
55. Chochinov HM, Wilson K, Schallow J, Tataryn D, Enns M, Lander S. Hopelessness and suicidal ideation in the hopelessly ill. Academy of Psychosomatics. November. 1997.
56. Chochinov HM, Wilson K, Enns M. Are you depressed? Brief Screening for depression in the terminally ill. Academy of Psychosomatics. November. 1996.
57. Breitbart, W., Jaramillo, J., Chochinov, HM., Lynch, M. Neuropsychiatric syndromes and psychological symptoms in patients with advanced cancer. Journal of Pain and Symptom Management. 10:121-141, 1995.
58. Brown P, Pritchard KI, Koopmans J, Chochinov HM, Navarro M, Linn G, Steggles S, Bellissimo A, Goodwin PJ. The BEST Randomized Trial of Group Psychosocial Support in Metastatic Breast Cancer: Pilot Results. International Association for Breast Cancer Research, Biennial Meeting. April 25-28; Calgary, Alberta. 1993. p. A71.
59. Chochinov HM, Peters B, Maharaj A, Benjamison P. Psychosocial Support Group on an Inpatient Oncology Unit. Current Concepts in Psycho-oncology V Syllabus. Memorial Sloan Kettering Cancer Center. New York, New York. 1993.

60. Chochinov HM, Wilson KG, Enns M, Mowchun N, Levitt M. Depression and desire for death in the terminally ill. Fourth annual Canadian Palliative Care Research Forum. October; Montreal, Quebec. 1992.
61. Chochinov HM, Wilson KG, Enns M, Mowchun N, Levitt M. Desire for Death Among the Terminally Ill. Symposium on Euthanasia and Suicide in the Terminally Ill. Proceedings, American Psychiatric Association Annual Meeting. Washington, D.C. 1992. p. 271.
62. Breitbart W, Chochinov HM, Cassum N, Zisook S. Psychiatry's Role in Palliative Care. Proceedings, American Psychiatric Association Annual Meeting. San Francisco, CA. 1992.
63. Chochinov HM, Wilson KG, Enns M, Mowchun N, Levitt M. Diagnosing Depression among the Terminally Ill; Effects of Diagnostic Criteria Symptom Thresholds. Current concepts in psycho-oncology Update IV Syllabus. Memorial Sloan Kettering Cancer Center. New York, New York. 1991.
64. Chochinov HM. Psychosocial support in a neuro oncology unit. Current Concepts in psycho-oncology and Aids, Syllabus III Memorial Sloan Kettering Cancer Center. New York. 1987.

Abstracts under review

1. MacKinnon, C. J., Smith, N. G., Henry, M., Milman, E., Chochinov, H.M., Körner, A., Berish, M., Farrace, A., Liarikos, N. & Cohen, S. R.(conditional acceptance). Reconstructing meaning with others in loss: Results of a bereavement group pilot randomized controlled trial. Death Studies.

Books

Published

1. Chochinov, H. Dignity Therapy Final Words for Final Days. (Hungarian Translation). Oriold Es Tarsai, Budapest 2014.
2. Chochiniov, H. Dignity Therapy Final Words for Final Days. Kita-Oji-Shobo. Published in Japan by arrangement with Oxford University Press. Translated into Japanese by Yasunaga Komori & Hikaru Okuno, 2013.
3. Chochinov H. Dignity Therapy: Final Words for Final Days. New York, NY: Oxford University Press, 2011.
4. Komori, Y & Chochinov, HM. Introduction to Dignity Therapy. Kongo Shuppan. 2011 (Japan)
5. Komori, Y & Chochinov, HM. Introduction to Dignity Therapy. Korea Hakjisa Publisher ISBN 978-89-6330-682-7. 2011
6. Chochinov HM, Breitbart W. Handbook of Psychiatry in Palliative Medicine. 2nd ed.. New York: Oxford University Press; 2009.
7. Chochinov HM, Breitbart W. Handbook of Psychiatry in Palliative Medicine (Japanese Translation): Seiwa Press; 2001.

8. Chochinov HM, Breitbart W. Handbook of Psychiatry in Palliative Medicine: 1st ed. Oxford University Press; 2000.

Book Chapters

In Press

1. Shuster, JL, Chochinov, HM, Jacobowski, N. End-of-Life Issues. In, Fogel, BS, Greenberg, DB, eds. Psychiatric Care of the Medical Patient 3rd Edition. Oxford University Press (In Press).
2. Chochinov, HM, Campbell-Enns, HJ. Healthcare Provider Communication: The Model of Optimal Therapeutic Effectiveness. In: Holland JC, Breitbart WS, Butow PN, Jacobson PB, Loscalzo MJ, McCorkle R, eds. Psycho-Oncology. 3rd Ed. New York, NY: Oxford University Press (In Press).
3. Chochinov HM, Kredentser MS. Dignity in the Terminally Ill: Empirical Findings and Clinical Applications. In: Holland JC, Breitbart WS, Butow PN, Jacobson PB, Loscalzo MJ, McCorkle R, eds. Psycho-Oncology. 3rd Ed. New York, NY: Oxford University Press (In Press).
4. Chochinov, H.M., McClement, S.E., & Kredentser, M.S. Dignity in Palliative End-of-Life Care. In N. Cherny, M. Fallon, S. Kassa, R. Portenoy, D.C. Currow, & J. Morita, Eds. Oxford Textbook of Palliative Medicine, 5th Ed. Oxford: Oxford University Press (In Press).
5. McClement, S.E. & Chochinov, H.M. Spiritual Issues in Palliative Medicine. In N. Cherny, M. Fallon, S. Kassa, R. Portenoy, D.C. Currow, & J. Morita, Eds. Oxford Textbook of Palliative Medicine, 5th Ed. Oxford: Oxford University Press (In Press).
6. Chochinov HM, Harlos M, Cory S, Horst G, Nelson F, Hearson B. Canadian Virtual Hospice: A Template for Online Communication and Support. In: Holland JC, Breitbart WS, Butow PN, Jacobson PB, Loscalzo MJ, McCorkle R, eds. Psycho-Oncology. 3rd Ed. New York, NY: Oxford University Press (In Press).

Published

1. McClement, S.E., Chochinov, H.M., Kredenster, M.S. Dignity in Palliative Care. In E. Bruera, I. J. Higginson, C. F. von Gunten, & T. Morita, Eds. Textbook of Palliative Medicine and Supportive Care, 2nd Ed. London: Hodder Arnold; 2015: 127-134.
2. Sinclair, S. & Chochinov, HM. Research and Practice: Spiritual Perspectives of a Good Death within Evidenced-Based Healthcare. in Spirituality in Hospice Palliative Care. (Bramadat, P., Stajudhar, K., Coward, H. eds.). SunyPress, 2013.
3. Scott, I., Montross, L., Chochinov, HM. What treatments are effective for anxiety in patients with serious illness? Chapter 34 in Evidence-Based Practice in Palliative Medicine. (Goldstein, N., & Morisson, S, Eds.) Elsevier, Inc. pp 191 – 197. 2012.
4. Sinclair, S. & Chochinov, HM. Dignity: A Novel Pathway into the Spiritual Landscape of the Human Heart, Chapter 21 in The Oxford Textbook of Spirituality and Health. (Puchalski, C.; Cobb, M.; Rumbold, B. eds.). Oxford University Press. Pp 145-150. 2012

5. Sinclair, S. & Chochinov, HM. Dignity Conserving Care: Research Evidence, chapter 40 in The Oxford Textbook of Spirituality in Healthcare. (Puchalski, C.; Cobb, M.; Rumbold, B. eds.). Oxford University Press. Pp 285-292. 2012.
6. Breitbart, W., Chochinov, HM., Alici, Y. End-of-Life. Chapter 19 in Care in Clinical Psycho-oncology: An International Perspective. (Grassi, L. & Reba, M. eds). Wiley-Blackwell, pp 249-270. 2012.
7. Johnston, BM., Chochinov, HM. The Therapeutic Implications of Dignity in Palliative Care. Emanuel, LL. & Librach, SL, editors. Palliative Care: Core Skills and Clinical Competencies. 2nd edition. Saunders. pp. 696-. 2011.
8. Shuster, John., Chochinov, HM, Greenberg, D., Jacobowski, A. End of Life Issues. Barry Fogel and Donna Greenberg (eds.) Psychiatric Care of the Medical Patient, 3rd ed. Oxford University Press. New York, New York. chp 85. 2011.
9. Chochinov, HM & McKeen, N. Dignity Therapy. Watson, M. and Kissane, D., Editors, Handbook of Psychotherapy in Cancer Care, John Wiley & Sons, Sussex, UK, pp 79-88, 2011.
10. McClement, SE. & Chochinov HM. Spirituality in Supportive Oncology. In C. Zimmerman, (Ed.), Supportive Oncology (1st edition) New York: Elsevier (pp.521-525) 2011.
11. Breitbart, W., Chochinov, HM., Passik, S., Casper, D. Psychiatric symptoms in palliative medicine. In the Oxford Textbook of Palliative Medicine 4th Edition. G. Hanks, NI Cherny, NA Christakis, M. Fallon, S. Kaasa, RK. Portnoy (Eds.) Oxford University Press, Oxford, UK, pp 1453-1482, 2010.
12. Breitbart, W., Chochinov, HM., Alici, Y. Palliative Care. In Levenson, J. (ed.) Textbook of Psychosomatic Medicine: Psychiatric care of the medically ill. 2nd ed. Washington, DC: American Psychiatric Publishing Inc. pp1053-1084. 2011.
13. Chochinov, HM.. Dignity-Conserving Care – A New Model for Palliative Care: Helping the Patient Feel Valued. Chapter 27 (pp 353-362) in: Care at the Close of Life: Evidence and Experience. McPhee, S.J., Winker, M.A., Rabow, M.W., Pantilat, S.Z., Markowitz, A.J. (eds). McGraw Hill 2011.
14. Thompson G, Ens C, Chochinov HM. Patient Centred Supportive and Palliative Care. Chapter 14 pp 259-276. Cancer Control. Elwood, M; Sutcliffe, S, Series ed. Oxford: Oxford University Press 2010.
15. Thompson, G., & Chochinov, H. Palliative Care: Special Considerations for Older Adults with Cancer (pp. 293-324) in Hurria A, & Balcucci I (eds.) Geriatric Oncology, Springer, New York. (invited chapter). 2009.
16. McClement S, Chochinov HM. Spiritual Issues in Palliative Care. In Hanks, G., Cherny, N., Christakis, N., Fallon, M., Stein, K., Portenoy, R. (eds.) Oxford Text of Palliative Medicine. 4th ed. Oxford, UK: Oxford University Press pp 1403-1419. 2009
17. McClement, S.E., Chochinov H.M. (2009). Depression. In T.D. Walsh et al (eds.), *Palliative Medicine*. Philadelphia: Saunders Elsevier (pp. 865-871).

18. Treece, C., Breitbart, W., McKeen, N., Chochinov, HM. Dignity, Meaning and Demoralization: Emerging Paradigms in End of Life Care. Chapter 20 pages 324-340. In: Chochinov, HM. & Breitbart, W. (eds). Handbook of Psychiatry in Palliative Medicine 2nd edition. Oxford: Oxford University Press. 2009
19. Breitbart, W., Chochinov, HM., Alici, Y. Palliative Care. (Chapter 41) The American Psychiatric Publishing Textbook of Psychosomatic Medicine; 2009.
20. Dickerman A, Breitbart W, Chochinov HM. Spiritual Care of Persons with HIV and AIDS. Comprehensive Textbook of AIDS Psychiatry. Cohen, Mary Ann & Gorman, Jack, M., Series ed. Oxford University Press; 2008. p. 417 - 437.
21. Mehnert A, Chochinov HM. Würde aus der Perspektive todkranker und sterbender Patienten. In: Koch U, Lang K, Mehnert A, Schmeling-Kludas C, editors. Die Begleitung schwer kranker und sterbender Menschen. Stuttgart: Schattauer: Grundlagen und Anwendungshilfen in der Palliativversorgung; p. 53-64. 2006.
22. Skakum K, Chochinov HM. Anxiety and Depression. In: MacDonald N, Oneschuk D, Hagen N, Doyle D, editors. Palliative Medicine: A Case-Based manual. Chapter 9: Oxford University Press; 2005.
23. Breitbart W, Gibson C, Chochinov HM. Psychiatric Issues in End of Life Care. In: Levenson J, editors. Textbook of Psychosomatic Medicine. American Psychiatric Publishing Inc.; pp. 979-1007. 2004.
24. Ganzini L, Chochinov HM. Psychiatry at the end of life. In: Grossberg G, Sadavoy J, Jarvik L, Meyers B, editors. Comprehensive Review of Geriatric Psychiatry. 3rd ed. New York: Norton Press; 2004. p. 1265-1280.
25. Breitbart W, Chochinov HM, Passik S. Psychiatric symptoms in palliative medicine. In: Doyle D, Hanks G, editors. Oxford Textbook of Palliative Medicine. Third ed. New York, NY: Oxford University Press; 2003. p. 746-774.
26. Schwartz L, Chochinov HM. Depression and the will to live in terminally ill patients. In: Hendin H, Foley K, editors. The Case Against Assisted Suicide. Johns Hopkins Press; 2002. p. 261-277.
27. Chochinov HM. Depression in the Terminally Ill: Prevalence and measurement Issues. In: Portenoy RK, Bruera E, editors. Issues in Palliative Care Research. Oxford University Press; 2002. p. 189-202.
28. Schwartz L, Chochinov HM. Euthanasia and Physician-Assisted Suicide: Psychiatric Considerations. In: Ratnaike RN, editors. An Essential Guide to Geriatric Practice. Australia: McGraw-Hill; 2002. p. 890-901.
29. Chochinov HM. A guide to end-of-life care for seniors. In: Fisher R, Ross MM, MacLean MJ, editors. National Advisory Committee. Health Canada; 2000.
30. Wilson K, Chochinov HM, de Faye BJ, Breitbart W. Diagnosis and Management of Depression in Palliative Care. In: Breitbart W, editors. Handbook of Psychiatry in Palliative Medicine. New York: Oxford University Press; 2000.

31. Schuster J, Chochinov HM, Greenberg D. Psychiatric Aspects of Palliative CarePsychiatric Care of the Medical Patient. In: Stoudemire A, Fogel B, Greenberg D, editors. Second ed. Oxford Press; 2000.
32. Rosenfeld B, Krivo S, Breitbart W, Chochinov HM. Suicide, assisted suicide and euthanasia in the terminally ill. In: Chochinov HM, Breitbart W, editors. Handbook of Psychiatry in Palliative Medicine. New York: Oxford University Press; 2000.
33. Chochinov HM, Katz L, Holland J. Bereavement. In: Holland J, editors. Textbook of Psycho-oncology. New York: Oxford University Press; 1998. p. 1016-1032.
34. Lander M, Chochinov HM. Depression in the Terminally Ill. In: Joisly SK, editors. Palliative Medicine Secrets. Hanley and Belfus, Inc; 1998. p. 185-188.
35. Chochinov HM, Lander M. Desire for Death in the Terminally Ill. In: Joisly SK, editors. Palliative Medicine Secrets. Hanley and Belfus, Inc.; 1998. p. 181-184.
36. Chochinov HM. Euthanasia, Social Policy and Empirical Date. In: Eguchi, K., Klastersky, J., Feld, R. (eds). Current Perspectives and Future Directions in Palliative Medicine. Tokyo: Spring-Verlag; 1998. p. 83-92.
37. Breitbart W, Jaramillo J, Chochinov HM. Palliative and Terminal Care. In: Holland J, editors. Psycho-oncology. New York: Oxford University Press; 1998. p. 437-449.
38. Chochinov HM, Breitbart W. Special Issue of Psychosomatic Research. In: Holland J, editors. Psycho-oncology. New York: Oxford University Press; 1998. p. 185-300.
39. Katz L, Chochinov HM. The Spectrum of Grief in Palliative CareTopics in Palliative Care. In: Bruera E, Portenoy R, editors. Oxford University Press; 1998. p. 295-310.
40. Breitbart W, Chochinov HM, Passik S. Psychiatric Aspects of Palliative Care. In: Doyle D, Hanks G, MacDonald N, editors. Oxford Textbook of Palliative Medicine. Second ed. New York, NY: Oxford University Press; 1997. p. 933-954.
41. Chochinov HM. Management of Grief in the Cancer Setting. In: Breitbart W, editors. Holland's Psychiatric Aspects of Symptom Management in Cancer Patients. Washington, D.C: American Psychiatric Press; 1993.
42. Chochinov HM, Holland JC. Bereavement: A special issue in oncology. In: Holland JC, Rowland JH, editors. Handbook of psycho-oncology. New York: Oxford University Press; 1989.

Editorials

1. Chochinov HM. Getting MAD (Medical Aid in Dying) in Canada. Palliative and Supportive Care. 2014;12:423-424.
2. Chochinov HM. Palliative and Supportive Care. The Secret is out: Patients are People with Feelings that Matter. (2013), 11, 287–288.
3. Chochinov HM. Invited Guest Editor. Canadian Journal of Psychiatry Volume 53. 2008.
4. Chochinov HM, Steinstra D, Invited Guest Editors. Vulnerable Populations and End-of-life Care. Journal of Palliative Care, target publication, Fall Issue; 2006.

5. Breitbart W, Chochinov HM, Guest Editors. Psycho-oncology research. Journal of Psychosomatic Research Volume 45. 1998.

Articles in Professional Publications

1. Chochinov, HM., Balfour, M. Mount. In lieu of palliative care options, is it time to allow assisted suicide? Canadian Health Care Network.ca (2014).
2. Chochinov, HM. End-of-Life Care and the Elderly. Psychiatric Times
3. Chochinov HM. The Canadian Virtual Hospice. Newsletter of the Canadian Society of Palliative Care Physicians. 2002.
4. Chochinov HM. Treating depression in the terminally ill. Knoll Pain Management Newsletter. 1997;154:674-676.
5. Chochinov HM. Treating depression in the terminally ill. Knoll Pain Management Newsletter. 1997;10:5-6.
6. Chochinov HM. Treating Depression in the Terminally Ill (Parts I/II). Knoll Pharmaceutical Newsletter. 1995;8.

Articles Published Non-Referred

1. Chochinov, HM. Vulnerability and palliative care. Editorial in Palliative and Supportive Care, 2012 10: 1-2.
2. Chochinov, HM. End-of-Life Care and the Elderly. Psychiatric Times. December 2008:25(14); 19-25.

Reviews

1. Chochinov HM. Review of: The Human Side of Cancer. by Holland J, Lewis S. Voices in the Night Newsletter. 2001.
2. Chochinov HM. Review of: The Cry for Myth. by May R. Canadian Journal of Psychiatry. 1992;37.
3. Chochinov HM. Review of: The Call of Stories; Teaching and the Moral Imagination. by Coles R. Journal of Palliative Care. 1991;714(Winter):59-60.
4. Chochinov HM. Review of: Palliative Care in Terminal Illness. by Hanratty JF, Higginson I. Psychosomatic Research. Second ed.
5. Chochinov HM. Review of: Psychiatric Care of the Medical Patient. by Stoudermire A, Fogel B. General Hospital Psychiatry.

Reports

1. Chochinov HM. Expert testimony/affidavit in Taylor versus British Columbia Supreme Court. March 2012.
2. Thompson, G., & Chochinov H. (2012). Understanding the Meaning of Dignity in Care in Personal Care Homes. Dignity in Care Project, Winnipeg Regional Health Authority.

3. Annable G, Stientra D, Chochinov HM. Addressing disability in Cancer Care. Canadian Partnership Against Cancer. March 2010
4. Chochinov HM. Commissioned Brief for the Public Interest Law Centre, Winnipeg, MB. Re: Compassionate Care Benefits. Dying, Dignity and the Role of Family Support. 2005.
5. Chochinov HM. Submission to the Standing Committee on Social Affairs, Science and Technology within their study of mental health and mental illness. 2003. Chairman: Senator Kirby.

Comments

1. Chochinov HM. Cruising for a bruising. Journal of Palliative and Supportive Care. 2005;3:171.
2. Chochinov HM. Re: Dignity Conserving Care: A New Model for Palliative Care. JAMA. 2002;288.
3. Chochinov HM. Reply to, Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide. Arch Intern Med. 2000;160:2454-60.
4. Chochinov HM, Tataryn D, Dudgeon D, Clinch J. Will to Live in the Terminally Ill, authors' reply. Lancet. 1999.
5. Chochinov HM, Wilson KG. Patients with amyotrophic lateral sclerosis and physician-assisted suicide. NEJM. 1999;340:817.
6. Chochinov HM, Wilson KG. Re: Are you depressed? Screening for depression in the terminally ill. American Journal of Psychiatry. 1998;155:994-995.
7. Chochinov HM. Reply to Breitbart et al Interest in Physician-Assisted Suicide Among Ambulatory HIV-Infected Patients. American Journal of Psychiatry. 1997;154:294.
8. Chochinov HM. Reply to Bachman et al Special Article, February 1, 1996. New England Journal of Medicine. 1996;335:518-519.

Newspaper Articles

1. Canada failing on palliative care. The Toronto Star, Toronto, ON. Feb.18, 2015. The same article was reprinted in the following newspapers and online news sources under various titles: National Newswatch, Feb.23, 2015; The Province, Vancouver, BC. Feb.23, 2015; The Daily Courier, Kelowna, BC, Feb.25, 2015; Trail Daily Times, Trail, BC. Feb.25, 2015; Red Deer Express, Red Deer, AB. Feb.25, 2015; Windsor Star, Windsor, ON. Feb.25, 2015; The Whitehorse Daily Star, Whitehorse, YT. Feb.24, 2015; Brandon Sun, Brandon MB. Feb.25, 2015; Huffington Post, Feb.25, 2015; Canadian Health Network.ca. Feb.26, 2015.
2. We need to have end-of-life talks: Discussing death allows us to make plans and to make our wishes known to our loved ones. The same article was reprinted in the following newspapers and online news sources: Medical Post, April 23, 2014; Vancouver Province, Vancouver, BC. April 25, 2014; Slave Lake Lakeside Leader, Slave Lake, AB. April 30, 2014.
3. Chochinov, H.M. Dying Well: Why we all need to have end of life conversations. The Globe and Mail, April 22.2014. (In top 10 most widely shared articles 2014; EvidenceNetwork.ca)

4. Chochinov, HM. The concept of dignity is key. Montreal Gazette. August 25, 2010. Letter to the editor.
5. Chochinov HM. In search of a good death. Globe & Mail 2000 July 19.

Electronic Documents

1. CMAJ Blogs, October 14, 2014, http://cmajblogs.com/?s=Chochinov
2. Huffington Post, October 24 2014, http://www.huffingtonpost.ca/../../harvey-max-chochinov/assisted-suicide-canada_b_6036716.html
3. Globe and Mail, April 22 2014, http://www.theglobeandmail.com/globe-debate/why-we-all-need-to-have-end-of-life-conversations/article18090462/
4. Waterloo Region Record, April 25 2014, http://www.therecord.com/opinion-story/4483781-don-t-put-off-expressing-final-wishes-about-palliative-care/
5. Huffington Post, May 10 2014, http://www.huffingtonpost.ca/harvey-max-chochinov/how-to-die-well_b_5297538.html?utm_hp_ref=tw
6. Huffington Post Quebec (in French) May 26 2014, http://quebec.huffingtonpost.ca/harvey-max-chochinov/mourir-dignement-discuter-de-la-fin-de-la-vie_b_5390088.html
7. Healthy Debate, May 26 2014, http://healthydebate.ca/opinions/need-end-life-conversations
8. KevinMD, May 31 2014, http://www.kevinmd.com/blog/2014/05/acknowledging-death.html
9. Ottawa Life Magazine: June 18 2014, http://www.ottawalife.com/2014/06/dying-well-why-we-all-need-to-have-end-of-life-conversations/
10. Chochinov,HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, Sinclair S, Murray A. The Patient Dignity Inventory: A Novel Way of Measuring Dignity-Related Distress in Palliative Care (electronic copy) 2009 http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/The+Exchange/Current/The+Patient+Dignity+Inventory_+A+Novel+Way+of+Measuring+Dignity_Related+Distress+in+Palliative+Care.aspx
11. Skakum K, Chochinov HM. Delirium. E PEC-O Participant Handbook. 2006.
12. Annable, G, Steinstra D, Chochinov HM. Addressing Disability in Cancer Care. Canadian Partnership Against Cancer. March 2010 http://www.partnershipagainstcancer.ca/sites/default/files/Disability%20in%20Cancer%20Care_ENG.pdf

Presentations

Completed

1. **Chochinov, HM.** (2015). Dying with Dignity in Canada, Manning Networking Conference, Ottawa, ON, March 6, 2015.
2. **Chochinov, HM.** (2015) Dignity, Personhood and the Culture of Medicine, Dr. John P. Maclean Memorial Lecture, University of Manitoba Department of Internal Medicine, Winnipeg, MB February 3, 2015.
3. **Chochinov, HM.** (2014) Dignity and Palliative End of Life Care Webinar, National Association of Jewish Chaplains, November 20, 2014.
4. **Chochinov, HM.** (2014) The Experiential Landscape of Terminal Illness, Dignity and Existential Suffering at End of Life Conference. University Medical Center of the Johannes Gutenberg University Mainz. Mainz, Germany, November 3, 2014.
5. **Chochinov, HM.** (2014) Dignity Therapy A Dignity Based Intervention, Dignity and Existential Suffering at End of Life Conference. University Medical Center of the Johannes Gutenberg University Mainz. Mainz, Germany, November 4, 2014.
6. **Chochinov, HM.** (2014) The Importance of Dignity in Palliative End-of-Life Care,, Dignity and Existential Suffering at End of Life Conference. University Medical Center of the Johannes Gutenberg University Mainz. Mainz, Germany, November 5, 2014.
7. **Chochinov, HM.** (2014) Considering Dignity in Palliative End-of-Life Care, ASCO Palliative Care in Oncology Symposium, Boston, Massachusetts, October 25, 2014
8. **Chochinov, HM.** (2014) Dignity, Personhood and Palliative End of Life Care, Human Values Forum, Advocate Lutheran General Hospital, Illinois, October 8, 2014.
9. **Chochinov, HM.** (2014) Enhancing Communication in Healthcare Workshop, Human Values Forum, Advocate Lutheran General Hospital, Illinois, October 8, 2014.
10. **Chochinov, HM.** (2014) Dignity and new Opportunities in Palliative Care, Rainbow Hospice, Illinois, October 7, 2014.Community Cancer Programs Network, My Patient Has a Mental Illness: Implications for Patient-Centered Cancer Care, October 3, 2014
11. **Chochinov, HM.** (2014) Scott & White Healthcare Bereavement Conference Dignity Therapy, Temple, Texas, September 19, 2014.
12. **Chochinov, HM.** (2014) Dignity in Care Dignity in Care presentation to WRHA Quality, Patient Safety and Innovation (QPSI) Committee of the Board Meeting, September 5, 2014.
13. **Chochinov, HM.** (2014) Dignity, Personhood and the Culture of Medicine, Spiritual Well Being across Cancer Care, MASCC Psychosocial Study Group, Miami, FL June 26, 2014
14. **Chochinov, HM.** (2014) Dignity and New Opportunities in Palliative End of Life Care: Communication between Medical Staff and Patients, Shanghai, China, June 21, 2014 (Keynote)
15. **Chochinov, HM.** (2014) Dignity Therapy Training Workshop, Winnipeg, MB May 28- 30, 2014.
16. **Chochinov, HM.** (2014) Dignity and End of Life Care, Lanny Remis Speakers Forum, Shaarey Zedek Synagogue, June 3, 2014
17. **Chochinov, HM.** (2014) Oncology Grand Rounds, CHU, Quebec City, Quebec May 14, 2014.

18. **Chochinov, HM.** (2014) Presentation 24th Congress of Palliative Care Network, Quebec City, Quebec May 13, 2014.
19. **Chochinov, HM.** (2014) Dignity Psychotherapy Presentation, CL Psychiatry Service, Quebec City, Quebec, May 13, 2014
20. **Chochinov, HM.** (2014) Workshop, 24th Congress of Palliative Care Network, Quebec City, Quebec May 13, 2014.
21. **Chochinov, HM.** (2014) Dignity, Caring and the Culture of Medicine, 24th Congress of Palliative Care Network, presenting with Dr. Luc Sauveur, Quebec City, Quebec May 13, 2014.
22. **Chochinov, HM.** (2014) Palliative & End of Life Care: Challenges & Opportunities for Applied Cancer Research, Applied Research in Cancer Control Conference, Toronto, ON May 12, 2014.
23. **Chochinov, HM.** (2014) Communication Skills, 2014 Palliative Care Awareness (PAW) St. Paul's Hospital, Vancouver. May 5 & 6, 2014.
24. **Chochinov, HM.** (2014) Dignity, Care and the Culture of Health Care, Canadian Association of Psychosocial Oncology Conference, Winnipeg, MB May 1, 2014.
25. **Chochinov, HM, Shariff, M., Schaefer, A.** (2014) Should we have the right to die? The Evolution of the Rights Culture; Featured speaker along with Dr. Mary Shariff and Dr. Arthur Schafer, University of Manitoba Visionary Conversations, Winnipeg, MB April 30, 2014
26. **Chochinov, HM.** (2014) Health Care Provider Communication: An Empirical Model of Therapeutic Effectiveness, Canadian Association of Psychosocial Oncology Conference, Pre Conference Workshop, Winnipeg, MB April 30, 2014
27. **Chochinov, HM.** (2014) Dignity, Caring and End-of-Life Conversations, Shaarey Zedek synagogue talk, Winnipeg, MB April 19, 2014
28. **Chochinov, HM.** (2014) Dignity and End of Life Care, Canadian Association for Spiritual Care, National Conference, Winnipeg, MB April 10, 2014
29. **Chochinov, HM.** (2014) Grand Rounds, Princess Alexandra Hospital, Brisbane, Australia, February 2014
30. **Chochinov, HM.** (2014) Care, Caring and the Culture of Medicine, CancerCare Manitoba Nursing Rounds, Winnipeg, MB. March 21, 2014.
31. **Chochinov, HM.** (2014) Dignity, Caring and the Culture of Caring, The Carmelita Lawlor Lectureship, Hospice Palliative Care Ontario Annual Conference, Toronto, ON, April 27, 2014
32. **Chochinov, HM.** (2014) Dignity Therapy Workshop, Princess Alexandra Hospital, Brisbane, Australia February 26-28, 2014.
33. **Chochinov, HM.** (2014) Public lecture at an End of Life Forum, sponsored by Sudbury Hospice and Palliative Care. Sudbury, ON January 9, 2014.
34. **Chochinov, HM.** (2013) Dying with Dignity: New Opportunities in Palliative Care, The Joint Distribution Committee Building, Jivat Ram, Jerusalem, Video Lecture. December 19, 2013.

35. **Chochinov, HM.** (2013) Dignity, Caring and the Culture of Medicine, Keynote speaker at the Health Innovation Conference hosted by the Manitoba Patient Access Network and the George and Fay Yee Centre for Healthcare Innovation. November 18, 2013.
36. Zacharias, J., Davison, S. **Chochinov, HM.** (2013) Dignity and Distress in End-of-Life ESRD Populations, American Society for Nephrology, Atlanta, Georgia November 8, 2013. Presented by James Zacharias.
37. **Chochinov, HM.** (2013) Dignity and Insights into the Culture of Caring, National Hospice and Palliative Care Organization, Washington, DC, November 5, 2013.
38. **Chochinov, HM.** (2013) The Patient Dignity Question: A practical means of placing personhood on the clinical radar. Canadian Cancer Research Conference, Toronto, ON, (part of a concurrent presentation on Methodological Challenges in Interventional Research in Palliative Care with Gary Rodin, Camilla Zimmermann, Edward Chow & Serge Dumont), November 4, 2013.
39. **Chochinov, HM.** (2013) Community Cancer Care 2013 Conference, 'New Frontiers in Communication: Is Personhood on your Clinical Radar?' Winnipeg, MB. September 19.13.
40. **Chochinov, HM.** (2013) University of Dundee, Scotland Dalhousie Lecture theatre, Dignity research and the frail elderly. Dundee, Scotland, August 22.2013.
41. Martens, P.J., **Chochinov HM.,** Prior, H. The end-of-life experience for people living with schizophrenia: where do people die, and of what cause? A population-based comparative study in Manitoba, Canada. Canadian Public Health Association National Conference. Ottawa, ON. June 10, 2013. Presented by P. Martens.
42. **Chochinov, HM.** (2013) Breitbart Family Memorial Lecture, Memorial Sloan-Kettering Cancer Center Psychiatry Grand Rounds, Dying Dignity and Data: New Opportunities in Palliative Care, New York, NY, June 7, 2013
43. **Chochinov, HM.** (2013) International Dignity Therapy Workshop, Winnipeg, MB May 22-24, 2013.
44. **Chochinov, HM.** (2013) Hungarian Hospice Foundation, Budapest Affective Psychology Department, Eötvös Lorand University, Budapest, May 10, 2013.
45. **Chochinov, HM.** (2013) Dignity Research Česká lékařská společnost (Czech Medical Association), Prague, Czech Republic, May 6, 2013.
46. **Chochinov, HM.** (2013) Dignity Research: Recent findings and clinical applications. Research Meet and Greet, Riverview Health Centre, Winnipeg, MB, April 29, 2013
47. **Chochinov, HM.** (2013) Dignity in the Terminally Ill: New Insights and Opportunities in Palliative End-of-Life Care. Association for Death Education and Counselling 35th Annual Conference, Hollywood, CA USA, April 25, 2013
48. **Chochinov, HM.** (2013) Law Society of Manitoba. Understanding Dignity: Insights on Vulnerability and Communication Skills, Winnipeg, MB, April 17, 2013
49. **Chochinov, HM.** (2013)Dignity Workshop, The North Simcoe Muskoka Palliative Care Network, Casino Rama, Orillia, Ontario, March 22, 2013

50. **Chochinov, HM.** (2013)Dignity, disability and the hazards of marginalization. Speaker Series: Visioning Inclusion and Access: Blazing Innovative Disability Research Trails, University of Manitoba, Winnipeg, MB, February 13, 2013
51. **Chochinov, HM.** (2013) Spiritual Care Grand Rounds, Dignity Therapy and Opportunities in Palliative End of Life Care. Telephone rounds, United States Department of Veterans Affairs, Hampton, VA, USA, January 8, 2013
52. **Chochinov, HM.** (2012) Dignity Therapy Workshop, San Diego, California, November 28 – 30, 2012,
53. **Chochinov, HM.** (2012) Are therapeutic approaches the answer: Testing Dignity Therapy. Interdisciplinary Palliative Care: Conundrums in the 21st Century, Memorial Sloan Kettering Cancer Center, New York, NY, November 9-10, 2012
54. **Chochinov, HM.** (2012) A New Model of Therapeutic Efficacy, King's College, London, UK, November 7, 2012
55. MacKinnon, C., Smith,N., Henry, M., Milman, E., Berish, M., Farrace, A., Körner, A., **Chochinov, HM.**, Cohen, R. (2012) Meaning-based group counseling intervention. 19th International Congress on Palliative Care, Montreal, PQ, October 12, 2012
56. **Chochinov, HM.** (2012) Stenekes, S., Ens, C., Harlos, M., Chochinov, HM., Mytopher, K. An evolution in perinatal palliative care programming: Healthcare Providers Perspectives. 19th International Congress on Palliative Care, Montreal, PQ, October 11, 2012
57. **Chochinov, HM.** (2012) Dignity at the End of Life. (Keynote) 19th International Congress on Palliative Care, Montreal, PQ, October 10, 2012.
58. **Chochinov, HM.** (2012) Canadian Psychiatric Association Annual Meeting. Keynote speaker. Montreal, PQ, Sept 28, 2012
59. Malchay, J., Cory, S., **Chochinov, HM.,** Harlos, M., Hearson, B., Nelson, F., Horst, G, (2012) Hospice and Palliative Care Manitoba, Closing Plenary, CVH, A story about care. September 21, 2012.
60. **Chochinov, HM.** Steinstra, S., Derksen, J., Latiffiya, Z., Kaufert, J. (2012) Hospice and Palliative Care Manitoba, Inclusive Palliative Care – Good care for all. September 20, 2012
61. **Chochinov, HM.** (2012) Hospice and Palliative Care Manitoba, Keynote Speaker, September 20, 2012
62. **Chochinov, HM.** (2012) Dean's Hour Lecture, University of North Dakota, School of Medicine and Health Sciences, Grand Forks, ND, July 12, 2012
63. **Chochinov, HM.** (2012) International Dignity Therapy Workshop, Winnipeg, MB May 30-June 1, 2012.
64. **Chochinov, HM.** (2012) Dignity in Care: The Interface of Mental Health and Palliative Care, WA Cancer and Palliative Care Network, Psycho-Oncology Collaborative, Perth, Australia, March 29, 2012.
65. **Chochinov, HM.** (2012) Briefing, Members of Western Australia Parliament on Dignity Therapy, March 29, 2012.

66. **Chochinov, HM.** (2012) Dignity Therapy Workshop, Curtin University, Perth, Australia, March 26-28, 2012.
67. **Chochinov, HM.** (2012) 2nd Whole Person Care National Symposium, Presentation Title: Dignity and the Shaping of Clinical Encounters, Sydney, Australia, March 22, 2012.
68. **Chochinov, HM.** (2012) 2nd Whole Person Care National Symposium, Sydney, Australia, March 21, 2012
69. **Chochinov, HM.** (2012) Palliative Care Congress, Plenary Session Title: The Role of Dignity in End-of-Life Care, Gateshead, England, March 15, 2012.
70. **Chochinov, HM.** (2012) Spiritual Care and Health: Improving Outcomes and Enhancing Wellbeing International Conference, Presentation title: Dying with Dignity: New Opportunities at the end-of-life care. Glasgow, March 13, 2012.
71. **Chochinov, HM.,** Stienstra, D., Lutfiyya, Z., Kaufert, J., Derksen, J.(2012) Vulnerable Populations NET Including: Good Palliative Care for All, Calgary January 20, 2012.
72. **Chochinov, HM,** Stienstra, D., Lutfiyya, Z., Kaufert, J., Derksen, J. (2012) Vulnerable Populations NET Including: Good Palliative Care for All, Winnipeg January 12, 2012.
73. MacKinnon, C.J. Smith, N.G., Henry, M., Milman, E., Berish, M., Copeland, L., Körner, A., **Chochinov, HM,** & Cohen, S.R. (2011). Invited Presentation, Palliative Care McGill Research Rounds, Montreal General Hospital, Montreal, QC. Towards developing more effective group interventions for uncomplicated grief: Initial results of a meaning-based clinical-research study. December, 2011.
74. **Chochinov, HM,** Stienstra, D., Lutfiyya, Z., Kaufert, J., Derksen, J. Vulnerable Populations NET Including: Good Palliative Care for All, Toronto November 27, 2011.
75. **Chochinov, HM,** Stienstra, D., Lutfiyya, Z., Kaufert, J., Derksen, J. (2011) Vulnerable Populations NET Including: Good Palliative Care for All, Halifax November 26, 2011.
76. **Chochinov, HM.** (2011) Supreme Court of British Columbia, Carter vs Attorney General of Canada & Attorney General of British Columbia, Expert Witness, November 25, 2011.
77. **Chochinov, HM.** (2011) Information session on palliative care and people with disabilities. Good Palliative Care for All. Toronto, ON, November 24, 2011,
78. **Chochinov, HM.** (2011) Information session on palliative care and people with disabilities. Good Palliative Care for All. Halifax, NS, November 24, 2011,
79. **Chochinov, HM.** (2011) Sooner Palliative Care Institute, Grand Rounds: The Morris Wizenberg Lecture: Hope and Despair in the Terminally Ill, Oklahoma City, Oklahoma,US, November 3, 2011.
80. **Chochinov, HM.** (2011) Sooner Palliative Care Institute, University of Oklahoma College of Nursing. Dying with Dignity: A Contemporary Challenge, Oklahoma City, Oklahoma, US, November 2, 2011,
81. **Chochinov, HM.** (2011) Sooner Palliative Care Institute, University of Oklahoma College of Nursing. Identifying the Needs of Patients, Families and Caregivers, Oklahoma City, Oklahoma, US, November 2, 2011,
82. **Chochinov, HM.** (2011) Sooner Palliative Care Institute, University of Oklahoma College of Nursing ABCD's of Dignity Conserving Care, Oklahoma City, Oklahoma, US, November 1, 2011,

83. **Chochinov, HM.** (2011) Sooner Palliative Care Institute, University of Oklahoma College of Nursing. How to Teach the Concept of Dignity, Oklahoma City, Oklahoma, US, November 1, 2011,
84. **Chochinov, HM.** (2011) Memorial Sloan-Kettering Cancer Center, Pain & Palliative Care Grand Rounds, New York, NY, October 20, 2011.
85. **Chochinov, HM.** (2011) XVII Brazilian Congress of Clinical Oncology, Dignity and care at the end-of-life, Gramado City, Brazil, . October 26,2011.
86. **Chochinov, HM.** (2011) XVII Brazilian Congress of Clinical Oncology, Understanding patients experience with death at the end of life, Gramado City, Brazil, October 29, 2011.
87. **Chochinov, HM.** (2011) San Diego Hospice Grand Rounds, San Diego, California, July 21, 2011
88. **Chochinov, HM.** (2011) University of California San Diego, Department of Psychiatry Grand Rounds, San Diego, California, July 22, 2011.
89. **Chochinov, HM.** (2011) International Dignity Therapy Workshop, Winnipeg, MB May 25-27, 2011.
90. **Chochinov, HM.** (2011) Grand Rounds, McGill University, Montreal, Quebec April 26, 2011.
91. **Chochinov, HM.** (2011) The George and Fay Yee Centre for Healthcare Innovation: Promoting Innovation in the Healthcare System – Optimizing use of Knowledge, University of Manitoba, April 18th-19th, 2011
92. **Chochinov, HM.** (2011) Grand Rounds, Psychiatric Department, Hamilton Health Sciences Centre May19, 2011
93. **Chochinov, HM.** (2011) Presentation at Riverview Health Centre Foundation 100th Anniversary Gala, April 12, 2011
94. **Chochinov, HM.** (2011) Dignity Therapy Workshop. Warmhearts Palliative Caregivers Sudbury/Manitoulin. Sudbury, Ontario. March 29, 2011.
95. **Chochinov, HM.** (2011) Canadian Psychiatric Association 14th International Continuing Professional Development Conference, Interactive Lectures and workshops onboard Celebrity Eclipse Cruise line: 4 lectures March 19 – 26, 2011.
96. **Chochinov, HM.** (2011) 2011 Long Term & Continuing Care Association of Manitoba, Annual Provincial Conference and Exhibition. Keynote speaker: What's dignity got to do with it? May 17, 2011
97. **Chochinov, HM.** (2011) American Academy of Hospice and Palliative Medicine, Vancouver, BC. February 2011.
98. **Chochinov, HM.** (2011) What's dignity got to do with it? Innovations in Supportive Cancer Care in Western Canada. Forum for Healthcare Professionals. Telehealth, February 9, 11.
99. **Chochinov, HM.** (2010) What's Dignity got to do with it? Considerations for end of life care. Seminar School of Nursing and Midwifery, Dundee, Scotland, November 22, 2010
100. **Chochinov, HM.** (2010) A, B, C, D's of Dignity Conserving Care. 5th Conference on ALS, Winnipeg, MB November 1, 2010.

101. **Chochinov, HM.** (2010) Keynote Address at Palliative Care and Serious Mental Illness...Marking it Work. Department of Veterans Affairs Employee Education System (VAMC), Pennsylvania, VG, US, October 19, 2010.
102. **Chochinov, HM.** (2010) Depression, Suicide & Hopelessness at the 6th Annual Chicago Supportive Oncology Conference, Chicago, Illinois, US, October 7, 2010.
103. **Chochinov, HM.** (2010) Dignity for the Frail Old. European Conference, Bergen, Norway, Sept 2-5, 2010.
104. **Chochinov, HM.** (2010) International Dignity Therapy Training Workshop, Winnipeg, MB June 13-16, 2010.
105. **Chochinov, HM.** (2010) IPOS Building a Case for Canadian Virtual Hospice in Psychosocial care, May 28, 2010.
106. **Chochinov, HM.** (2010) IPOS Measuring Outcomes: Existential and Specific Psychosocial Issues, May 27, 2010.
107. **Chochinov, HM.** (2010) IPOS Psychopharmacologic management of depression, delirium and anxiety in psycho-oncology for non-psychiatrists, May 27, 2010.
108. **Chochinov, HM.** (2010) Dignity Therapy Training Workshop, Winnipeg, MB May 13 and 14, 2010.
109. **Chochinov, HM.** (2010) Latin American Congress of Palliative Care, Buenos Aires, Argentina, March 18, 2010.
110. **Chochinov, HM.** (2009) Grand Rounds Cross Cancer Institute, Calgary, AB, December 9, 2009.
111. **Chochinov, HM.** (2009) 2nd International Symposium on Recent Advances in Basic, Clinical and Social Medicine, Shantou University, Shantou, China, November 24-26, 2009.
112. **Chochinov, HM.** (2009) 16th Hong Kong International Cancer Congress, Hong Kong, November 4-6, 2009.
113. **Chochinov, HM.** (2010) Whole Person Care Symposium, Commentary: Responding to the challenges, Sydney, Australia, October 31, 2009.
114. **Chochinov, HM.** (2009) Whole Person Care Symposium, Plenary: The Impact of life threatening illness on the whole person, Sydney, Australia, October 30, 2009.
115. **Chochinov, HM.** (2009) MacKay Memorial Hospital, Depression, Dignity and Distress: Caring for Patients Nearing the End-of-Life: An Overview for the Psychiatrist and the Non-Psychiatrist, Taipei City, Taiwan, October 25, 2009.
116. **Chochinov, HM.** (2009) Cancer and Emotion: New Era of Cancer Care, Taipei City, Taiwan, October 24, 2009.
117. **Chochinov, HM.** (2009) Distress, Depression and Dignity in End-of-Life Care, Tainan, China, October 23, 2009.
118. **Chochinov, HM.** (2009) Distress, Depression and Dignity in End-of-Life Care, Taichung, China, October 22, 2009.
119. **Chochinov, HM.** (2009) Chung Shan Medical University Hospital, Taichung, China October 22, 2009.

120. **Chochinov, HM.** (2009) China Medical University Hospital, Taichung, China, October 22, 2009.
121. **Chochinov, HM.** (2009) Symposium 20 Jahre Pflegewissenschaft in der Praxis, Zurich, Switzerland, September 11,2009.
122. **Chochinov, HM.** (2009) Psycho-Oncology and relationship with patient, 2nd Faculty of Medicine Sapienza, University of Rome, July 4, 2009.
123. **Chochinov, HM.** (2009) Medicina et Persona, Milan Italy, June, 2009.
124. **Chochinov, HM.** (2009) International Psycho-Social Oncology Society, Vienna, Austria, June, 2009.
125. **Chochinov, HM.** (2009) Cancer Quality Council of Canada (CQCO) Signature Event, Using Technology to Improve the Patient Experience in Cancer Care, Virtual Hospice, Toronto, June, 2009.
126. **Chochinov, HM.** (2009) Cross Cancer Center Special Rounds (Palliative Care Week). Edmonton, Alberta.
127. **Chochinov, HM.** (2009) New interventions for dying patients. Society of Behavioural Medicine, End of Life and Supportive Care: Enhancing Future Research. Montreal, PQ April 2009.
128. **Chochinov, HM.** (2009) What affects your mental health? CIHR – Café Scientifique at McNally Robinson, Winnipeg, MB April 20, 2009.
129. **Chochinov, HM.** (2009) Research in Support of the Palliative Care Services and Main lines of Work (sponsored by Health Partners International of Canada and CIDA. Special Work Group for Continuous Care of the National Cancer Control Unit, Havana, Cuba; November 12, 2008.
130. **Chochinov, HM.** (2008) Scottish Partnership for Palliative Care (Royal College of Physicians of Edinburgh), Edinburgh, Scotland; 2008 October.
131. **Chochinov, HM.** (2008) National Cancer Research Institute, Birmingham, England; October, 2008.
132. **Chochinov, HM.** (2008) Department of Pediatric Grand Rounds, Faculty of Medicine, University of Manitoba, Winnipeg, MB; October, 2008.
133. Thompson G, Menec V, **Chochinov HM**. (2008) Improving End-of-Life Care in Long Term Care: Suggestions from bereaved family members. Canadian Hospice Palliative Care Conference, Charlottetown, PEI; October 27, 2008.
134. **Chochinov, HM.** (2008) Philippa Harris Lecture Series on Bioethical Issues in Cancer Care. Princess Margaret Hospital, Toronto, ON; October, 2008.
135. **Chochinov, HM.** (2008) Suicide in Cancer Patients. Psychological Medicine Research, University of Edinburh, Edinburgh, Scotland, October, 2008.
136. **Chochinov, HM.** (2008) The A,B,C,D's of Dignity Conserving Care. The Winnipeg Regional Health Authority AGM, Winnipeg; 2008 October 21.
137. Thompson G, Menec V, **Chochinov HM.** (2008) To transcribe or not to transcribe: Using digital-editing software in data analysis. 9th Advances in Qualitative Methods Conference, Banff, AB, October 10, 2008.

138. **Chochinov, HM.** (2008) 2nd Symposium Future of Heart Health, Winnipeg, MB, September 20, 2008.
139. Thompson G, Menec V, **Chochinov HM.** End-of-Life care for the elderly in long-term care: Family members' experiences and satisfaction with care. 17th International Congress on Palliative Care, Montreal, PQ; September 24, 2008.
140. Thompson G, Menec V, **Chochinov HM.** Improving Care of the Elderly at the End-of-Life: Family Members' Perspectives. 18th Annual Provincial Hospice and Palliative Care Manitoba, Winnipeg, MB; September 11, 2008.
141. **Chochinov HM,** Streeter L, Stenekes S, Cory S, Harlos M. The Canadian Virtual Hospice - Pioneering E communication in Palliative Care. 17th International Congress on Palliative Care; Montreal, PQ, September 24, 2008.
142. **Chochinov, HM.** (2008) Singapore Palliative Care Conference 2008, Singapore; August, 2008.
143. **Chochinov, HM.** (2008) 13th Annual Conference of the Japanese Society of Palliative Medicine, Shizuoka, Japan; July, 2008.
144. **Chochinov, HM.** (2008) Grand Rounds. Shaary Zedek Hospital, Hebrew University, Jerusalem, Israel, March, 2008.
145. **Chochinov, HM.** (2008) Palliative Care in Different Cultures. Israel Palliative Medical Society, Eilat, Israel, March, 2008.
146. **Chochinov, HM.** (2008) Faculty of Medical and Health Sciences, University of Auckland & Mercy Hospice, Auckland, New Zealand, February, 2008.
147. **Chochinov, HM.** (2008) Improving End of Life Care in Critical Care. London Health Sciences Centre, London, Ontario, January 18, 2008.
148. **Chochinov, HM.** (2007) Dignity and the Essence of Medicine. 2007 John Taylor Family Foundation Visiting Artist, Rochester, Minnesota, December 4, 2007.
149. Dying with Dignity: Opportunities and Challenges in End of Life Care. Department of Psychiatry and Psychology Grand Rounds, Rochester, Minnesota; 2007 December 3.
150. A Space Between. Hospice of the Highlands, Inverness, Scotland; 2007 November 6.
151. Altru Health System. Univeristy of North Dakota, Department of Medicine Grand Rounds, Grand Forks, North Dakota, USA; 2007 November.
152. Dean's Hour Lecture. University of North Dakota School of Medicine and Health Sciences, Grand Forks, North Dakota, US; 2007 November.
153. University Health Network Dept of Psychiatry Grand Rounds, Toronto, ON; 2007 October.
154. "Dignity Therapy", A case example. St. Mary's of the Lake Hospital, Kingston, ON; 2007 October 11. Interactive Workshop.
155. Dignity and End-of-Life Care: Challenges and Opportunities. Providence Care, St. Mary's of the Lake Hospital, Kingston, ON; 2007 October 10. Public Lecture.
156. Dying with Dignity: A Contemporary Challenge in End of Life Care and Perceptions of Canadians. School of Public Administration, Segelberg Lecture Series, Dalhousie University, Halifax; 2007 October 24.

157. Dying, Dignity and End of Life Care. Department of Medicine Grand Rounds Robert C Dickson Lecture, Dalhousie University, Halifax, NS; 2007 October 23.
158. Integrating Wellness into Cancer Care Conference. University of Toronto, Toronto, ON; 2007 October.
159. The ABC's of Dignity Conserving Care. Oncology Grand Rounds, Dalhousie University, Halifax, NS; 2007 October 25.
160. 3rd Annual Chicago Supportive Oncology Conference, Chicago, Illinois; 2007 September 27.
161. Dignity Conserving Care in the Terminally Ill. Massachusetts, Boston, MA; 2007 September 26.
162. Dignity Considerations and End of Life Care. Dana Farber Cancer Institute Ethics Grand Rounds, Boston, MA; 2007 September 24.
163. Dignity Considerations and End of Life Care. Stephen E. and Catherine Pappas Annual Grand Rounds Lecture in Pediatric Palliative Care, Boston, MA; 2007 September 26.
164. Dignity in Palliative Care - History and New Developments. Copenhagen, Denmark; 2007 May 12.
165. Post graduation course in Palliative Care. Catholic University of Lisbon, Lisbon, Portugal; 2007 May.
166. Dying with Dignity - A Contemporary Challenge in Palliative Cancer Care. Hong Kong; 2007 April 15.
167. Walking, Gawking and Talking: Communication and End of Life Care. CancerCare Manitoba, CCPN, Winnipeg; 2007 April 19.
168. Canadian ICU Collaborative, Montreal, Quebec; 2007 March 28.
169. American Association of Hospice and Palliative Care, Salt Lake City, Utah; 2007 February.
170. 14th Hospice Palliative Care Workshop. Peace House Hospice, Tokyo, Japan; 2007 February.
171. University of Lausanne, Geneva, Switzerland; 2006 November.
172. New Principal Investigators Meeting. CIHR Institutes Genetics and Cancer Research, Lake Simcoe; 2006 November.
173. Italian Society of Psycho-Oncology, the next 8th World Congress of Psycho-Oncology, Venice, Italy; 2006 October.
174. Continuing Supportive and Palliative Care Section II Congreso SEOM de Cuidados Continuos de Sevilla, Seville, Spain; 2006 September.
175. Faculty of Health and Social Sciences, The Hong Kong Polytechnic, Hong Kong, China; 2006 September.
176. Joe Doupe Memorial Lecture, University of Manitoba, Winnipeg, MB; 2006 September.
177. Multinational Association of Supportive Care in Cancer, Toronto, ON; 2006 June.
178. McMaster University, Hamilton, ON; 2006 June.
179. Nova Scotia Hospice Palliative Care Association, Truro, NS; 2006 May.
180. Canadian Association of Psychosocial Oncology, Montreal, QC; 2006 May.
181. Institute of Aging. Winnipeg, MB; 2006 May.

182. Cancer Care Ontario, Palliative Care Signature Event, Toronto, ON; 2006 March.
183. Juravinski Regional Cancer Center, Bal Mount Visiting Professor, Hamilton, ON; 2006 March.
184. Improving Care at the End of Life. National Institutes of Health State of Science Conference, Washington, DC; 2005 December.
185. University of Manitoba and the Shantou University International Symposium. Shantou, China; 2005 December.
186. Hospice of the Piedmont, Charlottesville, VA; 2005 November.
187. Dept of Medicine Grand Rounds, University of Manitoba, Winnipeg, MB; 2005 November.
188. Balfour Mount Visiting Professor. Royal College of Physicians and Surgeons of Canada, Saskatoon, SK; 2005 November.
189. Northern Health Palliative Care Conference, Prince George, BC; 2005 September.
190. Chochinov HM. Canadian Palliative Care Association Annual Meeting, Edmonton, AB; 2005 September.
191. Dept Palliative Care and Policy, King's College, London, England; 2005 July.
192. Primary Palliative Care Research Unit, Edinburgh, Scotland; 2005 July.
193. Wellcome Trust Clinical Research Facility, Western General Hospital, Edinburgh, Scotland; 2005 July.
194. CIHR and NCIC, Mount Tremblay, QC; 2005 May.
195. St. Columba's Hospice, Edinburgh, Scotland; 2005 January.
196. Balfour Mount Visiting Professor, McMaster University, Hamilton, ON; 2005 January.
197. Portuguese Palliative Care Association, Lisbon, Portugal; 2004 November.
198. Academy of Psychosomatic Medicine, Fort Myers, Florida; 2004 November.
199. Provincial Palliative Care Association Meeting, PEI; 2004 October.
200. 15th International Congress on the Care of the Terminally Ill, Montreal, QC; 2004 September.
201. Manitoba Hospice and Palliative Care Association Annual Meetingq, Winnipeg, MB; 2004 September.
202. Dept of Psychiatry Grand Rounds, Winnipeg, MB; 2004 June.
203. Jocelyn House Annual General Meeting, Winnipeg, MB; 2004 June.
204. Human Dignity, Narrative Integrity and Ethical Decision-making at the End-of-Life. St. John's, NL; 2004 June.
205. Psychiatric Care Across the Life Span. The Pas, MB; 2004 June.
206. Women's Canadian Club of Winnipeg, Winnipeg, MB; 2004 May.
207. Nordisk Forening for Palliativ Vard, Aarhus, Denmark; 2004 May.
208. Palliative Care Service of the Hawkesbury & District General Hospital, Hawkesbury, ON; 2004 April.
209. St. Mary's Hospital, Montreal, QC; 2004 April.
210. Lung Cancer Symposium. Unversity of Kentucky, Lexington, KN; 2004 April.

211. National Hospice and Palliative Care Organization, Las Vegas, Nevada; 2004 March.
212. Beth Israel Medical Center, New York, New York; 2004.
213. North Shore: Long Island Jewish Health System, Hillside Hospital, Glen Oaks, NY; 2004.
214. John's Hopkins Hospital 6th annual Palliative Care Lecture Series, Baltimore, MD; 2003 November.
215. Memorial Sloan Kettering Cancer Center Fellowship Alumni Reunion, New York, NY; 2003 November.
216. North Memorial Medical Center, Minneapolis, MN; 2003 November.
217. University of Hawaii, Section of Geriatric Medicine, Honolulu, Hawaii; 2003 November.
218. Australian Society of Clinical Oncology, Perth, Australia; 2003 November.
219. Live and Let Die. Queen's Medical Center, Honolulu, Hawaii; 2003 November.
220. University Research Speakers Series, Winnipeg, MB; 2003 October.
221. Family Medicine Research Day, Winnipeg, MB; 2003 October.
222. Swedish Medical Center First Hill Campus, Seattle, Washington; 2003 October.
223. Mental Health Symposium. Norman Regional Health Center Mental Health, The Pas, MB; 2003 October.
224. Manitoba Hospice and Palliative Care Association Annual Meeting, Winnipeg, MB; 2003 September.
225. Mayo Clinic, Rochester, MN; 2003 July.
226. Dept of Psychiatry Grand Rounds, Winnipeg, MB; 2003 June.
227. Canadian Hospice and Palliative Care Association Annual Meeting, Quebec City, QC; 2003 June.
228. Hospice Niagara, Niagara on the Lake, ON; 2003 June.
229. International Psycho-oncology Congress, Banff, AB; 2003 May.
230. Community Cancer Program Network, CCMB, Winnipeg, MB; 2003 May.
231. Selkirk Hospital Psychiatric Interest Group, Selkirk, MB; 2003 April.
232. Saskatchewan Palliative Care Conference, Regina, SK; 2003 April.
233. Eastern Virginia Medical School, Norfolk, VG; 2003 April.
234. Selkirk Manitoba Psychiatry Grand Rounds, Selkirk, MB; 2003 March.
235. Humber College, Toronto, ON; 2003 March.
236. Depression in Cancer Patients, Psyko-oncologisk projectgruppe. Copenhagen University Hospital Herlev, Copenhagen, Denmark; 2003 March.
237. Last Acts Conference. Innovations on End of Life Care; Boston, MS.,2003 February.
238. University of Kentucky, Lexington, KN; 2002 December.
239. 14th International Congress on the Care of the Terminally Ill, Montreal, QC; 2002 October.
240. Academy of Psychosomatics, Visiting Professorship, Quebec City, QC; 2002 October.
241. Centre de recherce de l'hotel-dieu de Quebec, Quebec, QC; 2002 October.
242. Conference du centre-jour de la Maison Michel Sarrazin, Quebec City, QC; 2002 October.

243. Conference des mercredis d'oncologie, l'hotel-dieu de Quebec, Quebec City, QC; 2002 October.
244. Universite Laval Robert-Gifford, Quebec City, QC; 2002 October.
245. Keynote Address. Canadian Psychiatric Association, Banff, AB; 2002 October.
246. Thunder Bay Regional Palliative Care Program, Thunder Bay, ON; 2002 September.
247. Canadian Association of Nursing Oncology Annual Meeting, Winnipeg, MB; 2002 September.
248. Manitoba Hospice and Palliative Care Association, Winnipeg, MB; 2002 September.
249. Palliative Care Association of Nova Scotia, Sydney, NS; 2002 July.
250. Hospice Palliative Care Association of PEI, Charlottetown, PE; 2002 July.
251. Queen Elizabeth II Health Sciences Centre, Halifax, NS; 2002 July.
252. Psychiatric Consortium on End of Life Care, University of Alabama, Tuscaloosa, Alabama; 2002 June.
253. Dept of Psychiatry Grand Rounds, University of Manitoba, Winnipeg, MB; 2002 June.
254. Calgary Palliative Care Meeting, Calgary, AB; 2002 May.
255. British Columbia Hospice and Palliative Care Society Meeting, Vancouver, BC; 2002 May.
256. Canadian Pain Society Meeting, Winnipeg, MB; 2002 May.
257. Ottawa Palliative Care meeting, Ottawa, ON; 2002 May.
258. Workshop on Suicide and Physical Illness. National Institutes of Mental Health, Bethesda, MD; 2002 May.
259. Palliative Care Congress, Sheffield, UK; 2002 April.
260. King's College Dept of Palliative Care and Policy, London, UK; 2002 April.
261. Enhancing End of Life Care. WRHA, Winnipeg, MB; 2002 April.
262. Edmonton Palliative Care Program, Alberta Cancer Board, Edmonton, AB; 2002 March.
263. American Society of Clinical Oncology Symptom Management Symposium. Tampa, Florida; 2002.
264. University of Iowa, Dept of Psychiatry Grand Rounds, Iowa City, Iowa; 2001 November.
265. Academy of Psychosomatics, San Antonio, TX; 2001 November.
266. Keynote. Bethany Palliative Care Meeting, Calgary, AB; 2001 November.
267. University of Iowa Health Care, Iowa City, Iowa; 2001 October.
268. Victoria Psychiatric Continuing Education Meeting, Victoria, BC; 2001 October.
269. Canadian Palliative Care Association, Victoria, BC; 2001 October.
270. Manitoba Hospice and Palliative Care Annual Meeting, Winnipeg, MB; 2001 September.
271. Dept of Psychiatry Grand Rounds, University of Manitoba, Winnipeg, MB; 2001 June.
272. Princess Elizabeth Guild Annual Visiting Lecturer, Winnipeg, MB; 2001 May.
273. American Society of Clinical Oncology, San Francisco, CA; 2001 May.
274. Canadian Association of Psychosocial Oncology, Winnipeg, MB; 2001 May.
275. North Central Cancer Treatment Group, Mayo Clinic, Rochester, MN; 2001 April.

276. Lee Moffitt Cancer Center and Research Institute, University of South Florida, Tampa, Florida; 2001 March.
277. Making Death a part of life. Division of Palliative Care, Dept of Family Practice, British Columbia College of Family Physicians, Vancouver, BC; 2001.
278. Palliative Care WA and Edith Cowan University, Perth, Australia; 2000 November.
279. First International Geriatric Palliative Care Congress, New York, New York; 2000 October.
280. Mayo Clinic, Rochester, MB; 2000 October.
281. Virginia Oncology Society, Irvington, Virginia; 2000 October.
282. Psychiatry Grand Rounds, Memorial Sloan-Kettering Cancer Center, New York, New York; 2000 September.
283. Dignity in Palliative Care. Victoria General Hospital, Winnipeg, MB; 2000 July.
284. Dept of Psychiatry Grand Rounds, University of Manitoba, Winnipeg, MB; 2000 May.
285. ASCO Symptom Management Symposium. American Society of Clinical Oncology, New Orleans; 2000 May.
286. Centre on Aging's 17th Annual Spring Research. University of Manitoba, Winnipeg, MB; 2000 May.
287. National Cancer Institute, Rio de Janeiro, Brazil; 2000 April.
288. III International Seminar of Palliative Care, Brazilian Association for Palliative Care, Sao Paulo, Brazil; 2000 April.
289. Manitoba Long Term Care Conference, Nursing Home Association of Manitoba and Non-profit long term care association, Winnipeg, MB; 2000 March.
290. Riverview Health Centre, Winnipeg, MB; 2000.
291. Victoria General Hospital, Winnipeg, MB; 2000.
292. Testimony to the Parliamentary Subcommittee on Euthanasia and Assisted Suicide. Ottawa, ON; 2000.
293. 16th Annual British Psychosocial Oncology Meeting, The Royal College of Physicians, London, UK; 1999 December.
294. St. Christopher's Hospice, London, UK; 1999 December.
295. Academy of Psychosomatic Medicine, New Orleans; 1999 November.
296. International Conference of Comprehensive Cancer Care, New York, New York; 1999 November.
297. PanAmerican Congress on PsychoOncology, New York, New York; 1999 October.
298. End of Life, Depression and Drug Treatment Issues from Psychosocial and Behavioural Viewpoints. OmegaMed, New York, New York; 1999 October.
299. Interdisciplinary Symposium on PsychoOncology. New York, New York; 1999 September.
300. Canadian Association of Psychosocial Oncology, Edmonton, AB; 1999 May.
301. Dept of Psychiatry Mayo Clinic, Rochester, Minn; 1999 May.
302. Humber College Palliative Care Conference, Toronto, ON; 1999 April.
303. Holding on to Dignity at the End of Life. Winnipeg Community and Long Term Authority, Winnipeg, MB; 1999 April.

304. Vancouver Island Cancer Centre, Victoria, BC; 1999 March.
305. Palliative Grand Rounds, McGill University, Montreal, QC; 1998 December.
306. Practical Palliative Medicine: A skill building workshop on end of life care. University of Texas Medical Branch, Galveston, TX; 1998 November.
307. Psychiatric care and quality of life in cancer and AIDS. Academy of Psychosomatic Medicine, Orlando, FL; 1998 November.
308. Alternatives to Assisted Suicide. School of Law Bloomington and the Poynter Center for the Study of Ethics and American Institutions, Indiana; 1998 October.
309. Manitoba Hospice Foundation, Winnipeg, MB; 1998 September.
310. Canadian Cancer Society, Manitoba Division, Winnipeg, MB; 1998 June.
311. Canadian Association of Psychosocial Oncology, Thunder Bay, ON; 1998 May.
312. First International Meeting on Research in Palliative Care: Methodological and Outcomes, Bethesda, MD; 1998 May.
313. Oncology Grand Rounds, Tom Baker Cancer Center, Calgary, AB; 1998 May.
314. Psychiatric Grand Rounds, Foothills Hospital, Calgary, AB; 1998 May.
315. Psychosocial Grand Rounds, Tom Baker Cancer Centre, Calgary, AB; 1998 May.
316. The Science Writers Symposium; In Honor of the CCS 60th Anniversary, Toronto, ON; 1998 April.
317. Institute Jules Bordet, Brussels, Belgium; 1998 April.
318. Palliative Care Grand Rounds, McGill University, Montreal, QC; 1998 January.
319. First meeting of the Brazilian Palliative Care Association, Sao Paulo, Brazil; 1998.
320. Dept of Psychiatry Grand Rounds, University of Manitoba, Winnipeg, MB; 1997 December.
321. The Academy of Psychosomatic Medicine, Coronado, California; 1997 November.
322. Japanese Ministry of Health and Japan Intractable Disease Research Foundation, Tokyo, Japan; 1997 October.
323. Psycho-oncology Grand Rounds. Dept of Psychiatry, University of Toronto, Toronto, ON; 1997 October.
324. Institute for the study of Society and Medicine, Paris, France; 1997 June.
325. Human Dimension in Cancer. MD Anderson, Houstan, Texas; 1997 June.
326. Presentation to the Federal Minister of Health, Honourable David Dingwall. Ottawa, ON; 1997 April.
327. Supportive Care in Cancer. Texas Oncology PA Physician Reliance Network, Baylor Sammons Cancer Centre, Banff, AB; 1997 March.
328. Distinguished Alumni Lecture, Psychiatry Service, Memorial Sloan- Kettering Cancer Centre, New York, New York; 1997 January.
329. Psychiatric Dimensions of Palliative Medicine: Will to Live in the Terminally Ill. Dept of Psychology Colloquium, University of Manitoba, Winnipeg, MB; 1997.
330. Academy of Psychosomatics, San Antonio, Texas; 1996 November.
331. Third World Congress of Psycho-Oncology, New York, New York; 1996 October.

332. 8th Annual Palliative Care Conference: Education and Research Days. Neil MacDonald Lecture University of Alberta, Edmonton, AB; 1996 October.
333. 6th Annual Provincial Hospice and Palliative Care Conference, Winnipeg, MB; 1996 September.
334. 11th International Congress on Care of the Terminally Ill, Montreal, QC; 1996 September.
335. Grand Rounds lecture. Sacred Heart Hospice, Sydney, Australia; 1996 August.
336. Hospice New Zealand Conference, Christchurch, New Zealand; 1996 July.
337. Grand Rounds Lecture, Peter MacCallum Cancer Institute, Melbourne, Australia; 1996 July.
338. Keynote. Australia and New Zealand Society of Palliative Medicine Meeting, Christchurch, New Zealand; 1996 July.
339. VIII International Conference on Supportive Care and Cancer, Toronto, ON; 1996 June.
340. Psychiatric Dimensions of Palliative Medicine. American Psychiatric Association Meeting, New York, New York; 1996 May.
341. Agents of Hope. Helen Hudson Memorial Awards, Keynote address, Winnipeg, MB; 1996 April.
342. Clinical Depression in the Terminally Ill. Carlton Palliative Care Conference, Ottawa, ON; 1996 April.
343. Understanding Depression in the Terminally Ill. Humber College Palliative Care Conference, Toronto, ON; 1996 April.
344. Coping with Cancer. Canadian Cancer Society, Winnipeg, MB; 1996.
345. Outcome Measurements and Psychiatry. Canadian Palliative Care Association, Toronto, ON; 1996.
346. Psychiatry and the Euthanasia Debate. The Mayo Clinic, Rochester MN; 1996.
347. Us Too. Prostate Cancer Support Group, Winnipeg, MB; 1995 December.
348. Brief Screening Instruments for Depression in the Terminally Ill. Academy of Psychosomatics, Palm Springs, CA; 1995 November.
349. Death Wishes and Competence for Decision Making. Health Ethics Rounds, Dept of Internal Medicine, University of Manitoba, Winnipeg, MB; 1995 November.
350. Update in Psycho-oncology. University of Toronto, Toronto, ON; 1995 October.
351. Future Directions for Canadian Palliative Care Research. Health Canada, Ottawa, ON; 1995 September.
352. Depression in Primary Care. The Pas, Health Complex, The Pas, MB; 1995 April.
353. Pulling the Plug. Shaarey Zedek Synagogue Panel Discussion, Winnipeg, MB; 1995.
354. Correlates of Desire for Death. Academy of Psychosomatics, Phoenix, AZ; 1994 October.
355. Coping and Palliative Care. Manitoba Hospice Foundation, Winnipeg, MB; 1994 September.
356. Correlates of desire for Death among the Terminally Ill. 10th International Conference on care of the Terminally Ill, Montreal, QC; 1994 September.

357. Psychosocial Oncology in Manitoba. Dept of Continuing Medical Education, University of Manitoba, Winnipeg, MB; 1994 September.
358. Witness - Special Senate Committee on Euthanasia and assisted suicide. Winnipeg, MB; 1994 September.
359. Coping with caring for the cancer patient. Canadian Association of Medical Radiation Technologists, Winnipeg, MB; 1994 June.
360. Depression in the Oncology Setting. Manitoba Cancer Treatment and Research Foundation, Winnipeg, MB; 1994 June.
361. An Update on Selective Serotonin Reuptake Inhibitors. The Pas Health Complex, The Pas, MB; 1994 April.
362. Bereavement. Gimli Cancer Outreach Centre, Gimli, MB; 1994 March.
363. Psychiatry Euthanasia. Dept of Psychiatry Grand Rounds, University of Manitoba, Winnipeg, MB; 1994.
364. Communication Research and Breast Cancer. Subcommittees of National Forum on Breast Cancer; 1993 November.
365. Update: Psychopharmacology in Palliative Care. National Cancer Institute of Canada, Banff, AB; 1993 November.
366. Depression in the Terminally Ill. Canadian Palliative Care Conference, Winnipeg, MB; 1993 October.
367. Psychopharmaceuticals in the Oncology Setting. Canadian Psychiatric Association Annual Meeting, Winnipeg, MB; 1993 September.
368. Depression and Terminal Illness, Palliative Care Grand Rounds Sunnybrook Hospital, Toronto, ON; 1993 June.
369. Depression and the Desire for Death among the Terminally Ill. University of Toronto Psychsomatic Research Rounds, Toronto, ON; 1993 June.
370. Attitude, Outlook and Cancer Outcome. Manitoba Oncology Interest Group, Winnipeg, MB; 1993 May.
371. The Role of Psychiatry in Palliative Care. American Psychiatric Association Annual Meeting, San Francisco; 1993 May.
372. Psychiatry's Role in Oncology. Canadian Society of Hospital Pharmacists, Banff, AB; 1993 March 20.
373. Depression and the Desire for Death among the Terminally Ill. Regional Mental Health Presentation, The Pas, MB; 1992 November 17.
374. Depression and the Desire for Death among the Terminally Ill. 9th International Congress on the Care of the Terminally Ill, Montreal, QC; 1992 October 31.
375. Group Supportive Psychotherapy for Women with Metastatic Breast Cancer. Toronto, ON; 1992 October.
376. Hope and Despair in the Terminally Ill. Manitoba Hospice Foundation, Winnipeg, MB; 1992 October 5.
377. Staff Support in an Oncology Setting. Canadian Association of Nursing Oncology, Winnipeg, Mb; 1992 September 20.

378. Desire for Death among the terminally ill. American Psychiatric Association Annual meeting, Washington, DC; 1992 May 7.
379. Managing stress. Manitoba Cancer Treatment and Research Foundation Outreach Symposium, Gimli, MB; 1992 May.
380. Suicidal tendencies in palliative care. Manitoba Cancer Treatment and Research Foundation Outreach symposium, Gimli, MB; 1992 May. Invited Guest paper presentation.
381. Promoting collaboration in provincial palliative care. Winnipeg, MB; 1992 April 24. Group Facilitator.
382. Euthanasia/Living wills. Manitoba Hospice Association, Winnipeg, MB; 1992 January.
383. Panel discussion on euthanasia. The Winnipeg Municipal Hospitals, Winnipeg, MB; 1991 October.
384. Psychiatric complications of cancer and cancer therapy. Manitoba Branch of the Canadian Society of Hospital Pharmacists, Winnipeg, MB; 1991 September.
385. Depression and suicidality in the terminally ill. Grand rounds presentation, Dept of Psychiatry, U of M, Winnipeg, MB; 1991 May.
386. Community Care: There's no place like home outreach program. Manitoba Cancer Treatment and Research Foundation, Winnipeg, MB; 1991 April.
387. Identifying the needs of patients, families and caregivers. National conference on community cancer programs, Winnipeg, MB; 1990 October. Chairman of the workshop.
388. The role of psychiatric oncology in Manitoba. Cancer 2000, The Manitoba Provincial working group, Strategies for Cancer Control in Canada, Winnipeg, MB; 1990 September.
389. New advances in depression. Family Physician continuing education, Thunder Bay, ON; 1990 March.
390. The dying patient. Manitoba Psychiatric Association Psychotherapy Section Meeting, Winnipeg, MB; 1990.
391. Psychosocial and emotional aspects of cancer, patient services emotional support update workshop. Canadian Cancer Society, Winnipeg, MB; 1989 November.
392. Psychiatric Complications of cancer care a multi disciplinary approach. Oncology nursing workshop, Manitoba Cancer Treatment and Research Foundation, Winnipeg, MB; 1989 October.
393. Preventative intervention in child, adults and family bereavement. Canadian Psychiatric Association Annual Meeting, St. John's, NL; 1989 September.
394. Diagnosed, now what? Malignancy disease community management of cancer patients. Continuing Education for Family Physicians, U of M, Winnipeg, MB; 1989 May.
395. Cognitive Behaviour Techniques in the Oncology Setting. Cansurmount Support Program, Winnipeg, MB; 1989 March.
396. Psychiatric Complications of Cancer, Cancer Care a multi-disciplinary approach. Manitoba Cancer Treatment and Research Foundation, Winnipeg, MB; 1988 November.

397. The Role of Psychiatry in an Oncology Setting. Terminal Care Interest Group, The Winnipeg Municipal Hospital; 1988 June.
398. Psychosocial Impacts of Cancer, Outreach: A Decade of Service to Rural Patients. Manitoba Cancer Treatment and Research Foundation, Winnipeg; 1988 April.
399. Psychiatric Aspects of Oncology. Social Work Oncology Interest Group, Winnipeg; 1988 March.
400. Psychiatric Complications of Cancer. Manitoba Oncology Nurses Interest Group, Winnipeg; 1988 March.

Symposia Contributions

1. Chochinov HM. Palliative Care Knowledge Translation Symposium. Laval University, Quebec City, QC; 2006.
2. Chochinov HM. Cicely Saunders. Cicely Saunders Foundation Scientific Advisory Committee Symposium, London, England; 2004.

Broadcast Interviews

1. Uhttp://www.npr.org/2011/09/12/140336146/for-the-dying-a-chance-to-rewrite-lifeU
2. Uhttp://www.npr.org/2011/09/15/140508715/recording-a-life-in-ones-final-daysU
3. Uhttp://www3.mdanderson.org/streams/FullVideoPlayer.cfm?xml=cfg%2Ficare-ACE-20120426-ChochinovU
4. Uhttp://www3.mdanderson.org/streams/FullVideoPlayer.cfm?xml=cfg%2Ficare-Roundtable-ChochinovU

Websites

1. virtualhospice.ca
2. dignityincare.ca

Memberships

2015 – Present	Canadian Cancer Society Research Institute, End 3- Quality of Life Advisory Committee
2008 - Present	Manitoba Regional Partnership Program, Chair of the Advisory Committee
2008 – 2010	Manitoba Health Research Council, Chair of Advisory Committee
2008 – 2009	Improving the Quality of Spiritual Care as a Dimension of Palliative Care Project, Advisory Committee
2008 - 2009	CHPCA National Conference, Advisory Committee
2008 - 2009	CHPCA National Conference Committee, Research Program Sub-Committee

2007	5th Research Forum of the European Association for Palliative Care, Advisory Board
2006 – 2008	Canadian Palliative Care Association, Chair of the Research Committee
2006 - Present	Scientific Advisory Council for the National Palliative Care Research Centre
2005 – 2012	Canadian Institutes for Health Research, Governing Council
2005 – 2012	Canadian Institutes for Health Research, Chair, Standing Committee on Ethics
2005 - Present	College of Reviewers for CIHR Research Chairs
2003 - Present	College of Reviewers for the New Opportunities Fund (CFI), Member
2002 - Present	Cicely Saunders International, Member
1996 - Present	Canadian Psychiatric Association Research Network
1994 - Present	Manitoba Oncology Society
1987 - Present	American Society of Psychiatric Oncology/AIDS
1987 - Present	Canadian Medical Association
1987 - Present	Canadian Psychiatric Association
1987 - Present	Manitoba Medical Association

Other Scholarly Activities

Dignity Therapy Training – Completed
Winnipeg, Canada; Ottawa, Canada; Quebec City, Canada; Kentucky, United States; New York, New York; Copenhagen, Denmark; Perth, Australia; Hong Kong, China; London, United Kingdom; Edinburgh, United Kingdom; Hamilton, Canada; Lisbon, Portugal; Tokyo, Japan; Seville, Spain; Venice, Italy; Singapore

Dignity Therapy Training – Requested
Sweden, Ireland, Philippines

Consulting

1987 - 2010	Psychiatric Consultant, The Pas, Manitoba
1987 - Present	Psychiatric Consultant, CancerCare Manitoba
1987 - 1996	Staff Psychiatrist: Consultation-Liaison Service: provide regular clinical supervision and teaching for C/L residents

Review Activities

Journal Review

Annals of Behavioural Medicine

Archives of General Psychiatry

Australian and New Zealand Journal of Psychiatry

British Journal of Psychiatry

British Medical Journal
Canadian Psychiatric Association Journal
Cancer
Indian Journal of Cancer
International Journal of Nursing Studies
Journal of Clinical Oncology
Journal of Pain and Symptom Management
Journal of Palliative Medicine
Journal of Psycho-Oncology
Journal of Psychosomatic Research
Journal of the American Medical Association
The Lancet
New England Journal of Medicine
Palliative Medicine
Pediatric Blood & Cancer
Quality of Life Research
Social Science and Medicine

Books and Manuscript Review

Oxford University Press

Other Review

2012	Health Care Chaplaincy; John Templeton Foundation Grant Competition
2003 - Present	Member of the College of Reviewers for the New Opportunities Fund, CFI
2001 & 2003	Personnel Awards Panel, National Cancer Institute of Canada
1998	Behavioural Research Grant Review Panel (Panel K), National Cancer Institute of Canada

Editorial Activities

Journals

Palliative and Supportive Care (Co-Editor)
Cancer
Quality of Life Research
Social Science and Medicine
Psychosomatics
Journal of Palliative Care
Journal of Palliative Medicine
Supportive Cancer Therapy

Supportive Oncology

Advisory Activities

Service on Boards

2011 – 2012	European Association for Palliative Care (EAPC) Advisory Board for the 2012, 7th Research Congress.
2007 -	Scientific Advisory Board, National Palliative Care Research Centre, New York, NY
2011-2012	Senior Advisory Committee, 19th International Congress on Palliative Care, October 8-12, 2012
2010 – 2011	Advisory Board, 12th Research Congress of the EAPC
2009 – 2010	Advisory Board, 11th Research Congress of the EPAC
2006 – present	National Palliative Care Research Centre, Scientific Advisory Board, Mt Sinai Hospital, NYC.
1996 - Present	Manitoba Breast Cancer Advisory Council, Manitoba Cancer Treatment and Research Foundation
1996 - Present	National Medical Advisory Council Opinion Leaders Network, National Cancer Institute of Canada
1998	Advisory Board, First International Meeting Research in Palliative Care: Methodologies and Outcomes, March 12-14

Professional Activities

2005 - 2012	Governing Council, Canadian Institutes for Health Research
2005 - 2012	Chair, Standing Committee on Ethics, Canadian Institutes for Health Research
2002 - Present	International Scientific Expert Panel of The Cicely Saunders Foundation
2001 - Present	Chair, Canadian Virtual Hospice
1998 - Present	National Cancer Institute of Canada, National Speakers' List
1998 – 2000	Board of Directors, Palliative Care Foundation of Canada
1997 – 2000	Research Committee and Ethics Committee, Academy of Psychosomatic Medicine
2006	Co-Chair, Canadian Student Health Research Forum, Health and Aging, Winnipeg
2006	Co-Chair, Vulnerable Persons and End-of-Life Care: Spring Institute, Winnipeg
2006	Canadian Association of Psychosocial Oncology Annual National Meeting, Winnipeg, Manitoba
2000 - 2004	National Advisory Committee, "Guide for End of Life Care for Seniors", Age Wise Inc.

2000 - 2004	Palliative Care Working Group, Cancer Institute, Canadian Institutes for Health Care Research
2000 - 2003	Chair, Research Committee, Canadian Palliative Care Association
2002	Steering Committee, Secretariat on Palliative and End-of-Life Care invitational workshop on End-of-Life/Palliative (EOL/PC) on March 2-4, Health Canada
2001	Co-Chair, Canadian Association of Psychosocial Oncology, Winnipeg, Canada
1999 - 2000	Chair: Depression Module, American Society of Clinical Oncology (ASCO) Curriculum: Optimizing Cancer Care – The Importance of Symptom Management
1998 - 1999	Past President, Canadian Association of Psychosocial Oncology
1998 - 1999	Ethics Committee, Winnipeg Hospital Authority
1997 - 1998	Co-chairman, Canadian Palliative Care Initiative
1996 - 1998	President, Canadian Association of Psychosocial Oncology
1994 - 1996	Vice President, Canadian Association of Psychosocial Oncology
1995	Canadian Breast Cancer Research Initiative Task Force on Communication Research
1994	Sub-Committee of Psychosocial Services, Supportive Care and Rehabilitation, Manitoba Cancer Control Committee
1990 - 1994	Member, Board of Directors, Canadian Association of Psychosocial Oncology
1990 - 1994	Chairman, Clinical Committee, Canadian Association of Psychosocial Oncology
1989	International Work Group on Death, Dying and Bereavement

Committee Service

2014	Scientific committee of the 8th World Research Congress of the European Association for Palliative Care (EAPC).
2013 – 2014	Planning Committee Member of ASCO's Palliative Care in Oncology Symposium. October 24-25, 2014, Boston, Massachusetts.
2011	Advisory Committee for Setting the Strategic Research Agenda for Chaplaincy Care in Health Care, New York, NY, USA.
2011	Chaired session of Canadian Cancer Research Conference, Palliative/End of Life Care. November 29, 2011, Toronto, ON (with Neil Hagen, Gary Rodin, Murray Krahn)
2012-	Planning committee for the Canadian Partnership Against Cancer Palliative and End-of-Life initiative

2008 - present	Advisory Committee, City of Hope-GWish project, Improving the Quality of Spiritual Care as a Dimension of Palliative Care Project., The George Washington Institute for Spirituality and Health, Washington DC
2008 - present	Manitoba Cancer Control Committee
2008 - present	Chair Research Advisory Committee, Manitoba Health Research Council
2008 - present	Exofficio Member Research Council Board of Directors, Manitoba Health Research Council
2008 - 2010	Programme Committee, 18th International Congress on Palliative Care
2008 - 2009	Member of the Program Committee, Canadian Hospice and Palliative Care Association
2006	Organizing Committee, Psychosocial Academy Pre-congress workshops: Ferrara, October 16-17; Congress: Venice, October 18-21, 8th World Congress of Psycho-Oncology "Multidisciplinary psychosocial oncology: dialogue and interaction"
1999 - present	Integration Committee and Research Committee, Canadian Cancer Control Strategy
1998	Scientific Committee, International de Cuidados Paliativos da Associacao Brasileira de Cuidados Paliativos, February 13, 14
1998 - 1999	Ethics Committee, Winnipeg Regional Health Authority
1996	Scientific Committee, Third World Congress in Psycho-oncology, October 4 - 6, New York, N.Y
1995	Scientific Committee, Second International Congress of Psycho-oncology, October 19-22, Kobe, Japan
1992 - 1993	Ethics Committee, Manitoba Medical Association
1987 – present	National Representation Committee / Co-chair Clinical Committee, International Psycho-oncology Society (IPOS)

Teaching

Psychiatry Resident lectures:

- Psycho-oncology
- Biostatistics
- Psychiatric Epidemiology

"HMC-2" This is the exhibit marked "**HMC-2**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

Dignity in the terminally ill: a cross-sectional, cohort study

Harvey Max Chochinov, Thomas Hack, Thomas Hassard, Linda J Kristjanson, Susan McClement, Mike Harlos

Summary

Background Considerations of dignity are often raised in reference to the care of dying patients. However, little research that addresses this issue has been done. Our aim was to identify the extent to which dying patients perceive they are able to maintain a sense of dignity, and to ascertain how demographic and disease-specific variables relate to the issue of dignity in these individuals.

Methods We did a cross-sectional study of a cohort of terminally ill patients with cancer, who had a life expectancy of less than 6 months. We enrolled 213 patients from two palliative care units in Winnipeg, Canada, and asked them to rate their sense of dignity. Our main outcome measures included: a 7-point sense of dignity item; the symptom distress scale; the McGill pain questionnaire; the index of independence in activities of daily living (IADL); a quality of life scale; a brief battery of self-report measures, including screening for desire for death, anxiety, hopelessness, and will to live; burden to others; and requirement for social support.

Findings 16 of 213 patients (7·5%; 95% CI 4–11) indicated that loss of dignity was a great concern. These patients were far more than likely than the rest of the cohort to report psychological distress and symptom distress, heightened dependency needs, and loss of will to live.

Interpretation Loss of dignity is closely associated with certain types of distress often seen among the terminally ill. Preservation of dignity should be an overall aim of treatment and care in patients who are nearing death.

Lancet 2002; **360:** 2026–30
See Commentary page 1997

Department of Psychiatry (H M Chochinov MD), **Faculty of Nursing** (T Hack, S McClement PhD), **and Community Health Sciences** (H M Chochinov, T Hassard PhD), **University of Manitoba, Winnipeg, Manitoba R3E 3N4, Canada; CancerCare Manitoba, Winnipeg** (H M Chochinov, T Hack Cpsych); **St Boniface General Hospital, Winnipeg** (M Harlos MD); **and Edith Cowan University, Perth, Australia** (H M Chochinov, L J Kristjanson PhD)

Correspondence to: Dr Harvey Max Chochinov
(e-mail: chochin@cc.UManitoba.CA)

Introduction

Considerations of dignity are often raised in reference to the care of dying patients.[1-2] For many palliative patients with cancer, their families, and caregivers, dignity conveys an inherent respect to be granted to patients in preparation for death. Support for assisted suicide or euthanasia is often based on a concern for patients' dignity, with those on either side of this debate invoking considerations of dignity at the heart of their respective positions.[3-9] Nevertheless, little research that addresses the issue of dignity, and involves dying patients as primary informants, has been done.[10,11] Our aim was to assess the extent to which patients near the end of life perceive that they are able to maintain a sense of dignity, and to identify how various demographic and disease-specific variables are related to the issue of dignity in the terminally ill.

Methods

Participants

Between June, 1996, and May, 2000, we recruited individuals with cancer from two palliative care units in Winnipeg, Canada. The units are located at St Boniface General Hospital and the Riverview Health Centre; both are urban, extended-care hospitals with specialty palliative care units. The units provide inpatient, and coordinate community-based, end-of-life care services. The medical status of every patient at these units was reviewed by the treatment staff, who independently ascertained their eligibility for the study on the basis of clinical consensus. Patients were not referred to the study if they were cognitively impaired, unable to give informed consent, or too gravely ill to take part in the protocol. Eligibility criteria included: age older than 18 years; diagnosis of terminal cancer with a life expectancy of less than 6 months; ability to read and speak English; no evidence of dementia or delirium that might make completion of study protocol difficult; and ability to provide informed consent.

The Faculty of Medicine ethics committee, University of Manitoba, approved the study, and the hospital research review board granted formal access to patients. Before participation, all patients provided written informed consent.

Protocol

Experienced palliative care research nurses administered the protocol, with regular monitoring by the principal investigator (HMC) to ensure data integrity and standardised application of the protocol.

We asked patients to rate their sense of dignity on a 7-point sense of dignity item (0=no sense of lost dignity, 1=minimum, 2=mild, 3=moderate, 4=strong, 5=severe, and 6=extreme sense of lost dignity). This item was developed by Wilson and colleagues, and has good inter-rater reliability (r=0·98).[12] The protocol also included methods that measured various factors often raised in association with a patient's sense of dignity. Each patient's sense of symptom distress was measured with the symptom distress scale, a 13-item scale designed for use with cancer patients.[13] The scale measures the degree of distress associated with nausea, appetite, insomnia, pain, fatigue, bowel pattern, concentration, appearance, breathing, coughing, and mood. Responses related to each of these symptoms are rated on a 5-point scale, with high scores indicating more distress than low scores. Pain was further assessed with the McGill pain questionnaire.[14] The questionnaire comprises 15 word descriptors that examine the sensory and affective experience of pain. It also includes a present pain intensity scale, which is rated on a scale of 0–5 (0=no pain, 1=mild, 2=discomforting, 3=distressing, 4=horrible, and 5=excruciating pain).

We used the index of independence in activities of daily living (IADL) to measure functional dependency.[15] The IADL comprises a rating form that is completed by an observer based on a patient's responses to questions about his or her degree of independent functioning. On a two-point scale, the observer rates the degree of independence maintained by the patient in six areas of functioning, including bathing, dressing, toileting, continence, transferring, and feeding. The scores for each function are then summed to work out the degree of dependence maintained by the patient, generating a performance score ranging from 0–6.

A brief global quality of life measure was obtained, by use of the quality of life scale.[16] This scale consists of two items, formatted with a 10-point Likert-type scale, with higher scores indicating a higher quality of life than lower scores; one question rating the quality of the patient's life and a second question rating the patient's satisfaction with his or her current quality of life. Each patient also completed a brief battery of self-report measures to provide a further assessment of their emotional state. These measures included a single item-screening method for desire for death, ranging from no desire for death (0) to an extreme desire for death (5).[17] Furthermore, patients completed four 10 cm visual analogue scales, addressing anxiety, hopelessness, will to live,[18] and burden to others (with higher scores indicating more anxiety and hopelessness, a greater sense of will to live, and a greater sense of being a burden to others than lower scores).

We measured two conceptual dimensions of social support: the availability of social support and the extent of the patient's satisfaction with the degree of support provided. 10-cm visual analogue scales were used, anchored with the descriptions "Not at all supportive" (0) to "Extremely supportive" (10). With this approach, we assessed patients' perceptions of support from their family members, friends, and health-care providers.

Statistical analysis

We divided participants into two subsets—those whose sense of dignity was intact (scoring ≤2 on the sense of dignity item), and those who reported a significant fracturing of their sense of dignity (scoring ≥3). We compared results of these two subgroups with *t* tests, Mann-Whitney *U* tests, χ^2 tests, and Fisher's Exact tests, as appropriate. The conjoint predicative value of the individual variables that were significantly associated with dignity was examined with a stepwise multiple logistic regression procedure. Unless otherwise specified, all tests were done on a two-tailed basis, and a p value of less than 0·05 was judged significant.

Role of the funding source

The sponsors of the study had no role in study design, data collection, data analysis, data interpretation, writing of the report, or in the decision to publish the article.

Results

Of the 369 patients identified as candidates, five died before the interview could take place, 13 were transferred to a different care setting, and one denied having cancer. Furthermore, 55 patients had sufficient symptom distress or further deterioration in their general condition, or both, that they were unable to participate. Of the remaining 295 patients, 213 (72%) agreed to participate in the study (43 outpatients, 170 inpatients), with a median length of survival from the time of study entry to death being 71 days. Those who refused to participate in the study did not differ from participants by virtue of sex, disease site distribution, or mean age. The mean age of participants was 69 years (SD 12·6), and 95 (45%) were men. 46% of the study group had less than a high-school education, 20% had graduated from high school, and 34% had some college or postgraduate training. 49% of patients were married or cohabiting, with the remainder being divorced (12%), never married (11%), widowed (26%), or separated (2%). Religious affiliation was Protestant 38%, Catholic 25%, Jewish 3%, other 22%, and no religious affiliation 12%. Primary tumour sites included lung (31%), gastrointestinal tract (23%), genitourinary system (17%), breast (14%), and head and neck (3%). A further 6% of individuals had haematological cancers, and the remainder (6%) had various solid tumours.

Table 1 shows distribution of sense of dignity item scores of participants. More than half of patients rated their sense of dignity as strong or intact. 99 patients (46%; 95% CI 39–53) indicated that they had at least some, or occasional, dignity concerns. Only 16 (7·5%; 4–11) patients indicated that loss of dignity was a great problem (sense of dignity item score ≥3). These patients reported often feeling degraded, ashamed, or embarrassed.

Patients with and without an intact sense of dignity did not differ with respect to sex, marital status, education (less than high school *vs* high school or more), ethnic

		Number of patients (%) (n=213)
Sense of dignity item score and description		
0	No sense of loss of dignity	114 (54)
1	Minimum—eg, only occasionally feels some sense of loss of dignity, but it is not regarded as a particular concern	64 (30)
2	Mild—eg, often experiences low-grade worry about loss of dignity; might occasionally (but infrequently) feel some degree of shame or degradation because of symptoms or situation; sense of loss of dignity occasionally regarded as a minor problem	19 (9)
3	Moderate—eg, most of the time has definite concerns about loss of dignity; might often feel somewhat degraded, ashamed, or embarrassed; sense of loss of dignity is regarded as a significant problem	11 (5)
4	Strong—eg, most of the time feels a clear sense of loss of dignity; frequently feels degraded, ashamed, or embarrassed; sense of loss of dignity is regarded as a significant, prominent, and ongoing problem	5 (2)
5	Severe—eg, sense of loss of dignity is almost always present; very frequently feels degraded, ashamed, or embarrassed; sense of loss of dignity is regarded as a troubling, serious, and ongoing problem	0
6	Extreme—eg, sense of loss of dignity is virtually constant; almost always feels degraded, ashamed, or embarrassed; sense of loss of dignity is regarded as a pervasive, consuming, and constant problem	0

Table 1: **Sense of dignity item scores**

	Patients with intact sense of dignity		Patients with fractured sense of dignity		p before controlling for age*	p after controlling for age†
	Number of patients	Mean (SD)	Number of patients	Mean (SD)		
Variable						
Desire for death[17]	196	0·54 (0·81)	16	1·3 (1·3)	0·096	0·008
Present pain intensity[14]	194	0·66 (0·66)	16	1·1 (1·1)	0·116	0·140
Pain severity[13]	195	2·7 (1·35)	16	3·4 (3·44)	0·042	0·135
Pain frequency[13]	194	2·3 (1·14)	16	2·9 (1·18)	0·046	0·158
Bowel concerns[13]	195	2·7 (1·52)	16	3·6 (1·46)	0·028	0·042
Appearance[13]	191	2·7 (1·19)	16	3·7 (1·20)	0·003	0·010
Outlook[13]	189	2·1 (1·26)	16	2·9 (1·54)	0·050	0·118
Anxiety	195	2·0 (2·36)	16	3·9 (3·19)	0·013	0·007
Depression	195	1·8 (2·45)	16	3·5 (3·19)	0·033	0·015
Hopelessness	195	2·1 (2·93)	16	3·9 (3·07)	0·057	0·026
Will to live[18]	194	8·8 (2·14)	16	7·3 (3·83)	0·216	0·012
Sense of burden	195	4·0 (3·41)	16	7·5 (2·82)	0·0004	0·0008
Quality of life rating[16]	195	6·1 (2·45)	16	4·4 (2·89)	0·013	0·017
Quality of life satisfaction[19]	194	6·2 (2·81)	16	4·4 (2·94)	0·014	0·042

*Calculated with Mann-Whitney *U* test. †Tested with χ^2 test. The total number of patients varies since not every patient completed every measure.

Table 2: **Response characteristics by dignity group**

origin (white *vs* other), or religious affiliation (Catholic *vs* Protestant *vs* all others). There were, however, many differences that were significant between patients with and without an intact sense of dignity (tables 2 and 3). All 16 patients with a fractured sense of dignity were seen in a hospital setting versus only 78% (154 of 197) of those whose sense of dignity was intact (Fisher's exact test, p=0·047), suggesting that patients who are cared for in hospitals or other institutional settings are more likely to have their sense of dignity undermined. We noted no significant differences, however, in median length of survival from time of interview to time of death between the intact dignity group (72 days) and the fractured dignity group (68 days; log-rank test, χ^2=3·02, p=0·09), suggesting that dignity status was not related to proximity to death. Patients with a fractured sense of dignity tended to be younger (mean 62 years, SD 12·5) than did those with an intact sense of dignity (70 years, 12·4; p=0·024). We used logistic regression analysis to test the response characteristics to dignity group associations, after controlling for this age difference (tables 2 and 3).

Patients with intact dignity were less likely to indicate a desire for death, or loss of will to live. Consistent with this finding, patients whose dignity was intact were less likely to indicate that they felt depressed, hopeless, or anxious. The two groups also seemed to differ physically, with the group whose dignity was intact reporting less difficulty with bowel functioning, and less preoccupation about their physical appearance (table 1). Patients whose sense of dignity was intact were less likely to report a need for help with the intimate dependencies of care (table 3)—eg, bathing (odds ratio 13·55, 95% CI 1·6–113·7), dressing (3·12, 1·0–9·8), or incontinence (4·44, 1·4–13·7). Overall quality of life ratings and satisfaction with quality of life were significantly higher in those with a greater sense of dignity than those without (table 2). The significant correlation between quality of life and dignity ratings (*r*=0·23; p=0·002) suggests that these are overlapping, although by no means identical, constructs.

To investigate the conjoint predictive value of these measures, we did a stepwise multiple logistic regression analysis. Appearance emerged as the strongest predictor of group classification (χ^2=7·29; p=0·007), followed by "burden to others" (χ^2=8·28; p=0·004), requiring assistance with bathing (χ^2=4·09; p=0·047), present pain intensity (χ^2=4·78; p=0·03), and location of care—ie, inpatient or outpatient (χ^2=4·53; p=0·04). Increasing degrees of perceived change in appearance, an increasing sense of being a burden to others, increasing dependency on others, increasing amounts of present pain intensity, and inpatient status were all associated with a raised risk of a fractured sense of dignity. The overall model was highly significant (χ^2=38·83; p<0·0001).

Discussion

Although nearly half the patients in our sample reported at least some, or occasional, dignity concerns, most patients claimed a strong sense of personal dignity. This finding suggests that a person's sense of dignity is a particularly resilient construct and, in most instances, is able to withstand the various physical and psychological challenges that face patients who are terminally ill. Although the process of dying is often described in terms of inevitable indignities, reports from patients would suggest that a great, pervasive undermining of dignity is the exception, rather than the norm.[19] However, that our patients all received expert palliative care should be borne in mind. Individuals who get less than optimum end-of-life care might experience the types of distress that would predispose them to an undermining or fracturing of their sense of dignity.

	Patients with intact sense of dignity		Patients with fractured sense of dignity		p before controlling for age	p after controlling for age*
	Number of patients	% (SD)	Number of patients	% (SD)		
Requires help						
Bathing	194	62·4 (3·5)	15	93·3 (6·5)	0·022†	0·016†
Dressing	194	41·8 (3·5)	15	66·7 (12·2)	0·061*	0·051
Toileting	194	35·1 (3·4)	15	40·0 (12·6)	0·699*	0·507
Transferring	194	33·5 (3·4)	15	46·7 (12·9)	0·301*	0·208
Continence	194	24·7 (3·1)	15	53·3 (12·9)	0·016*	0·010
Feeding	194	6·2 (1·7)	15	6·7 (6·4)	1·000†	0·992
Dependency score	195	2·0 (1·9)§	15	3·1 (1·8)§	0·027‡	0·024

*Calculated with χ^2 test. †Calculated with Fisher's exact test. ‡Calculated with Mann-Whitney *U* test. §Mean (SD). The total number of patients varies since not every patient completed every measure.

Table 3: **Scores on the index of independence in activities of daily living by dignity group**

We identified a small group of patients who reported that loss of dignity was a problem. These patients indicated that an impaired sense of dignity was something they experienced most of the time, and was associated with a feeling of being degraded, ashamed, or embarrassed. It is noteworthy that there was not a significant difference in the survival time between these patients and patients whose dignity was intact. This finding suggests that illness acuity or proximity to death did not, in and of itself, account for the perceptual differences in dignity reported by the two groups. Results of the univariate analysis emphasised several other issues, differentiating patients with fractured dignity from most of those who reported an intact sense of dignity. First, all patients with a sense of fractured dignity were inpatients, suggesting that the degree of autonomy and independence that can be maintained in a home setting with community based care, as opposed to care enabled by an institution, is an important mediator of ones sense of dignity. Second, younger patients were more likely to have a fractured sense of dignity than older patients. This finding is consistent with results of other studies,[20-23] which show that older patients with cancer might have lower rates of diagnosed depressive disorders or self-reported psychological distress than younger patients.

Patients whose dignity was compromised reported a higher desire for death and loss of will to live than patients whose sense of dignity was intact. These findings accord with previous reports,[5,6,9] citing loss of dignity as one of the most common reasons doctors offer when reporting why their patients sought euthanasia or assisted suicide. Loss of sense of dignity could be part of a final common pathway, leading some patients to covet an early, or hastened, death. Similarly, we noted a significant association between fractured dignity, and depression and hopelessness. Results of other studies have confirmed clinical depression and hopelessness as strong predictors of desire for death and suicidal ideation, respectively, in terminally ill patients.[24] A fractured sense of dignity, heightened depression, and a sense of hopelessness may comprise a constellation of emotions, undermining patients' desire to continue living in the face of their approaching death.

A deterioration in one's appearance, a sense of being a burden to others, needing assistance with bathing, requiring inpatient hospital care, and having pain, were the most significant issues related to a fracturing of sense of dignity. Each of these factors is associated with an altered sense of personal competence and autonomy and, perhaps most burdensome, with an altered sense of self and inherent worth. Dignity has been defined in terms of being worthy of honour, respect, or esteem. Patients with a fractured sense of dignity not only felt their appearance had deteriorated, but—in the face of increasing needs and dependency—reported a sense of being regarded as less worthy of respect or esteem. As one 68-year-old gentleman with metastatic lung cancer stated: "God, who would have ever thought it would ever come down to this. I got these diapers or whatever it is that they call them... And that's presenting a problem. I don't like to think of myself as that . . . that's my dignity . . . ".

In our previous qualitative work,[10,11] we have reported that the notion of dignity is understood and applied by dying patients, in various ways, to a broad range of issues and concerns.[10,11] For some, maintained dignity is highly dependent on the tone of care, referring to the overall sensitivity of the support network within which care is delivered (we have described this as the social dignity inventory). For others, the undermining of dignity is mediated by the illness experience itself (illness related issues), and proportionate to the degree of symptom distress and physical limitations or losses imposed by an advancing malignant disease. For some patients, a dignity conserving repertoire—consisting of personal approaches or outlooks that are often determined by long-standing personality characteristics, attitudes, or philosophies—are most important to maintaining a sense of dignity. This broad application of the term dignity probably explains why, in some instances, there were small—albeit significant—mean differences between the two groups. One might anticipate that to ask a patient to conform to a uniform, prescribed definition of dignity would have yielded wider group separation. The fact that patients used their own sense of dignity as a point of reference, increased the variability of responses, making the significant findings all the more noteworthy.

The association between depression and heightened desire to die has been previously reported, as has the predictive relation between hopelessness and suicidal ideation.[17,24] Less has been said about the issue of hope, although among the dying, this notion seems to depend more on a person's ability to find or maintain a sense of meaning or purpose than on prognostic expectation.[25] Thus, strategies that enhance meaning and purpose could be integral to maintaining dignity. Care that confers honour, and recognises the deservedness of respect and esteem of every individual—despite their dependency, infirmity, and fragility—could lie at the heart of care that conserves dignity.[11]

Our study had some limitations. The study took place among a group of primarily older cancer patients who were receiving palliative care. A younger cohort could have yielded different findings, since a person's life experience and sense of an untimely death might affect perceptions of dignity. Also, patients with non-malignant illness, such as HIV-1-related disorders, neurodegenerative disorders, end stage renal or cardiac illness have a different disease trajectory and, thus, perhaps a different constellation of dignity considerations. Furthermore, some aspects of dignity might be culturally determined. Although there was some cultural diversity in our sample, our numbers were insufficient to examine this issue adequately. Further detailed qualitative studies are needed to explore the relation between culture and perceptions of dignity. Finally, we report cross sectional findings in a group of patients within several weeks of death. An individuals sense of dignity and its determinants change as death draws nearer. Prospective, longitudinal studies of dignity as illness advances towards death, are required.

This study points to the importance of dignity considerations in dying patients. Palliative care has long struggled with the extent to which it can address suffering beyond the realm of physical symptom distress. Although there have been many advances in our understanding and treatment for physical sources of discomfort in patients near the end of life, less headway has been made in our ability to intervene effectively when suffering lies outside the domain of somatic discomfort.[26-29] Hence, understanding the dignity concerns of patients near the end of life could raise our sensitivity to many important aspects of human pain, and provide the groundwork required to develop effective management strategies. Dignity-conserving care needs to become part of the palliative care lexicon, and an overarching therapeutic aim and standard of care for all patients close to death.

Contributors

H M Chochinov, T Hack, L J Kristjanson, S McClement, and M Harlos contributed to the protocol design; and H M Chochinov, T Hack, L J Kristjanson, S McClement, and T Hassard to the analysis and interpretation of the data. The report was written by H M Chochinov, with critique and approval by the full research team.

Conflict of interest statement

None declared.

Acknowledgments

We thank our research nurses Sheila Lander and Kathy Cullihall. The work was supported by grants from the National Cancer Institute of Canada, with funding from the Canadian Cancer Society and the Open Society Institute, Project on Death in America.

References

1 Council on Scientific Affairs. Good care of the dying patient. *JAMA* 1996; **275:** 474–78.

2 Pannuti F, Tanneberger S. Dying with dignity: illusion, hope or human right? *World Health Forum* 1993; **14:** 172–73.

3 Back AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington state: patient requests and physician responses. *J Am Med Assoc* 1996; **275:** 919–25.

4 Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet* 1996; **347:** 1805–10.

5 Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon Death with Dignity Act. *N Engl J Med* 2000; **342:** 557–63.

6 Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998; **338:** 1193–201.

7 Sullivan AD, Hedberg K, Fleming DW. Legalized physician-assisted suicide in Oregon: the second year. *N Engl J Med* 2000; **342:** 598–604.

8 Pullman D. Dying with dignity and the death of dignity. *Health Law J* 1996; **4:** 197–219.

9 Van der Maas PJ, Van Delden JJM, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991; **338:** 669–674.

10 Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med* 2002; **54:** 433–43.

11 Chochinov HM. Dignity conserving care: a new model for palliative care. *JAMA* 2002; **287:** 2253–60.

12 Wilson KG, Scott JF, Graham ID, et al. Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide. *Arch Intern Med* 2000; **160:** 2454–60.

13 McCorkle R, Young K. Development of a symptom distress scale. *Cancer Nursing* 1978; **1:** 373–78.

14 Melzack R. The McGill pain questionnaire: major properties and scoring methods. *Pain* 1975; **1:** 277–99.

15 Brorsson B, Asberg KH. Katz index of independence in ADL: reliability and validity in short-term care. *Scand J Rehabil Med* 1984; **16:** 125–32.

16 Graham KY, Longman AJ. Quality of life in persons with melanoma: preliminary model testing. *Cancer Nursing* 1987; **10:** 338–46.

17 Chochinov HM, Wilson K, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry* 1995; **152:** 1185–91.

18 Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. *Lancet* 1999; **354:** 816–19.

19 Madan TN. Dying with dignity. *Soc Sci Med* 1992; **35:** 425–32.

20 Kathol RB, Noyes R Jr, Williams J, Mutgi A, Carroll B, Perry P. Diagnosing depression in patients with medical illness. *Psychosomatics* 1990; **31:** 434–44.

21 Levine PM, Silberfarb PM. Mental disorders in cancer patients: a study of 100 psychiatric referrals. *Cancer* 1978; **42:** 1385–91.

22 Craig TJ, Abeloff MD. Psychiatric symptomatology among hospitalized cancer patients. *Am J Psychiatry* 1974; **131:** 1323–26.

23 Noyes R, Kathol RG, Debelius-Enemark P, et al. Distress associated with cancer as measured by the illness distress scale. *Psychosomatics* 1990; **31:** 321–30.

24 Chochinov HM, Wilson KG, Enns M, Lander S. Depression, hopelessness, and suicidal ideation in the terminally ill. *Psychosomatics* 1998; **39:** 366–70.

25 Chochinov HM, Wilson K, Tataryn D, Enns M, Lander S. Prognostic awareness and the terminally ill. *Psychosomatics* 2000; **41:** 500–04.

26 Caraceni A, Portenoy RK. An international survey of cancer pain characteristics and syndromes. *Pain* 1999; **82:** 263–74.

27 Quill TE, Lee BC, Nunn S. Palliative treatments of last resort: choosing the least harmful alternative. *Ann Intern Med* 2000; **132:** 488–93.

28 Quill TE, Byock IR. Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids. *Ann Intern Med* 2000; **132:** 408–14.

29 Wanzer SH, Federman DD, Adelstein SJ, et al. The physician's responsibility toward hopelessly ill patients: a second look. *N Engl J Med* 1989; **320:** 844–49.

"HMC-3"

This is the exhibit marked "**HMC-3**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

PERSPECTIVES ON CARE AT THE CLOSE OF LIFE

Dignity-Conserving Care— A New Model for Palliative Care

Helping the Patient Feel Valued

Harvey Max Chochinov, MD, PhD, FRCPC

The basic tenets of palliative care may be summarized as the goal of helping patients to die with dignity. The term "dignity" provides an overarching framework that may guide the physician, patient, and family in defining the objectives and therapeutic considerations fundamental to end-of-life care. Dignity-conserving care is care that may conserve or bolster the dignity of dying patients. Using segments of interviews with a patient with advanced lung cancer, his wife, and his palliative care physician, this article illustrates and explores various aspects of dignity-conserving care and the model on which it is based. Dignity-conserving care offers an approach that clinicians can use to explicitly target the maintenance of dignity as a therapeutic objective and as a principle of bedside care for patients nearing death.

JAMA. 2002;287:2253-2260 www.jama.com

THE PATIENT'S STORY

Mr S is a 62-year-old man with primary lung cancer diagnosed 18 months ago, with metastases to the liver, brain, and adrenal glands. He has recently developed severe weakness of the left upper and lower extremities with an inability to bear weight, likely related to his brain metastasis. He recently discontinued steroids because of unpleasant adverse effects and completed a 2-week course of antibiotics for pneumonia. His symptoms—which include shortness of breath, seizures, constipation, and occasional agitation—are controlled with ipratropium, phenytoin, senna, haloperidol, and clonazepam, respectively. He now receives comfort care only.

Mr S is a thoughtful and articulate man. He had an unhappy childhood and was later troubled by alcohol abuse associated with extensive difficulties sustaining meaningful, lasting relationships or vocational commitments. He states his life "turned around" 30 years ago, after meeting his wife and joining Alcoholics Anonymous; he has been sober ever since. He and his wife describe a close, trusting relationship. They do not have children. While he had a variety of jobs over the years, "none of which I liked," he worked most recently as a truck driver. His finances are "difficult," but he indicates that he and his wife manage to make ends meet. Mr S is participating in a study of "Dignity Psychotherapy," a new intervention designed to preserve dignity at the end of life. He, his wife, and his physician, Dr F, were interviewed for this article by the author.

PERSPECTIVES

MR S: *Dignity is a state of the soul. Dignity is the sense of peace that passes all understanding. I am sure that there is something beyond this lifetime. As a matter of fact, I believe the consciousness goes on from here. Now what the big plan is, nobody has ever got back to me on that, but I am sure it is wonderful . . . because in this lifetime, I have been groping around in the dark and making choices; some of them good and some not so good.*

MRS S: *Our dignity has been maintained because of the care we have been receiving in the hospital. The staff has been marvelous. They have been helping us as much as they can. I think part of dignity is trying to make him feel that he is still of value.*

DR F: *I think that individuality and dignity may be the same thing in the end. It ends up being what you see as dignity for yourself, doesn't it? It is trying to preserve the person as they are; you know, the sensible things like keeping them clean, keeping them comfortable, but also enabling their way of being, what made that person that person.*

Why Is the Notion of Dignity Important?

The basic tenets of palliative care, including symptom control, psychological and spiritual well-being, and care of the family, may all be summarized under the goal of helping patients to die with dignity.[1,2] Considerations of dignity are frequently invoked as the ultimate justification for various, even diametrically opposite, approaches to the care of dying patients, whether in reference to euthanasia and assisted suicide, hydration and nutrition, terminal sedation, or basic symptom management.[3-10] In many circles, the term "death with

---

Author Affiliations: Department of Psychiatry, University of Manitoba, and CancerCare Manitoba, Winnipeg, Manitoba.
Corresponding Author and Reprints: Harvey Max Chochinov, MD, PhD, FRCPC, PX246, 771 Bannatyne Ave, Winnipeg Manitoba. R3E 3N4 Canada (e-mail: chochin@cc.umanitoba.ca).

Perspectives on Care at the Close of Life is produced and edited at the University of California, San Francisco, by Stephen J. McPhee, MD, Michael W. Rabow, MD, and Steven Z. Pantilat, MD; Amy J. Markowitz, JD, is managing editor.
Perspectives on Care at the Close of Life Section Editor: Margaret A. Winker, MD, Deputy Editor, *JAMA*.

dignity" has become synonymous with the right to assisted suicide and euthanasia, removing it from its place as a principle of bedside care for patients nearing death. When the preservation of dignity becomes the clear goal of palliation, care options expand well beyond the symptom management paradigm and encompass the physical, psychological, social, spiritual, and existential aspects of the patient's terminal experience. Systematically broaching these issues within discussions of end-of-life care could allow patients to make more informed choices, achieve better palliation of symptoms, and have more opportunity to work on issues of life closure.

Dignity is defined as "the quality or state of being worthy, honored, or esteemed."[11] Despite its unfortunate politicization by the physician-assisted suicide and euthanasia movements, dignity does not relate exclusively to considerations of assisted dying.[5,7,8] As exemplified by the statements of Mr S, Mrs S, and Dr F, individuals are likely to ascribe their own unique meaning or importance to the notion of dying with dignity, including practical matters such as basic comfort, the tone or quality of care, and considerations of the "soul" or spirit. Dignity provides an overarching framework that may guide the physician, patient, and family in defining the objectives and therapeutic considerations fundamental at the end of life.[12]

A Model of Dignity in Dying Patients

If the preservation of dignity is to be a targeted goal of palliation, the patient's sense of dignity must first be thoroughly understood. Few studies have addressed this issue directly, although several have examined it from the vantage point of a "good death," or a "quality of life" paradigm.[13,14] Stewart and colleagues,[13] for example, reviewed the literature to develop a conceptual framework that outlines various domains of influence on the quality of life of dying persons in the context of health care. This framework was meant to guide the development of a comprehensive set of outcome measures, and to evaluate the quality of life of dying persons and the care they require. Others have identified important domains of quality end-of-life care, listing both physical and psychosocial sources of influence.[15-17] The latter domains are variably described as "support of function and autonomy" and "patient and family satisfaction";[15] "overall quality of life" and "psychological well-being and functioning";[16] and "achieving a sense of control" and strengthening relationships."[17] However, without a careful examination of what satisfaction, psychological comfort, or feeling in control and supported means to the dying patient—and because of a paucity of intervention strategies that specifically target these sources of distress—achieving them as therapeutic outcomes remains challenging, and all too often beyond reach.

The notion of a "good death" has been studied in a variety of ways.[14,18-20] Emanuel and Emanuel[19] described a detailed framework for a good death. While not empirically validated, it does synthesize the dying experience as a process with 4 critical components, including the fixed patient characteristics, the modifiable elements of the patient's experience, the various interventions that are available, and the overall outcome. Steinhauser and colleagues[20] invited patients and caregivers to cite factors that they consider most important at the end of life. These factors included pain and symptom management, preparation for death, decisions about treatment preferences, and being treated as a "whole person." However, these were not further explicated, nor were clinical strategies provided.

Payne et al[14] indicated that "dignity" was often deemed important by patients describing a "good death." Without further clarification, however, the term remains vague and implications for therapeutic responses ambiguous. One study asked members of the patient's care team within 24 hours of the patient's death to rate the deceased's level of dignity during their last 3 days of life.[21] A list of factors generated by the investigator and health care staff were used as criteria against which to make dignity score ratings. The authors concluded that they were unable to shed light on the deeper meaning and personal relevance of patient dignity, describing it as "an elusive concept" that needed to be studied from the vantage point of patients themselves.

One of the few studies to specifically examine the construct of dignity using patient informants provides a model that helps to describe the notion of dignity-conserving care.[22] This study analyzed qualitative interviews of 50 patients in an advanced stage of terminal cancer, and documented their understanding and perceptions of dignity. The dignity-conserving model of care considers 3 broad areas of influence on individual perceptions of dignity: *illness-related concerns*, ie, those things that directly result from the illness; the *dignity-conserving repertoire*, ie, those influences related to the patient's psychological and spiritual resources or makeup; and the *social dignity inventory*, ie, those environmental influences that can affect dignity (TABLE). This model is empirically based on patients dying from cancer, and bears further validation in other specific illnesses or special populations to confirm its generalizability. In addition, this study was conducted in Canadian patients and should be evaluated in other settings to determine whether components such as autonomy are as salient among individuals from other cultures.[23] Although notions of dignity may be influenced by the nature of one's illness, or culturally bound by issues such as religion or ethnicity, the proffered model may be sufficiently broad to encompass these various considerations. Acknowledgment of personal attributes, unique differences, and the essential or even subtle qualities each person embodies is fundamental to the preservation of dignity. As such, although further testing of the model will be required, it appears elastic enough to support its consideration for broad application among patients nearing death.

Illness-Related Concerns

Illness-related concerns refer to those things that result from the illness itself, and threaten to, or actually do, impinge on the patient's sense of dignity. These concerns are directly related to the patient's illness experience, described in the model as *symptom distress* and *level of independence.* For many patients with an advanced illness, symptom distress (denoting the experience of discomfort or anguish related to the progression of one's disease) is a defining characteristic of the dying experience.[24-28] According to this model, symptom distress can be further characterized as *physical distress* and *psy-*

Table. A Model of Dignity and Dignity-Converting Interventions for Patients Nearing Death

Factors/Subthemes	Dignity-Related Questions	Therapeutic Interventions
	Illness-Related Concerns	
Symptom distress		
Physical distress	"How comfortable are you?" "Is there anything we can do to make you more comfortable?"	Vigilance to symptom management Frequent assessment Application of comfort care
Psychological distress	"How are you coping with what is happening to you?"	Assume a supportive stance Empathetic listening Referral to counseling
Medical uncertainty	"Is there anything further about your illness that you would like to know?" "Are you getting all the information you feel you need?"	Upon request, provide accurate, understandable information and strategies to deal with possible future crises
Death anxiety	"Are there things about the later stages of your illness that you would like to discuss?"	
Level of independence		
Independence	"Has your illness made you more dependent on others?"	Have patients participate in decision making, regarding both medical and personal issues
Cognitive acuity	"Are you having any difficulty with your thinking?"	Treat delirium When possible, avoid sedating medication(s)
Functional capacity	"How much are you able to do for yourself?"	Use orthotics, physiotherapy, and occupational therapy
	Dignity-Conserving Repertoire	
Dignity-conserving perspectives		
Continuity of self	"Are there things about you that this disease does not affect?"	Acknowledge and take interest in those aspects of the patient's life that he/she most values See the patient as worthy of honor, respect, and esteem
Role preservation	"What things did you do before you were sick that were most important to you?"	
Maintenance of pride	"What about yourself or your life are you most proud of?"	
Hopefulness	"What is still possible?"	Encourage and enable the patient to participate in meaningful or purposeful activities
Autonomy/control	"How in control do you feel?"	Involve patient in treatment and care decisions
Generativity/legacy	"How do you want to be remembered?"	Life project (eg, making audio/video tapes, writing letters, journaling) Dignity psychotherapy
Acceptance	"How at peace are you with what is happening to you?"	Support the patient in his/her outlook Encourage doing things that enhance his/her sense of well-being (eg, meditation, light exercise, listening to music, prayer)
Resilience/fighting spirit	"What part of you is strongest right now?"	
Dignity-conserving practices		
Living in the moment	"Are there things that take your mind away from illness, and offer you comfort?"	Allow the patient to participate in normal routines, or take comfort in momentary distractions (eg, daily outings, light exercise, listening to music)
Maintaining normalcy	"Are there things you still enjoy doing on a regular basis?"	
Finding spiritual comfort	"Is there a religious or spiritual community that you are, or would like to be, connected with?"	Make referrals to chaplain or spiritual leader Enable the patient to participate in particular spiritual and/or culturally based practices
	Social Dignity Inventory	
Privacy boundaries	"What about your privacy or your body is important to you?"	Ask permission to examine patient Proper draping to safeguard and respect privacy
Social support	"Who are the people that are most important to you?" "Who is your closest confidante?"	Liberal policies about visitation, rooming in Enlist involvement of a wide support network
Care tenor	"Is there anything in the way you are treated that is undermining your sense of dignity?"	Treat the patient as worthy of honor, esteem, and respect; adopt a stance conveying this
Burden to others	"Do you worry about being a burden to others?" "If so, to whom and in what ways?"	Encourage explicit discussion about these concerns with those they fear they are burdening
Aftermath concerns	"What are your biggest concerns for the people you will leave behind?"	Encourage the settling of affairs, preparation of an advanced directive, making a will, funeral planning

chological distress, with the latter including the anguish associated with not knowing, or being unaware of, aspects of one's health status or treatment (*medical uncertainty*), and the worry or fear associated with the process or anticipation of death and dying (*death anxiety*).[29,30] Level of independence reflects the degree of reliance an individual has on others and is often determined by the ability to maintain *cognitive acuity* and perform tasks of daily living (*functional capacity*).[31]

Dignity-Conserving Repertoire

The dignity-conserving repertoire incorporates those aspects of patients' psychological and spiritual landscape that influence their sense of dignity. This is often based on preexisting personality characteristics and on internal resources that patients bring to their illness experience.[32,33] According to the model, the dignity-conserving repertoire includes *dignity-conserving perspectives*, ie, ways of looking at or coping with one's situation, and *dignity-conserving practices* that can be invoked to bolster or reinforce one's sense of dignity.

The dignity-conserving perspectives include 8 subthemes, each describing a particular influence on a patient's sense of dignity. These perspectives are not hierarchical. No one of them is more potent than any other; one or a few may be as effective for one patient as invoking many or all may be for another. *Continuity of self* refers to a sense that the essence of who one is remains intact, in spite of an advancing illness.[34,35] *Role preservation* is the ability of patients to function or remain invested in their usual roles, as a way of maintaining congruence with a prior view of themselves.[35] *Maintenance of pride* is the ability to maintain a positive sense of self-regard or self-respect.[36] *Hopefulness* is seeing life as enduring, or as having sustained meaning or purpose.[37,38] *Autonomy/control* is the ability to maintain a sense of control over one's life circumstances.[30] *Generativity/legacy* is the solace or comfort of knowing that something of one's life will transcend death.[39,40] *Acceptance* is an ability to accommodate to changing life circumstances.[41,42] Finally, *resilience/fighting spirit* is the mental determination exercised in an attempt to overcome illness or to optimize quality of life.[43,44]

Dignity-conserving practices refer to the variety of personal approaches or techniques that patients use to bolster or maintain a sense of dignity. These include 3 subthemes: *living in the moment* to focus on immediate issues in the service of not worrying about the future; *maintaining normalcy* to carry on usual routines and schedules in spite of changing health circumstances; and *finding spiritual comfort*, which is the dignity-sustaining effect of turning toward or finding comfort within one's religious or spiritual beliefs.[45,46]

Social Dignity Inventory

The defining characteristic of the social dignity inventory is its reference to social issues or relationship dynamics that enhance or detract from a patient's sense of dignity. This facet of the model describes influences on dignity that derive from the patient's environment, and consists of 5 subthemes: *privacy boundaries*, which is the extent that dignity can be influenced by encroachments on one's personal environment during the course of receiving care or support[47]; *social support*, the presence of an available and helpful community of friends, family, or health care providers[48-50]; *care tenor*, the attitude others demonstrate when interacting with the patient[51]; *burden to others*, the distress engendered by having to rely on others for various aspects of one's personal care or management[29,52]; and *aftermath concerns*, the worry or fear associated with anticipating the burden or challenges that one's death will impose on others. Unlike burden to others, aftermath concerns refer more specifically to worries about the impact that one's death will have on those left behind.

Differing Notions of Dignity

While the model covers general influences on dignity, each individual will ascribe varying degrees of importance to each of its components. The notion of dignity will vary from individual to individual, and between one circumstance and the next. The difference in how Mr S and Mrs S view the notion of dignity is both striking and illustrative. For Mr S, dignity refers to something from within, and seems to resonate with his core spiritual identity. In other words, his conception of dignity is not dependent on physical or environmental factors (ie, illness-related concerns or the social dignity inventory), but rather seems related to his ability to maintain a positive sense of self-regard (maintenance of pride), a feeling that the essence of who he is remains intact (continuity of self), along with an ability to invest in and gain strength from a rich spiritual life (finding spiritual comfort).[45,46] For Mrs S, on the other hand, the maintenance of dignity is connected to how she and her husband are treated, and the extent to which they are valued (ie, care tenor). Although it is often argued that palliative care must be philosophically rooted in an acknowledgment of the inherent dignity of individuals, this example illustrates that the question, "what is death with dignity?" requires the important corollary, "according to whom?"[1-4,24]

For some patients, a sense of dignity is indivisible from their core being or essence. The notion of "basic dignity" has been described as referring to a universal moral quality that is internally held, and inherent in and inalienable from life itself.[3,53] From this philosophical vantage point, as long as there is life there is dignity. On the other hand, "personal dignity" is frequently invoked in reference to the potential indignities of death and dying.[3,53,54] Loss of dignity is one of the most common responses given by physicians in studies examining why patients select euthanasia or assisted suicide.[8,9,53-55] Personal dignity is a construct that is more individualistic, transient, and tied to personal goals and social circumstances. As such, illness-related concerns or components of the social dignity inventory may infringe on personal dignity, perhaps mediated by the resiliency of one's dignity-conserving repertoire. Depending on one's internal resources, individual autonomy may be conflated with the notion of dignity, and the inability to maintain independence while dying may be experienced as a fundamental loss of dignity, undermining the value of life itself. The experience of other cultures that do not emphasize individual autonomy may provide insights into perspectives in which dignity without independence is possible.[23]

Dignity-Conserving Interventions

MR S: *I have been there for other people and it has really done me so much good to be of service. Well, now it is my turn. Somebody may feel as good about taking care of me as I did when I was being of service to other people.*

The physician's challenge in palliative care is to understand how a particular patient and his or her family perceive dignity and create interventions that enhance it. Without adequate strategies to address either terminal distress or suffering for which there is no apparent effective intervention, physicians providing end-of-life care can become demoralized and nihilistic.[56] Thus, dignity-conserving care, with its expanded range of therapeutic possibilities, has implications for the well-being of patient, family, and care provider alike. According to Sulmasy,[57] "to treat oneself or others with less than the proper esteem is to behave in an undignified manner." Therefore, delivering care that bestows dignity on others confers and safeguards the dignity of the provider.

Every facet of the dignity model offers guidance on how to provide care that may conserve or bolster the dignity of dying patients. If thought of as a therapeutic map, the dignity model points to directions for care that include biomedical, psychological, psychosocial, existential, and spiritual considerations (Table). Each of these components may be applied to Mr S' experience to better understand the care characteristics most important to him to maintain his dignity.

Managing Illness-Related Concerns

DR F: *If symptom management isn't well handled, discomfort can get in the way of people being themselves, and therefore get in the way of maintaining their dignity.*

MR S: *You know these people wouldn't allow my lights to go out without keeping me as comfortable as possible.*

The illness-related concerns component of the model speaks to the need for attentive management of physical and psychological symptoms. Steinhauser et al[20] reported that patients, families, and physicians all agree that pain and symptom management is important at the end of life and integral to the success of improving care for the dying. Symptom distress is a central concern to many patients with an advanced malignancy, because pain is positively associated with depression, anxiety, mood disturbance, and psychological maladaption.[26-28,32,58,59] Vigilant symptom management is clearly a cornerstone of quality palliation, and an integral feature of dignity-conserving care. Medical uncertainty and death anxiety, both specific types of psychological distress, suggest that providing information about treatment options or the anticipated unfolding of an illness may further help conserve the dignity of patients and families plagued by not knowing sufficiently what the future holds in store.[29,30]

Bolstering Independence

MR S: *I am so angry when I have only one side that works, when I have been a hands-on person all my life. I get angry and frustrated because I can't do things that used to be so easy for me to do.*

The model suggests that the degree of reliance on others can usually be understood in terms of how much one is able to do for oneself (functional capacity), and the patient's degree of mental intactness (cognitive acuity).[16,31] As such, therapeutic strategies should attempt to bolster the patients' sense of autonomy and their ability to function as independently as possible. Judicious application of orthotic devices, along with physical and occupational therapy, can often bolster functional capacity and the patient's overall level of independence. For patients who are able to be cared for at home, arranging main-floor access, appropriate medical accoutrements (eg, special bedding if required, commodes, braces, orthopedic supports), and sufficient home care and family respite supports can allow patients to remain at home and maximize autonomy within the constraints of their deteriorating health.[31]

Dignity-Conserving Strategies

MR S: *If somebody has to go and wipe off my private parts, well, that is what they do and I am sorry, I didn't do it on purpose but that is their job and I can allow them to do it. I don't see that as having anything to do with my dignity. I have other things to be proud of.*

The dignity-conserving repertoire facet of the model speaks to the internal resources that a patient brings to an illness, based on past experience, psychological makeup, and the richness of their spiritual life. Many of the subthemes within the dignity-conserving repertoire focus on the patient's sense of continued worth, and approximate Cassell's notion of suffering.[34] According to Cassell, to the degree that personhood is threatened or compromised, suffering will be proportionate. However, it can be difficult to maintain one's sense of essence (continuity of self) or self-regard (maintenance of pride), or to believe that prior roles are still worthy of investment (role preservation) in the face of deteriorating health circumstances.[34-36]

Even though Mr S was no longer able to work or anticipate a prolonged life span, having him participate in discussions about his treatment options, care planning, and financial issues affecting his wife's future seemed to enhance his sense of being an active and vital participant in a life that was not yet completed. Dignity-conserving strategies should attempt to reinforce the patient's sense of self-worth by adopting a therapeutic stance that conveys steadfast respect for the patient as a whole person with feelings, accomplishments, and passions independent of the illness experience. This is supported by Cassem's notion that dying patients

Box. Dignity Psychotherapy Question Protocol

Can you tell me a little about your life history, particularly those parts that you either remember most or think are the most important?

When did you feel most alive?

Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?

What are the most important roles (eg, family, vocational, community service) you have played in life?

Why are they so important to you, and what do you think you accomplished in those roles?

What are your most important accomplishments, and what do you feel most proud of?

Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?

What are your hopes and dreams for your loved ones?

What have you learned about life that you would want to pass along to others?

What advice or words of guidance would you wish to pass along to your____(son, daughter, husband, wife, parents, other[s])?

Are there words or perhaps even instructions you would like to offer your family, in order to provide them with comfort or solace?

In creating this permanent record, are there other things that you would like included?

derive self-respect from a sense that others value them for what they have done and for who they are.[60] It is no coincidence that patients who feel more appreciated are less likely to have considered euthanasia or physician-assisted suicide.[61] Ascribing importance to the things that the patient holds dear acknowledges individual personhood, while at the same time strengthening the empathic, therapeutic connection between the patient, the patient's family, and the care provider (Table).

Hopefulness, an ability to see life as enduring or having sustained meaning or purpose, is another subtheme of the dignity-conserving repertoire.[37,38] According to Viktor Frankl,[62] "what matters is not the meaning of life in general, but rather the specific meaning of a person's life at a given moment." For dying patients, such meaning can derive from visits with loved ones, reviewing lifetime photographs or stories, bequeathing gifts to loved ones, or engaging in meaning-engendering projects (such as organizing photo albums, writing journals, or even preparing one's own obituary).[63] In each instance, these activities provide the patient with a sense that they continue to serve a vital function, and that life maintains its purpose and dignity.

Several studies have reported that the undermining of autonomy has the potential to undermine the value patients ascribe to life, with hopelessness and loss of control correlated with a heightened interest in death-hastening measures.[63-68] Therefore, strategies that bolster autonomy and control are paramount to the conservation of dignity. One basic strategy is to ensure that patients are involved in their care and treatment decisions, if they wish. Dr F indicated that when Mr S was first admitted, he was medicated because of an apparent problem with insomnia, disruptive to the ward routine. This resulted in him becoming more confused and agitated. In an attempt to heighten his sense of autonomy and self-reliance, and to facilitate a return to his normal routines, Dr F and Mr and Mrs S decided that reducing his nighttime sedatives and spending time outdoors would be helpful. Loss of autonomy and control is a pervasive experience for patients with an advancing illness. Measures that return control to the patient should be considered and instituted whenever feasible.

For some patients, the preservation of dignity can be achieved by a connection to a spiritual or religious practice or community (finding spiritual comfort).[45,46] Facilitating these connections and enabling the expression of culturally held beliefs or denominationally appropriate practices constitute dignity-conserving care. For others, ensuring that some aspect of life may transcend death (ie, the generativity/legacy subtheme) holds the key to a maintained sense of dignity.[39,40] For these patients, participating in a life project such as making an audiotape or videotape, writing letters, keeping a journal, or engaging in dignity psychotherapy (as described below) can offer the comfort of knowing that something of their essence or personhood will survive beyond death.

Dignity Psychotherapy

MRS S: *Being able to read his words will be a way of helping me to remember him, and to think of him. I didn't always understand him, because he was a free spirit and I was the worrier. Maybe I didn't trust God enough. I'm glad I'll have his words to comfort me.*

For many patients, the maintenance of dignity seems connected to the notion that something of their essence will survive beyond the event of death itself (ie, the generativity/legacy subtheme). The psychotherapy clinical trial in which Mr S participated is based in part on this premise. In dignity psychotherapy, patients dying of any cause and thought to be within the last 6 months of life are asked to speak on tape about various aspects of life they would most want permanently recorded and ultimately remembered. Patients are asked a series of questions, based on the dignity model, which focus on things that they feel are most important and that they would most want their love one(s) to remember. Whether or not they feel they have made an important contribution in life, this intervention can engender a sense that they will leave something of value, whether to thank loved ones, ask for forgiveness, leave important information or instructions, or provide words of comfort (BOX).

Dignity psychotherapy interviews are transcribed and then edited so that they read like well-honed narratives. The "life manuscript" is returned to the patient, in most instances to be left for surviving loved ones. This therapeutic process is intended to enhance a sense of meaning and purpose for dying patients. In providing a lasting legacy for their loved ones, patients may sense that their dignity has been duly honored and therefore enhanced.

The Social Dignity Inventory

MRS S: *[The staff] have showed an interest in us and that is very important. They have been open to my coming to them and exploring [every] possibility. They have just been so helpful . . . that is really appreciated. I really admire them.*

DR F: *If all you see when cleaning someone up is excrement, that patient's dignity will suffer. If, on the other hand, you can see the whole person, that person's dignity is more likely to stay intact.*

The social dignity inventory component of the model points to environmental or contextual influences on the patient's sense of dignity. Studies find that dying patients' perceptions of support are significantly related to psychological adjustment.[48-50,69] As such, measures that use the social support network—involving family, friends, health care providers, other patients, spiritual practitioners, and others—fall within the realm of dignity-conserving care. This must be balanced by each individual's wish or need for maintaining stricter privacy boundaries, with sensitivity toward both personal and social boundaries (Table).

Burden to others can be a particularly difficult source of distress for patients, with some studies reporting that it is highly associated with an interest in physician-assisted suicide and euthanasia.[55,61,64] When patients perceive that their illness is weighing heavily on their support network, or that death will continue to inflict a burden on those who will be left behind (ie, aftermath concerns), clinicians should encourage open, frank discussion about these issues. Fears often can be allayed, and patients reassured that burdens are usually counterbalanced by the privilege of others' being able to be with them, or look after them, in the little time they have left. Aftermath concerns can most readily be addressed by encouraging patients to settle their affairs, write an advance directive, name a health care proxy, make a will, or even—should they so wish—be involved in funeral planning.

Burden to others can be accentuated when patients perceive that their personhood or net worth has been reduced to their illness and its associated encumbrances.[28,52] One of the most potent dignity-conserving strategies lies in understanding the notion of care tenor.[51] This denotes the affective and attitudinal tone of care and, if dignity is to be maintained, must convey respect and an affirmation of the patient's continued worth. While this can sometimes be achieved by inquiry into the things that have mattered and still matter most to the patient (see "Dignity-Conserving Repertoire"), it is most fundamentally based in the ability to see the patient as a whole person, deserving of honor and esteem. Maintaining dignity goes beyond what one does with or to a patient, and often resides in how one sees the patient.

CONCLUSIONS

Although dignity-conserving care should be evaluated and validated in diverse populations, the concept of conserving dignity in end-of-life care should become part of the palliative care lexicon, and the overarching standard of care for all patients nearing death. Such care should encompass a broad range of interventions, based on an understanding of the many sources of distress that may infringe on a patient's sense of dignity. What defines dignity for each patient and his or her family is unique and should be considered by clinicians to provide the most comprehensive, empathic end-of-life care possible. The model of dignity offers a framework by which clinicians can consider this task, enabling dying with dignity to become an explicitly targeted outcome.

Dignity-conserving care comprises not only what one does to patients, but how one sees patients. Affirmation can "remind the dying of their dignity . . . [which] is precisely what it means to comfort the dying."[57] When dying patients are seen, and know that they are seen, as being worthy of honor and esteem by those who care for them, dignity is more likely to be maintained. In turn, caregivers are imbued with the dignity rendered by their actions, better enabling them to provide care and comfort to those nearing death.

Funding/Support: The Perspectives on Care at the Close of Life section is made possible by a grant from the Robert Wood Johnson Foundation. Other support for this article was provided by grants from the National Cancer Institute of Canada with funding from the Canadian Cancer Society, the Canadian Institutes for Health Research, the Open Society Institute's Project on Death in America, and the American Foundation for Suicide Prevention.
Other Resources: For a list of relevant Web sites, see the *JAMA* Web site at http://jama.ama-assn.org/issues/v287n17/abs/jel10003.html.
Acknowledgment: I am grateful to the patient, his wife, and his physician for their willingness to share their story. I wish to acknowledge my research team: Tom Hack, PhD, Linda Kristjanson, PhD, Susan McClement, PhD, Mike Harlos, MD, Tom Hassard, PhD, and Kathy Cullihall, RN.

REFERENCES

1. Abiven M. Dying with dignity. *World Health Forum*. 1991;12:375-381.
2. Madan TN. Dying with dignity. *Soc Sci Med*. 1992;35:425-432.
3. Pullman D. Dying with dignity and the death of dignity. *Health Law J*. 1996;4:197-219.
4. Kade WJ. Death with dignity: a case study. *Ann Intern Med*. 2000;132:504-506.
5. Sullivan AD, Hedberg K, Fleming DW. Legalized physician-assisted suicide in Oregon: the second year. *N Engl J Med*. 2000;342:598-604.
6. Chater S, Viola R, Paterson J, Jarvis V. Sedation for intractable distress in the dying: a survey of experts. *Palliat Med*. 1998;12:255-269.
7. Quill TE. Death and dignity: a case of individualized decision making. *N Engl J Med*. 1991;324:691-694.
8. Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon Death with Dignity Act. *N Engl J Med*. 2000;342:557-563.
9. van der Maas PJ, van Delden JJM, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet*. 1991;338:669-674.
10. van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med*. 1996;335:1699-1705.
11. *Webster's International Dictionary*. 2nd ed. Springfield, Mass: Merriam; 1946:730.

12. Quill TE. Perspectives on care at the close of life: initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room." *JAMA*. 2000;284:2502-2507.

13. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. *J Pain Symptom Manage*. 1999;17:93-108.

14. Payne SA, Langley-Evans A, Hillier R. Perceptions of a "good" death: a comparative study of the views of hospice staff and patients. *Palliat Med*. 1996;10:307-312.

15. Lynn J. Measuring quality of care at the end of life: a statement of principles. *J Am Geriatr Soc*. 1997;45:526-527.

16. Field MJ, Cassel CK, eds. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997.

17. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA*. 1999;281:163-168.

18. Cohen SR, Mount BM. Quality of life in terminal illness: defining and measuring subjective well-being in the dying. *J Palliat Care*. 1992;8:40-45.

19. Emanuel EJ, Emanuel LL. The promise of a good death. *Lancet*. 1998;351 (suppl 2): S1121-S1129.

20. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284:2476-2482.

21. Turner K, Chyle R, Aggarwal G, Phillip J, Skeels A, Lickiss JN. Dignity in the dying: a preliminary study of patients in the last three days of life. *J Palliat Care*. 1996;12:7-13.

22. Chochinov HM, Hack T, McClement S, Harlos M, Kristjanson L. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med*. 2002;54:433-443.

23. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "you got to go where he lives." *JAMA*. 2001;286:2993-3001.

24. Wanzer SH, Federman DD, Adelstein SJ, et al. The physician's responsibility toward hopelessly ill patients: a second look. *N Engl J Med*. 1989;320:844-849.

25. Breitbart W, Jaramillo J, Chochinov HM. Palliative and terminal care. In: Holland J, ed. *Textbook of Psycho-oncology*. New York, NY: Oxford University Press; 1998:437-449.

26. Institute of Medicine. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997.

27. Caraceni A, Portenoy RK, for the International Association for the Study of Pain IASP Task Force on Cancer Pain. An international survey of cancer pain characteristics and syndromes. *Pain*. 1999;82:263-274.

28. Portenoy, RK,Thaler HT, Kornblith AB, et al. Symptom prevalence, characteristics and distress in a cancer population. *Qual Life Res*. 1994;3:183-189.

29. Hinton J. The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. *Palliat Med*. 1999;13:19-35.

30. Hinton J. Sharing or withholding awareness of dying between husband and wife. *J Psychosom Res*. 1981;25:337-343.

31. Tigges KN. Occupational therapy. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. New York, NY: Oxford University Press; 1999;829-837.

32. Lichter I. Some psychological causes of distress in the terminally ill. *Palliat Med*. 1991;5:138-146.

33. Cherny NI, Coyle N, Foley KM. Suffering in the advanced cancer patient: a definition and taxonomy. *J Palliat Care*. 1994;10:57-70.

34. Cassell EJ. The nature of suffering and the goals of medicine. *N Engl J Med*. 1982;306:639-645.

35. Byock IR.The nature of suffering and the nature of opportunity at the end of life. *Clin Geriatr Med*. 1996;12:237-252.

36. Byock IR. When suffering persists. . . . *J Palliat Care*. 1994;10:8-13.

37. Chochinov HM, Wilson KG, Enns M, Lander S. Depression, hopelessness, and suicidal ideation in the terminally ill. *Psychosomatics*. 1998;39:366-370.

38. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284:2907-2911.

39. Lichter I, Mooney J, Boyd M. Biography as therapy. *Palliat Med*. 1993;7:133-137.

40. Fisher BJ. Successful aging, life satisfaction, and generativity in later life. *Int J Aging Hum Dev*. 1995;41:239-250.

41. Taylor SE. Adjustment to threatening events: a theory of cognitive adaptation. *Am Psychol*. 1983;38:1161-1173.

42. Wool MS. Understanding denial in cancer patients. *Adv Psychosom Med*. 1988;18:37-53.

43. Greer S. Fighting spirit in patients with cancer. *Lancet*. 2000;355:847-848.

44. Nelson DV, Friedman LC, Baer PE, Lane M, Smith FE. Attitudes of cancer: psychometric properties of fighting spirit and denial. *J Behav Med*. 1989;12:341-355.

45. Holland JC, Passik S, Kash KM, et al. The role of religious and spiritual beliefs in coping with malignant melanoma. *Psychooncology*. 1999;8:14-26.

46. Daaleman TP, VandeCreek L. Placing religion and spirituality in end-of-life care. *JAMA*. 2000;284:2514-2517.

47. Nemcekova M, Ziakova K, Mistuna D, Kudlicka J. Respecting patients' rights. *Bull Med Ethics*. 1998:13-18. No. 140.

48. Katz JS, Sidell M, Komaromy C. Dying in long-term care facilities: support needs of other residents, relatives, and staff. *Am J Hosp Palliat Care*. 2001;18:321-326.

49. Andershed B, Ternestedt BM. Development of a theoretical framework describing relatives' involvement in palliative care. *J Adv Nurs*. 2001;34:554-562.

50. Kristjanson LJ, Sloan JA, Dudgeon D, Adaskin E. Family members' perceptions of palliative cancer care: predictors of family functioning and family members' health. *J Palliat Care*. 1996;12:10-20.

51. Barthow C. Negotiating realistic and mutually sustaining nurse-patient relationships in palliative care. *Int J Nurs Pract*. 1997;3:206-210.

52. Kinsella G, Cooper B, Picton C, Murtagh D. A review of the measurement of caregiver and family burden in palliative care. *J Palliat Care*. 1998;14:37-45.

53. Pullman D. Human dignity and the ethics and aesthetics of pain and suffering. *Theor Med Bioeth*. In press.

54. Kant I. *The Fundamental Principles of the Metaphysics of Morals*. Abbott TK, trans. Buffalo, NY: Prometheus Books; 1987.

55. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med*. 1998;338:1193-1201.

56. Portenoy RK, Coyle N, Kash KM, et al. Determinants of the willingness to endorse assisted suicide: a survey of physicians, nurses, and social workers. *Psychosomatics*. 1997;38:277-287.

57. Sulmasy DP. Death and human dignity. *Linacre Q*. 1994;61:27-36.

58. Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry*. 1995;152:1185-1191.

59. Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. *Lancet*. 1999;354:816-819.

60. Cassem N. The dying patient. In: Hackett T, Cassem N, eds. *The Massachusetts General Hospital Handbook of General Hospital Psychiatry*. Littleton, Mass: PSG Publishing Co Inc; 1987:332-352.

61. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*. 2000;284:2460-2468.

62. Frankl VE. *Man's Search for Meaning*. New York, NY: Simon & Schuster; 1963:171.

63. Block SD. Perspectives on care at the close of life: psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA*. 2001;285:2898-2905.

64. Wilson KG, Scott JF, Graham ID, et al. Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide. *Arch Intern Med*. 2000;160:2454-2460.

65. Back AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington state: patient requests and physician responses. *JAMA*. 1996;275:919-925.

66. Seale C, Addington-Hall J. Euthanasia: why people want to die earlier. *Soc Sci Med*. 1994;39:647-654.

67. Block SD, Billings JA. Patient requests to hasten death: evaluation and management in terminal care. *Arch Intern Med*. 1994;154:2039-2047.

68. Ganzini L, Johnston WS, Hoffman WF. Correlates of suffering in amyotrophic lateral sclerosis. *Neurology*. 1999;52:1434-1440.

69. Dobratz MC. Causal influences of psychological adaptation in dying. *West J Nurs Res*. 1993;15:708-729.

Other Resources

The Canadian Palliative Care Association
http://www.cpca.net/
A national Web site providing an overview of palliative care in Canada, including access to the *Norms of Practice for Hospice Palliative Care*, and the Senate of Canada's report, *Quality End-of-Life Care: The Right of Every Canadian*

International Psycho-Oncology Society
http://www.ipos-aspboa.org/
This Web site also serves as a home to the American Society for Psychosocial and Behavioral Oncology/AIDS (ASPBOA); contains a variety of educational materials and linkages, targeted at the psychosocial aspects of patient care

Pallium
http://www.pallium.ca/
A Web-based professional community of clinicians, educators, and academicians engaged in building Canada's palliative care capacity together

Project on Death in America
http://www.soros.org/death/
Provides a broad range of resources related to palliative care, including funding initiatives, educational materials, and summaries of international efforts related to end-of-life care

University of Ottawa Institute of Palliative Care
http://www.pallcare.org/
Provides access to a broad range of end-of-life educational material, including an online education center

"HMC-4"

This is the exhibit marked "**HMC-4**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at
this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

PERGAMON

Social Science & Medicine 54 (2002) 433–443

SOCIAL
SCIENCE
&
MEDICINE

www.elsevier.com/locate/socscimed

Dignity in the terminally ill: a developing empirical model

Harvey Max Chochinov[a,b,*], Thomas Hack[b,c], Susan McClement[c],
Linda Kristjanson[d], Mike Harlos[e]

[a] *Department of Psychiatry-PX246, University of Manitoba, PsycHealth Centre, Winnipeg, Man., Canada R3T 2N2*
[b] *CancerCare Manitoba, Winnipeg, Canada*
[c] *Faculty of Nursing, University of Manitoba, Canada*
[d] *Edith Cowan University, Perth, Australia*
[e] *St. Boniface General Hospital, Winnipeg, Canada*

Abstract

Despite use of the term *dignity* in arguments for and against a patient's self-governance in matters pertaining to death, there is little empirical research on how this term has been used by patients who are nearing death. The objective of this study was to determine how dying patients understand and define the term *dignity*, in order to develop a model of dignity in the terminally ill. A semi-structured interview was designed to explore how patients cope with their advanced cancer and to detail their perceptions of dignity. Interviews were audiotaped and transcribed verbatim. A consecutive sample of 50 consenting patients with advanced terminal cancer were recruited over a 15-month period of time from an urban extended care hospital housing a specialized unit for palliative care. This unit provides both inpatient services, and coordinates end-of-life care community based programming. Data were analysed using latent content analysis and constant comparison techniques. Four members of the research team independently coded the transcribed data, to develop conceptually meaningful categories of responses. Operational definitions were written for major categories, themes and sub-themes. Three major categories emerged from the qualitative analysis, including illness-related concerns; dignity conserving repertoire; and social dignity inventory. These broad categories and their carefully defined themes and sub-themes form the foundation for an emerging model of dignity amongst the dying. The concept of dignity and the dignity model offer a way of understanding how patients face advancing terminal illness. This will serve to promote dignity and the quality of life of patients nearing death. © 2002 Elsevier Science Ltd. All rights reserved.

Keywords: Canada; Dignity; Palliative care; Cancer; Qualitative research

Introduction

For many palliative cancer patients, their families, and caregivers, the term *dignity* conveys an inherent respect to be granted patients in preparation for death (Abiven, 1991; Council on Scientific Affairs, 1996; Kade, 2000; Pannuti & Tanneberger, 1993). Emphasis on the terminally ill individual has been heightened by public and health professional concerns regarding the rights and needs of dying patients. Support for assisted suicide or euthanasia is often anchored by concerns for the patient's dignity (Back, Wallace, Starks, & Pearlman, 1996; Emanuel, Fairclough, Daniels, & Clarridge, 1996; Ganzini et al., 2000; Meier et al., 1998; Sullivan, Hedberg, & Fleming, 2000). Loss of dignity is one of the most common reasons physicians cite when asked why they agreed to a patient's request for euthanasia or some form of self-assisted suicide (Ganzini et al., 2000; Meier et al., 1998; Van der Maas, Van Delden, Pijnenborg, & Looman, 1991). However, it is not uncommon for people on either side of this debate to invoke considerations of dignity as lying at the heart of

---

*Corresponding author. Department of Psychiatry-PX246, PsycHealth Centre, University of Manitoba, Winnipeg, Man., Canada R3T 2N2..

E-mail address: chochin@cc.umanitoba.ca
(H.M. Chochinov).

PII: S0277-9536(01)00084-3

their respective positions (Pullman, 1996). Notions of death with dignity may also guide health care professionals in the manner with which they attend to those preparing for death.

Despite the use of the term *dignity* in arguments for and against a patient's self-governance in matters pertaining to death, there is a notable lack of empirical data examining dignity from the vantagepoint of patients themselves. More specifically, no studies have addressed this concept in the context of the terminally ill. Latimer (1991) argued that palliative care must be philosophically rooted in an acknowledgement of the inherent dignity of individuals, and Geyman (1983) listed dignity as one of the five basic requirements that must be satisfied in caring for dying patients. However, neither provided a definition of dignity, empirically derived or otherwise. Although dictionary definitions of the term are available, patients' and health care providers' definitions and conceptualizations of dignity are noticeably absent in the scientific research literature. This lack of precision and possibly consensus or understanding about the term *dignity* has important care and policy-related implications.

Although some studies have argued that palliative care must be philosophically rooted in an acknowledgment of the inherent dignity of individuals (Brant, 1998; Bronstein & Jones, 1986; Coppens, 1998; Madan, 1992; Pickett, 1993; Quill, 1994; Sampaio, 1992), the construct of dignity remains poorly defined. The goal of this current study was to explicate the meaning of dignity for palliative cancer patients and to develop a conceptual framework that describes dignity from the perspective of individuals living with an advanced cancer diagnosis. As part of a comprehensive semi-structured interview, we asked dying patients how they understood and defined the term *dignity*, and what experiences or issues supported or undermined their personal sense of dignity. Given the fact that loss of dignity may be a final common pathway leading patients towards death-hastening decisions, we also asked patients about the role their perceptions of dignity might play in considering death-hastening measures. We offer these findings as an initial framework for understanding the term *dignity* from the perspective of terminally ill cancer patients.

Methods

Sample criteria

Patients were recruited from an urban extended care hospital that houses a specialized unit for palliative care service delivery to terminally ill cancer patients. This unit provides inpatient services and coordinates community based end-of-life care services. A consecutive sample of consenting cancer patients meeting the inclusion criteria was recruited over a 15-month period of time. Eligibility criteria included the following: the patient had to be at least 18 years of age, have a terminal cancer diagnosis, be able to read and speak English, demonstrate no evidence in the medical chart of dementia or delirium that might make it difficult to complete the protocol, and be able to provide informed consent. During this time period, 124 consecutively referred individuals were approached to participate in the study. Of those, 29 were too sick or confused and thus deemed ineligible. Of the remaining 95 patients, the following reasons for non-participation were cited: 39 (41%) were not interested; 5 (5%) died before the interview could be conducted; one denied having cancer, with the refusal rate thus being 47%. Fifty patients agreed to participate in the study (27 outpatient, 23 inpatient), with their median length of survival from the time of study entry to death being 82 days. Demographic characteristics and illness-related variables of participants are shown in Table 1.

Table 1
Summary characteristics of the participants ($N = 50$)

Variable	N	%
Sex		
Male	23	46
Female	27	54
Age (mean = 69 yr: range = 37–90 yr)		
31–50	5	10
51–65	14	28
>65	31	62
Site (primary)		
Lung	18	36
Breast	10	20
Gastrointestinal	10	20
Prostate	5	10
Other[a]	7	14
Survival: days from interview until death (median; range) total sample = 82 days (4–816 days); inpatients = 59 days (4–317 days); outpatients = 132 days (16–816 days)		
<1 month	9	18
1–3 months	16	32
3–6 months	9	18
6–12 months	11	22
>12 months (three alive at time of reporting)	5	10

[a] Brain, laryngeal, multiple myeloma, osteochondrosarcoma.

Recruitment procedure and data collection

The Faculty of Medicine Ethics Committee, University of Manitoba approved the study and the hospital research review board granted formal access to patients. The unit staff and home care coordinator identified patients who met the study criteria. Permission was obtained to release the patients' names to the research nurse, who in turn approached the patients, provided a detailed explanation of the study, and obtained written consent.

A semi-structured interview was conducted to explore how patients cope with their advanced cancer and detail their perceptions of dignity. A multi-disciplinary expert panel of clinicians experienced in care of the dying and researchers familiar with the literature determined the scope of the interview. Each patient's sense of dignity was explored by asking questions that covered the following issues: (1) In terms of your own illness experience, how do you define the term *dignity*? (2) What supports your sense of dignity? (3) What undermines your sense of dignity? (4) Are there specific experiences you can recall in which your dignity was compromised? (5) Are there specific experiences you can recall in which your dignity was supported? (6) What would have to happen in your life for you to feel that you no longer had a sense of dignity? (7) Some people feel that life without dignity is a life no longer worth living. How do you feel about that? (8) Do you believe that dignity is something you hold within you, and/or is it something that can be given or taken away by others? Experienced palliative care research nurses conducted the interviews, after being trained in qualitative interviewing techniques by the study investigators. Ongoing review of the study transcripts also provided a means of quality assurance. Investigators monitored consistency with the study protocol, provided feedback to the research nurses regarding the quality of the data obtained, and refined the interview protocol. Interviews lasting approximately 60 min were conducted either in the patients' rooms on the palliative care unit, or in the home setting. Each interview was audiotaped and subsequently transcribed verbatim.

Method of analysis

Data were analysed over a 15-month period using latent content analysis and constant comparison techniques (Field & Morse, 1985; Fox, 1982; Glaser & Strauss, 1967). All four investigators independently coded the transcribed interviews using an open coding approach (Strauss & Corbin, 1990). A word or phrase that captured the meaning within a section of the text was written in the margin of the transcript. A unit of analysis could be a word, phrase or paragraph that described an experience, feeling or perception reported by the participant. As much as possible, the actual words of participants were used as code labels. Coding labels were continuously compared and discussed to determine the extent of agreement amongst coders, using a consensus method of coding agreement. Codes emerging from early interviews formed a developing coding taxonomy that was used to analyse subsequent interviews. In some instances, the coding was revised based on new interview data and re-coding and discussion took place in an effort to ensure that codes matched the data accurately as it was obtained. A final review of the codes was undertaken with minor adjustments to some specific coding labels. Analysis continued until all categories were saturated (when no new information on the characteristics of the category was forthcoming). Discussion amongst investigators was then undertaken to determine the broader categories and themes that captured these initial codes. These codes then became sub-themes of the broader themes and over-arching categories. As part of this analysis step, investigators defined the themes and sub-themes, presenting these to each other for confirmation. Once consensus was reached, operational definitions were written for all major categories, themes and sub-themes. Proposed relations amongst these categories, themes and sub-themes were then mapped using examples from the transcripts to support them. This resulted in a preliminary model that reflects associations amongst the categories, themes and sub-themes.

Results

Three major categories emerged from the qualitative analysis, including (1) illness-related concerns, (2) dignity conserving repertoire and (3) social dignity inventory. These categories refer to experiences, events, or feelings, where dignity or lack of dignity becomes a salient concern in the course of the patient's approaching death. Each of these categories contains several carefully defined themes and sub-themes (see Table 2). Exemplars for each of these themes and sub-themes provide 'a voice', illustrating the concepts contained therein.

1. *Illness-related concerns that influence dignity*

Illness-related concerns that influence dignity are those that derive from or are related to the illness itself, and threaten to or actually do impinge on the patient's sense of dignity. The defining characteristic of these issues is that they are illness mediated, and the sub-themes contained within these issues are specific to the patients' illness experiences. Two themes within this category are 'level of independence' and 'symptom distress'.

1a. *Level of independence*. This theme is defined by the degree of reliance an individual has on others and is characterised by two sub-themes: cognitive acuity and functional capacity.

The sub-theme of cognitive acuity refers to an ability to maintain one's mental/thinking capacity. A 59-year-old woman with metastatic breast cancer described the effect of experiencing diminished cognitive capacity on her sense of personal dignity.

> Like the 4 or 5 weeks that I was on morphine I'm not aware of that time in my life at all... lost it completely. I've seen pictures of myself at the table having Christmas dinner and I don't even remember Christmas. Who was here? And I have a feeling that I might have said something to a couple of people and yet I can't bring myself to ask them if I did...so in that real case, I lost my dignity.

The sub-theme functional capacity refers to a patient's ability to perform tasks associated with activities of daily living. For example, an 85-year-old woman with an advanced haematological malignancy discussed her loss of dignity as it related to her declining level of independence:

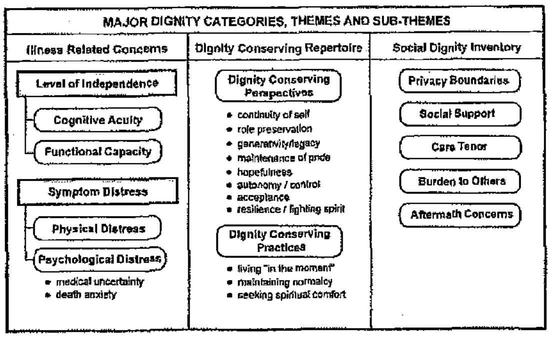
> Well I think you lose your dignity when you've got to be fed. I mean you feel so foolish. You know I really did not want to be fed. But they kind of...they forced me. Having to be waited on and looked after and maybe even fed. I don't know. But I...oh I would hate that. I like to be independent.

These examples provide evidence for an inverse relationship between level of independence and sense of dignity. In each instance the loss of independence or functional capacity resulted in a corresponding fracturing of the patient's sense of personal dignity.

1b. *Symptom distress.* This theme refers to the experience of discomfort or anguish related to the progression of one's disease. It was characterised by two sub-themes: physical distress and psychological distress.

In some rare instances, before symptoms can be brought under adequate control, the intensity of physical symptom distress was reported as so severe as to leave the patient feeling that death might be their only option. Patients were asked, "Some people feel that life without dignity is no longer worth living. How do you feel about this?" A 50-year-old gentleman with advanced colon cancer and liver metastasis responded in the following way:

Table 2
Major dignity categories, themes and sub-themes



MAJOR DIGNITY CATEGORIES, THEMES AND SUB-THEMES		
Illness Related Concerns	Dignity Conserving Repertoire	Social Dignity Inventory
Level of Independence Cognitive Acuity Functional Capacity **Symptom Distress** Physical Distress Psychological Distress • medical uncertainty • death anxiety	Dignity Conserving Perspectives • continuity of self • role preservation • generativity/legacy • maintenance of pride • hopefulness • autonomy / control • acceptance • resilience / fighting spirit Dignity Conserving Practices • living "in the moment" • maintaining normalcy • seeking spiritual comfort	Privacy Boundaries Social Support Care Tenor Burden to Others Aftermath Concerns

> I: Can you tell me what the term *dignity* means to you?
>
> P: To die in peace...not suffering too much. Because towards the end, that's when people seem to suffer the worst. Just before the end. It's not emotional pain. It's...real pain....Sometimes I hurt so much, I'd like to take all my pills and get it over with so I wouldn't hurt.

An 87-year-old woman, recounting her experience of symptom distress prior to being admitted to the palliative care program, responded to the question of 'life without dignity no longer being worthy of living' as follows:

> Oh yes when I had that terrible pain and it got so bad. I phoned Dr. B. and I said I can't stand it anymore. I just can't. I lie at night and I have for months and they don't help, those pills that he gave me didn't help. I said what...what shall I do? Well he says I can't do anything about it. And then of course I had days when I thought oh God take me, take me home...take me home. I'm ready to go right now. Right now.

Given the intensity of the feelings associated with extreme symptom distress and their association with dignity, an inverse relationship between symptom distress and a sense of dignity would be expected.

The sub-theme psychological distress refers to the mental anguish that individuals experience related to their progressing illness, and how it affects their sense of dignity. Psychological distress was described in two ways: medical uncertainty and death anxiety.

Medical uncertainty pertains to the anguish associated with not knowing, or being unaware of aspects of one's health status or treatment. Several patients raised the issue of uncertainty regarding their treatment and anticipated disease course when questioned about the types of things that might affect their sense of dignity. Death anxiety was described by participants as the worry or fear specifically associated with the process or anticipation of death and dying. This 47-year-old gentleman diagnosed with colon cancer described both medical uncertainty and death anxiety in the context of his dignity concerns as follows:

> P: But I guess that [dignity] is something that I've lost....[Knowing] it's going to get worse. I know it will [be] quick, or I hope so. When I get to the point where I can't go to the bathroom anymore or where I can't... all the things that I still have control over.... I suppose maybe you get to the point where you have

> to be all plugged into a whole bunch of stuff and tubes and everything else. But maybe you go so far down the road those tubes ... Maybe it doesn't matter anymore. But I'm not looking forward to that day.... You know, I just heard in the last couple of minutes you sort of...[I'm] worried and scared. But its just something that you thought about the timing and circumstance of... I guess I worry about it more than I think.....Yeah. I don't know what's in store and I think my fate is, you know, the time and what it brings me sort of thing. It doesn't make it easy.

In response to questions about those things that affected their sense of dignity, participants frequently mentioned distressing symptoms (physical or psychological). Overall, illness-related concerns such as loss of independence, fears of loss of cognitive acuity and concerns about symptom distress featured prominently in patients' statements about how their dignity might be threatened.

2. *Dignity conserving repertoire*

The second major category that emerged was labelled dignity conserving repertoire. Broadly speaking, these issues can be divided into two themes: dignity conserving perspectives (i.e., a way of looking at one's situation that helps to promote dignity) and dignity conserving practices (i.e., personal actions that can bolster or reinforce one's sense of dignity).

2a. *Dignity conserving perspectives* refer to internally held qualities that may be based on long standing personal characteristics, attributes, or an acquired world view, and consists of eight sub-themes, including (1) continuity of self, (2) role preservation, (3) generativity/legacy, (4) maintenance of pride, (5) hopefulness, (6) autonomy/control, (7) acceptance, and (8) resilience/fighting spirit.

Continuity of self refers to the sense that the essence of who one is continues to remain intact, in spite of one's advancing illness. Some individuals described their sense of dignity by presenting a view of themselves that was positive, respectful and consistent with previous personal perceptions. A 64-year-old woman with lung cancer and brain metastasis described this notion in terms of how she still viewed herself as someone worthy of respect.

> I: Can you in our own words define for me what the word dignity means to you?
>
> P: I guess to me a lot of it would be the respect, the recognising that you are still an individual that you know...you're a person whose had a life...you know. I guess it's being treated with respect [that] would probably be a big thing. Being allowed input and taking your requests seriously and your decisions seriously.

Role preservation referred to a patient's ability to continue to function in usual roles as a way of maintaining a sense of dignity and congruence with prior views of self. One 55-year-old woman with carcinoma of the breast described, as a way of maintaining dignity, how she had to take action to help preserve her role as mother of the groom at her son's wedding:

> I: What does dignity mean to you?
>
> P: Being allowed to (sigh)... ..a perfect example was at the wedding. Everybody just assumed that I wasn't going to do the dance. My husband too. And I just decided that I was. So when it came the time for us to get up he sat there and sat there and sat there. So I got up out of my chair and I said, will you dance with me? ... And he did.

Generativity/legacy described how patients sometimes found solace and comfort in knowing that following their death, they would leave behind something lasting and transcendent of death. Patients also responded to a question about how they maintained their dignity and a sense of value in their lives when they identified their accomplishments, contributions, and connections to life (e.g., children, good work). For example, an 88-year-old woman with breast cancer and bone metastases responded in the following way:

> I: What gives your life dignity now?
>
> P: The accomplishments of my children. And I keep on joking saying that well with a grandmother like me what would you expect you know. I would love to see my grandchildren graduate. I'm not in a hurry to go anywhere.

Maintenance of pride described the loss of dignity patients felt when they were unable to maintain their sense of pride in the face of diminishing independence. The essence of lost pride was an inability to maintain a positive sense of self-regard or self-respect, leaving patients with a feeling of being diminished, not so much in the eyes of others, as in their own eyes. For example, one 68-year-old man with lung cancer, which had metastasised to his brain, described his loss of pride when he was unable to use the toilet by himself.

> And I was on the commode and I had to be wiped and I just about cried my eyes out because of...you know, I never felt...I said to the nurses, God, who would have ever thought it would ever come down to this. I got these diapers or whatever it is that they call it... And that's presenting a problem. I don't like to think of myself as that. Things like that. That's my dignity and it comes down to types of things like that really...So I get mad.

This passage describes a waning sense of pride associated with a loss of functional independence. This gentleman's inability to carry out this extremely personal and usually private function was an assault on his self-regard and feeling of competence. The contrast between his former self, a stubborn and independent individual, and the weeping man who needed the help of nurses to use the toilet presented a deep violation of his sense of dignity. Therefore, aspects of dependency may be particularly difficult for patients to accept, not only in terms of the physical limitations they represent, but also in terms of the profound alteration they bring about in sense of self.

Hopefulness was important to patients as they endeavoured to retain their sense of dignity. For patients nearing death, hopefulness seemed to be associated with an ability to see life as enduring, or having sustained meaning or purpose. A 66-year-old woman with pancreatic cancer described the issue in response to questions about her sense of dignity.

> I: Explain to me what dignity means.
>
> P: I hold this dignity because I have something to look forward to.
>
> I: So what are the things in your life that give it dignity at this point in time?
>
> P: Looking forward to...to the main event of the wedding right now.

Autonomy/control refers to the extent to which patients have a sense of control over their life circumstances and the degree to which it can foster their sense of dignity. Although the earlier themes of level of independence, which included the sub-theme, functional capacity may appear similar to autonomy/control, these concepts were described differently. Autonomy/control refers to an internally mediated viewpoint or sense of self, and not so much to what the patient can or cannot do, but rather the degree of autonomy that the patient subjectively feels. In some instances, for example, a patient may have few functional deficits, but may still experience a loss of dignity if he/she perceives a loss of autonomy. As this 85-year-old woman with breast cancer indicated:

> Well it's the same thing as living in your own home you know. You are your own person. And..and if anybody started telling me to do this do that you know, and you've got to be in bed at a certain time and you've got to have help being undressed and all that, I think...God Lord, that...would be the worst thing that could happen. That would really be losing dignity. I wouldn't have any then.

Acceptance refers to an internal process of resigning one's self to changing life circumstances in the attempt to maintain one's sense of dignity. Acceptance can be particularly challenging in the context of an advancing illness and anticipation of death. In response to a question concerning how she maintained her sense of dignity, an 87-year-old woman with cancer of the lung stated the following:

> P: ...[to] die with dignity. That means...they accept it. You have to...kind of grow into this whole thing from year to year. You get wiser and you get to know what the consequences are and what you have to do. So that dignity would come in that.

Resilience or fighting spirit refers to the mental determination that some patients exercise to overcome their illness-related concerns or to optimise their quality of life. While for some patients Acceptance seemed to serve as a dignity enhancing strategy, for others, railing against their illness seemed to bolstering their sense of dignity. For example, a 73-year-old woman with metastatic breast cancer described her dignity conserving strategy as follows:

> I: How are you able to maintain your dignity now?
>
> P: Not giving up. Seems to me [some people] are giving up, not me. I wouldn't give up that easy. See I'm not the kind of person to give up that easy.

The dignity conserving perspectives may be a reflection of the unique characteristics of patients who are facing their impending death. These qualities likely mediate, or in some instances even buffer the extent to which their sense of dignity is maintained rather than fractured in the face of their advancing illness. Not every perspective will be held or exercised by all patients. The extent to which patients invoke or manifest these perspectives will depend upon the individual and his or her particular style. These dignity conserving perspectives are not hierarchical, in that no one perspective appeared to be more potent than another, and one or few of them may be as effective for one patient as the invoking of many or all of them for another.

2b. *Dignity conserving practices* is a theme that refers to the variety of personal approaches or techniques that patients use to bolster or maintain their sense of dignity. Three sub-themes of dignity conserving practices were identified: living in the moment, maintaining normalcy, and seeking spiritual comfort.

Living in the moment involves focusing on immediate issues in the service of not worrying about the future. For example, when asked how she maintained her sense of dignity, a 76-year-old woman with metastatic breast cancer responded as follows:

> I: What gives your life dignity now?
>
> P: Well there's always something worth living for. I mean, you can look out the window and see flowers

> growing or children on the street and hear somebody laughing you know...that makes life worth living. Right now the most important thing in life is to try to live every day and be considerably happy. And not try to let anything burden you down. Right. You know, try to enjoy the day as much as I can.

A 67-year-old outpatient with breast cancer responded to the same question as follows:

> Just living from day to day. Enjoying time with my husband. And right now, you know, just enjoying this beautiful summer weather.

Maintaining normalcy refers to carrying on usual routines and schedules while coping with the physical and emotional challenges of being ill. Although this sub-theme appears to be closely related to the sub-theme 'living in the moment', 'maintaining normalcy' has a sense of continuous or routine behaviour that helps individuals manage day to day challenges. For example, a 69-year-old woman with metastatic lung cancer described her strategy for maintaining dignity as follows:

> Well dignity means being able to get up and have breakfast with my grandchildren before they leave for school....and have supper with them. The simple things like having meals with them.

Seeking spiritual comfort refers to the dignity-sustaining effect of turning toward or finding solace within one's religious or spiritual belief system. An 87-year-old woman with lung cancer described the dignity-enhancing effect of her spiritual support as follows:

> I: What does dignity mean?
>
> P: Dying with dignity means...that is facing death is, I would say, out of 100%, there're 95 that will call to God. They pray. So that is a natural thing. When you face death it's in born in us that we have something else in us. We know that this life is not the end of it you know. And that...and that is dignity....And I thought isn't that just wonderful that you have that feeling...the Holy Spirit...he guides us and if I ever get into a little bit of fear you know, when I have this pain, that the faith never...never changes. I have never lost my dignity.

As distinct from dignity conserving perspectives, practices are actual techniques or things that patients can do or invoke to maintain their sense of dignity. It is possible that those with a more positive perspective as expressed within the theme, dignity conserving perspectives were also able to invoke more dignity conserving practices.

3. *Social dignity inventory*

The defining characteristic of the themes within this category is that they refer to social concerns or relationship dynamics that enhance or detract from a patient's sense of dignity. Five themes emerged: privacy boundaries, social support, care tenor, burden to others and aftermath concerns.

3a. *Privacy boundaries* is a theme that denotes the extent to which dignity can be influenced by having one's personal environment encroached upon during the course of receiving care or support. In answering the question about those things that influenced her sense of dignity, a 61-year-old female patient with lung cancer illustrated this theme as follows:

> I: Are there other things that would take dignity away from you?
>
> P: Having that young woman come in here the other day was very, very hard on me. Or to ask her to do anything for me, I find it very hard to ask her anything. I don't know how to describe it. For one thing, I've never had too much self-esteem I suppose and I always preferred to meld into a wall. I felt more comfortable there. ...Uh, things like not being able to go to the washroom by myself. Oh to me, that would take everything away from me because I am so modest.

The following excerpt describes the concerns of a 76-year-old woman who had metastatic breast cancer. This example refers to loss of privacy due in part to the fact that she is living with her son and had her bedroom set up on the main floor of the house in the family room, and concerns about loss of privacy when using the toilet. She responded to the question about the things might affect her sense of dignity as follows:

> I: What would take dignity away from your life?
>
> P: Oh my God, maybe putting me on the toilet seat. These are private things, you know... I still feel like I like my privacy. Even for my sleeping in, it's kind of embarrassing if I'm still sleeping if they come downstairs. You know I've got to be... I've got to be up first and get dressed and be here...

3b. *Social support* refers to the presence of an available and helpful community of friends, family, or health care providers. In responding to the question about what things influenced his sense of dignity, an 80-year-old gentleman with metastatic prostate cancer spoke of the importance of his social support network:

> I: What gives your life dignity?
>
> P: Having a family. Having the little fellow that lives next door. That gives me a lot of cheer. Well it doesn't matter how bad things get. I always know that my family is there and I'm very lucky. Not

> everybody's family is supportive. But I know that they love me. Yeah, because I belong to somebody and they belong to me.

3c. *Care tenor* refers to the attitude others demonstrate when interacting with the patient. This attitude may or may not promote dignity. For example, one 86-year-old woman with metastatic breast cancer described how an uncaring attitude might affect her sense of dignity:

> I: Is there something that a person could say or do to you that you would find take your dignity away?
>
> P: Oh, anybody that said any miserable, sarcastic remark would make me angry. That's taking your dignity away.

3d. *Burden to others* referred to the distress engendered by having to rely upon others for various aspects of one's personal care or management. Distress may arise either from feeling that one is a burden, or from the fear of becoming a burden to care givers. Burden to others was a particularly poignant source of distress that frequently appeared to threaten an individual's sense of dignity. For example, a 76-year-old woman with metastatic breast cancer discussed her worries about being a burden to others:

> I: Would you feel that your dignity was taken away if your children needed to help you?
>
> P: Well, yes if I knew…I wouldn't want them to take on the burden of doing that. That I have to depend on people just to look after me, to wash me, to take me to the bathroom and to cleanse…clean me up…I know this happens but I wish it didn't happen to me.

3e. *Aftermath concerns* referred to the worry or fears associated with anticipating the burden or challenges that one's death will impose on others. This type of psychological distress is similar to burden to others, but refers more specifically to worries that the patient holds about the impact that death will have on those that are left behind. A 51-year-old male outpatient with metastatic lung cancer expressed aftermath concerns regarding the future of his children, and how they would fair in the wake of his death.

> Well I've got four young children. They're all at home still. And my last boy, he's only age 12 and I'm really concerned about, you know, their future. Sometimes I worry about the family and things like that….

A review of the transcribed interviews suggested that the cumulative effect of experiences subsumed under social dignity inventory (e.g. loss of privacy boundaries, lack of social support, poor care tenor, a strong sense of being a burden to others and numerous aftermath concerns) would diminish an individual's sense of dignity.

The poignancy of the term *dignity* was also apparent when patients were asked whether dignity was something internally held, rather than externally bestowed or withdrawn. While the theoretical distinction between these ideas has been explored elsewhere (Pullman, 1996; Madan, 1992; Sampaio, 1992), actually asking this question of patients elicited strong opinions from most, with a difference noted between outpatients and those cared for within the hospital setting. Outpatients were more likely than hospital patients to state that dignity was intrinsically held and could not be taken away. In fact, nearly every patient receiving care in the community endorsed this internally held notion of dignity. On the other hand, nearly two-thirds of patients receiving care in hospital expressed the belief that dignity could be taken away by others. Some hospitalized patients expressed frustration when they perceived that their care and treatment stripped them of their dignity. The discordance between these two groups of patients' perceptions of dignity may be a product of the greater degree of personal autonomy afforded outpatients. This finding suggests that patients who are cared for in hospitals or other institutional settings are more vulnerable than outpatients to experiencing a fractured sense of dignity.

Proposed model of dignity

The results of this study provide the basis for a developing conceptual model of dignity, comprised of three main categories. These categories include illness-related issues, dignity conserving repertoire, and social dignity inventory. The themes and sub-themes under each of the three broad categories provide detail that helps to articulate these issues. One proposed model suggests that the inter-relatedness of these themes is as illustrated schematically in Fig. 1. The outcome concept in this model is dignity. Both burdensome illness-related concerns and a taxing social dignity inventory are shown

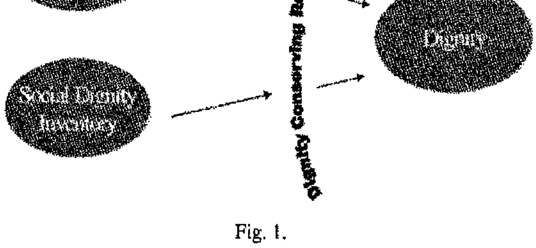


Fig. 1.

as having a deleterious effect on dignity. The model also shows that these negative influences might be buffered by a positive dignity conserving repertoire that includes dignity conserving perspectives and/or dignity conserving practices. In contrast, the model postulates that individuals with a limited dignity conserving repertoire would be more likely to have a diminished sense of dignity.

Discussion

This study provides information on the issue of dignity in patients who are terminally ill. There are limits to the generalizability of our findings. First, the patient group was composed largely of older individuals. Hence, it is unclear whether perceptions of dignity would have been different amongst younger patients facing similar life-limiting conditions, or if there are age specific issues that might influence one's sense of dignity. Second, all members of the patient group were in an advanced stage of terminal cancer. It cannot be assumed that perceptions of dignity or factors influencing it would be identical for patients dying from other illnesses, such as AIDS, progressive neuromuscular disorders, or advanced cardiac and respiratory conditions. Finally, the model of dignity generated in this study was arrived at through cross-sectional data. Given that advancing illness fluctuates in its clinical presentation, perceptions of dignity may be similarly dynamic and subject to change. While this may or may not influence the general model of dignity proposed, it could very well change the order of priority among the various dignity categories, themes and sub-themes and their ability to influence dignity at any given point in time. We thus offer our model as one that requires further testing and refinements within the context of future empirical end-of-life care research.

Patients in the study had no trouble identifying issues that might impinge upon or enhance their sense of dignity. The term *dignity* evoked stories and anecdotes, and was described as meaningful to them. Patients provided countless examples of times when the behaviours of family, friends, and health providers served to enhance or diminish their dignity. Patients also shared descriptions about those things that gave their life meaning in the face of impending death, and named the essential life activities, attitudes, and self-philosophies that fostered their feelings of personal dignity. For many patients, particularly those in hospital and those with more debility, life without dignity was described as a life no longer worthy of living. For those patients less encumbered by illness, a personal sense of dignity was inseparable from life itself. Thus, the concept of dignity and the dignity model may offer a way of understanding how patients navigate the wish to go on living—or the wish to die—in the face of an advancing terminal illness.

The word *dignity* is frequently used both in clinical and philosophical discourse when referring to and describing the ideal conditions of the patient's treatment, particularly the dying patient. In Johnston's (1998) review, he observes that the term *dignity* is often applied in an ambiguous manner. Perhaps this helps explain why patients in our study used the term *dignity* in reference to a broad range of concerns, feelings and activities, subsumed with the three broad categories of the proposed dignity model, as previously described. Terms such as pride, self-respect, quality of life, well being, hope and self-esteem all overlap conceptually with the term *dignity*, and the way in which dying patients use the term in reference to their circumstances. While most of these terms refer to internal states of mind, dignity is distinctive in that it also has an external component based on the perception of one's worthiness of honour and esteem from others. This is consistent with the proposed dignity model, which sees dignity mediated via internal, bodily (dignity conserving repertoire and illness-related concerns, respectively), and external factors (social dignity inventory). Johnston concludes that rather than viewing death with dignity as a separate construct, it might be viewed as an interactive process between the dying and their caretakers. This would appear to be consistent with the proposed model of dignity arrived at in this study.

When it comes to addressing distress that reaches beyond the typical symptom distress paradigm, the current range of therapeutic options available to palliative care providers may seem limited. This model invites the clinician to consider a broader range of intervention options, based on an understanding of sources of distress that may infringe upon the patient's sense of dignity. Each aspect of the model may provide direction about how to care for patients nearing death in a way that is most likely to bolster or preserve their sense of dignity. The illness-related concerns component of the model dictates the need for attentive management of physical and psychological symptoms. Illness-related concerns such as pain have been shown to be positively associated with depression, anxiety (Breitbart, Jaramillo, & Chochinov, 1998; Derogatis et al., 1983) mood disturbance (Speigel & Bloom, 1983) and psychological adaptation (Weisman & Worden, 1995; Breitbart, Bruera, Chochinov, & Lynch, 1995). Symptom distress is obviously a central concern to many patients with an advanced malignancy. For most, it is a defining characteristic of the cancer experience (Caraceni & Portenoy, 1999; Portenoy et al., 1994; Wanzer et al., 1989). Within this framework, a range of activities such as systematically attending to a delirium as a way of maintaining cognitive acuity, treating pain, and providing information about treatment options could all be conceived of as part of dignity conserving care. Practitioners working within the illness-related concerns domain of the model would be attentive to possible death anxiety and offer information concerning the anticipated medical course and way in which the end stages of the illness can be managed.

The dignity conserving repertoire aspect of the model offers insight into how to provide dignity conserving care, and possibly how in turn to develop dignity specific interventions. The sub-theme, dignity conserving perspectives, provides a number of different approaches that might be employed to help dying patients preserve their sense of dignity. Clinical applications may be used to help patients adopt or expand their perspective on their illness situation. For example, patients who are given opportunities to maintain autonomy by participating in decisions about their care, or contributing something that might serve as a lasting legacy for their family (e.g., life narrative, painting, etc.), may feel that their sense of dignity has been honoured and enhanced. Thus, care that inherently recognises the value of individuals and tends to the patient with respect, all falls under the rubric of dignity conserving care. This aspect of the model might also direct the clinician to help patients to adopt dignity conserving practices. For example, engaging patients in familiar daily routines, or supporting them in seeking out spiritually resonant sources of support might be effective ways of enhancing their dignity conserving practices.

Studies of social support in terminally ill cancer patients have shown that perceptions of support are significantly related to psychological adjustment (Dobratz, 1993; Plumb & Holland, 1977). The social dignity inventory component of the model suggests that safeguarding the patient's privacy, offering or bolstering social support (by involving family, health care providers, spiritual practitioners) and doing so with a tone of care that denotes respect and empathy for the patient is fundamental to dignity preserving care. Similarly, the social dignity inventory aspect of the model guides the clinician to support the patient in attending to personal affairs (e.g. the making or reviewing of a will, leaving final instructions, making funeral arrangements).

One of the most compelling reasons for addressing the issue of dignity lies in the fact that prior studies have documented loss of dignity as the most common response given by physicians when asked why their patients had selected euthanasia or some form of self-assisted suicide. Physicians cited loss of dignity in 50–60% of cases, followed by pain in 40–50% of cases (Pannuti & Tanneberger, 1993; Van der Maas et al., 1991). Meier and colleagues (1998) reported that loss of dignity was the second only to discomfort other than pain as the reason why physicians complied with requests for physician-assisted suicide or euthanasia. Thus, loss of dignity may be a part of a common pathway leading some dying patients to lose their will to live (Chochinov, Tataryn, Clinch, & Dudgeon, 1999).

The research literature describing patients' preferences for hastened death has demonstrated that patients have less desire to continue living if they are depressed or feel hopeless (Chochinov et al., 1995; Chochinov, Wilson, Enns, & Lander, 1998; Ganzini, Johnston, & Hoffman, 1999). Because loss of dignity may enhance depression, hopelessness, and a desire for hastened death, an understanding of the relationship between dignity and these psychosocial variables is important to the overall management of terminally ill patients, particularly those being managed in hospital settings. Further empirical research is necessary to develop and evaluate interventions that promote dignity and the quality of life of dying patients. Whether lost dignity leads to a wish for hastened death, or merely explains the patient's compromised quality of life, understanding dignity offers an opportunity to respond more sensitively and purposefully to those nearing death.

Acknowledgements

Supported by grants from the National Cancer Institute of Canada with funding from the Canadian Cancer Society and the Open Society Institute, Project on Death in America.

References

Abiven, M. (1991). Dying with dignity. *World Health Forum, 12*, 375–381.

Back, A. L., Wallace, J. I., Starks, H. E., & Pearlman, R. A. (1996). Physician-assisted suicide and euthanasia in Washington state: Patient requests and physician responses. *Journal of the American Medical Association, 275*, 919–925.

Brant, J. M. (1998). The art of palliative care: Living with hope, dying with dignity. *Oncology Nursing Forum, 25*, 995–1004.

Breitbart, W., Bruera, E., Chochinov, H., Lynch, M. (1995). Neuropsychiatric syndromes and psychological symptoms in patients with advanced cancer. *Journal of Pain Symptom Management, 10*.

Breitbart, W., Jaramillo, J., & Chochinov, H. M. (1998). Palliative and terminal care. In J. Holland (Ed.), *Textbook of psycho-oncology* (pp. 437–449). New York: Oxford University Press.

Bronstein, J. M., & Jones, C. A. (1986). Ethics, technology, and the high cost of dying: A public forum. *Southern Medical Journal, 79*, 1485–1488.

Caraceni, A., & Portenoy, R. K. (1999). An international survey of cancer pain characteristics and syndromes. IASP Task Force on Cancer Pain. International Association for the Study of Pain. *Pain, 82*, 263–274.

Chochinov, H. M., Tataryn, D., Clinch, J. J., & Dudgeon, D. (1999). Will to live in the terminally ill. *Lancet, 354*, 816–819.

Chochinov, H. M., Wilson, K. G., Enns, M., Mowchun, N., Lander, S., Levitt, M., & Clinch, J. J. (1995,). Desire for death in the terminally ill. *American Journal of Psychiatry*, *152*, 1185–1191.

Chochinov, H. M., Wilson, K. G., Enns, M., & Lander, S. (1998,). Depression, hopelessness, and suicidal ideation in the terminally ill. *Psychosomatics*, *39*, 366–370.

Coppens, M. (1998). Death with dignity. *American Journal of Nursing*, *98*, 23.

Council on Scientific Affairs (1996). Good care of the dying patient. American Medical Association. *JAMA*, *275*, 474–478.

Derogatis, L. R., Morrow, G. R., & Fetting, J., et al. (1983). The prevalence of psychiatric disorders among cancer patients. *JAMA*, *249*, 751–757.

Dobratz, M. C. (1993). Causal influences of psychological adaptation in dying. *Western Journal of Nursing Research*, *15*, 708–729.

Emanuel, E. J., Fairclough, D. L., Daniels, E. R., & Clarridge, B. R. (1996). Euthanasia and physician-assisted suicide: Attitudes and experiences of oncology patients, oncologists, and the public. *Lancet*, *347*, 1805–1810.

Field, P., & Morse, J. M. (1985). *Nursing research: The application of qualitative research methods*. London: Croom Helm.

Fox, D. J. (1982). *Fundamentals of research in nursing* (4th ed.). Toronto: McGraw-Hill.

Ganzini, L., Johnston, W. S., & Hoffman, W. F. (1999). Correlates of suffering in amyotrophic lateral sclerosis. *Neurology*, *52*, 1434–1440.

Ganzini, L., Nelson, H. D., Schmidt, T. A., Kraemer, D. F., Delorit, M. A., & Lee, M. A. (2000). Physicians' experiences with the Oregon Death with Dignity Act. *New England Journal of Medicine*, *342*(8), 557–563.

Geyman, J. P. (1983). Dying and death of a family member. *The Journal of Family Practice*, *17*, 125–134.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine.

Kade, W. J. (2000,). Death with dignity: A case study. *Annals of Internal Medicine*, *132*, 504–506.

Johnson, P. R. (1998). An analysis of dignity. *Theoretical Medicine & Bioethics*, *19*, 337–352.

Latimer, E. (1991). Caring for seriously ill and dying patients: The philosophy and ethics. *Canadian Medical Association Journal*, *144*, 859–864.

Madan, T. N. (1992). Dying with dignity. *Social Science & Medicine*, *35*, 425–432.

Meier, D. E., Emmons, C. A., Wallenstein, S., Quill, T., Morrison, R. S., & Cassel, C. K. (1998). A national survey of physician-assisted suicide and euthanasia in the United States. *New England Journal of Medicine*, *338*, 1193–1201.

Pannuti, F., & Tanneberger, S. (1993). Dying with dignity: Illusion, hope, or human right? *World Health Forum*, *14*, 172–173.

Pickett, M. (1993). Cultural awareness in the context of terminal illness. *Cancer Nursing*, *16*, 102–106.

Plumb, M. M., & Holland, J. F. (1977). Comparative studies of psychological function of patients with advanced cancer. *Psychosomatic Medicine*, *39*, 264–276.

Portenoy, R. K., Thaler, H. T., Kornblith, A. B., Lepore, J. M., Friedlander-Klar, H., Coyle, N., Smart-Curley, T., Kemeny, N., Norton, L., & Hoskins, W., et al. (1994). Symptom prevalence, characteristics and distress in a cancer population. *Quality of Life Research*, *3*, 183–189.

Pullman, D. (1996). Dying with dignity and the death of dignity. *Health Law Journal*, *4*, 197–219.

Quill, T. E. (1994). Physician-assisted death: Progress or peril? *Suicide and Life-Threatening Behavior*, *24*, 315–325.

Sampaio, L. (1992,). To die with dignity. *Social Science & Medicine*, *35*, 433–441.

Speigel, D., & Bloom, J. R. (1983). Pain in metastatic breast cancer. *Cancer*, *52*, 341–345.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Sage: Newbury Park.

Sullivan, A. D., Hedberg, K., & Fleming, D. W. (2000). Legalized physician-assisted suicide in Oregon—the second year. *New England Journal of Medicine*, *342*, 598–604.

Van der Maas, P. J., Van Delden, J. J. M., Pijnenborg, L., & Looman, C. W. N. (1991). Euthanasia and other medical decisions concerning the end of life. *Lancet*, *338*, 669–674.

Wanzer, S. H., Federman, D. D., Adelstein, S. J., Cassel, C. K., Cassem, E. H., Cranford, R. E., Hook, E. W., Lo, B., Moertel, C. G., & Safar, P., et al. (1989). The physician's responsibility toward hopelessly ill patients. A second look. *New England Journal of Medicine*, *320*, 844–849.

Weisman, A. D., & Worden, J. W. (1975). Psychosocial analysis of cancer deaths. *Omega*, *6*, 61–75.

"HMC-5" This is the exhibit marked "**HMC-5**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

VOLUME 22 · NUMBER 7 · APRIL 1 2004

JOURNAL OF CLINICAL ONCOLOGY

THE ART OF ONCOLOGY
When the Tumor Is Not the Target

Dignity and the Eye of the Beholder

Harvey Max Chochinov

From the Department of Psychiatry, University of Manitoba and the Manitoba Palliative Care Research Unit, CancerCare Manitoba, Winnipeg, Manitoba, Canada.

Submitted December 16, 2003; accepted December 23, 2003.

Author's disclosures of potential conflicts of interest are found at the end of this article.

Address reprint requests to Harvey Max Chochinov, MD, PhD, FRCPC, Manitoba Palliative Care Research Unit, CancerCare Manitoba, Room 3021, 675 McDermot Ave. Winnipeg, Manitoba R3E 0V9, Canada; e-mail: harvey.chochinov@cancercare.mb.ca.

DOI: 10.1200/JCO.2004.12.095

Here's the Case

Mr. J was a 67-year-old man with an end-stage gastrointestinal malignancy. Having decided he no longer wished to go on living, he had gone on a hunger strike, precipitating an admission to an inpatient tertiary palliative care unit. He reported that, aside from some minor discomforts, his symptom management was quite reasonable. Psychiatric consultation was initiated to determine if depression might be a factor influencing his wish to die. While he was not overtly suicidal, and in fact seemed ambivalent about his wish to die, he did state, "if I were in a European country where I could 'press the button now,' I would." After careful evaluation, it was determined that rather than depression, the driving force behind his desire for death was a sense that life no longer held purpose, meaning, nor hope. While he spoke of a lingering wish to participate in various life activities, he bemoaned the fact that his body was simply too weak and too ill to allow him to do so. That being the case, he expressed the conviction that living had become redundant, his life had no worth, and there was little reason for him to carry on.

How can we offer comfort to patients whose distress is primarily in the realm of the existential, or beyond the reach of an easily administered psychopharmaceutical or analgesic drug? While these matters are often deferred to the expertise of pastoral care professionals, there is a growing movement—particularly in reference to dying patients—for physicians to expand their caring with attentiveness to psychosocial, existential, or spiritual suffering.[1-3] In the absence of a clinical depression or formal psychiatric disorder, the paucity of therapeutic options or formatted approaches can leave oncology practitioners at somewhat of a loss. There may be aspects of despair toward the end of life that may be inherent to the dying process itself. If such distress is not primarily an aberration of neurochemistry, but rather reflects a paucity of hope, meaning, and self worth, what can be done to safeguard or enhance those life-sustaining attributes? And if loss of meaning, hope, and self-worth are the essence of such despair, what implications does this have for palliative care providers?

The Wish to Die

The expression of a desire for death, or of a loss of will to live, is often misconstrued as being synonymous with a request for euthanasia or assisted suicide. There is good evidence, however, that in the context of advanced illness, desire for death can be thought of along a continuum. At its most extreme, desire for death is synonymous with suicidal intent and preoccupation with the wish to die. Far more common, however, are the many patients who, over the course of their cancer illness, experience occasional and fleeting thoughts that not awakening to another day might offer the kind of escape and comfort they perceive life can no longer provide.[4,5] People tire of pain, disability, changing roles, mounting losses, and fewer prospects for remediation. In the face of depression, poor symptom control, and lack of appropriate supports, these thoughts can become overwhelming. Conversely, in response to appropriate palliation and the rallying of a community of support, thoughts about the wish to die can dramatically recede.[4-10]

A variety of studies over the last decade have attempted to profile those patients whose distress has led to a request for hastened death.[4-9,11,12] The social policy implications of these studies aside, the implications for practitioners attempting to provide quality end of life care are substantial. This literature has provided clear evidence that patients expressing a consistent wish to die are most often burdened by various physical symptoms (particularly pain, dyspnea, and fatigue), psychological symptoms (especially depression), lack of social support, along with various existential concerns (especially worries about being a burden to others), losing control, hopelessness, and general concern that the future only holds a worsening of their distress.

But what does it mean to be hopeless in the face of a hopeless prognosis? Several studies have reported that hopelessness is an ardent predictor of suicidal ideation, even among the terminally ill, and that hopelessness is usually most pronounced in patients meeting criteria for major depression.[13-15] While depression is present in a minority of dying patients (10% to 25%, depending on what criteria are used and the manner in which they are applied), neither hopelessness nor depression define the experience of most individuals nearing death.[16] If hopelessness is not based on prognostic expectation, how is it then to be understood?

Dignity in the Terminally Ill

To broach the question of hope in patients with advanced illness, we must look toward the broader notion of what it means to die with dignity. Several studies have drawn a connection between loss of dignity toward the end of life and a wish to die. Some Dutch studies have reported that loss of dignity, according to physicians, is the most highly cited reason why patients seek out and receive assistance hastening their death.[11] The topic of dignity, however, has not been extensively researched, and most often enters palliative care discourse within the context of social policy and philosophical or religious considerations. Thus, while many caregivers give lip service to the idea of providing care that preserves dignity at the end of life, few specifically target maintained dignity as an objective standard of quality end of life care.

Over the last 5 years, some of the first studies have been published regarding the issue of dignity among the dying.[17-19] One such study examined a cohort of 213 terminal cancer patients, with a life expectancy of less than 6 months, asking them to rate their sense of dignity.[17] Of these patients, only 16 patients (7.5%) indicated that loss of dignity was a significant concern. These patients were far more likely to have significantly increased pain, decreased quality of life, difficulty with bowel functioning, heightened dependency needs (bathing, dressing, incontinence), loss of will to live, increased desire for death, depression, hopelessness, and anxiety. This report also noted that the issue of appearance seemed to highly correlate with perceptions of personal dignity. For those near the end of life, the notion of appearance extended beyond mere looks, and included their own perception of how they are seen by others.

Mr J, being a man with an end-stage bowel malignancy, had many of the various medical problems that go along with this diagnosis. However, to have known him only in this capacity would have overlooked his core identity, and placed his sense of dignity in jeopardy. If care provider perception is limited to gastrointestinal considerations, then the patient's perception of how he is perceived—accurately—is as an advanced bowel malignancy. Therefore, appreciation and acknowledgment of his personhood or core identity as father, grandfather, husband, and someone with a diverse range of interests, can serve to alter the perception of those looking after Mr J, offering him the comfort of knowing that his core identity has been acknowledged and affirmed.

The Dignity Model

An empirically based model of dignity in the terminally ill has been developed (Fig 1).[18,19] This model provides caregivers a therapeutic map, incorporating a broad range of physical, psychological, social, and existential issues that may affect individual perceptions of dignity. While many palliative care clinicians provide empathic care, the Dignity Model offers a broad framework that can be used to inform dignity-conserving care.

Three major categories have emerged from qualitative analysis of dying patients perceptions of their sense of dignity,[18,19] including: (1) Illness-Related Issues; (2) Dignity Conserving Repertoire; and (3) Social Dignity Inventory. These categories refer to broad issues that determine how individuals experience a sense of dignity in the course of their approaching death. Each of these categories contains several carefully defined themes and sub-themes, serving as the foundation for a model of understanding dignity amongst the dying.

Illness-Related Issues and Concerns

These are issues that derive from the illness itself, and threaten to, or actually do, impinge on the patients' sense of dignity. The defining characteristic of these issues is that they are illness mediated, and very specific to the patient's illness experience. The two broad themes subsumed within this category consist of "Level of Independence" (which is determined by one's ability to maintain cognitive acuity, as well as functional capacity, referring to the ability to perform daily living tasks), and "Symptom Distress." Symptom distress was further divided into the subthemes of

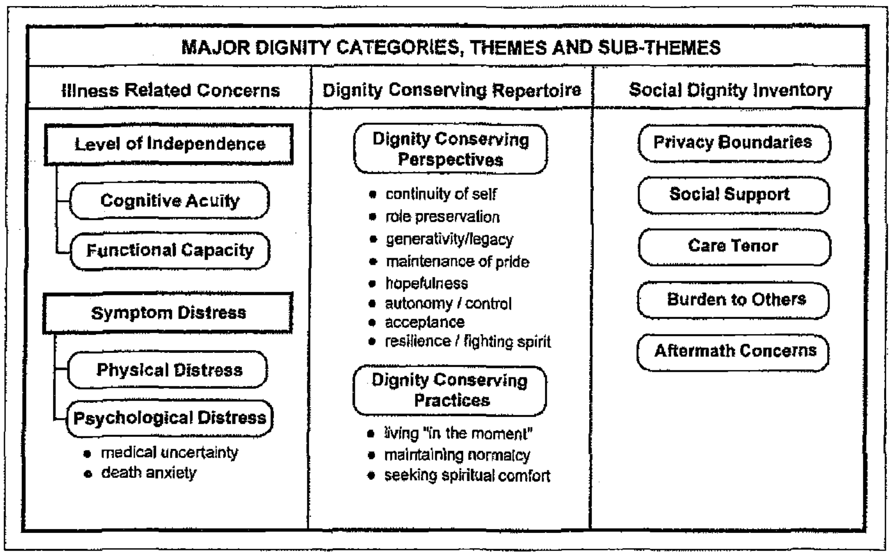


Fig 1. Reprinted with permission from Social Science and Medicine, Vol 54, No 3, pp 433-443, Chochinov et al: "Dignity in the terminally ill: An empirical model." Copyright 2002, with permission from Elsevier.

physical distress and psychological distress. Psychological distress was divided into the following sub-themes: (1) uncertainty (ie, the distress associated with the uncertainties of ones health status) and (2) death anxiety (ie, worry or fear specifically associated with the process or anticipation of death and dying).

Dignity Conserving Repertoire

The second major category that emerged was the Dignity Conserving Repertoire. This category was divided into two major themes, including Dignity Conserving Perspectives and Dignity Conserving Practices.

Dignity Conserving Perspectives are internally held qualities, or a world view consisting of eight sub-themes, including (1) continuity of self (a sense that the essence of who one is continues to remain intact, despite one's advancing illness), (2) role preservation (the ability to continue to function in usual roles, as a way of maintaining a sense congruence with prior views of self), (3) generativity/legacy (the solace and comfort in knowing that something lasting of oneself will transcend death), (4) maintaining pride (the ability to maintain a positive sense of self regard or respect), (5) maintaining hope (an ability to see life as enduring, or having sustained meaning or purpose), (6) autonomy/control (a sense of control over one's life circumstances), (7) acceptance (the internal process of resigning one's self to changing life circumstances), and (8) resilience/fighting spirit (the mental determination to overcome illness-related concerns and optimize quality of life).

Dignity Conserving Practices refer to a variety of personal approaches or techniques that patients used to bolster or maintain their sense of dignity. Three components of theses practices were identified: "Living in the Moment" (focusing on immediate issues or tasks in the service of not worrying about the future), "Maintaining Normalcy" (continuous or routine behaviors, which help individuals manage day-to-day challenges), and "Seeking Spiritual Comfort" (turning toward or finding solace in one's religious or spiritual belief system).

Social Dignity Inventory

This refers to the quality of interactions with others that enhance or detract from one's sense of dignity. The defining characteristic of this inventory is that it refers to external sources or issues that nevertheless impinge on a patient's sense of dignity. Five primary inventory themes were identified, including: (1) "Privacy Boundaries" (the extent to which one's personal environment is encroached on during the course of receiving care or support), (2) "Social Support" (the presence of an available and helpful community of friends, family, or health care providers), (3) "Care Tenor" (the attitude others demonstrate when interacting with the patient that may or may not promote dignity), (4) "Burden to Others" (the distress engendered by having to rely on others for various aspects of one's personal care or management), and (5) "Aftermath Concerns" (the worry or fears in anticipation of the burden or challenges that one's death will impose on others).

This Dignity Model provides an empirically derived theoretical framework, helping us understand the notion of dignity in those nearing death. Furthermore, it provides a foundation on which to both understand how a dying patient may experience a waning of their dignity, and, in turn, provides direction for how to construct dignity-enhancing

Table 1. Dignity Psychotherapy Question Protocol

Tell me a little about your life history; particularly the parts that you either remember most, or think are the most important? When did you feel most alive?
Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
What are the most important roles you have played in life (family roles, vocational roles, community service roles, etc)? Why were they so important to you, and what do you think you accomplished in those roles?
What are your most important accomplishments, and what do you feel most proud of?
Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?
What are your hopes and dreams for your loved ones?
What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, other(s))?
Are there words or perhaps even instructions you would like to offer your family, to help prepare them for the future?
In creating this permanent record, are there other things that you would like included?

NOTE. Reprinted with permission from the Journal of the American Medical Association, Vol 287, pp 2253–2260, 2003. Copyrighted 2003, American Medical Association. All rights reserved.

interventions for patients nearing death. One such intervention, for example, is a brief psychotherapeutic intervention called Dignity Psychotherapy. This approach is comprised of tape-recorded sessions, which gives patients the opportunity to speak to aspects of life of which they feel proudest, things they feel are, or were, most meaningful, and their personal history they would most want remembered. They are also able to speak about what they might provide in the service of helping to look after their soon-to-be bereft loved ones (Table 1). These sessions are transcribed, edited, and returned to the patient, thereby bolstering the patient's sense of purpose, meaning, and worth, while tangibly experiencing their thoughts and words as having continued value, and satisfying their generativity needs.

Mr J was invited to participate in the Dignity Psychotherapy clinical trial. From the moment he agreed to do so, he indicated that he would defer any decision to "push the button, at least not until this task was completed." He used this therapeutic trial, mere days before his natural death, as an opportunity to share recollections about his own parents; the trials of living through a devastating war; life as an immigrant; getting married and developing a vocation; the deep and tragic losses that continued to weigh heavily; and the joyful pride he took in his children, grandchildren, and extended community. The role of the therapist was to gently facilitate these poignant disclosures, and to convey the message that Mr J's words, thoughts, and feelings were important, and that the task of sharing these disclosures was profoundly meaningful.

In the absence of such a trial, how might a health care provider otherwise attend to Mr J's distress? While his suffering is considerable, it does not appear to solicit a specific medical response. Intuitively, what might be done? Likely, little time would pass before a care provider would take a seat at the bedside and begin to talk, or perhaps simply listen. And what might be said or heard? The first words would likely be questions about what is happening to him, what matters to him, how he understands what is taking place. Perhaps the care provider might find himself or herself listening to some personal or intimate thought or reflection. In either case, the provider's presence holds tremendous therapeutic power; by taking a place at the bedside, whether asking questions about what matters, or listening to heartfelt disclosures, the provider becomes the beholder. By listening to patients, our perception of who they are extends beyond the confines of their illness, thereby shifting the patient's perception of how they are seen and heard. Validation of their concerns and ascribing meaning to their experience, according to the Dignity Model, can bolster hope, even for those whose illness has long since extended beyond the reach of cure. The reflection that patients see of themselves in the eye of the care provider must ultimately affirm their sense of dignity. At least in part, it would appear, dignity resides in the eye of the beholder.

■ ■ ■

Author's Disclosures of Potential Conflicts of Interest

The author indicated no potential conflicts of interest.

REFERENCES

1. Thiel MM, Robinson MR: Physicians' collaboration with chaplains: Difficulties and benefits. J Clin Ethics 8:94-103, 1997

2. Post SG, Puchalski C, Larson DB: Physician and patient spirituality: Professional boundaries, competency, and ethics. Ann Intern Med 132:578-583, 2000

3. Lo B, Quill T, Tulsky J: Discussing palliative care with patients. ACP-ASIM end-of-life care consensus panel. American College of Physicians-American Society of Internal Medicine. Ann Intern Med 130:744-749, 1999

4. Chochinov HM, Wilson K, Enns M, et al: Desire for death in the terminally ill. Am J Psychiatry 152:1185-1191, 1995

5. Chochinov HM, Tataryn D, Dudgeon D, et al: Will to live in the terminally ill. Lancet 354:816-819, 1999

6. Back AL, Wallace JI, Starks HE, et al: Physician-assisted suicide and euthanasia in

Washington state: Patient requests and physician responses. JAMA 275:919-925, 1996

7. Emanuel EJ, Fairclough DL, Daniels ER, et al: Euthanasia and physician-assisted suicide: Attitudes and experiences of oncology patients, oncologists, and the public. Lancet 347:1805-1810, 1996

8. Ganzini L, Nelson HD, Schmidt TA, et al: Physicians' experiences with the Oregon Death with Dignity Act. N Engl J Med 342:557-563, 2000

9. Meier DE, Emmons CA, Wallenstein S, et al: A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 338:1193-1201, 1998

10. Sullivan AD, Hedberg K, Fleming DW: Legalized physician-assisted suicide in Oregon--the second year. N Engl J Med 342:598-604, 2000

11. Van der Maas PJ, Van Delden JJM, Pijnenborg L, et al: Euthanasia and other medical decisions concerning the end of life. Lancet 338:669-674, 1991

12. Wilson KG, Scott JF, Graham ID, et al: Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide. Arch Intern Med 160:2454-2460, 2000

13. Chochinov HM, Wilson KG, Enns M, et al: Depression, hopelessness, and suicidal ideation in the terminally ill. Psychosomatics 39:366-370, 1998

14. Breitbart W, Rosenfeld B, Pessin H, et al: Depression, hopelessness, and desire for hastened death in terminally ill cancer patients. JAMA 284:2907-2911, 2000

15. Breitbart W, Rosenfeld B, Passik S: Interest in physician assisted suicide among ambulatory HIV infected patients. Am J Psychiatry 153:238-242, 1996

16. Chochinov HM, Wilson KG, Enns M, et al: Prevalence of depression in the terminally ill: Effects of diagnostic criteria and symptom threshold judgements. Am J Psychiatry 151:537-540, 1994

17. Chochinov HM, Hack T, Hassard T, et al: Dignity in the terminally ill: a cross sectional cohort study. Lancet 360:2026-2030, 2002

18. Chochinov HM, Hack T, McClement S, et al: Dignity in the terminally ill: An Empirical Model. Soc Sci Med 54:433-443, 2002

19. Chochinov HM: Dignity conserving care: A new model for palliative care. JAMA 287:2253-2260, 2002

"HMC-6"

This is the exhibit marked "HMC-6" referred to in the affidavit of **Harvey Max Chochinov** affirmed at this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

Desire for Death in the Terminally Ill

**Harvey Max Chochinov, M.D., Keith G. Wilson, Ph.D., Murray Enns, M.D.,
Neil Mowchun, M.D., Sheila Lander, R.N., Martin Levitt, M.D., and Jennifer J. Clinch, M.A.**

Objective: Euthanasia and physician-assisted suicide have become prominent medical and social issues. This study investigated the prevalence of the desire for death in terminally ill patients, the stability of this desire over time, and its association with psychiatric disorders. Method: Two hundred terminally ill inpatients were given semistructured interviews that assessed their desire for death and evaluated them for major and minor depressive episodes according to the Research Diagnostic Criteria. Each patient also completed a short form of the Beck Depression Inventory and provided ratings of pain and social support. When possible, patients who expressed a desire for death received a follow-up interview after a 2-week interval. Results: Although occasional wishes that death would come soon were common (reported by 44.5% of the patients), only 17 (8.5%) of these individuals acknowledged a serious and pervasive desire to die. The desire for death was correlated with ratings of pain and low family support but most significantly with measures of depression. The prevalence of diagnosed depressive syndromes was 58.8% among patients with a desire to die and 7.7% among patients without such a desire. Follow-up interviews were conducted with six patients; in four cases, the desire to die had decreased during the 2-week interval. Conclusions: The desire for death in terminally ill patients is closely associated with clinical depression—a potentially treatable condition—and can also decrease over time. Informed debate about euthanasia should recognize the importance of psychiatric considerations, as well as the inherent transience of many patients' expressed desire to die.

(Am J Psychiatry 1995; 152:1185–1191)

Few problems in contemporary medicine have generated as much controversy as the issues of euthanasia and physician-assisted suicide. Among the general public, support for the "right to die" has grown steadily since the 1950s, with over 60% of the population now favoring the legalization of voluntary euthanasia for patients with terminal illness (1, 2). Within the medical community, concern has been raised in response to several highly publicized case reports in which physicians have complied with patients' requests for assisted death (3, 4). These cases have promoted a spirited debate (5–11), including the publication of proposed clinical criteria and procedural safeguards for euthanasia and physician-assisted suicide (12, 13). Recent surveys suggest that 35%–60% of responding physicians believe that laws prohibiting these practices should be changed (14–16); 28%–40% of physicians have reported that if euthanasia were legally condoned, they would be willing to perform it in some circumstances (14–17). In the Netherlands, where euthanasia has been decriminalized, 54% of physicians have acknowledged assisting in at least one death at the patient's request (18).

Although it is clear that euthanasia has a strong base of support, there remain a number of central issues that are still poorly understood. First, little is known about how common it is for terminally ill patients to desire death in order to relieve their suffering. In North America, overt requests for assisted death are apparently rare (15–17), but they might become more frequent with changes in social, medical, and legal policies. In the Netherlands, voluntary euthanasia and assisted suicide account for an estimated 2.1% of all deaths (18). Patients with advanced cancer constitute the majority of these cases; in this population, 6%–7% of patients eventually choose to die with physician assistance (18).

A second issue that requires clarification is the stability over time of the desire for death in patients who are

---

Received Nov. 2, 1994; revisions received Feb. 14 and March 21, 1995; accepted April 6, 1995. From the Departments of Psychiatry and Medicine, University of Manitoba; the Manitoba Cancer Treatment and Research Foundation, Winnipeg; the Department of Medicine and School of Psychology, University of Ottawa; the Rehabilitation Centre, Ottawa; and the World Health Organization Collaborating Centre for Quality of Life in Cancer Care, Winnipeg. Address reprint requests to Dr. Chochinov, Department of Psychiatry, University of Manitoba, 771 Bannatyne Ave., Winnipeg, Man. R3E 3N4, Canada.

Supported by grants from the Manitoba Cancer Treatment and Research Foundation and the Manitoba Mental Health Research Foundation.

The authors thank Mr. Kuldip Maini for statistical assistance.

terminally ill. This is an important consideration, because the act of euthanasia is irrevocable but is based on an assumption that the patient involved would never have had misgivings about this choice and eventually would have withdrawn the request. Hence, in any informed debate it is necessary to have some basic understanding of the temporal stability of the desire for death.

Third, there is a need for more information about the factors that influence terminally ill patients to desire death, especially the factors that might be remediable with medical or social intervention (19–21). Concerns about euthanasia and assisted suicide have been expressed in particular by mental health professionals, who have cautioned that the patients most likely to request assisted death would be "the elderly, those frightened by illness, and the depressed of all ages" (19). This concern is based on the view that a desire for death, even among the terminally ill, may be indicative of a potentially treatable psychiatric disorder (19, 20). Although leading proponents of the right to die sometimes dismiss this argument out of hand (22), in fact the limited psychiatric data that are available provide evidence that is consistent with it (23, 24). Similar concerns have been raised with respect to the roles of uncontrolled pain (19, 24–27) and various social factors that may undermine the capacity to cope (26, 27).

In the present study, we addressed these aspects of the euthanasia debate by conducting semistructured interviews with terminally ill patients to investigate the prevalence of the desire for death in this group, to examine the stability over time of this desire, and to determine its association with the putative risk factors of depression, pain, and low levels of social support.

METHOD

The study was approved by the ethical review committee of the University of Manitoba Faculty of Medicine. Prior to participation, all patients gave written acknowledgement of informed consent.

Patients were recruited from the palliative care units of two hospitals in Winnipeg, Man., Canada. A total of 868 patients with a primary medical diagnosis of terminal cancer were admitted to these units during the course of data collection. Following admission, each patient was given at least a week to accommodate to the ward routine before being approached for the study. The patient's medical status was then reviewed with the ward staff, who independently determined the patient's eligibility for the study on the basis of clinical consensus. Patients were not referred to the study if they were considered to be impaired cognitively (and unable to give informed consent) or were too gravely ill to take part in a detailed interview. Given the nature of the palliative care population, these were common reasons for exclusion and resulted in 653 patients (75.2%) being screened out. Of the 216 patients who were approached for participation, 16 (7.4%) refused. Thus, the final group of 200 patients (97 men and 103 women) represented 23.0% of all admissions. The median survival time from the date of initial interview to the date of death was 43 days.

Each patient underwent a semistructured diagnostic interview for depression that incorporated an assessment of the desire for death. In most cases, the interview was administered by a psychiatric nurse who had been trained in the protocol, although in some cases the interviewer was a psychiatrist or clinical psychologist.

The diagnostic interview was adapted from the Schedule for Affective Disorders and Schizophrenia (SADS) (28), a semistructured interview protocol designed to assist in the formulation of psychiatric diagnoses based on the Research Diagnostic Criteria (RDC) (29). Because of the need for a relatively brief screening procedure to use with severely ill patients, only the diagnosis of depression was considered. All SADS items relevant to the diagnosis of current major and minor depressive episodes were included in the interview, along with items pertaining to prior history of depression.

When evaluating current psychiatric symptoms with the SADS protocol, the interviewer was required to rate the severity of each symptom on 6- or 7-point scales. Trained psychiatric nurses show good concordance with psychiatrists' ratings in structured clinical judgments of this type (30). To establish the clinical significance of each individual criterion symptom of depression, we adhered to severity thresholds specified in DSM-III-R. An earlier report (31), based on a subset of the patients in the present study, found that this approach results in diagnostic classifications that are minimally confounded by the patients' medical illness.

To inquire about the desire to die, a specific item was written and incorporated into the diagnostic interview. This item asked, "Do you ever wish that your illness would progress more rapidly so that your suffering could be over sooner?" If the patient responded affirmatively to this lead item, a series of follow-up questions was administered to assist the interviewer in clarifying how serious and pervasive was the patient's desire to die. The follow-up included such questions as "Do you wish you were already dead?" "Do you pray for an early death?" "Have you discussed with anyone that your desire is to have an early death?" In keeping with the format of other SADS items, the interviewer scored the extent of the desire for death on a 6-point rating scale.

In addition to the diagnostic interview, each patient completed a brief battery of self-report scales to provide a more quantitative assessment of emotional distress, as well as to measure the extent of the patient's social support network and the level of pain. In most cases, these scales were administered orally or with assistance by the interviewer.

The short form (13 items) of the Beck Depression Inventory (32), an abbreviated version of the standard 21-item inventory (with which it is highly correlated), was used to measure affective distress. The short form was developed as a brief screening measure of depressive symptoms appropriate for use with medical patients.

The measurement of social support has become a central focus in recent stress research; it is based on the assumption that supportive interpersonal relationships provide a buffer against the adverse effects of stressful life experiences (33). A number of investigators have drawn distinctions between two conceptual dimensions of social support: the structural aspects of the support network (i.e., the number of supportive relationships that are available) and the extent of one's satisfaction with the degree of support provided by that network (34, 35). Both dimensions were addressed in the present study. Network availability was measured by having the patient indicate the number of family members and friends with whom he or she maintained regular weekly contact. Subjective ratings of the perceived supportiveness of these contacts were made with the use of 100-mm visual analog scales, anchored with the descriptions "Not at all supportive" and "Extremely supportive." Separate ratings were made for family members and friends. In addition, because the patients were residing in a palliative care facility in which the hospital staff could be expected to play an important supportive role, a further visual analog scale was included to assess the perceived supportiveness of the nursing staff.

Pain intensity was measured in two common formats taken from the Memorial Pain Assessment Card (36). The first was a verbal rating scale comprising seven descriptors of pain intensity ranging from "No pain" to "Excruciating." The second was a 100-mm visual analog scale anchored with the descriptors "Least possible pain" and "Worst possible pain." The patient was instructed to complete both scales with reference to the typical or average level of pain experienced while on the ward. Both types of ratings are used widely in pain research and are generally considered to provide reliable and valid indexes of pain severity (37).

After the initial interview, and in consultation with the ward staff involved in the care of the patient, the interviewer rated the patient's functional level on the Karnofsky Functional Performance Status

Scale (38). The Karnofsky scale is a clinician estimate of functional limitation due to illness, on which scores can range from 0 (indicating that the patient has died) to 100 (no functional limitation in activities of daily living).

A central issue in the euthanasia debate is the stability over time of the desire for death. In this study, this issue was addressed by conducting 2-week follow-up interviews with the patients who had expressed a desire to die at the initial assessment. The follow-up interview consisted of a readministration of the SADS.

In the statistical analyses, unadjusted responses from the first interview were used to determine the overall prevalence of the desire-for-death phenomenon. Demographic, psychiatric, and psychosocial correlates of the desire for death were then examined. Given the ordinal nature of the desire-for-death rating scale, a nonparametric procedure (Spearman's rank-order correlation) was used.

Correlations were computed initially across the entire study group. The measures showing a reliable association with desire-for-death ratings were then probed further by using t tests for independent groups. For these analyses, the subjects were divided into two subsets—those with and those without a desire for death to come soon—to create a categorical classification, as would be required in clinical decisions regarding euthanasia and assisted suicide. This dichotomous grouping was also used for the analyses of nominal data with chi-square procedures (with Yates's correction) or exact tests. The conjoint predictive value of the individual variables found to be associated with the desire for death was then examined using a stepwise multiple logistic regression procedure.

Unless otherwise specified, the criterion for statistical significance was set at $p<0.05$ in a two-tailed test.

RESULTS

The mean age of the patients was 70.9 years (SD=10.6, range=31–94). Primary tumor sites were the lung (25.5% of the 200 cases), gastrointestinal tract (19.5%), genitourinary system (13.0%), and female breast (11.5%). A further 9.0% of patients had hematologic malignancies, while the remainder (21.5%) had various solid tumors.

Prior to hospitalization, 50.0% of the study group had lived at home with their families or friends, 47.0% had lived alone, and 3.0% had been residents of other institutions. A total of 41.5% of the patients were married or living in common-law relationships, 34.5% were widowed, 16.0% were separated or divorced, and 8.0% had never been married.

Sixty-nine percent of the study group had less than a high school education, 12.0% were high school graduates, and 19.0% had some academic training beyond high school. The majority of patients identified themselves as members of Protestant religious faiths (66.0%), followed by Roman Catholicism (25.0%) and other religions (7.0%), while 2.0% of respondents indicated no religious affiliation.

The reliability of the interview ratings was determined by having a second rater attend a random sample of 27 interviews (13.5%). At the diagnostic level, the concordance between raters (kappa) in depression classification was 0.76. Ratings for individual symptoms of depression were also made reliably, with intraclass correlations ranging from 0.79 to 1.00. In the reliability sample, there was perfect concordance between raters in the scoring of the desire-for-death item.

The prevalence of the desire for death is shown in table 1. One patient refused to take part in this section of the interview (but completed other parts), thus reducing the size of the study group to 199 respondents.

TABLE 1. Distribution of Scores of 200 Terminally Ill Patients on a Desire-for-Death Rating Scale

Score	Definition	N	%
0	No information/refusal to answer	1	0.5
1	No desire to die soon	110	55.0
2	Slight desire (has had occasional fleeting thoughts)	60	30.0
3	Mild desire (often feels that he/she would like to die, but not always)	12	6.0
4	Moderate desire (has a genuine desire for death; has discussed this desire with others, but is not consumed with the prospect)	15	7.5
5	Strong desire (has difficulty diverting thoughts from the desire to die; prays for death)	1	0.5
6	Extreme desire (obsessed with the wish for death; talks of little else; asks for euthanasia; prays for death almost constantly)	1	0.5

As is evident in table 1, occasional wishes to die were reported to be common occurrences; 44.5% of the patients acknowledged at least fleeting desires for death. In most cases, however, these episodes were identified as brief experiences and did not reflect a sustained or seriously committed desire as would be required in euthanasia decisions.

To identify the patients with a serious or pervasive desire for death, a cutoff score of 4 or more on the desire-for-death rating scale was used. This corresponds to unequivocal reports by the patient that he or she hopes that death will come soon and that this desire is held in a consistent way over time. Such apparently genuine desires for death were reported by 17 patients, or 8.5% of the study group.

Patients with and without a desire for death did not differ (all p values >0.10) with respect to gender distribution, age, marital status (married/common-law versus other), living arrangements (alone versus other), education (less than high school versus high school or more), or religious affiliation (Protestant versus Roman Catholic).

There was a strong association between interviewer ratings on the desire-for-death scale and the presence of clinical depression on the basis of SADS diagnostic interviews (table 2). Across the entire study group, a total of 25 individuals (12.5%) met the RDC for either major depressive episodes (N=16, 8.0%) or minor depressive episodes (N=9, 4.5%). Of the patients expressing a serious desire for death, 58.8% were among those who received a diagnosis of depression (eight had major depression and two minor). Among the patients who had no desire for death, or who reported greater fluctuation in the strength of such wishes, the prevalence of depression was 7.7% (eight major depression and six minor).

In the study group as a whole, there was also a significant correlation between ratings on the desire-for-death scale and scores on the Beck Depression Inventory (which

TABLE 2. Psychiatric and Psychosocial Characteristics of 199 Terminally Ill Patients With or Without a Desire for Death

Variable	Patients With Desire for Death (N=17)		Patients Without Desire for Death (N=182)		Analysis
	N	%	*N*	%	
Current diagnosis of depression	10	58.8	14	7.7	χ^2=33.66, df=1, p<0.001[a]
Prior history of depression[b]	6	37.5	31	17.0	p=0.09, Fisher's exact test[c]
Moderate pain or greater	13	76.5	84	46.2	χ^2=4.57, df=1, p=0.03[d]
	Mean	*SD*	*Mean*	*SD*	
Beck Depression Inventory (short form) score[e]	14.1	8.2	6.4	4.0	t=–6.58, df=194, p<0.001
Pain score, visual analog scale	44.8	33.5	32.4	29.8	t=–1.62, df=197, p=0.11
Family members with weekly contact	3.4	3.1	3.2	3.0	t=–0.25, df=197, p=0.80
Friends with weekly contact	3.5	3.8	4.2	8.4	t=0.32, df=197, p=0.75
Family support score, visual analog scale	66.1	42.4	85.0	27.5	t=2.57, df=197, p=0.01
Friend support score, visual analog scale	61.4	38.8	69.9	36.1	t=0.92, df=197, p=0.36
Staff support score, visual analog scale	91.6	13.2	91.4	16.3	t=–0.06, df=197, p=0.95
Karnofsky Functional Performance Status Scale score	44.7	11.2	49.7	11.7	t=1.68, df=197, p=0.09

[a] Odds ratio=17.1, 95% confidence interval=5.0–60.0.
[b] N=16 for patients with a desire for death.
[c] Odds ratio=2.9, 95% confidence interval=0.9–9.6.
[d] Odds ratio=3.8, 95% confidence interval=1.1–14.4.
[e] N=16 for patients with a desire for death; N=180 for patients without a desire for death.

were available for only 196 patients) (r_s=0.29, N=196, p<0.001). As shown in table 2, subjects with and without a desire for death differed substantially on this self-report measure of depressive symptoms.

The robust association with current depressive symptoms leads to the hypothesis that the desire for death may occur with greater frequency among patients who have a particular vulnerability to depressive episodes, as might be reflected in psychiatric histories. This hypothesis received partial support, in the sense that prior histories of major depression (defined as depressive episodes with an onset more than 2 years from the time of the present interview) tended to be more common among the patients with a desire for death (table 2). However, the association was not strong, and most individuals expressing a desire to die (62.5%, or 10 of 16) indicated no history of previous depressive episodes.

To identify other psychosocial variables associated with the desire for death, a series of correlations was computed between desire-for-death ratings and ratings of pain, ratings of social support, and scores on the Karnofsky scale. Across the entire study group, significant positive correlations were found for both visual analog measures (r_s=0.20, N=199, p=0.004) and verbal ratings (r_s=0.19, N=199, p=0.009) of pain. Of the patients with a desire for death, 76.5% reported pain severity that was moderate or greater on the verbal rating scale, compared to 46.2% of the patients without a desire for death (table 2). However, not every patient with a desire for death reported a high pain level; in fact, three individuals (17.6%) reported no pain at all. Hence, comparisons based on visual analog ratings, which reflected this high degree of variability within groups, were not significantly different between patients with and without a desire for death (table 2).

The desire-for-death ratings were not correlated reliably with scores on the Karnofsky scale or with the structural aspects of the social support network (i.e., the number of family members and friends who maintained regular weekly contact with the patient). However, on the visual analog ratings of the degree of satisfaction with one's level of support from family, friends, and nursing staff, the rating of family support showed a small negative correlation, of marginal significance, with desire-for-death ratings (r_s=–0.13, N=199, p=0.06). This trend emerged more reliably in a direct comparison of the patients with and without a desire to die. As shown in table 2, patients classified as having a serious desire for death gave significantly lower ratings than other patients on the family support scale but not on the scales pertaining to friends and nursing staff.

In the univariate analyses, three main variables emerged as significant correlates of the desire for death: depression, pain, and low level of family support. To investigate the conjoint predictive value of these measures, a stepwise multiple logistic regression analysis was conducted in which Beck Depression Inventory scores, pain verbal ratings (coded dichotomously as moderate pain or greater versus less than moderate pain), and visual analog ratings of family support were included as independent variables. Beck Depression Inventory scores were entered first into the equation and emerged as a strong predictor of group classification (F=23.33, df=1, 193, p<0.001). However, subsequent entry of the pain and family support measures did not improve the accuracy of prediction. Scores on the Beck Depression Inventory showed significant collinearity with ratings of pain (r=0.33, N=196, p<0.001) and family support (r=–0.25, N=196, p<0.001). Hence, the latter two measures did not make a unique contribution to the regression model once the effect of Beck Depression Inventory scores had been removed.

Although 17 patients qualified for follow-up on the basis of their responses at the first assessment, in practice only six could be reinterviewed. The others had either died (N=4), become too ill to participate (N=4), or opted for discharge to home care and were not available for follow-up (N=3). The small number of remaining subjects precluded the application of formal statistical analysis, but patterns of individual response provide relevant preliminary information about the temporal stability of the desire for death.

Of the six patients who took part in both interviews, four showed a decline in their desire to die to the extent that they no longer scored above our operational cutoff for defining a serious and pervasive desire (i.e., a score of 4 or above on the desire-for-death rating scale). However, the other two individuals continued to report a sustained wish to die that remained above the criterion cutoff score.

These two patients arrived at a desire for death in quite different ways, and their experience helps to frame the terms of reference in the euthanasia debate. One was a 72-year-old married man with prostate cancer who indicated that he was in severe pain. His wife had also been diagnosed recently with a major illness that prevented her from visiting. This patient met the diagnostic criteria for major depression at both interviews and had a history of three prior episodes. He received the highest score on the desire-for-death rating scale of anyone in the study. He frequently prayed that his suffering would soon be ended by death, and he was the only study patient who had actually requested euthanasia. After the second interview, he lived for another 40 days.

The other patient was a 61-year-old married woman with lung cancer. She had good palliative symptom control and experienced no pain. She was not depressed at either interview and had no psychiatric history. Rather, she recognized that her life was coming to an end, and she hoped to die while she still retained her mental competence, reasonable bodily self-control, and what she perceived as an acceptable level of dignity. She died 9 days after the second interview.

DISCUSSION

This study provides information about the prevalence of the desire for death in the terminally ill, the stability over time of this desire, and selected psychiatric and psychosocial variables that are associated with it. Although the results are important for the ongoing debate regarding euthanasia, there are limits to which the findings can be generalized. First, the patient group was composed mostly of older individuals, all of whom were in an advanced stage of terminal cancer. Hence, it is not clear that the findings would be comparable with those for younger populations or for patients dying from other illnesses, such as AIDS, progressive neuromuscular disorders, or advanced cardiac and respiratory conditions. Second, it should also be noted that all of the study patients had opted to receive palliative care in an institutional setting organized around hospice principles. It has been suggested that people who are planning to end their lives by suicide might be less likely to accept this type of institutional care if it could be avoided (39). If so, they would have been underrepresented in the present study group. Third, the study group was restricted to those individuals who were mentally competent and well enough to respond to a detailed interview. This was a minority of the patients admitted to the participating units. However, the issue of euthanasia is largely addressed to the rights of competent individuals to specify the timing and circumstances of their death. In this context, the patients involved in the study appear to be representative of those at the center of the euthanasia debate. Finally, the median survival time of 43 days from the time of the initial interview indicates that for most patients, death was not immediately imminent. Although they were generally in their final weeks of life, they were not in their final hours, when concerns about the relief of unnecessary suffering may be all the more poignant (13, 40).

Even with these constraints, our findings are relevant to an understanding of who would be likely to make requests for euthanasia or physician-assisted suicide if these practices were to be given legal and medical sanction. The results indicate that occasional desires for death are very common among the terminally ill; they were acknowledged by 44.5% of the study group. In most cases, these were recognized as relatively transient occurrences; the more characteristic attitude was the desire to carry on with life. Nevertheless, at the initial interview, 8.5% of the patients reported an apparently sincere and sustained wish to die. Although only one of these patients had actually requested euthanasia, in a climate of greater accessibility to assisted death, this group as a whole would comprise those individuals most likely to make such requests. Recall that in the Netherlands, 6%–7% of patients with advanced cancer are choosing physician-assisted death (18).

When our study patients were followed prospectively, it was found that the desire for death could be quite variable over time. Over the course of a 2-week interval, four of the six patients who were reinterviewed showed a decrease in the extent of their desire to die. Clearly, it must be acknowledged that this is a small number of patients on whom to base generalizations. Furthermore, our epidemiologic approach to investigating the desire for death did not focus only on individuals who had actually made explicit euthanasia requests; thus, it remains to be determined whether this specific group would show greater temporal stability of the desire to die than was evident in the present study. Nevertheless, the potential significance of our preliminary finding is highlighted by a consideration of the Dutch experience with euthanasia. Although the Dutch guidelines are explicit with respect to the requirement that the request for an assisted death must be persistent over time (41–43), it has been reported that in practice, 65% of all euthanasia deaths occur within 2 weeks of the initial request (44). Again, the degree to which our study patients are similar to those receiving euthanasia in the Netherlands is uncertain, but the temporal instability of the desire for death that was observed in our group underscores the central importance of this criterion.

Patients who reported a serious desire for death at the initial interview differed from the rest of the study group on the dimensions of pain, family support, and depression, including a much higher prevalence of diagnosed depressive disorders. These findings provide empirical confirmation for the concerns raised by other authors (19–21, 23–26) that some of the factors leading to the desire for death may be remediable with improved pain management and the treatment of psychological distress. The role of depression in this context appears to be particularly important. We found that depression, pain, and low family support were significantly intercorrelated with one another, and in the logistic regression analysis, depression emerged as the only predictor of the desire for death. This suggests that depression may lie closest to the desire for death in a causal pathway in which pain and family support exert more indirect influences. That is, prolonged physical pain may increase the risk of depression, while supportive family relationships may protect against it. Once depression has developed, however, the emergence of a desire for death may be a more direct step.

Of all the issues that must be factored into the euthanasia debate, psychiatric considerations are likely to be among the most controversial. In the Netherlands, the official guidelines include mental suffering as a criterion that supports the medical decision for euthanasia, but not in circumstances where there is a reasonable prospect for improvement (40). In practice, this must be a difficult distinction to make without actually initiating a course of treatment. It has been reported that depression in the terminally ill can be responsive to both antidepressant medications and psychotherapeutic interventions (45–47), although admittedly there is no well-developed body of controlled research on this issue. Nevertheless, our findings indicate that a substantial proportion of terminally ill patients who express a desire to die could potentially benefit from a trial of treatment for depression. Although concurrent depression does not necessarily imply that a desire for death is implicitly "irrational," the reasoning processes of depressed patients are characteristically biased by negative mental sets that may affect their capacity to make well-considered life-and-death decisions (48). Furthermore, demoralization and a lack of assertiveness may render the depressed terminally ill patient more vulnerable to the suggestions of others, thereby increasing the potential for abuse (8).

Finally, it should also be noted that in contrast to previous research (23), not all of the patients who expressed a desire for death were clinically depressed. On the basis of the experience in the Netherlands, it is probably inevitable that even with good palliative care, there will still be psychologically stable patients who are determined to end their struggle with terminal illness through euthanasia (42). We as a society will continue to wage our own struggle over their right to do so. It is important that this debate be informed by an appreciation of the significance of psychiatric considerations, as well as by the recognition of the inherent transience of many patients' expressed desire to die.

REFERENCES

1. Blendon RJ, Szalay US, Knox RA: Should physicians aid their patients in dying? the public perspective. JAMA 1992; 267: 2658–2662
2. Genuis SJ, Genuis SK, Chang W-C: Public attitudes toward the right to die. Can Med Assoc J 1994; 150:701–708
3. It's over, Debbie. JAMA 1988; 259:272
4. Quill TE: Death and dignity: a case of individualized decision making. N Engl J Med 1991; 324:691–694
5. Cassel CK, Meier DE: Morals and moralism in the debate over euthanasia and assisted suicide. N Engl J Med 1990; 323:750–752
6. Gaylin W, Kuss LR, Pellegrino ED, Siegler M: "Doctors must not kill." JAMA 1988; 259:2139–2140
7. Misbin RI: Physicians' aid in dying. N Engl J Med 1991; 325: 1307–1311
8. Singer PA, Siegler M: Euthanasia: a critique. N Engl J Med 1990; 322:1881–1883
9. Wanzer SH, Federman DD, Adelstein SJ, Cassel CK, Cassem EH, Cranford RE, Hook EW, Lo B, Moertel CG, Safar P, Stone A, van Eys J: The physician's responsibility toward hopelessly ill patients: a second look. N Engl J Med 1989; 320:844–849
10. Quill TE: Doctor, I want to die. Will you help me? JAMA 1993; 270:870–873
11. Pellegrino ED: Compassion needs reason too. JAMA 1993; 270: 874–875
12. Quill TE, Cassel CK, Meier DE: Care of the hopelessly ill: proposed clinical criteria for physician-assisted suicide. N Engl J Med 1992; 327:1380–1384
13. Benrubi GI: Euthanasia—the need for procedural safeguards. N Engl J Med 1992; 326:197–199
14. Kuhse H, Singer P: Doctors' practices and attitudes regarding voluntary euthanasia. Med J Aust 1988; 148:623–627
15. Kinsella TD, Verhoef MJ: Alberta euthanasia survey, I: physicians' opinions about the morality and legalization of active euthanasia. Can Med Assoc J 1993; 148:1921–1926
16. Fried TR, Stein MD, O'Sullivan PS, Brock DW, Novack DH: Limits of patient autonomy: physician attitudes and practices regarding life-sustaining treatment and euthanasia. Arch Intern Med 1993; 153:722–728
17. Shapiro RS, Derse AR, Gottlieb M, Schiedermayer D, Olson M: Willingness to perform euthanasia: a survey of physician attitudes. Arch Intern Med 1994; 154:575–584
18. van der Maas PJ, van Delden JJM, Pijnenborg L, Looman CWN: Euthanasia and other medical decisions concerning the end of life. Lancet 1991; 338:669–674
19. Hendin H, Klerman G: Physician-assisted suicide: the dangers of legalization. Am J Psychiatry 1993; 150:143–145
20. Cain ED, Conwell YC: Self-determined death, the physician, and medical priorities: is there time to talk? JAMA 1993; 270:875–876
21. American Medical Association Council on Ethical and Judicial Affairs: Decisions near the end of life. JAMA 1992; 267:2229–2233
22. Humphry D: Rational suicide among the elderly. Suicide Life Threat Behav 1992; 22:125–129
23. Brown JH, Henteleff P, Barakat S, Rowe CJ: Is it normal for terminally ill patients to desire death? Am J Psychiatry 1986; 143:208–211
24. Breitbart W: Suicide in cancer patients. Oncology 1987; 1:49–53

25. Foley KM: The relationship of pain and symptom management to patient requests for physician-assisted suicide. J Pain and Symptom Management 1991; 6:289–297
26. Richman J: A rational approach to rational suicide. Suicide Life Threat Behav 1992; 22:130–141
27. Cherny NI, Coyle N, Foley KN: The treatment of suffering when patients request elective death. J Palliat Care 1994; 10:71–79
28. Endicott J, Spitzer RL: A diagnostic interview: the Schedule for Affective Disorders and Schizophrenia. Arch Gen Psychiatry 1978; 35:837–844
29. Spitzer RL, Endicott J, Robins E: Research Diagnostic Criteria: rationale and reliability. Arch Gen Psychiatry 1978; 35:773–782
30. Lesage AD, Cyr M, Toupin J: Reliable use of the Present State Examination by psychiatric nurses for clinical studies of psychotic and nonpsychotic patients. Acta Psychiatr Scand 1991; 83:121–124
31. Chochinov HM, Wilson KG, Enns M, Lander S: Prevalence of depression in the terminally ill: effects of diagnostic criteria and symptom threshold judgments. Am J Psychiatry 1994; 151:537–540
32. Beck AT, Beck RW: Screening depressed patients in family practice: a rapid technic. Postgrad Med 1972; 52:81–85
33. Alloway R, Bebbington P: The buffer theory of social support—a review of the literature. Psychol Med 1987; 17:91–108
34. Barrera M Jr, Ainlay SL: The structure of social support: a conceptual and empirical analysis. J Community Psychol 1983; 9: 435–447
35. O'Reilly P: Methodological issues in social support and social network research. Soc Sci Med 1988; 26:863–873
36. Fishman B, Pasternak S, Wallenstein SL, Houde RW, Holland JC, Foley KM: The Memorial Pain Assessment Card: a valid instrument for the evaluation of cancer pain. Cancer 1987; 60: 1151–1158
37. Jensen MP, Karoly P: Self-report scales and procedures for assessing pain in adults, in Handbook of Pain Assessment. Edited by Turk DC, Melzack R. New York, Guilford Press, 1992
38. Karnofsky DA, Burchenal JH: The clinical evaluation of chemotherapeutic agents in cancer, in Evaluation of Chemotherapeutic Agents. Edited by McCleod CM. New York, Columbia University Press, 1949
39. Clarke DB Jr: Voluntary euthanasia and the Hemlock Society (letter). Am J Psychiatry 1986; 143:1503
40. van der Wal: Unrequested termination of life: is it permissible? Bioethics 1993; 7:330–339
41. Final report of the Netherlands State Commission on Euthanasia: an English summary. Bioethics 1987; 1:163–174
42. de Wachter MAM: Active euthanasia in the Netherlands. JAMA 1989; 262:3316–3319
43. Rigter H, Borst-Eilers E, Leenen HJJ: Euthanasia across the North Sea. Br Med J 1988; 297:1593–1595
44. Keown J: On regulating death. Hastings Cent Rep 1992; 22(2): 39–43
45. Cassem EH: The dying patient, in Massachusetts General Hospital Handbook of General Hospital Psychiatry, 2nd ed. Edited by Hackett TP, Cassem EH. Littleton, Mass, PSG, 1987
46. Massie MJ, Holland JC: Depression and the cancer patient. J Clin Psychiatry 1990; 51(July suppl):12–17
47. Woods SW, Tesar GE, Murray GB, Cassem EH: Psychostimulant treatment of depressive disorders secondary to medical illness. J Clin Psychiatry 1986; 47:12–15
48. Beck AT, Rush AJ, Shaw BF, Emery G: Cognitive Therapy of Depression. New York, Guilford Press, 1979

"HMC-7"

36 Mino M, Nishino H. Fetal and maternal relationship in serum vitamin E level. *J Nutr Sci Vitaminol* 1973; 19: 475–82.

37 Schiff E, Friedman SA, Stampfer M, Kao K, Barrett PH, Sibai BM. Dietary consumption and plasma concentrations of vitamin E in pregnancies complicated by preeclampsia. *Am J Obstet Gynecol* 1996; 175: 1024–28.

38 Stratta P, Canavese C, Porcu M, et al. Vitamin E supplementation in preeclampsia. *Gynecol Obstet Invest* 1994; 37: 246–49.

39 Gulmezoglu AM, Hofmeyr GJ, Oosthuizen MM. Antioxidants in the treatment of severe pre-eclampsia: an explanatory randomised controlled trial. *Br J Obstet Gynaecol* 1997; 104: 689–96.

40 Nishikimi M. Oxidation of ascorbic acid with superoxide anion generated by the xanthine-xanthine oxidase system. *Biochem Biophys Res Commun* 1975; 63: 463–68.

41 Jialal I, Grundy SM. Effect of dietary supplementation with alpha-tocopherol on the oxidative modification of low density lipoprotein. *J Lipid Res* 1992; 33: 899–906.

42 Fuller CJ, Grundy SM, Norkus EP, Jialal I. Effect of ascorbate supplementation on low density lipoprotein oxidation in smokers. *Atherosclerosis* 1996; 119: 139–50.

43 May JM, Qu ZC, Whitesell RR, Cobb CE. Ascorbate recycling in human erythrocytes: role of GSH in reducing dehydroascorbate. *Free Radic Biol Med* 1996; 20: 543–51.

44 Higgins JR, Walshe JJ, Halligan A, et al. Can 24-hour ambulatory blood pressure measurement predict the development of hypertension in primigravidae? *Br J Obstet Gynaecol* 1997; 104: 356–62.

Will to live in the terminally ill

Harvey Max Chochinov, Douglas Tataryn, Jennifer J Clinch, Deborah Dudgeon

Summary

Background Complex biomedical and psychosocial considerations figure prominently in the debate about euthanasia and assisted suicide. No study to date, however, has examined the extent to which a dying patient's will to live fluctuates as death approaches.

Methods This study examined patients with cancer in palliative care. Will to live was measured twice daily throughout the hospital stay on a self-report 100 mm visual analogue scale. This scale was incorporated into the Edmonton symptom assessment system, a series of visual analogue scales measuring pain, nausea, shortness of breath, appetite, drowsiness, depression, sense of well-being, anxiety, and activity. Maximum and median fluctuations in will-to-live ratings, separated by 12 h, 24 h, 7 days, and 30 days, were calculated for each patient.

Findings Of 585 patients admitted to palliative care during the study period (November, 1993, to May, 1995), 168 (29%; aged 31–89 years) met criteria of cognitive and physical fitness and agreed to take part. The pattern of median changes in will-to-live score suggested that will to live was stable (median changes <10 mm on 100 mm scale for all time intervals). By contrast, the average maximum changes in will-to-live score were substantial (12 h 33·1 mm, 24 h 35·8 mm, 7 days 48·8 mm, 30 days 68·0 mm). In a series of stepwise regression models carried out at 12 h, 24 h, and 1–4 weeks after admission, the four main predictor variables of will to live were depression, anxiety, shortness of breath, and sense of well-being, with the prominence of these variables changing over time.

Interpretation Among dying patients, will to live shows substantial fluctuation, with the explanation for these changes shifting as death approaches.

Department of Psychiatry (H M Chochinov FRCPC) **and Faculty of Nursing** (D Tataryn PhD), **University of Manitoba; St Boniface Hospital Research Foundation** (J J Clinch MA), **Winnipeg, Manitoba; and Department of Medicine, Queen's University, Kingston, Ontario** (D Dudgeon FRCPC), **Canada**

Correspondence to: Dr Harvey Max Chochinov, Department of Psychiatry, University of Manitoba, PX 246-771 Bannatyne Avenue, Winnipeg, Manitoba, R3E 3N4, Canada
(e-mail: chochin@cc.umanitoba.ca)

Lancet 1999; **354:** 816–19

Introduction

A patient's state of mind is the single most important factor in understanding of a request for physician-hastened death. Euthanasia and physician-assisted suicide raise critical issues about the psychological underpinnings of death-hastening requests. This study is part of a programme of research that has addressed various psychiatric dimensions of palliative care.[1-4] The defining characteristic of this research has been that dying patients have served as the key informants. These studies have helped establish the prevalence of clinical depression among the terminally ill[1] and the extent to which dying patients may endorse a desire for death.[2] A limitation of the latter study was its largely cross-sectional design, with very little information on whether there are fluctuations in patients' will to live over the course of a terminal disease. Thus, although we now know that occasional or fleeting thoughts of a desire for death are common among the terminally ill and that some of these patients express a genuine desire for death, little is known about how these thoughts may change over the course of time.[2] Although the stability and determinants of will to live in a palliative-care setting are fundamental issues, they have received surprisingly little critical attention.

No previous studies have specifically examined the issue of will to live per se, but a few have addressed constructs that may serve as its proxy. Some studies, using responses to hypothetical scenarios before and after treatment, have documented the extent to which treatment of depression can favourably influence a patient's endorsment of life-sustaining therapy.[5,6] Other studies have shown a strong association between interest in physician-assisted suicide and depression,[2,4,7,8] pain,[2,7,9-11] and other distressing symptoms.[7,9-11] To date, only one small study reported that a desire for death may fluctuate over a brief period in a palliative-care setting.[2] Our study prospectively addressed the temporal stability of will to

This is the exhibit marked **"HMC-7"** referred to in the affidavit of **Harvey Max Chochinov** affirmed at
this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

live and its correlates in a large cohort of terminally ill patients.

Methods

Patients

The ethics review committee of the University of Manitoba Faculty of Medicine approved this study. Before participation, all patients gave written acknowledgment of informed consent. Patients were recruited from the Riverview Palliative Care Unit in Winnipeg, Manitoba, Canada. This unit admits patients on a voluntary basis for various palliative-care needs, primarily including symptom management, respite for patients and families, and terminal care. All patients admitted to the hospital during the study period (November, 1993, to May, 1995) had a primary diagnosis of terminal cancer. After admission, each patient was given 24–48 h to become used to the ward routine before being approached for the study. The patient's medical status was reviewed with the ward staff. Patients who were too cognitively impaired, weak, or ill to complete the daily assessments were classified as ineligible and not approached for the study. When informed consent was obtained, patients completed Folstein's mini-mental status examination[14] (MMSE). Those scoring 21 or higher out of 30 (a cut-off point recommended in routine screening for cognitive impairment in the elderly[15]) were enrolled in the study.

Procedures

Data were collected by means of the Edmonton system assessment system[16] (ESAS). The ESAS is a self-report instrument consisting of a series of visual analogue scales designed specifically for patients in palliative care; it assesses pain, anxiety, depression, sense of well-being, dyspnoea, nausea, activity, drowsiness, and appetite. For the purpose of this study, we added an additional will-to-live visual analogue scale (with "complete will to live" and "no will to live" as the extremes). Each patient's subjective sense of constipation was also recorded once daily as being present or absent. To maintain consistency across the different items with visual analogue scales, a high score on any ESAS variable reflects high symptom distress. Thus, a high will-to-live score indicates a low endorsement of will to live. All participants were asked to make a vertical mark indicating the intensity of the particular symptom, at that point in time. For all participants, symptom distress was measured twice daily (morning and late afternoon) from the time they entered the study until they could no longer provide data (even with the assistance of a research nurse), they died, or they were discharged from the unit. The MMSE was administered on entry to the study, and once a week thereafter. This instrument enabled monitoring of cognitive status as well as providing a validity check of all ESAS data.

	Non-participants	Participants	p
Number of admissions			
1	346 (83·0%)	146 (86·9%)	0·591
2	54 (12·9%)	19 (11·3%)	
3	9 (2·2%)	3 (1·8%)	
4	5 (1·2%)	0	
5	2 (0·5%)	0	
6	1 (0·2%)	0	
Sex			
Male	221 (53·0%)	83 (49·4%)	0·431
Female	196 (47·0%)	85 (50·6%)	
Marital status			
Married	199 (47·7%)	80 (47·6%)	0·805
Widowed	126 (30·2%)	50 (29·8%)	
Divorced	32 (7·7%)	15 (8·9%)	
Single	37 (8·9%)	15 (8·9%)	
Other	18 (4·3%)	8 (4·8%)	
Unknown	5 (1·2%)	0	
Living arrangements			
With spouse	203 (48·7%)	81 (48·2%)	0·402
With child	38 (9·1%)	13 (7·7%)	
Alone	134 (32·1%)	63 (37·5%)	
Other	42 (10·1%)	11 (6·5%)	
Primary diagnosis			
Lung cancer	107 (25·7%)	61 (36·3%)	0·009
Gastrointestinal cancer	99 (23·7%)	44 (26·2%)	
Genitourinary cancer	55 (13·2%)	19 (11·3%)	
Breast cancer	26 (6·2%)	12 (7·1%)	
Gynaecological cancer	16 (3·8%)	9 (5·4%)	
Head and neck cancer	14 (3·4%)	7 (4·2%)	
Melanoma	15 (3·6%)	2 (1·2%)	
Brain cancer	22 (5·3%)	1 (0·6%)	
Other diagnosis	63 (15·1%)	13 (7·7%)	
Median (IQR) age at entry to study	73 (65–81)	70 (58·5–76)	0·0017
Median (IQR) survival (days)			
After study	..	1 (1–2)	
Total from admission	15 (5–46)	31·5 (15–64)	0·0018

Demographic and clinical characteristics of participants and non-participants

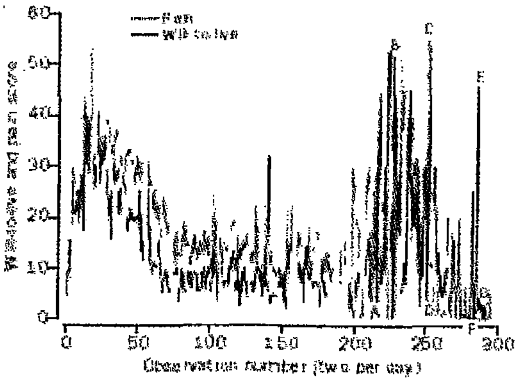


Figure 1: **Will-to-live and pain scores in an 82-year-old woman with colorectal cancer**

Maximum 12 h change=C–D; maximum 24 h change=E–F; maximum 7-day change=A–B; maximum 30-day change=B–G.

Statistics

Unless otherwise indicated, statistical significance was set at a probability level of 0·05. The will-to-live visual analogue scores were used to examine the temporal stability of this construct. Temporal stability addresses the consistency with which will to live is held by an individual patient across time. Maximum and median changes (differences) in will to live were calculated for each individual over consecutive 12 h, 24 h, 7-day, and 30-day intervals. Thus, the 7-day fluctuations in will to live were calculated between morning assessments of days 1 and 8, 2 and 9, 3 and 10, and so on; the calculations were repeated for the evening assessments across the same intervals.

Stepwise multiple regression procedures were used to predict will to live at six temporal cross-sections of the data (12 h, 24 h, 1 week, 2 weeks, 3 weeks, and 4 weeks after admission to the study). All variables for the revised ESAS, and constipation, were allowed to enter the model in a stepwise fashion. The criterion for entry was a significance level of $p<0·1$, and the criterion for deletion from the model was set at $p>0·05$ in a two-tailed test.

Results

There were 585 admissions during the data-collection period. 153 (26·2%) patients were not referred to the study because the initial screening showed that they were cognitively impaired or too weak or ill to participate. 39 (6·7%) other patients were found to be ineligible, since they scored below the critical threshold of 21 on the MMSE. 148 (25·3%) patients admitted to the unit refused to take part in the study. 77 (13·2%) were otherwise unavailable (away from the ward at the time of data collection, or too brief a stay to allow enrolment in the study). The remaining 168 participants, ranging in

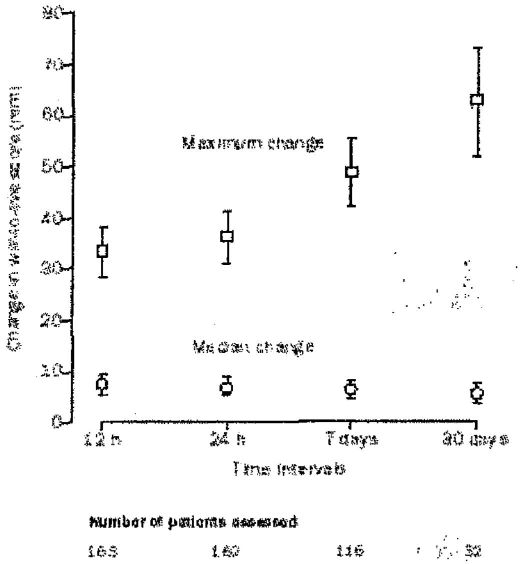


Figure 2: **Average median and maximum changes in will to live**
Error bars=95% CI.

age from 31 to 89 years, represent 29% of the total possible sample.

Since more than 55% of the non-participants died before the study started or were too ill or cognitively impaired to participate, there were significant differences in age and survival time between participants and non-participants (table); those participating were slightly younger and lived an average of 18 days or 50% longer than those who did not participate (median survival 31·5 *vs* 15 days, p=0·0018). Participants and non-participants were similar in diagnosis at time of admission, with the exceptions of lung, brain, and other tumours. The higher prevalence of brain tumours among the non-participants is related to the adverse effect of such tumours on cognitive function. The two groups differed substantially in status at the end of the hospital stay: 68% of participants compared with 81% of non-participants had died (p<0·001). The two groups were similar in distributions of sex, marital status, and previous living arrangements.

Among participants, the median length of time followed within the study was 12 days (IQR 5–27; mean 21·6 days [SD 27·1]). Complete ESAS data were collected to within 1 day (median) of death. As an example, figure 1 shows the profile of will-to-live scores in an 82-year-old woman with colorectal cancer. This unusually long data record was selected to provide a clear illustration of how will to live was tracked, and demonstrate the way in which the maximum time interval fluctuations were calculated. In the first 2 weeks after admission, her will to live weakened, peaking at a score of 55 mm. It then gradually improved, such that by day 60 most of her will-to-live scores were between 0 and 10 mm. Her scores remained stable until day 100 (observation 200). As death approached and pain became more difficult to control, her will-to-live score became very changeable.

Figure 2 shows the distribution of the average maximum and median fluctuations in will-to-live scores. The pattern of median changes in will to live over various time intervals suggest that will to live was stable. On a 100 mm scale, median changes in will-to-live score were less than 10 mm across all time intervals. However, the maximum fluctuation in each individual patient's will-to-live score shows a different pattern. For example, the average maximum change in score was 33·1 mm (95% CI 28·4–37·8) for the 12 h time interval and 35·8 mm (30·8–40·7) for the 24 h interval. Wider time intervals showed greater fluctuations in will-to-live score (7 days 48·8 mm [42·2–55·3]; 30 days 63·0 mm [52·2–73·7]). For each of these time intervals, the greatest will-to-live score fluctuation was 100 mm, indicating extreme changes within some individuals over even the shortest time period examined. These large fluctuations suggest that will to live is highly unstable.

To clarify the relation between will to live and various common sources of symptom distress among dying patients, we constructed several multiple regression models. These models examined cross-sectional data at 12 h, 24 h, 1 week, 2 weeks, 3 weeks, and 4 weeks since entry to the study, with will-to-live score as the outcome variable. Initially, all ESAS variables (and constipation) were allowed to enter in a stepwise way. Sense of well-being was highly significant (p<0·0001) in four of the six regression equations (all but the 2-week and 3-week models). Since sense of well-being is not a well-circumscribed symptom that can be specifically targeted by palliative interventions, a second series of models was constructed in which this variable was omitted. As a result of attrition due to medical deterioration or death, the number of patients entering each model decreased with the broadening time interval examined in each subsequent model. Anxiety entered the 12 h model first (r=0·4, F=29·2, df=1,157, p<0·0001) followed by dyspnoea (r=0·46, F=21·3, df=2,156, p<0·0002) and activity (r=0·5, F=17·3, df=3,155, p<0·0001). In the 24 h model, only anxiety entered as a predictor variable of will to live (r=0·3, F=14·43, df=1,139, p<0·0002). In the 1-week model, depression was the factor accounting for most of the variance in will to live (r=0·37, F=13·90, df=1,89, p<0·003), as it did also in the 2-week model (r=0·49, F=20·73, df=1,64, p<0·0001). The 3-week and 4-week models reflective of a time frame approaching death, showed the critical role of dyspnoea (r=0·37, F=5·46, df=1,42, p<0·02; and (r=0·33, F=4·11, df=1,33, p<0·05). These findings suggest that, as death drew nearer, psychological variables were replaced by physical mediators of variation in will to live.

Discussion

The findings of this study suggest that will to live is highly unstable among terminally ill cancer patients. Although median changes in will-to-live score suggest less fluctuation, the maximum changes showed substantial variation over even the shortest time intervals studied. These findings are perhaps not surprising, given that only 10–14% of individuals who survive a suicide attempt commit suicide during the next 10 years, which suggests that a desire to die is inherently changeable.[17]

The regression models begin to offer some insight into the potential influences on the will to live of dying patients. These models show that factors accounting for variance in will to live change as death approaches. Initially, anxiety was the most significant predictor of will to live. Since most of the patients were enrolled in the study within 24 h of admission, these models may be addressing the transitional phase while the patient adapts from community to inpatient palliative care. In later models, depression replaced anxiety, and in the final models dyspnoea was the most important variable. The prominent place of the psychological determinants of will to live in the earlier models was taken by more physically mediated distress as death approached.

Although the findings of this study may be relevant to the debate on euthanasia, there are limits to which they can be generalised. The patients studied were mostly elderly, and all were in an advanced stage of terminal cancer. We cannot say what would be found for younger populations or for patients dying from other illnesses, such as AIDS, progressive neuromuscular disorders, or advanced cardiac and respiratory disorders. The study group was also restricted to individuals who were mentally competent and well enough to fill out the self-report measures twice daily. This group was a minority of patients admitted to the participating palliative-care unit. However, the issue of euthanasia is largely concerned with the rights of competent individuals to specify the timing and circumstances of their death. As such, the patients involved in the study appear to be representative of those at the centre of the euthanasia debate.

For jurisdictions considering legislation enabling physician-assisted suicide or euthanasia, the likely transience of a request to die is one of the most important considerations. For the reasons confirmed in this study, demonstration of a sustained wish to die must be part of evaluating any death-hastening request. This study provides empirical, prospective data, showing the changing pattern of will to live in the palliative-care setting. Understanding of the temporal patterns of will to live and its correlates represents an important step toward improving care for dying patients. The ability of clinicians and researchers to understand and track will to live as an outcome measure in this vulnerable population will no doubt lead to better palliative care for patients approaching death.

Contributors

Harvey Chochinov devised and designed the study protocol, supervised all phases of the study including recruitment of patients, data management and evaluation, and the writing of the paper. Douglas Tataryn contributed to the concept of the study, designed the data collection and management strategy, evaluated the data, and was involved in writing of the paper. Deborah Dudgeon and Jennifer Clinch contributed to the concept of the study and protocol development and reviewed the paper.

Acknowledgments

We thank Tom Harrigan and Raymond Poirier for computer programming and analysis assistance; Bryan Mueller for text and figure preparation; and the research nurses in this study—including Sheila Lander, Susan McClement, Gerri Anderson, Marilyn Kilpatrick, Marriette Chartier, Michelle Lobchuk, and Pauline Steinberg—for their conscientious attention to the data collection protocol. The study was supported by grants from the National Cancer Institute of Canada with funding from the Canadian Cancer Society and the Open Society Institute, Project on Death in America.

References

1 Chochinov HM, Wilson KG, Enns M, Lander S. Prevalence of depression in the terminally ill: effects of diagnostic criteria and symptom threshold judgments. *Am J Psychiatry* 1994; 151: 537–40.

2 Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry* 1995; 152: 1185–91.

3 Chochinov HM, Wilson KG, Enns M, Lander S. Are you depressed? Screening for depression in the terminally ill. *Am J Psychiatry* 1997; 154: 674–76.

4 Chochinov HM, Wilson KG, Enns M, Lander S. Depression, hopelessness, and suicidal ideation in the hopelessly ill. *Psychosomatics* 1998; 39: 366–70.

5 Ganzini L, Lee MA, Heintv RT, et al. The effect of depression treatment on elderly patients' preferences for life-sustaining medical therapy. *Am J Psychiatry* 1994; 51: 1631–36.

6 Hooper SC, Vaughan KV, Tennant CC, Perz JM. Major depression and refusal of life-sustaining medical treatment in the elderly. *Med J Aust* 1996; 165: 416–19.

7 Breitbart W, Rosenfeld BD, Passik SD. Interest in physician assisted suicide among ambulatory HIV-infected patients. *Am J Psychiatry* 1996; 153: 238–42.

8 Brown JH, Henteleff P, Barakat S, Rowe CJ. Is it normal for terminally ill patients to desire death? *Am J Psychiatry* 1986; s142: 208–11.

9 Foley KM. The treatment of cancer pain. *N Engl J Med* 1991; 153: 217–29.

10 Foley KM. The relationship of pain and symptom management to patient requests for physician-assisted suicide. *J Pain Symptom Manage* 1991; 6: 289–97.

11 Seale C, Addington-Hall J. Euthanasia: why people want to die earlier. *Soc Sci Med* 1994; 39: 647–54.

12 Jorm AF, Henderson AS, Scott R, Korten AE, Christensen H, MacKinnon AJ. Factors associated with the wish to die in elderly people. *Age Aging* 1995; 24: 389–92.

13 Portnenoy RK, Thaler HT, Inturrisi CE, et al. Symptom prevalence, characteristics and distress in a cancer population. *Qual Life Res* 1994; 3: 183–89.

14 Folstein MF, Folstein SE, McHugh PR. "Mini-Mental State": a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975; 12: 189–98.

15 MacKenzie DM, Copp P, Goodwin GM. Brief cognitive screening of the elderly: a comparison of the Mini-Mental State Examination (MMSE), abbreviated mental test (AMT) and the mental status questionnaire (MSQ). *Psychol Med* 1996; 26: 427–30.

16 Bruera E, Kuehn N, Miller M, et al. The Edmonton symptom assessment system (ESAS): a simple method for the assessment of palliative care patients. *J Palliative Care* 1991; 7: 6–9.

17 Diekstra R. An international perspective on the epidemiology and prevalence of suicide. *J Affect Disord* 1995; 36: 11–20.

"HMC-8"

This is the exhibit marked "**HMC-8**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at
this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

Original Article

The Patient Dignity Inventory: A Novel Way of Measuring Dignity-Related Distress in Palliative Care

Harvey Max Chochinov, MD, PhD, Thomas Hassard, PhD, Susan McClement, PhD, Thomas Hack, PhD, CPsych, Linda J. Kristjanson, PhD, Mike Harlos, MD, Shane Sinclair, BA, MDiv, PhD (C), and Alison Murray, MD, CCFP, MPH

Departments of Psychiatry (H.M.C.), Family Medicine (H.M.C.), Community Health Sciences (H.M.C., T.Has.), and Faculty of Nursing (S.M., T.Hac.), University of Manitoba, Winnipeg; and Manitoba Palliative Care Research Unit (H.M.C., S.M.) and Patient and Family Support Services (H.M.C., T.Hac.), CancerCare Manitoba, Winnipeg, Canada; Curtin University of Technology (H.M.C., L.J.K.), Perth, Australia; St. Boniface General Hospital (M.H.), Winnipeg, Canada; Tom Baker Cancer Centre (S.S.) and Department of Oncology (S.S.), Faculty of Medicine, University of Calgary, Calgary; and Calgary Health Region (A.M.), Calgary, Canada

Abstract

Quality palliative care depends on a deep understanding of distress facing patients nearing death. Yet, many aspects of psychosocial, existential and spiritual distress are often overlooked. The aim of this study was to test a novel psychometric—the Patient Dignity Inventory (PDI)—designed to measure various sources of dignity-related distress among patients nearing the end of life. Using standard instrument development techniques, this study examined the face validity, internal consistency, test–retest reliability, factor structure and concurrent validity of the PDI. The 25-items of the PDI derive from a model of dignity in the terminally ill. To establish its basic psychometric properties, the PDI was administered to 253 patients receiving palliative care, along with other measures addressing issues identified within the Dignity Model in the Terminally Ill. Cronbach's coefficient alpha for the PDI was 0.93; the test–retest reliability was $r = 0.85$*. Factor analysis resulted in a five-factor solution; factor labels include Symptom Distress, Existential Distress, Dependency, Peace of Mind, and Social Support, accounting for 58% of the overall variance. Evidence for concurrent validity was reported by way of significant associations between PDI factors and concurrent measures of distress. The PDI is a valid and reliable new instrument, which could assist clinicians to routinely detect end-of-life dignity-related distress. Identifying these sources*

The work was supported by a grant from the National Cancer Institute of Canada, with funding from the Canadian Cancer Society; Dr. Chochinov is a Canada Research Chair in Palliative Care, funded by the Canadian Institutes for Health Research.

Address correspondence to: Harvey M. Chochinov, MD, PhD, CancerCare Manitoba, 675 McDermot Avenue, Room 3017, Winnipeg, Manitoba R3E 0V9, Canada E-mail: harvey.chochinov@cancercare.mb.ca

Accepted for publication: December 28, 2007.

0885-3924/08/$–see front matter
doi:10.1016/j.jpainsymman.2007.12.018

of distress is a critical step toward understanding human suffering and should help clinicians deliver quality, dignity-conserving end-of-life care. J Pain Symptom Manage 2008;36:559–571.

Key Words
Dignity, psychometrics, measurement, distress, palliative care

Introduction

Palliative care faces many pressing challenges, not the least of which is finding efficient and reliable ways to identify various types of distress encountered among dying patients. Providing quality palliative care is predicated on a deep understanding of patient experience and potential causes of suffering. Furthermore, distress at this time of life may be physical, psychosocial, spiritual, or existential in nature, or as is often the case, some combination thereof.[1–4]

Various strategies have been used to identify end-of-life distress, each with their own inherent strengths and weaknesses. The clinical interview is, of course, a critical element of any comprehensive assessment. The information it yields, however, depends on the skill of the individual clinician and the degree of reticence patients may feel in sharing the extent or nature of their distress. Self-report screening instruments are sometimes used to elicit the characteristics of patient distress. Unidimensional scales, such as some measures of quality of life[5] or the generic distress thermometer,[6] are able to quantify distress without necessarily eliciting its exact nature or description. Some of the multidimensional scales are either encumbered by their length or may be limited because they tend to narrowly focus on traditional dimensions of patient distress.[7,8]

In spite of an assortment of newer scales that tap into various aspects of the end-of-life experience, few have been broadly applied to the clinical practice of palliative care. So, for example, although there are measures for desire for death,[9,10] will to live,[11] and demoralization,[12] these tend to be used almost exclusively for research purposes, with limited application to most patients nearing death. Some instruments, such as the Structured Interview Assessment of Symptoms and Concerns in Palliative Care (SISC), address various dimensions of end-of-life distress, but must be administered by a trained interviewer and thus limit their routine application. On the other hand, self-report instruments, such as the Edmonton Symptom Assessment Scale (ESAS), seem to have achieved a higher degree of uptake within palliative care. The ESAS consists of a series of visual analog scales, covering primarily physical, along with a few common psychological, symptoms that are common toward the end of life. Aside from depression and anxiety, however, the ESAS does not address other psychosocial, existential, or spiritual sources of discomfort or distress.

Clearly, the field of palliative medicine would be well served by a clinically relevant self-report instrument, which has sufficient breadth and depth to tap into a variety of sources of distress facing patients nearing death. To define the scope of such an instrument, we turned to our empirical work on dying with dignity, particularly the Model of Dignity in the Terminally Ill.[13–16] This model, with each of its major themes and subthemes (previously reported),[13] encapsulates a broad range of issues—physical, psychosocial, spiritual, and existential—that may influence a dying patient's sense of dignity. This broad and eclectic range of issues can be subsumed under the rubric of dignity-related distress. To measure this, we produced a prototype of a Patient Dignity Inventory (PDI), with individual questions being written to correspond to specific Dignity Model themes and subthemes (see Table 1). For example, the subtheme entitled "role preservation" resulted in a question about being able to carry out important roles, while the theme "burden to others" informed a question about "feeling a burden to others."

The prototype PDI was vetted by 18 patients receiving end-of-life care from the Winnipeg Regional Health Authority Palliative Care

Table 1
Dignity Model and the Basis of the Patient Dignity Inventory

Major Dignity Categories, Themes, and Subthemes		
ILLNESS-RELATED CONCERNS	DIGNITY CONSERVING REPERTOIRE	SOCIAL DIGNITY INVENTORY
Level of independence (1, 2)	Dignity conserving perspectives	Privacy boundaries (20)
Cognitive acuity (9)	Continuity of self (4, 11)	
Functional capacity (8)	Role preservation (13)	Social support (21, 22)
Symptom distress	Generativity/legacy (15, 16)	
Physical distress (3)	Maintenance of pride (12)	Care tenor (25)
Psychological distress (5, 6)	Hopefulness (14)	
Medical uncertainty (7)	Autonomy/control (19)	Burden to others (18)
Death anxiety (8)	Acceptance (24)	
	Resilience/fighting spirit (23)	
	Dignity conserving practices	Aftermath concerns
	Living in the moment (10)	
	Maintaining normalcy (10)	
	Seeking spiritual comfort (17)	

Numbers in parentheses correspond to the PDI item number that derives from each individual theme and subtheme.

Sub-Program. To arrive at this sample, 33 patients were identified as potential participants (see selection criteria described below), two of whom refused, one of whom did not speak English, and 12 of whom were either too tired or felt too ill to take part. Of the remaining 18, nearly all had end-stage solid tumors; the median age was 73 (range 47–89), the median survival was 32 days (range 2–274), and eight (44%) were female. These patients were asked to provide their feedback regarding the prototype PDI. This provided an opportunity to clarify the exact wording for every item, along with reaffirming the content validity of this emerging instrument. This prototype, consisting of 22 items, was then administered to 211 patients within the Winnipeg Regional Health Authority Palliative Care Program (the specific demographics and recruitment details pertaining to this sample have been previously reported).[17] This phase of recruitment asked patients to indicate the degree that each item related to their sense of dignity (from "not at all" to "very much so").

Based on this initial experience, several revisions to the PDI prototype were made. First and most important, patients and clinicians pointed out the limitation of the instrument, given that each item was rated according to its association with sense of dignity, rather than the extent to which the issue was felt to be a problem. As such, each item was reframed accordingly. This is a critical distinction, given that patients and care providers are far more concerned if an issue is problematic as opposed to its putative association with the construct of dignity. Other revisions included dividing a question on social support into two questions, one addressing friend and family support and the other health care provider support, given that patients felt these were separate issues requiring individual items. For similar reasons, the item on psychological distress was divided into an item on depression and a separate item on anxiety; a question on unfinished business was added to supplement an item about "having made a meaningful contribution." In response to patient feedback, a question about "worrying how life might end" was revised to be somewhat more general and less jarring, that is, "worrying about the future."

This 25-item PDI serves as the basis for the current study (Fig. 1), whose aim was to test and establish the psychometric properties of this instrument. The PDI is meant to provide a measure of dignity-related distress and serve as a screening tool to assess a broad range of issues that have been reported to influence sense of dignity.[13,15] It thus offers a relatively easy way to help clinicians identify a broad range of issues that can cause distress among patients nearing death.

Method

Participants

Between March 2004 and July 2007, patients receiving palliative care from the Winnipeg Regional Health Authority Palliative Care Program, meeting eligibility criteria, were approached to participate in this study. This program provides comprehensive inpatient care and coordinated community-based end-of-life care services. In February 2006 and in

July 2006, the Palliative Care Program in Perth, Australia and the Calgary Health Region Palliative Care program, respectively, were invited to partner in participant recruitment. These programs were chosen because of our longstanding research affiliations with those centers. These centers also are affiliated with palliative care programs that provide end-of-life care services comparable to the primary recruitment site.

The medical status of every patient was reviewed by the treatment staff, who independently ascertained their eligibility for the study on the basis of clinical consensus. Eligibility criteria included being age 18 years or older; being enrolled in the palliative care program within the respective recruitment site; having a life expectancy of less than six months; having an ability to read and speak English; demonstrating no evidence of dementia or delirium that might make completion of the study protocol difficult; and having the ability to provide informed consent. Patients were not referred to the study if they were cognitively impaired, unable to give informed consent, or too gravely ill to take part in the protocol. Across the three recruitment sites, 806 patients were identified by the clinical staff as appropriate for referral to the study. Of these patients, the research staff found that 261 did not meet eligibility criteria, 205 were not interested in hearing about the study, and 28 were too ill. Of the remaining 312, 35 patients refused to take part. Of the remaining 277 patients, all of whom gave verbal and written consent, 24 dropped out for various reasons, primarily because they became too ill to complete the protocol. This left a final sample of 253 patients, consisting of 190 patients from Winnipeg, Canada; 42 from Calgary, Canada; and 21 from Perth, Australia.

The Faculty of Medicine Ethics Committees at the University of Manitoba, Curtin University of Technology in Perth and the University of Calgary Conjoint Health Research Ethics Board approved the study, with the various Hospital Research Review Boards at participating institutions granting formal patient access. Prior to the onset of data collection, all patients provided written informed consent.

Procedures

Patients were asked to complete the 25-item PDI. Each item was rated on a five-point scale (1=not a problem; 2= a slight problem; 3=a problem; 4=a major problem; 5=an overwhelming problem) (see Appendix). Five-point scales of this nature have been reported most reliable on measurements of attitude-judgment, with response categories above five not yielding significant additional discrimination.[18,19] Patients completed the PDI as a self-report, or were assisted by a highly experienced research nurse, who when required, read the questions aloud and recorded their responses. Patients who were willing and able to do so were asked to complete the PDI 24 hours later, to allow researchers to examine the inventory's stability over time.

To examine the instrument's concurrent validity, patients were also asked to complete a number of self-report measures, tapping into areas of distress identified within the Model of Dignity in the Terminally Ill.[13] This included the Revised ESAS (which included a "will to live" visual analog scale),[8] the Beck Depression Inventory (BDI);[20] and the suffering and dignity items from the SISC.[21] Quality of life was measured using the brief Quality-of-Life Scale.[5] This two-item scale rates the patient's self-assessed quality of life and his or her satisfaction with the current quality of life (ranging from 1 [poor] to 10 [excellent]). Likert-type scales, ranging from one to 10, were used to measure two conceptual dimensions of social support: the structural aspects of support network (i.e., the availability of social support) and satisfaction with the degree of support provided.[22,23] Using this approach, patients' perceptions of support from their families and friends, and health care providers were measured. The Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT-Sp), a measure of spiritual well-being for people with cancer and other chronic illnesses, was also administered to all participants.[24] As well, all participants completed the National Center for Health Statistics General Well-Being Schedule, which is a brief, reliable, and valid measure of subjective well-being that is widely used as an indicator of psychological health and dysfunction.[25] Basic demographic information was also collected from every patient.

Experienced palliative care research nurses administered the study psychometrics, with regular monitoring by the principal investigator (HMC) to ensure data integrity and standardized application of the protocol. The protocol was generally well tolerated by patients, taking between 30 and 45 minutes to administer.

Statistical Analysis

To assess the instrument's internal structure, a factor analysis using the conventional approach of an initial principal components solution followed by varimax rotation was undertaken. The selection of factors for rotation was based on the dual criteria of eigenvalues greater than 1 and the assessment of a scree plot. To examine whether the orthogonal factor structure inherent to varimax rotation was appropriate, the data also were subjected to an oblique factor rotation in order to explore factor independence.

The internal consistency of the PDI was examined by determining Cronbach's coefficient alpha. Its test-retest reliability was assessed by correlating the initial PDI self-report with the PDI self-report obtained 24 hours later. To examine the concurrent validity, individual factors were analyzed by determining their correlation with other measures thought to be conceptually overlapping. Unless otherwise specified, all tests were carried out and reported on a two-tailed basis.

Results

The mean age of the 253 participants was 69 years (SD 13.5); 136 (58%) were female. Thirty-six percent had less than a high school education, 19% had completed only high school, and 45% had some college or postgraduate training. Fifty-four percent of patients were married or cohabiting, 27% were widowed, 10% were divorced, 8% were never married, and 2% were separated. Fifty-four percent of patients were living with a spouse or partner. Thirty-two percent were living alone, 19% were living with children, 3% with parents, 1% with children, and 7% with other. In terms of religious affiliation, 37% were Protestant, 23% Catholic, 20% other, 17% no religious affiliation, and 3% Jewish. Primary tumor sites included lung 25%, gastrointestinal 18%, genitourinary 11%, breast 7%, hematologic 6%, and other solid tumor 23%; 8% had noncancer diseases, such as chronic obstructive pulmonary disease, amyotrophic lateral sclerosis, and various other life-limiting ailments. Across the total sample, 149 (59%) were inpatients, with the remainder (41%) receiving treatment outside of the hospital setting. The mean duration of survival from the time of interview to the time of death was 78 (SE 6.5) days.

Cronbach's coefficient alpha for the PDI was calculated to be 0.93. The test-retest reliability for the full PDI was $r = 0.85$, with individual variables' test-retest reliabilities ranging from $r = 0.37$ to $r = 0.76$ (see Table 2).

As a result of the factor analysis, five factors, accounting for 58% of the overall variation, were selected for rotation. This was based on an examination of the factor scree plot; all selected factors had eigenvalues greater than 1, with a discontinuity in eigenvalue size judged to have occurred between factors five and six.

Table 2
Test-Retest Reliability
(mean time interval = one day)

Variable	Pearson r ($n = 133$)	P-value
Not being able to think clearly	0.76	0.001
Not able to perform tasks of daily living	0.71	0.001
Feeling have not made meaningful contribution	0.71	0.001
Not feeling worthwhile or valued	0.70	0.001
Not able to attend to bodily functions	0.69	0.001
Physically distressing symptoms	0.69	0.001
Concerns regarding spiritual life	0.69	0.001
Feeling of reduced privacy	0.67	0.001
Feeling depressed	0.65	0.001
Feeling anxious	0.65	0.001
Feeling no longer who I was	0.64	0.001
Feeling of not having control	0.62	0.001
Feeling of unfinished business	0.61	0.001
Not being able to accept things as they are	0.61	0.001
Feeling how you look has changed	0.59	0.001
Feeling uncertain	0.58	0.001
Not feeling supported by friends or family	0.58	0.001
Feeling a burden to others	0.57	0.001
Feeling life no longer has meaning or purpose	0.56	0.001
Not feeling able to mentally fight illness	0.52	0.001
Not able to continue usual routines	0.49	0.001
Worried about the future	0.48	0.001
Not able to carry out important roles	0.44	0.001
Not feeling supported by health care providers	0.43	0.001
Not being treated with respect	0.37	0.001
Total correlation PDI	0.85	0.001

The 10 largest initial eigenvalues, together with the percentage variance explained, are summarized in Table 3. The five rotated factors (variable loadings less than 0.55 are not shown) are presented in Table 4. These factors are labeled as follows: *Symptom Distress*, *Existential Distress*, *Dependency*, *Peace of Mind*, and *Social Support*. An oblique factor analysis demonstrated that the factors labeled *Symptom Distress* and *Existential Distress* were modestly positively correlated, while other factors were weakly correlated with one another. These correlations were insufficient to require treatment as a single scale (see Table 5).

Factor Details: Internal Consistency and Reliability

Further analysis was undertaken to establish the psychometric characteristics of each individual factor. Cronbach's coefficient alpha was calculated for the five factors using the items that loaded greater than 0.55 on each respective factor (Table 4). Thus, Cronbach's coefficient alpha was used to measure the reliability of the subscales created from the individual items loading heavily on each factor. The concurrent validity of each factor was examined by generating a list of hypothesized concurrent measures against which it might be correlated (Table 6 lists all measures tested and associated findings).

Symptom Distress. This factor comprised the PDI items that essentially covered physical as well as psychological sources of distress. Items contained within this factor had factor loadings that ranged from 0.57 to 0.71. This factor's internal consistency, as measured by Cronbach's coefficient alpha, was 0.80. To establish concurrent validity, this factor was examined in terms of how it correlated with other conceptually overlapping protocol measures (see Table 6). The *Symptom Distress* factor was significantly correlated (r=0.26–0.56;

Table 3
Initial Factor Loading for the PDI

	Initial Eigenvalues		
Initial Factor	Total	% of Variance	Cumulative %
1	8.937	35.747	35.747
2	1.695	6.781	42.529
3	1.515	6.061	48.590
4	1.304	5.215	53.805
5	1.267	5.069	58.874
6	1.039	4.155	63.029
7	0.992	3.970	66.998
8	0.838	3.353	70.351
9	0.736	2.944	73.295
10	0.700	2.799	76.094

Table 4
Factor Analysis (Five-Factor Solution)

Factor 1. Symptom Distress	Cronbach's Coefficient Alpha=0.80
Item	Factor Loading
Physically distressing symptoms	0.57
Feeling depressed	0.71
Feeling anxious	0.71
Feeling uncertain	0.68
Worried about future	0.64
Not being able to think clearly	0.58
Factor 2. Existential Distress	Cronbach's Coefficient Alpha=0.83
Item	Factor Loading
Feeling how you look has changed	0.57
Feeling no longer who I was	0.63
Not feeling worthwhile or valued	0.74
Not able to carry out important roles	0.65
Feeling life no longer has meaning or purpose	0.68
Feeling a burden to others	0.58
Factor 3. Dependency	Cronbach's Coefficient Alpha=0.77
Item	Factor Loading
Not able to perform tasks of daily living	0.77
Not able to attend to bodily functions	0.80
Reduced privacy	0.55
Factor 4. Peace of Mind	Cronbach's Coefficient Alpha=0.63
Item	Factor Loading
Feeling have not made meaningful contribution	0.61
Feeling of unfinished business	0.56
Concerns regarding spiritual life	0.82
Factor 5. Social Support	Cronbach's Coefficient Alpha=0.70
Item	Factor Loading
Not feeling supported by friends or family	0.81
Not feeling supported by health care providers	0.70
Not being treated with respect	0.76

Table 5
Oblique Factor Analysis Exploring the Extent of Correlation Between Factors in the Five-Factor Solution

Correlation Matrix

Factors	1	2	3	4	5
1	1.00	0.45	0.34	0.28	0.21
2	0.45	1.00	0.27	0.26	0.24
3	0.34	0.27	1.00	0.16	0.16
4	0.28	0.26	0.16	1.00	0.18
5	0.21	0.25	0.16	0.18	1.00

Table 6
Concurrent Validity

Factor 1. Symptom Distress

Instrument	Correlation with Factor 1	Significance
Current level of pain (ESAS)	0.283	0.001
Current level of anxiety (ESAS)	0.453	0.001
Current level of nausea (ESAS)	0.274	0.001
Current level of drowsiness (ESAS)	0.346	0.001
Current level of shortness of breath (ESAS)	0.260	0.001
Current level of satisfaction with pain relief (ESAS)	−0.256	0.001
Current will to live	−0.165	0.012
Current appetite	−0.153	0.019
Current level of activity	−0.076	0.247
Current level of well-being	−0.249	0.001
Beck Depression Inventory	0.374	0.001
General Well-Being total score	0.678	0.001
Suffering	0.434	0.001

Factor 2. Existential Distress

Instrument	Correlation with Factor 2	Significance
Current level of depression (ESAS)	0.301	0.001
Current level of anxiety (ESAS)	0.169	0.011
Current will to live (ESAS)	−0.045	0.497
Current level of well-being (ESAS)	−0.185	0.005
Current quality of life	−0.196	0.003
Current satisfaction with quality of life	−0.206	0.002
Beck Depression Inventory	0.381	0.001
Suffering (SISC)	0.163	0.012
Loss of dignity (SISC)	0.095	0.148
General Well-Being total score	0.246	0.005

Factor 3. Dependency

Instrument	Correlation with Factor 3	Significance
Current level of activity (ESAS)	−0.349	0.001
Ability to work (Beck)	0.224	0.001
Current quality of life	−0.367	0.001
Current satisfaction with quality of life	−0.284	0.001
Loss of dignity (SISC)	0.397	0.001

Factor 4. Peace of Mind

Instrument	Correlation with Factor 4	Significance
Current level of anxiety (ESAS)	0.152	0.021
Current will to live (ESAS)	0.009	0.894
Current level of well-being (ESAS)	0.007	0.918

(*Continued*)

$P<0.001$) with most of the ESAS symptom distress items (pain, anxiety, nausea, depression, drowsiness, and shortness of breath). While *Symptom Distress* did not significantly correlate with level of activity, it did correlate with will to live ($r=-0.17$; $P=0.012$), along with the General Well-Being Scale ($r=0.68$; $P<0.001$), the BDI ($r=0.37$; $P<0.001$), and the single item measure of suffering ($r=0.43$; $P<0.001$).

Existential Distress. The factor labeled *Existential Distress* consists of the following items: feeling how I look has changed (factor loading=0.57); no longer feeling like who I was (factor loading=0.63); not feeling worthwhile or valued (factor loading=0.74); not being able to carry out important roles (factor loading=0.65); feeling life no longer has meaning or purpose (factor loading=0.68); and feeling a burden to others (factor loading=0.58). Cronbach's coefficient alpha for this factor was 0.83. *Existential Distress* was significantly correlated with measures of suffering ($r=0.16$, $P<0.012$), well-being ($r=-0.18$, $P<0.005$ [ESAS]; $r=0.24$, $P<0.005$ [General Well-Being]); depression ($r=0.30$, $P<0.001$ [ESAS]; $r=0.38$, $P<0.001$ [BDI]); anxiety ($r=0.17$; $P<0.001$); and rating and satisfaction with quality of life ($r=-0.20$, $P<0.003$ and $r=-0.21$, $P<0.002$, respectively). It did not, however, correlate significantly with either sense of dignity or will to live.

Dependency. The items loading on this factor include not being able to perform task of daily living (factor loading=0.77), not being able to attend to bodily functions (factor loading=0.08) and reduced privacy (factor loading=0.55). Cronbach's coefficient alpha for the *Dependency* factor was 0.77. *Dependency* correlated with concurrent measures of activity ($r=-0.35$, $P<0.001$), ability to work ($r=0.22$, $P<0.001$), current rating and satisfaction with quality of life ($r=-0.36$, $P<0.001$ and $r=-0.28$, $P<0.001$,

Table 6
Continued

Factor 4. Peace of Mind

Instrument	Correlation with Factor 4	Significance
Current quality of life	−0.041	0.538
Satisfaction with quality of life	−0.101	0.128
Beck Depression Inventory	0.173	0.010
FACIT total	−0.062	0.368
FACIT inner peace	−0.213	0.002
FACIT faith/spirituality	0.035	0.618
FACIT meaning and spirituality	0.098	0.155
General Well-Being Scale	0.070	0.431
Suffering	0.010	0.881

Factor 5. Social Support

Instrument	Correlation with Factor 5	Significance
Availability of Support	−0.256	0.006
Satisfaction with Support	−0.362	0.001

Table 7
Initial Factor Loading for FACIT

	Initial Eigenvalues		
Initial Factor	Total	% of Variance	Cumulative %
1	5.188	43.23%	43.23%
2	1.547	12.89%	56.12%
3	1.138	9.49%	65.61%
4	0.885	7.38%	72.99%
5	0.624	5.20%	78.19%

respectively), and sense of dignity (r=0.40, P<0.001).

Peace of Mind. The items loading on this factor included concerns about one's spiritual life (factor loading=0.61), feelings of unfinished business (factor loading=0.56) and feelings of not having made a meaningful contribution (factor loading=0.82). Cronbach's coefficient alpha was 0.63. This factor was perhaps the most intriguing in terms of its correlational patterns. An initial examination of the correlations between this factor and various measures of current psychosocial well-being failed to show significant relationships, aside from a small but significant relationship with anxiety (r=0.15, P<0.021). Given that concerns regarding spiritual life loaded on this factor, correlations between *Peace of Mind* and the FACIT (Secular Subscale, Nonsecular Subscale, and Total Score) were examined. Surprisingly, this revealed no significant correlations. This finding was puzzling and thus led to a factor analysis on the FACIT data. This initial principal component factor analysis revealed three clear and distinctive factors—Inner Peace, Faith/Spirituality, and Meaning and Purpose (see Tables 7 and 8). There was a significant correlation between the FACIT Inner Peace factor and the PDI *Peace of Mind* Factor (r=−0.21, P<0.002). Each of the three individual items loading on the PDI *Peace of Mind* factor—feelings of not having made a meaningful contribution, feelings of unfinished business, and concerns regarding spiritual life—correlated significantly with the Inner Peace factor of the FACIT (r=−0.26 to −0.28, P<0.001).

Social Support. The PDI items loading of the *Social Support* factor included not feeling supported by friends and family (factor loading=0.81), not feeling supported by health care providers (factor loading=0.70), and not being treated with respect (factor loading=0.76). The Cronbach's coefficient alpha for this factor was 0.70. It correlated significantly with composite measures of friend, family, and health care provider support, that is, availability of support and satisfaction with

Table 8
FACIT Factor Analysis

Factor 1. Inner Peace

Item	Factor Loading
I feel peaceful	0.742
I have trouble feeling peace of mind	−0.696
I am able to reach down into myself for comfort	0.630
I feel a sense of harmony within myself	0.751
I know whatever happens with my illness, things will be ok	0.659

Factor 2. Faith/Spirituality

Item	Factor Loading
I find comfort in my faith or spiritual beliefs	0.889
I find strength in my faith or spiritual beliefs	0.910
My illness has strengthened my faith or spiritual beliefs	0.780

Factor 3. Meaning and Purpose

Item	Factor Loading
I have a reason for living	0.842
My life has been productive	0.589
I feel a sense of purpose in my life	0.669
My life lacks meaning or purpose	−0.712

support across these three sources ($r=-0.26$, $P<0.006$ and $r=-0.36$, $P<0.001$, respectively).

No PDI item loaded significantly on more that one factor, and each item loaded on its theoretically appropriate factor. There were, however, four items that did not obviously load on any of the five factors: not being able to continue usual routines, not feeling in control, not being able to fight the challenges of illness, and not being able to accept the way things are. Had we adjusted the critical threshold for variable loading to 0.4, not being able to carry out usual routines would have loaded on Factors 2 and 3 (*Existential Distress* and *Dependency* [factor loading=0.43]); not feeling in control also would have loaded on Factors 2 and 3 (factor loadings=0.42 and 0.46, respectively); not being able to fight the challenges of illness would have loaded on Factor 1 (*Symptom Distress* [factor loading=0.53]) and not being able to accept the way things are would have loaded on Factors 1 and 3 (*Symptom Distress* and *Dependency* [factor loadings=0.53 and 0.42, respectively]).

Discussion

The need to identify distress among patients nearing death is paramount in the field of palliative care. Any attempt to attenuate or ameliorate distress in this patient population must be predicated on an awareness of its presence.[4] Although the field has benefited from various screening approaches, symptom distress instruments and quality-of-life tools, few have become a routine part of clinical practice.

The development of the PDI is an attempt to provide the field with a feasible and reliable way of identifying dignity-related distress—distress that all too often contributes to suffering toward the end of life. Because this instrument is based on the empirical Model of Dignity in the Terminally Ill, it contains a wide range of items covering the physical, psychosocial, existential, and spiritual facets of patient experience. Even though many sources of disquietude may not be readily visible or easily articulated by sick patients, the degree to which these can shape end-of-life experience is profound. Yet, without a means of making their presence known, many sources of distress remain ubiquitous and intractable.

The basic standard psychometric properties of the PDI have been examined, following standard approaches that are required for the introduction of any new measure. A Cronbach's coefficient alpha of 0.93 provides evidence that this 25-item inventory shows excellent internal consistency, as do each of its component factors. The test—retest reliability, $r=0.85$, demonstrates that the ratings obtained using the instrument over a 24-hour time frame are highly consistent. This assumes that the items being measured are themselves relatively steady. Some lower individual item test—retest reliability may be based on expected distress fluctuations that are not uncommon in palliative care. Future studies may want to consider slightly longer time intervals to fully explore the temporal stability of dignity-related distress in the context of palliative end-of-life care.

The PDI factor analysis was particularly enlightening and revealed a five-factor solution, consisting of *Symptom Distress*, *Existential Distress*, *Dependency*, *Peace of Mind*, and *Social Support*. To establish the concurrent validity of the PDI, correlations between each individual factor and concurrent measures with putative theoretical overlap were examined. The correlational patterns involving *Symptom Distress*, *Dependency*, and *Social Support* were straightforward and predictable. In each of these instances, these factors correlated significantly with other protocol measures that were theoretically synchronous.

The factor labeled *Existential Distress*, as distinct from *Peace of Mind*, denotes issues or sources of distress that would be expected to resolve upon death (i.e., not feeling like who I once was, not feeling worthwhile or valued, a change in appearance, not being able to carry our important roles, feeling life no longer has meaning, and feeling a burden). *Existential Distress* correlated significantly with various measures of psychological distress, quality of life, and suffering. It did not, however, correlate significantly with will to live or sense of dignity. Our own research has shown that will to live fluctuates in response to various influences, depending on proximity to death.[11] For patients nearing death, symptom distress is one of the most ardent predictors of will to live; it is noteworthy that the *Symptom Distress* factor was significantly correlated with the variable will to live. Although a correlation between *Existential Distress* and sense of dignity might have been anticipated, its absence should come as no surprise. The construct of dignity, after all, is multifaceted and dependent on physical, psychological, social, and spiritual sources of distress. We have previously reported how dignity is often externally mediated, especially in terms of how one perceives himself/herself by others.[15] This latter observation is underscored by the finding that dignity correlates significantly with the PDI factor labeled *Dependency*.

The *Peace of Mind* factor proved to be the most challenging, and in some respects, most interesting. Unlike *Existential Distress, Peace of Mind*—consisting of the PDI items "not have made a meaningful contribution," "feelings of unfinished business," and "concerns about spiritual life"—address concerns that may transcend death itself. That is, dying patients might anticipate that spiritual matters, concerns about things they have left undone or the lack of having made difference in this life, could have ramifications beyond death. As such, none of the measures of current distress (such as depression, will to live, well-being, or quality of life) correlated significantly with *Peace of Mind*. It was this unexpected finding that led to our performing a factor analysis on the FACIT itself (see Table 7 for FACIT factor loading). When the relationship between the three FACIT factors and *Peace of Mind* was examined, the only significant correlation was with the Inner Peace factor (FACIT) [$r = -0.21$, $P < 0.002$]. Unlike the FACIT Faith and Spirituality factor, or the Meaning and Purpose factor, which largely speak to issues based on current patient experience, the FACIT Inner Peace factor addresses issues that could easily apply to any of the *Peace of Mind* items and their relationship to the transcendent. It is worth noting that the *Peace of Mind* factor, which included an item regarding spiritual concerns, had the lowest Cronbach's coefficient alpha. It is important to acknowledge that the term spirituality lacks definitional specificity.[26,27] Hence, idiosyncratic respondent interpretation may account for the lower internal consistency of this particular factor. Although future versions of the PDI may amend and revise the current spirituality item, clinicians are well advised to seek clarification from those patients using the PDI as a way of disclosing spiritual distress.

The PDI has excellent face validity and is easily completed by patients in various circumstances of deteriorating health (i.e., in hospital settings, palliative care units, and within community based settings). Depending on the patient's health and energy, it can take little more than a minute or two to complete; in other instances, particularly if the patient requires assistance, it can take longer (about 10–15 minutes).

Like any study, this one has its limitations. The participants were predominantly older patients with cancer. Although one might anticipate that the landscape of distress revealed by the PDI could be skewed by this select patient population, it should have little bearing on establishing the psychometrics of this new instrument. However, research examining how the PDI applies and performs among other populations, be they younger patients or those facing noncancer-related terminal conditions, would be well advised. There was also a large difference in the number of subjects recruited from across the three sites. The primary issue of concern, if any, is to what extent the patients recruited across the three sites differ from one another. Analysis of age, gender, and disease site distribution revealed no differences.

Of the 25 PDI items, four did not load on any of the five factors. These included not being able to continue usual routines, not feeling in control, not being able to fight the challenges of illness and not being able to accept the way things are. Although this might be used to justify eliminating these items from the PDI, there is good reason to retain them within this first iteration of the PDI. Although reporting the prevalence of distress as reflected by the PDI goes beyond the scope of this manuscript, each of the four items in question identified substantial distress; 51.8% of the cohort identified not being able to continue usual routines as a problem; not feeling in control, 29.4%; not being able to fight the challenges of illness, 12%; and not being able to accept the way things are, 11.5%. Although future versions of the PDI may see revisions consisting of somewhat fewer items, further field testing and broad experience with the current version would seem prudent.

The development of a new screening tool for palliative care offers some exciting and important opportunities. Like any novel instrument designed to disclose things that are otherwise difficult to see, the PDI will allow for a more precise and accessible view of dying patients' experiences. The data contained within this report provide initial evidence that the PDI is internally consistent, reliable, and valid. Its factor structure spans various domains, covering the spectrum of end-of-life distress. Because it takes little time or effort to complete, the PDI provides a feasible way of having patients disclose and discuss what specific issues are causing them distress.

The PDI could provide new opportunities to examine and better understand the landscape of dignity-related distress among patients nearing death. It could, for example, allow investigators to study the differential distribution of distress across various populations, care settings, and approaches to end-of-life care. It could enable routine screening for distress in palliative populations to be applied to at risk patients, or used to monitor and track dignity-related distress over time. First and foremost, however, the PDI should help clinicians detect areas of distress that are often overlooked, and are thus inaccessible. Identifying these sources of discomfort is a critical step toward acknowledging their importance within the realm of human suffering. Such acknowledgement should help pave the way toward greater insights into responding, and to the extent possible, ameliorating end-of-life distress. Hence, the PDI should help clinicians to deliver quality, dignity-conserving end-of-life care.[28]

Acknowledgments

The authors thank their research staff, including Kathy Cullihall (Winnipeg); Laureen Johnson, Amanda Stiles, Robert Van Dyke, Carla Stiles (Calgary); and Joanne Hale, Jenny Clarke, Sky Dawson, and Lynn Oldham (Perth).

References

1. Mount B. Whole person care: beyond psychosocial and physical needs. Am J Hosp Palliat Care 1993;10:28–37.

2. Portenoy RK, Thaler HT, Kornblith AB, et al. Symptom prevalence, characteristics and distress in a cancer population. Qual Life Res 1994;3: 183–189.

3. Morita T, Kawa M, Honke Y, et al. Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan. Support Care Cancer 2004;12:137–140.

4. Chochinov HM. Dying, dignity, and new horizons in palliative end-of-life care. CA Cancer J Clin 2006;56:84–103.

5. Graham KY, Longman AJ. Quality of life in persons with melanoma: preliminary model testing. Cancer Nurs 1987;10:338–346.

6. Hoffman BM, Zevon MA, D'Arrigo MC, Cecchini TB. Screening for distress in cancer patients: the NCCN rapid-screening measure. Psychooncology 2004;13:792–799.

7. Portenoy RK, Thaler HT, Kornblith AB, et al. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics, and distress. Eur J Cancer 1994;30A: 1326–1336.

8. Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care 1991;7:6–9.

9. Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. Am J Psychiatry 1995;152:1185–1191.

10. Rosenfeld B, Breitbart W, Galietta M, et al. The schedule of attitudes toward hastened death: Measuring desire for death in terminally ill cancer patients. Cancer 2000;88:2868–2875.

11. Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. Lancet 1999;354:816–819.

12. Kissane DW, Wein S, Love A, et al. The Demoralization Scale: a report of its development and preliminary validation. J Palliat Care 2004;20(4): 269–276.

13. Chochinov HM, Hack T, McClement S, Harlos M, Kristjanson L. Dignity in the terminally ill: an empirical model. Soc Sci Med 2002;54:433–443.

14. Chochinov HM. Dignity conserving care: a new model for palliative care. JAMA 2002;287:2253–2260.

15. Chochinov HM, Hack T, Hassard T, et al. Dignity in the terminally ill: a cross-sectional, cohort study. Lancet 2002;360:2026–2030.

16. Chochinov HM, Hack T, Hassard T, et al. Dignity therapy: a novel psychotherapeutic intervention for patients nearing death. J Clin Oncol 2005;23: 5520–5525.

17. Chochinov HM, Kristjanson LJ, Hack T, et al. Dignity in the terminally ill: revisited. J Palliat Med 2006;9(3):666–672.

18. McKelvie SG. Graphic ratings scales: how many categories. Br J Psychology 1978;69:185–202.

19. Johnson WL, Dixon PN. Response alternatives in Likert scaling. Educ Psychol Meas 1984;44:563–567.

20. Beck AT, Beck RW. Screening depressed patients in family practice. A rapid technic. Postgrad Med 1972;52:81–85.

21. Wilson KG, Graham ID, Viola RA, et al. Structured interview assessment of symptoms and concerns in palliative care. Can J Psychiatry 2004; 49(6):350–358.

22. Barrera M Jr, Ainlay SL. The structure of social support: a conceptual and empirical analysis. J Community Psychol 1983;11(2):133–143.

23. O'Reilly P. Methodological issues in social support and social network research. Soc Sci Med 1988;268:863–873.

24. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being scale (FACIT-sp). Ann Behav Med 2002;24(1):49–58.

25. Fazio AF. A concurrent validational study of the NCHS General Well-Being Schedule. Vital Health Stat 2 1977;Sep(73):1–53.

26. Sinclair S, Pereira J, Raffin S. A thematic review of the spirituality literature within palliative care. J Palliat Med 2006;9:464–479.

27. Rose S. Is the term 'spirituality' a word that everyone uses, but nobody knows what anyone means by it? J Contemp Relig 2001;16:193–207.

28. Chochinov HM. Dignity and the essence of medicine: the A, B, C & D of dignity-conserving care. BMJ 2007;335:184–187.

Appendix

Patient Dignity Inventory

For each item, please indicate how much of a problem or concern these have been for you within the last few days

1. Not being able to carry out tasks associated with daily living (e.g., washing myself, getting dressed).
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

2. Not being able to attend to my bodily functions independently (e.g., needing assistance with toileting-related activities)
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

3. Experiencing physically distressing symptoms (such as pain, shortness of breath, nausea).
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

4. Feeling that how I look to others has changed significantly.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

5. Feeling depressed.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

6. Feeling anxious.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

7. Feeling uncertain about my illness and treatment.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

8. Worrying about my future.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

9. Not being able to think clearly.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

10. Not being able to continue with my usual routines.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

11. Feeling like I am no longer who I was.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

12. Not feeling worthwhile or valued.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

13. Not being able to carry out important roles (e.g., spouse, parent).
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

14. Feeling that life no longer has meaning or purpose.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

15. Feeling that I have not made a meaningful and lasting contribution during my lifetime.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

16. Feeling I have 'unfinished business' (e.g., things left unsaid, or incomplete)
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

17. Concern that my spiritual life is not meaningful.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

18. Feeling that I am a burden to others.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

19. Feeling that I don't have control over my life.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

20. Feeling that my illness and care needs have reduced my privacy.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

21. Not feeling supported by my community of friends and family.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

22. Not feeling supported by my health care providers.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

23. Feeling like I am no longer able to mentally 'fight' the challenges of my illness.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

24. Not being able to accept the way things are.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

25. Not being treated with respect or understanding by others.
1☐ Not a problem 2☐ A slight problem 3☐ A problem 4☐ A major problem 5☐ An overwhelming problem

"HMC-9"

This is the exhibit marked "**HMC-9**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

Vol. 38 No. 5 November 2009 *Journal of Pain and Symptom Management* 641

Original Article

The Landscape of Distress in the Terminally Ill

Harvey Max Chochinov, MD, PhD, Thomas Hassard, PhD, Susan McClement, PhD, Thomas Hack, PhD, CPsych, Linda J. Kristjanson, PhD, Mike Harlos, MD, Shane Sinclair, BA, MDiv, PhD (C), and Alison Murray, MD, CCFP, MPH

Manitoba Palliative Care Research Unit (H.M.C.), Community Health Sciences (H.M.C., T.Has.), and Faculty of Nursing (S.M., T.Hac.), University of Manitoba, Winnipeg; Manitoba Palliative Care Research Unit (H.M.C., S.M.), and Patient and Family Support Services (H.M.C., T.Hac.) CancerCare Manitoba, Winnipeg, Manitoba, Canada; Western Australian Centre for Cancer & Palliative Care (H.M.C., L.J.K.), Curtin University of Technology, Perth, Australia; St. Boniface General Hospital (M.H.), Winnipeg, Manitoba; Tom Baker Cancer Centre (S.S.), Calgary; Department of Oncology (S.S.), Faculty of Medicine, University of Calgary, Calgary; and Calgary Health Region (A.M.), Calgary, Alberta, Canada

Abstract

Understanding the complexities of distress and knowing who is most vulnerable is foundational to the provision of quality, palliative end-of-life care. Although prior studies have examined the prevalence of symptom distress among patients nearing death, these studies have tended to largely focus on physical and, to a lesser extent, psychological challenges. The aim of this study was to use the Patient Dignity Inventory (PDI), a novel, reliable, and validated measure of end-of-life distress, to describe a broad landscape of distress in patients who are terminally ill. The PDI, a 25-item self-report, was administered to 253 patients receiving palliative care. Each PDI item is rated by patients to indicate the degree to which they experience various kinds of end-of-life distress. Palliative care patients reported an average of 5.74 problems (standard deviation, 5.49; range, 0–24), including physical, psychological, existential, and spiritual challenges. Being an inpatient, being educated, and having a partner were associated with certain kinds of end-of-life problems, particularly existential distress. Spirituality, especially its existential or "sense of meaning and purpose" dimension, was associated with less distress for terminally ill patients. A better appreciation for the nature of distress is a critical step toward a fuller understanding of the challenges facing the terminally ill. A clear articulation of the landscape of distress, including insight regarding those who are most at risk, should pave the way toward more effective, dignity-conserving end-of-life care. J Pain Symptom Manage 2009;38:641–649. *© 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

The work was supported by a grant from the National Cancer Institute of Canada, with funding from the Canadian Cancer Society. Dr. Chochinov is a Canada Research Chair in Palliative Care, funded by the Canadian Institutes for Health Research. The authors declare no conflicts of interest.

Address correspondence to: Harvey Max Chochinov, MD, PhD, Manitoba Palliative Care Research Unit, University of Manitoba, CancerCare Manitoba, Rm. 3021, 675 McDermot Avenue, Winnipeg, Manitoba R3E 0V9, Canada. E-mail: harvey.chochinov@cancercare.mb.ca

Accepted for publication: April 1, 2009.

0885-3924/09/$–see front matter
doi:10.1016/j.jpainsymman.2009.04.021

Key Words
Distress, Patient Dignity Inventory, palliative care

Introduction

Providing quality palliative care is predicated on a deep understanding of patient experience and potential causes of end-of-life distress.[1] Although some research has been undertaken to better understand this distress, for the most part, the focus has been relatively narrow, dominated by physical and, to a lesser extent, psychological sources of the distress.[2–4] Less work has been undertaken to identify the existential and spiritual challenges people face near the end of life.[5] Albeit not as readily quantified, nor as easily addressed, the latter are ubiquitous among the terminally ill.[6] Furthermore, these are issues that the patients want to have addressed within the context of palliative end-of-life care.[7,8]

To measure and track a broad spectrum of end-of-life distress, our research group developed a novel psychometric tool, coined the Patient Dignity Inventory (PDI, available online at www.jpsmjournal.com).[9] The PDI contains 25 items covering various physical, psychological, existential, and spiritual sources of end-of-life distress. Patients rate each item, indicating the extent to which they experience it as problematic. The construct and face validity, test-retest reliability, and factor structure of the PDI have been established and previously reported.[9] Hence, the PDI provides clinicians an easy way to identify various issues that can cause distress among patients nearing death. The aim of this study was to use the PDI to explore the broad spectrum of end-of-life distress and examine its various possible influences.

Methods

Participants

Between March 2004 and July 2007, the patients receiving palliative care from the Winnipeg Regional Health Authority Palliative Care Program and meeting eligibility criteria were approached to participate in this study. This program provides comprehensive inpatient care and coordinated, community-based, end-of-life care services. Then in February 2006 and in July 2006, the Palliative Care Program in Perth, Australia and the Calgary Health Region Palliative Care program in Calgary, Canada, respectively, were invited to partner in participant recruitment. These programs were chosen because of our long-standing research affiliations with those centers. These centers also are affiliated with palliative care programs that provide end-of-life care services comparable to the primary recruitment site.

Eligibility for the study was independently determined for each patient by the treatment staff, on the basis of clinical consensus. Eligibility criteria included being age 18 years or older; being enrolled in the palliative care program in their respective recruitment site; having a life expectancy of less than six months; an ability to read and speak English; demonstrating no evidence of dementia or delirium; and being able to provide informed consent. The patients were not referred to the study if they were cognitively impaired, unable to give informed consent, or too ill to take part in the protocol. Across the three recruitment sites, 806 patients were identified by the clinical staff as appropriate for referral to the study. Of these patients, the research staff found that 261 did not meet eligibility criteria, 205 were not interested in hearing about the study, and 28 were too ill. Of the remaining 312, 35 patients refused to take part. Of the remaining 277 patients, all of whom gave verbal and written consent, 24 dropped out for various reasons, primarily because they became too ill to complete the protocol. The final sample of 253 patients consisted of 190 patients from Winnipeg, Canada; 42 from Calgary; and 21 from Perth.

The Faculty of Medicine Ethics Committees at the University of Manitoba and Curtin University of Technology in Perth, and the University of Calgary Conjoint Health Research Ethics Board, approved the study, with the various Hospital Research Review Boards at participating institutions granting formal patient access. Prior to the onset of data collection, all the patients provided written informed consent.

Procedures

For this study, the patients were asked to complete the 25-item PDI (1 = no problem; 2 = somewhat of a problem; 3 = a problem; 4 = a big problem; 5 = an overwhelming problem).[9] The patients also completed the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp).[10] This is a psychometrically sound measure of spiritual well-being for people with cancer and other chronic illnesses. It consists of two subscales: Meaning and Peace, measuring existential well-being; and Faith, reflecting religious or faith-based dimensions of spirituality. Quality of life was measured using the brief Quality-of-Life Scale.[11] This two-item scale rates patients' self-assessed quality of life and satisfaction with their current quality of life (ranging from 1 [poor] to 10 [excellent]). Basic demographic information—including age, gender, marital status, living arrangements, religion, inpatient vs. outpatient status and education—also was collected from every patient.

Statistical Analysis

Descriptive statistics (mean, standard deviation [SD], and percentages, as appropriate) were calculated. The proportion of individuals experiencing a particular problem, defined as a PDI item rating of ≥ 3, was compared between groups using the Chi-squared test (when expected values fell below five, the Fisher's exact test was used). The total number of problems was compared between groups using the Student's *t*-test. Associations between FACIT scales and subscales and the individual PDI items were tested, using Spearman's Rank Correlation Coefficient. All tests were carried out on a two-tailed basis. Because of the number of tests of significance being carried out, the level of probability for significance was raised to 0.01. All statistical analyses were carried out using SPSS 15.0 (Chicago, IL).

Findings

The mean age of the 253 participants was 69 years (SD 13.5), and 136 (58%) were female. Thirty-six percent had less than a high school education, 19% had completed only high school, and 45% had some college or post-graduate training. Fifty-four percent of patients were married or cohabiting, 27% were widowed, 10% divorced, 8% were never married, and 2% were separated. Fifty-four percent of patients were living with a spouse or a partner. Thirty-two percent were living alone, 19% were living with children, 3% with parents, 1% with children, and 7% with others. In terms of religious affiliation, 37% were Protestant, 23% Catholic, 20% other, 17% no religious affiliation, and 3% Jewish. Primary tumor sites included lung (25%), gastrointestinal (18%), genitourinary (11%), breast (7%), hematologic (6%), and other solid tumors (23%); 8% had noncancer diseases, such as chronic obstructive pulmonary disease, amyotrophic lateral sclerosis, and various other life-limiting ailments. Across the total sample, 149 (59%) were inpatients, with the remainder receiving treatment outside of the hospital setting. The mean duration of survival from the time of interview to the time of death was 78 (standard error [SE] 6.5) days.

Patients reported an average of 5.74 problems each (SD 5.49; range 0–24). The five most prevalent problems reported (all greater than 30%) were not being able to continue usual routines (51.4%); experiencing physically distressing symptoms (47.8%); not being able to carry out important roles (37.5%); no longer feeling like who I once was (36.4%); and not being able to perform tasks of daily living (30.4%) (Table 1). Sixteen PDI items were rated as problematic by 10%–30% of the patients. These latter items fell within the domains of the physical (e.g., not being able to attend to bodily functions); the psychological (e.g., feeling depressed, feeling anxious); and the existential (e.g., feeling of not having control, feeling a burden to others, feeling life no longer has meaning). Only four PDI items were ranked by less than 10% of the sample as being problematic, including concerns regarding spiritual life (6.3%); not being treated with respect (2.8%); not feeling supported by health care providers (2%); and not feeling supported by friends or family (1.6%).

Patients with partners (either spouse or common law) reported more problems on average (6.67; SD 5.78) compared with patients without partners (widowed, divorced, separated) (4.68; SD 4.95) ($t = -2.811$; $P = 0.005$). Disease site, age, gender, living arrangements, religion, inpatient vs. outpatient status, and education were

Table 1
Prevalence of Distress in Palliative Care

PDI Item	Percentage with Problem
Not able to continue usual routines	51.4
Physically distressing symptoms	47.8
Not able to carry out important roles	37.5
Feeling no longer who I was	36.4
Not able to perform tasks of daily living	30.4
Feeling of not having control	29.2
Feeling uncertain	26.9
Not able to attend to bodily functions	26.5
Feeling anxious	24.5
Feeling of reduced privacy	24.5
Feeling a burden to others	24.1
Feeling how you look has changed	22.5
Feeling depressed	22.5
Worried about future	20.9
Not being able to think clearly	20.2
Feeling of unfinished business	19.4
Feeling life no longer has meaning or purpose	17.4
Not feeling worthwhile or valued	17.0
Feeling have not made meaningful contribution	11.9
Not feeling able to mentally fight illness	11.9
Not being able to accept things as they are	11.5
Concerns regarding spiritual life	6.3
Not being treated with respect	2.8
Not feeling supported by health care providers	2.0
Not feeling supported by friends or family	1.6

not significantly associated with the number of PDI items patients identified as problematic (Table 2). To further clarify the nature of distress in this patient population, the proportion of individuals experiencing specific problems, as indicated by the PDI, were calculated across each of the major demographic variables (Table 3). Within the bivariate comparisons, some significant relationships between patient characteristics and PDI-related distress emerged. For instance, younger patients reported more difficulty with feelings of not having control compared with older patients ($\chi^2 = 8.109$; $P = 0.004$). Although there were no significant gender differences for the average number of problems, men were more likely to report feeling a burden to others ($\chi^2 = 6.715$; $P = 0.010$). When compared with those without partners, the patients with partners were much more likely to report that not feeling in control was a problem ($\chi^2 = 15.855$; $P < 0.001$). The patients living with someone were more likely to report feeling worried about the future ($\chi^2 = 7.074$; $P = 0.005$), feelings of not having control ($\chi^2 = 7.955$; $P = 0.005$), and not being able to attend to bodily functions ($\chi^2 = 6.661$; $P = 0.010$). Inpatients were far more likely than outpatients to report "not being able to attend to bodily functions" as problematic ($\chi^2 = 20.89$, $P < 0.001$). Patients who were more educated were significantly more likely to report problems with feelings of having lost control ($\chi^2 = 10.256$; $P = 0.001$); this pattern held true for feelings of unfinished business ($\chi^2 = 10.063$; $P < 0.002$) and not being able to perform tasks of daily living ($\chi^2 = 9.637$; $P = 0.002$).

Table 2
Demographic Variables and Their Association with Distress and Quality of Life

Variable	Number of Problems	SD	*t*-Test	*P*-value	Quality of Life	SD	*t*-Test	*P*-value
Age (years)								
<70	6.34	5.69	1.672	NS	5.98	2.63	$t = 0.687$	NS
≥70	5.15	5.24			5.74	2.87		
Gender								
Male	5.94	5.63	0.521	NS	5.79	2.71	$t = -0.416$	NS
Female	5.57	5.38			5.93	2.79		
Inpatient vs. outpatient								
In	6.23	5.60	1.714	NS	5.53	2.85	$t = -2.312$	NS
Out	4.98	5.26			6.34	2.55		
Partner								
Yes	6.67	5.78	—	0.005	6.06	2.77	$t = 1.042$	NS
No	4.68	4.95	2.811		5.70	2.73		
Living alone vs. living with someone								
Yes	4.73	5.50	—	NS	5.80	2.85	$t = -0.257$	NS
No	6.20	5.44	1.924		5.89	2.71		
Education								
≤High school	5.38	5.51	—	NS	5.91	2.72	$t = 0.317$	NS
>High school	6.18	5.47	1.106		5.80	2.80		
Declared religion								
Yes	5.85	5.63	0.684	NS	5.78	2.76	$t = -1.209$	NS
No	5.20	4.76			6.26	2.71		

Table 3
Association Between Demographic Variables and Individual Sources of Distress

Variable	% With Problem	χ^2	*P*-value	χ^{2}[a]	*P*-value[a]
Age (younger [<70 years] vs. older [≥70 years])					
Feeling of not having control	Y 37.6, O 21.3	8.109	**0.004**	4.492	0.034
Feeling anxious	Y 31.2, O 18.0	5.984	0.014	5.844	0.016
Worried about future	Y 27.4, O 14.8	5.997	0.014	2.461	0.117
Gender (male vs. female)					
Feeling a burden to others	M 31.6, F 17.6	6.715	**0.010**	4.09	0.043
Not feeling worthwhile or valued	M 22.6, F 12.5	4.485	0.034	3.629	0.057
Partner vs. no partner					
Feeling of not having control	P 40.0, NP 17.1	15.855	**<0.001**	11.108	**<0.001**
Feeling no longer who I was	P 43.4, NP 28.2	6.261	0.012	6.111	0.013
Not able to attend to bodily functions	P 32.4, NP 19.7	5.206	0.023	1.601	0.206
Not feeling worthwhile or valued	P 22.1, NP 11.3	5.076	0.024	3.735	0.053
Feeling a burden to others	P 29.4, NP 17.9	4.517	0.034	3.276	0.070
Feeling life no longer has meaning or purpose	P 22.1, NP 12.0	4.460	0.035	0.006	0.939
Living with someone vs. living alone					
Worried about the future	LS 25.7, LA 11.1	7.074	**0.005**	4.704	0.030
Feeling of not having control	LS 34.9, LA 17.5	7.955	**0.005**	0.780	0.377
Not able to attend to bodily functions	LS 31.4, LA 16.0	6.661	**0.010**	1.038	0.308
Inpatient vs. outpatient					
Not able to attend to bodily functions	I 37.2, OP 11.4	20.892	**<0.001**	21.435	**<0.001**
Feeling of not having control	I 35.1, OP 21.2	5.756	0.016	9.853	**0.002**
Declared religion (yes vs. no)					
Feeling a burden to others	Y 21.4, N 37.2	4.858	0.028	4.409	0.036
Education ≤high school vs. >high school					
Feeling of not having control	≤H 21.0, >H 39.5	10.256	**<0.001**	12.090	**<0.001**
Feeling of unfinished business	≤H 12.2, >H 28.1	10.063	**0.002**	7.796	**<0.005**
Not able to perform tasks of daily living	≤H 22.3, >H 40.4	9.637	**0.002**	11.243	**<0.001**

Y = younger; O = older; M = male; F = female; P = partner; NP = no partner; LS = live with someone; LA = live alone; I = inpatient; OP = outpatient; C = cancer; NC = not cancer; H = high school.
Correlations that are significant at <0.01 are set off in bold.
[a] After controlling for all other demographic variables (i.e., age, gender, partner, living arrangements, inpatient vs. outpatient status, religion, and education).

To further examine the relationship between patient characteristics and PDI distress, logistic regression analyses were conducted. This allowed us to examine the strength of associations between individual sources of end-of-life distress and demographic variables, after controlling for the latter. Although initial bivariate associations reported for age, gender and living arrangement did not hold their significance, those for partner status, inpatient vs. outpatient status and education all remained highly significant (Table 3).

Besides simply a declaration of religious affiliation, the association between spirituality and symptom distress was explored on the basis of evaluating the connections between patient responses to the PDI and the FACIT-Sp and its two subscales, Meaning and Peace, and Faith (Table 4). A higher score on the FACIT-Sp and its subscales indicates a stronger sense of spirituality; higher scores on the PDI indicate more distress. Overall, there were significant negative associations between the total score on the FACIT-Sp and the number of PDI items rated as problematic ($r = -0.349$; $P < 0.001$) (i.e., higher spirituality scores corresponded to the fewer PDI-specific problems); the same held true for the FACIT Meaning and Peace subscale ($r = -0.411$; $P < 0.001$), but not for the Faith subscale. Eighteen of the 25 PDI items correlated significantly with the total FACIT-Sp score; 20 PDI items correlated significantly with the FACIT Meaning and Peace subscale. In contrast, only two of the PDI items (feeling depressed [$r = -0.190$, $P = 0.003$] and concerns regarding spiritual life [$r = -0.213$, $P = 0.001$]) were significantly correlated with the FACIT-Faith subscale.

Discussion

Understanding distress and its associated risk factors is vital to the field of palliative care. Even

Table 4
Spirituality and End-of-Life Distress

	FACIT Total		FACIT Meaning and Peace		FACIT Faith	
PDI Item	*r*	*P*	*r*	*P*	*r*	*P*
Not able to continue usual routines	−0.187	0.005	−0.250	<0.001	−0.026	0.690
Physically distressing symptoms	−0.253	0.001	−0.269	<0.001	−0.112	0.088
Not able to carry out important roles	−0.226	0.001	−0.263	<0.001	−0.044	0.500
Feeling no longer who I was	−0.316	<0.001	−0.366	<0.001	−0.105	0.107
Not able to perform tasks of daily living	−0.213	0.001	−0.222	0.001	−0.084	0.197
Feeling of not having control	−0.185	0.006	−0.238	<0.001	−0.090	0.172
Feeling uncertain	−0.308	<0.001	−0.336	<0.001	*−0.155*	0.017
Not able to attend to bodily functions	−0.0189	0.005	−0.221	0.001	−0.042	0.522
Feeling anxious	−0.295	<0.001	−0.382	<0.001	−0.102	0.118
Feeling of reduced privacy	−0.201	0.003	−0.236	0.001	−0.064	0.331
Feeling a burden to others	−0.200	0.003	−0.191	0.003	*−0.128*	0.050
Feeling how you look has changed	−0.129	0.054	−0.119	0.070	−0.032	0.623
Feeling depressed	−0.359	<0.001	−0.397	<0.001	−0.190	0.003
Worried about future	−0.178	0.008	−0.191	0.003	−0.092	0.158
Not being able to think clearly	*−0.17*	0.010	−0.188	0.004	−0.061	0.357
Feeling of unfinished business	*−0.164*	0.014	−0.181	0.006	−0.121	0.063
Feeling life no longer has meaning or purpose	−0.287	<0.001	−0.335	<0.001	−0.087	0.186
Not feeling worthwhile or valued	−0.276	<0.001	−0.290	<0.001	*−0.152*	0.020
Feeling have not made meaningful contribution	*−0.137*	0.042	*−0.150*	0.022	−0.047	0.471
Not feeling able to mentally fight illness	−0.276	<0.001	−0.323	<0.001	*−0.129*	0.049
Not being able to accept things as they are	−0.227	0.001	−0.281	<0.001	−0.050	0.447
Concerns regarding spiritual life	−0.236	<0.001	−0.190	0.004	−0.213	0.001
Not being treatedwith respect	−0.103	0.129	−0.124	0.059	−0.019	0.774
Not feeling supported by health care providers	0.047	0.490	−0.075	0.254	0.011	0.866
Not feeling supported by friends or family	0.011	0.870	−0.015	0.815	0.027	0.676

Correlations that are significant at <0.01 are bolded; correlations with significance levels between 0.05 and 0.01 are italicized.

though many sources of distress may not be readily visible or easily articulated by patients, the degree to which these shape end-of-life experience is profound. This study represents a first attempt, using the PDI, to explore the landscape of distress for patients nearing death.

The patients identified nearly six problems each, as determined by their PDI scores. The most highly endorsed items included a combination of physical challenges (distressing symptoms), functional limitations (not able to continue usual routines; not able to perform tasks of daily living; not able to carry out important roles), and existential concerns (no longer feeling like who I was). Although few of these, aside from symptom distress, are routinely evaluated, their prominence suggests that within the context of end-of-life care, they should be. Items not as highly endorsed should not be misconstrued as unimportant. We previously reported that 87.5% of palliative care patients felt "not being treated with respect" would have a profound influence on their sense of dignity.[12] The fact that only 2.8% of participants reported this to be problematic says less about the salience of this item and more perhaps about the quality of care they received.

The pattern that initially emerged in our analysis suggested that being younger, being male, being an inpatient, being more educated, and having a partner or living with someone was associated with a greater likelihood of certain kinds of distress. The fact that younger patients reported more problems than older patients is consistent with the literature.[13,14] The particular problems that younger patients identify indicate that anticipation of death raises various existential concerns, such as feeling a loss of control, generalized psychological distress, and a sense of unfinished business. These patients have had less time to realize their life goals or ambitions and may, more than older patients, sense their death is premature or untimely.

Further analysis using logistic regression indicated that the impact of age, gender, partner status, and living arrangements on individual sources of distress was noticeably reduced, when controlled for the other demographic variables

(Table 3). This suggests that age, gender, partner status, and living arrangements are strongly conflated with one another, reflecting the fact that older individuals were more likely to be female, have lost their partners, and to be living alone. Controlling for any three of these variables, therefore, inevitably substantially reduces the impact of the remaining variable. Partner status, however, continued to be very significantly associated with feelings of not having control, even after controlling for all the other demographic variables.

In contrast, education and inpatient/outpatient status retained their highly significant associations with individual sources of distress, after controlling for all the other demographic variables, implying that these variables operate independently of the age/gender/partner status/living arrangements complex. The modeling process, therefore, confirmed that being more educated, having a partner, and being an inpatient each had an independent and significant predictive influence on poorer coping, as assessed by the PDI-related variables.

Patients with education exceeding high-school completion were more likely to report PDI-related problems, including feelings of not having control, not being able to perform tasks of daily living and feelings of unfinished business. Some studies have linked higher education with better coping—for example, among cancer survivors[13] and women anticipating breast biopsy results;[16] however, few have looked at its influences on end-of-life coping. One palliative care study found more educated participants who reported significantly higher levels of suffering, suggesting a "greater tendency to extrapolate from concrete, individual problems to a more generalized abstraction of global suffering."[11] Another palliative care study reported higher education associated with a heightened sense of burden to others.[17] Perhaps more education correlates with a cognitive style, whereby intellectual processing, in the face of overwhelming life-threatening circumstances, allows for rumination without, necessarily, resolution. More educated individuals may also experience greater contrast effects, whereby greater pre-illness resources and expectations regarding control and independence may find them more overwhelmed and burdened by loss of control within their current end-of-life circumstances.[18,19]

Various studies have consistently shown that cancer inpatients tend to report more distress than do outpatients.[4] This is likely a proxy for illness severity; as such, it is not surprising that previous studies have reported inpatients demonstrate a poorer quality of life,[13] with more physical[20,21] and psychological[22] distress, than patients being looked after in the community. The association between distress, as measured by the PDI, and having a partner or living with someone is seemingly counterintuitive. After all, many studies have shown the benefits of psychosocial support for patients with life-threatening and life-limiting conditions.[10,15,23–25] Unlike previous studies, however, the PDI was able to expose various aspects of distress, covering a broad range of concerns. Patients with partners and those living with someone experienced the type of problems that could conceivably be magnified by another bearing witness. The experience of "feeling out of control" or "not being able to attend to bodily functions" can fundamentally be shaped by the presence and attitudes of people closest at hand. As such, individual distress, when perceived to be imposed on others, can intensify. However, it is important to note that people with partners or people living with someone did not report significant differences in their overall quality of life. Hence, relationships should be understood as one possible context within which nurturing and suffering give shape to the experience of approaching death.

The significant correlations between most of the PDI items and the total FACIT-Sp score confirm an association between general notions of spirituality and end-of-life distress. A heightened sense of spirituality and lack of symptom distress would appear to go hand in hand. PDI item endorsements were more closely aligned with the FACIT Meaning and Peace subscale than the FACIT-Faith subscale. This suggests that faith, in and of itself, may have less to do with end-of-life distress, relative to issues of existential well-being, such as feeling at peace with oneself or having a sense of meaning and purpose. Alternatively, a fuller understanding of the connection between faith and end-of-life distress may have to await future studies that target less secular, predominantly religious individuals approaching death.

Like any other study, this one also has its own limitations. The participants were predominantly older patients with cancer. The landscape of distress will likely vary according to age group, diagnosis, cultural affiliations, socioeconomic status, and place of terminal care. Future research, addressing these various constituencies, will add considerably to our understanding of end-of-life distress. There was also a large difference in the number of subjects recruited across the three sites. The primary issue of concern, if any, is to what extent the patients recruited across the three sites differ from one another. Analysis of age, gender, and disease site distribution revealed no differences. Finally, although we reported on associations between distress and spirituality, future studies, evaluating various aspects of religiosity such as personal beliefs and practices, will shed light on this important, yet poorly understood area.

Understanding and identifying the diversity of distress in palliative care is a critical step toward acknowledging its importance within the realm of human suffering. A clear articulation of the typography of distress, including insight regarding those who are most at risk, should pave the way toward more effective, dignity-conserving end-of-life care.[26,27]

Acknowledgments

The authors thank their research staff, including Kathy Cullihall (Winnipeg); Laureen Johnson, Amanda Stiles, Robert Van Dyke, Carla Stiles (Calgary); and Joanne Hale, Jenny Clarke, Sky Dawson, and Lynn Oldham (Perth).

Author contributions: H.M. Chochinov, L.J. Kristjanson, S. McClement, T. Hack, and M. Harlos contributed to the protocol design; T. Hassard and H.M. Chochinov to the analysis of the data. All team members contributed to the task of data collection and data interpretation. The report was written by H.M. Chochinov, with critique and approval by the full research team.

References

1. Mount B. Whole person care: beyond psychosocial and physical needs. Am J Hosp Palliat Care 1993;10:28–37.

2. Portenoy RK, Thaler HT, Kornblith AB, et al. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. Eur J Cancer 1994;30A: 1326–1336.

3. Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care 1991;7:6–9.

4. Portenoy RK, Thaler HT, Kornblith AB, et al. Symptom prevalence, characteristics and distress in a cancer population. Qual Life Res 1994;3: 183–189.

5. Morita T, Kawa M, Honke Y, et al. Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan. Support Care Cancer 2004;12:137–140.

6. Chochinov HM. Dying, dignity, and new horizons in palliative end-of-life care. CA Cancer J Clin 2006;56:84–103.

7. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000;284:2476–2482.

8. Daaleman TP, Nease DE Jr. Patient attitudes regarding physician inquiry into spiritual and religious issues. J Fam Pract 1994;39:564–568.

9. Chochinov HM, Hassard T, McClement SE, et al. The Patient Dignity Inventory: a novel way of measuring dignity-related distress in palliative care. J Pain Symptom Manage 2008;36:559–571.

10. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-sp). Ann Behav Med 2002;24:49–58.

11. Graham KY, Longman AJ. Quality of life and persons with melanoma. Preliminary model testing. Cancer Nurs 1987;10:338–346.

12. Chochinov HM, Krisjanson LJ, Hack TF, et al. Dignity in the terminally ill: revisited. J Palliat Med 2006;9:666–672.

13. Wilson KG, Chochinov HM, McPherson CJ, et al. Suffering with advanced cancer. J Clin Oncol 2007;25:1691–1697.

14. Herschbach P, Keller M, Knight L, et al. Psychological problems of cancer patients: a cancer distress screening with a cancer-specific questionnaire. Br J Cancer 2004;91:504–511.

15. Edmondson D, Park CL, Blank TO, Fenster JR, Mills MA. Deconstructing spiritual well-being: existential well-being and HRQOL in cancer survivors. Psychooncology 2008;17:161–169.

16. Drageset S, Lindstrom TC. Coping with a possible breast cancer diagnosis: demographic factors and social support. J Adv Nurs 2005;51:217–226.

17. Chochinov HM, Kristjanson LJ, Hack TF, et al. Burden to others and the terminally ill. J Pain Symptom Manage 2007;34:463–471.

18. Schieman S. Age, education, and the sense of control: a test of the cumulative advantage hypothesis. Res Aging 2001;23:153–178.

19. Chipperfield JG, Campbell DW, Perry RP. Stability in perceived control: implications for health among very old community-dwelling adults. J Aging Health 2004;16:116–147.

20. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. Cancer 2000;88:2164–2171.

21. Chang VT, Hwang SS, Feuerman M, Kasimis BS, Thaler HT. The Memorial Symptom Assessment Scale short form (MSAS-SF). Cancer 2000;89: 1162–1171.

22. Reuter K, Raugust S, Marschner N, Harter M. Differences in prevalence rates of psychological distress and mental disorders in inpatients and outpatients with breast and gynaecological cancer. Eur J Cancer Care 2007;16:222–230.

23. Parker PA, Baile WF, de Moor C, Cohen L. Psychosocial and demographic predictors of quality of life in a large sample of cancer patients. Psychooncology 2003;12:183–193.

24. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. Psychooncology 2001;10:19–28.

25. Mystakidou K, Tsilika E, Parpa E, et al. Beck Depression Inventory: exploring its psychometric properties in a palliative care population of advanced cancer patients. Eur J Cancer Care 2007; 16:244–250.

26. Chochinov HM. Dignity-conserving care—a new model for palliative care: helping the patient feel valued. JAMA 2002;287:2253–2260.

27. Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. BMJ 2007;335:184–187.

"HMC-10"

This is the exhibit marked "**HMC-10**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at
this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

JOURNAL OF PALLIATIVE MEDICINE
Volume 9, Number 3, 2006
© Mary Ann Liebert, Inc.

Dignity in the Terminally Ill: Revisited

HARVEY M. CHOCHINOV, M.D., Ph.D., F.R.C.P.C.,[1-5] LINDA J. KRISJANSON, Ph.D.,[5]
THOMAS F. HACK, Ph.D., C.Psych,[3,6] THOMAS HASSARD, Ph.D.,[4]
SUSAN McCLEMENT, Ph.D.,[2,6] and MIKE HARLOS, M.D.[7]

ABSTRACT

Background: Several studies have been conducted examining the notion of dignity and how it is understood and experienced by people as they approach death.

Objective: The purpose of this study was to use a quantitative approach to validate the Dignity Model, originally based on qualitative data.

Design: Themes and subthemes from the Dignity Model were used to devise 22 items; patients were asked the extent to which they believed these specific issues were or could be related to their sense of dignity.

Results: Of 211 patients receiving palliative care, "not being treated with respect or understanding" (87.1%) and "feeling a burden to others" (87.1%) were the issues most identified as having an influence on their sense of dignity. All but 1 of the 22 items were endorsed by more that half of the patients; 16 items were endorsed by more than 70% of the patients. Demographic variables such as gender, age, education, and religious affiliation had an influence on what items patients ascribed to their sense of dignity. "Feeling life no longer had meaning or purpose" was the only variable to enter a logistic regression model predicting overall sense of dignity.

Conclusions: This study provides further evidence supporting the validity of the Dignity Model. Items contained within this model provide a broad and inclusive range of issues and concerns that may influence a dying patient's sense of dignity. Sensitivity to these issues will draw care providers closer to being able to provide comprehensive, dignity conserving care.

INTRODUCTION

OVER THE PAST DECADE, our research group has conducted a number of studies addressing the issue of dying with dignity.[1-8] While most care providers attending to dying patients would espouse dignity as an overarching value or goal of end-of-life care, few empirical studies have provided guidance or direction on how this might be operationalized or systematically achieved.

One of our earlier studies within this program of research established an empirically based model of dignity in the terminally ill (Table 1).[1] From this study, it became apparent that individuals varied considerably in terms of what affected their sense of dignity. The model, however, suggests that

---

[1] Department of Psychiatry, Family Medicine, University of Manitoba, Winnepeg, Canada.
[2] Manitoba Palliative Care Research Unit, CancerCare Manitoba, Winnepeg, Canada.
[3] Patient and Family Support Services, CancerCare Manitoba, Winnepeg, Canada.
[4] Community Health Sciences, University of Manitoba, Winnepeg, Canada.
[5] Edith Cowan University, Perth, Australia.
[6] Faculty of Nursing, University of Manitoba, Winnepeg, Canada.
[7] St. Boniface General Hospital, Winnepeg, Canada.

TABLE 1. DIGNITY MODEL IN THE TERMINALLY ILL

Major Dignity Categories, Themes, and Subthemes[a]		
Illness-related concerns	*Dignity conserving repertoire*	*Social Dignity Inventory*

Level of independence
• Cognitive acuity[10]
• Functional capacity[8]
Symptom distress
• Physical distress[17,21]
• Psychological distress[19]
  • Medical uncertainty[20]
  • Death anxiety[22]
	Dignity-conserving perspectives
	• Continuity of self[14]
	• Role preservation[9]
	• Generativity/legacy[4]
	• Maintenance of pride[14]
	• Hopefulness[11]
	• Autonomy/control[3,5]
	• Resilience/fighting spirit[13]
	Dignity-conserving practices
	• Living in the moment[12]
	• Maintaining normalcy[12]
	• Seeking spiritual comfort[15]
		Privacy boundaries[18]
		Social support[7]
		Care tenor[1,6]
		Burden to others[2]
		Aftermath concerns

[a] Superscripts correspond to the variable items used to validate the Dignity Model (see Table 2).

these influences could be divided into three broad categories that we labeled: (1) Illness-Related Concerns (factors caused by, or associated with, the underlying illness); (2) the Social Dignity Inventory (social or externally mediated factors); and (3) The Dignity Conserving Repertoire (psychological and spiritual considerations).[1,2] Later quantitative studies helped us establish the importance of self-perception, and the way in which patients experience themselves to be seen or appreciated, as a powerful mediator of preservation of one's sense of dignity.[3,4,6,7] The data seemed to support that listening to patients, validating their concerns, and ascribing meaning to their experience could engender hope and ultimately bolster dignity toward the end of life.

Using a cross-sectional, quantitative approach, this current study was undertaken to test further the validity of the dignity model. Patients approaching the end of life were asked to indicate the extent to which they believed various issues and concerns (physical, psychological, social,

TABLE 2. PERCENTAGE OF PATIENTS WHO ASCRIBE VARIOUS SYMPTOMS OR EXPERIENCES TO THEIR SENSE OF DIGNITY

#	*Variable*	*% agree or strongly agree*
1	Not being treated with respect or understanding	87.1%
2	Feeling a burden to others	87.1%
3	Feeling you do not have control over your life	83.7%
4	Not feeling you made a meaningful or lasting contribution	83.3%
5	Not being able to independently manage bodily functions	82.9%
6	Not feeling worthwhile or valued	81.4%
7	Not feeling supported by your community	80.3%
8	Not being able to carry out tasks of daily living	79.6%
9	Not being able to carry out important roles	78.5%
10	Not being able to think clearly	77.3%
11	Feeling life no longer has meaning or purpose	75.1%
12	Not being able to continue with usual routines	74.9%
13	Not being able to mentally fight	74.5%
14	No longer feeling like who you were	74.4%
15	Not having a meaningful spiritual life	73.7%
16	Not being able to accept things the way they are	71.6%
17	Changes in physical appearance	66.4%
18	Feeling your privacy has been reduced	65.9%
19	Feeling depressed or anxious	59.7%
20	Uncertainly regarding illness	59.2%
21	Experiencing distressing symptoms	53.1%
22	Thinking how life might end	41.7%

and existential) derived from the model, were related to or could influence their sense of dignity (Table 2).

METHOD

Participants

Between January 2001 and January 2004, 411 patients with end-stage cancer, meeting eligibility criteria, were approached to participate in this study from two specialized palliative care units in Winnipeg, Manitoba. These units provide inpatient care and coordinate community-based end-of-life care services. The medical status of every patient was reviewed by the treatment staff, who independently ascertained their eligibility for the study on the basis of clinical consensus. Eligibility criteria included: being age 18 years or older; having a diagnosis of terminal cancer with a life expectancy of less than 6 months; an ability to read and speak English; demonstrating no evidence of dementia or delirium that might make completion of the study protocol difficult; and the ability to provide informed consent. Patients were not referred to the study if they were cognitively impaired, unable to give informed consent, or too gravely ill to take part in the protocol.

The Faculty of Medicine Ethics Committee, University of Manitoba, approved the study, and the Hospital Research Review Boards at both institutions granted formal access to patients. Prior to the onset of data collection, all patients provided written informed consent.

Protocol

Patients were asked to rate the extent to which they felt their own personal sense of dignity was related to, or could be influenced by, 22 individual items derived from the themes and subthemes contained within the Dignity Model[1,2] (1 = strongly agree; 2 = agree; 3 = uncertain; 4 = disagree; 5 = strongly disagree). These items covered a range of psychological, physical, social and existential issues (Table 2).

Patients were also asked to rate their sense of dignity on a 7-point Sense of Dignity Item [SDI] (0 = no sense of lost dignity, 1 = minimal, 2 = mild, 3 = moderate, 4 = strong, 5 = severe, and 6 = an extreme sense of lost dignity).[9] Demographic information was also collected from all participants. Experienced palliative care research nurses administered the study psychometrics and questionnaires, with regular monitoring by the principal investigator (H.M.C.) to ensure data integrity and standardized application of the protocol.

Statistical analysis

The frequency of item endorsement was calculated (collapsing agree and strongly agree) across 22 symptoms or concerns that might have an association with a dying patient's sense of dignity. The connection between individual item endorsement and various demographic variables that might have an influence on patients' sense of dignity toward the time of death was also examined, using t tests to examine continuous variables and χ^2 tests to test categorical variables.

Participants were divided into two subsets: those whose sense of dignity was intact (scoring ≤ 2 on the SD) and those who reported a significant fracturing of their sense of dignity (scoring ≥ 3). This approach to dividing the data was used successfully in our previous studies to differentiate patients whose dignity was fractured from those whose dignity was intact.[3] The results of these two subgroups with respect to total item endorsement were compared, using a t test. A forward stepwise logistic regression analysis was conducted in order examine the predictive value of individual item endorsement with sense of dignity. Unless otherwise specified, all tests were done on a two-tailed basis and a p value of less than 0.05 was judged significant.

RESULTS

Of the 411 patients identified as potential participants for the study, 10 died and the health of 39 deteriorated before the interview could take place; 27 felt too sick or confused to allow for their participation; 3 had communication problems (either were unable to speak, or did not speak English); 2 referred patients did not have cancer. Of the remaining 330 patients, 211 (64%) agreed to participate in the study (123 inpatients, 88 outpatients), with a median length of survival from the time of study entry to death being 52 days.

The mean age of participants was 67 years (standard deviation [SD] 13.5), and 89 (43%) were men. Forty percent of the study group had less

TABLE 3. INFLUENCES ON SENSE OF DIGNITY

- Psychological
  - Depression or anxiety
  - Difficulty with acceptance
  - Inability to mentally fight
  - Not being able to think clearly
- Physical
  - Experiencing distressing symptoms
  - Not being able to carry out usual routines
  - Not being able to carry out usual roles
  - Inability to attend to tasks of daily living
  - Inability to independently attend to bodily functions
  - Changes in physical appearance
- Existential
  - Thinking how life might end
  - Uncertainly about illness
  - Not having a meaning spiritual life
  - Not feeling any longer like who you were
  - Feeling life has no purpose
  - Not feeling worthwhile or valued
  - Not feeling you have made a meaningful contribution
  - Feeling you do not have control over your life
- Social
  - Privacy concerns
  - Not feeling adequately supported
  - Feeling a sense of burden to others
  - Not being treated with respect or understanding

than a high school education, 20% had graduated from high school, and 40% had some college or postgraduate training. Fifty-seven percent of patients were married or cohabiting, with the remainder being divorced (7%), never married (8%), widowed (25%), or separated (2%). Religious affiliation was Protestant, 46%; Catholic, 26%; Jewish, 2%; other, 15%; and no religious affiliation, 11%. Primary tumor sites included lung (26%), gastrointestinal tract (24%), genitourinary system (11%), and breast (13%). A additional 7% of individuals had hematological cancers, and the remaining 19% had various solid tumors.

Table 3 indicates the percentage of patients who agreed or strongly agreed that the designated item was or could be associated with their sense of dignity. Other than "thinking about how life might end," each item was endorsed by more than half of the patients as having a possible influence on their sense of dignity. Seven items were endorsed by more than 80% of patients, including "not feeling supported by your community" (80.3%); "not feeling worthwhile or valued" (81.4%); "not being able to manage bodily functions" (82.9%); "not feeling you made a meaningful or lasting contribution" (83.3%); "feeling you no longer have control over your life" (83.7%); "feeling a burden to others" (87.1%); and "not being treated with respect or understanding" (87.1%). The median number of items patients associated as having a possible influence on their sense of dignity was 16 (range, 0–22).

Various demographic variables, with respect to item endorsement, were examined. For example, younger patients were more likely to ascribe an inability to carry out tasks of daily living ($t = 2.96$, $p = 0.003$), problems attending to bodily functions ($t = 3.131$, $p = 0.002$); thoughts about how life might end ($t = 2.383$, $p = 0.018$), concerns related to their sense of privacy (1.834, $p = 0.068$), and difficulty with acceptance ($t = 2.137$, $p = 0.034$), as having a bearing on their sense of dignity. Women were found to be more likely to identify change in appearance ($\chi^2 = 4.91$, $p = 0.025$), the ability to think clearly ($\chi^2 = 4.34$, $p = 0.037$) and a meaningful spiritual life ($\chi^2 = 5.788$; $p = 0.016$) as being dignity related issues. People who were more educated (having or exceeding a high school education [60.5%]) were likely to identify more items as having a possible bearing on their sense of dignity, including an inability to carry out tasks of daily living ($t = 3.15$, $p = 0.002$); uncertainly about their illness ($t = 2.40$, $p = 0.017$); worries about how life might end ($t = 2.39$, $p = 0.018$); not feeling valued ($t = 2.36$, $p = 0.019$); and having difficulty with acceptance ($t = 3.59$, $p = 0.001$). Overall all, those with more education were likely to endorse more items as having possible dignity implications, compared to those with lesser education ($t = -2.557$, $p = 0.011$). Patients acknowledging a religious affiliation were more likely to identify difficulty with acceptance ($\chi^2 = 4.981$; $p = 0.026$) and not having a meaningful spiritual life ($\chi^2 = 4.128$; $p = 0.042$) as being dignity related issue, compared to those not identifying any religious affiliation.

Patients in more seemingly supportive or structured living arrangements appeared to indicate that lacking in these supports would have a negative influence on their sense of dignity. For example, patients living with someone were more likely to indicate that not being treated with respect could undermine their sense of dignity ($\chi^2 = 4.316$; $p = 0.038$); those who were married indicated that not feeling valued could challenge their sense of dignity; and, compared to outpatients, inpatients were more likely to report that not feeling supported by their community could weaken their sense of dignity ($\chi^2 = 4.274$; $p = 0.039$).

All items, aside from "being able to fight mentally," correlated significantly with the full SDI

($r = 0.133–0.319$; $p = 0.05–0.0001$). The correlation between the SDI and the total number of items endorsed was highly significant ($r = 0.40$; $p < 0.001$). The sample was divided between those whose sense of dignity was intact (SDI ≤ 2; 94.7%) versus those whose sense of dignity was fractured (SDI ≥ 3; 5.3%). Those patients whose dignity was fractured showed a trend toward endorsing more items as being associated with their sense of dignity compared to those whose dignity was intact (18.6 versus 15.9; $t = 1.757$, $p = 0.08$, not significant [NS]). A forward stepwise logistic regression analysis was conducted to examine the predictive value of individual item endorsement with sense of dignity. The only item to enter this model was "feeling life no longer had meaning or purpose" ($\chi^2 = 6.569$, $p = 0.01$).

DISCUSSION

This study provides a unique opportunity to validate the empirical model of dignity in the terminally ill, originally based on qualitative latent content analysis using constant comparison techniques. By reframing the major themes and subthemes into specific questions regarding symptoms or concerns toward the end of life, dying patients were able to indicate the extent to which they associated these items as having a possible bearing on their sense of dignity. Aside from "thinking about how life might end," more than half the study cohort endorsed all the remaining items (agreed or strongly agreed) as having a significant possible influence on their sense of dignity.

The most highly endorsed items included "not feeling supported by your community," "not feeling worthwhile or valued," "not being able to manage bodily functions," "not feeling you have made a meaningful or lasting contribution," "not feeling you have control over your life," "feeling a burden to others," and "not being treated with respect or understanding." It is noteworthy that each of these items has an interactional dimension, in that they address issues that might find patients either feeling devalued, or having to rely on others for aspects of care that could undermine their personal sense of autonomy and worth. This is consistent with our previously reported findings, which have illustrated the importance of patient self perception as an important mediator of maintained sense of personal dignity.[2-4]

It is also noteworthy that "not feeling treated with respect or understanding" and "feeling a burden to others" were the most highly endorsed dignity-related concerns. The connection between these items is critical, in that patients who feel a burden to others often sense that their lives lack purpose or meaning, or perceive that others consider them to no longer be worthy of respect or esteem. Research into desire for death has quite consistently identified feeling a burden to others as a significant factor in suicidal behavior.[10-12] This suggests that for health care providers and family members alike, maintaining a relationship or therapeutic stance anchored in respect and understanding, offers some protection against sensing oneself having become a burden to others, or life no longer feeling worth living.[2,4,8]

The data also yielded some interesting demographic implications regarding dignity related concerns. For example, younger people, for whom approaching death is often considered untimely, were more likely to ascribe dignity concerns to losses that older patients, over time, may have come to accommodate to (e.g., not being able to carry out usual tasks, not being able to manage bodily functions, anticipating how life might end, compromises to privacy imposed by advancing illness, and generalized difficulty accepting the way life had changed). There were gender differences as well, with women being more likely to associate "changes in appearance," "difficulty with thinking clearly," and "concerns about having a meaningful spiritual life" as having dignity implications.

Not surprisingly, people who were more educated were much more inclined to intellectualize the notion of dignity, hence assigning more items as having possible dignity eroding implications. It is noteworthy that other investigators have associated higher educational level with modestly higher endorsement of desire for hastened death.[13] People who were more religious were also more likely to endorse difficulty with acceptance and concerns about a meaningful spiritual life as having dignity related significance. These findings are consistent with other studies that have shown that spiritual well-being offers some protection against end-of-life despair in those for whom death is imminent.[14]

Finally, people in seemly more supportive relationships, such as being married, living with someone, or being looked after within a hospital setting, were more likely to see the relinquishment of "being valued," "being respected," or "feeling supported by their community," respectively, as having a possible bearing on their sense of dignity. Again, this is consistent with the salutary effects reported by palliative care patients regarding the positive effects of social support and perceived improvement in their quality of life.[15]

The small to modest correlations between sense of dignity and each of the individual items is understandable, in light of the fact that patients were asked to rate the extent to which these questions or concerns could have a bearing on their sense of dignity. In other words, because the goal of this study was model validation, patients were asked about the theoretical connection between these items and the construct of dignity, rather than the extent to which each item currently contributed to their current overall sense of dignity. That notwithstanding, it is notable that in relation to loss of sense of dignity, the logistic model underlines the importance of "feeling that life no longer had meaning or purpose." This is consistent with the two most highly endorsed individual items (i.e., "feeling a burden to others" and "not being treated with respect"). Clearly, engendering a sense of meaning or purpose, as a way of staving off feelings of being a burden and no longer feeling worthy of respect, is a cornerstones of dignity conserving care.[2,8]

This study has several limitations. Data were collected primarily from a group of older patients with cancer, all of whom were receiving palliative care. A younger cohort may have yielded different findings, because a person's life experience may influence perceptions of dignity. Patients with nonmalignant illness, such as human immunodeficiency virus (HIV)-related disorders, neurodegenerative conditions, or end stage renal or cardiac disease—particularly those being treated in nonpalliative care specialty units—may have manifest a different constellation of dignity-related concerns. Dignity might also be culturally mediated, and while our cohort had some cultural diversity, the sample size was insufficient to examine this issue adequately. Finally, the construct of dignity may be temporally unstable. Although we reported items that might influence a dying patient's sense of dignity within weeks of death, it could be that the determinants of dignity shift as death draws nearer. To address this issue of temporal stability, prospective longitudinal studies of dignity as life-limiting illness advances are required.

This study offers the first validation of the Dignity Model, with results that both support and are consistent with the previously reported findings. Although the items presented within this model are nonhierarchical, they do nevertheless provide a broad and inclusive range of issues and concerns that may influence a dying patient's sense of dignity. Clinicians should consider each item within the Dignity Model in terms of its clinical and therapeutic implications. Indeed, the model suggests that in order to deliver comprehensive quality end-of-life care, close attention must be paid to the various physical, psychological, social, and spiritual concerns and challenges that patients face as they near death. Sensitivity to these issues will draw care providers closer to being able to provide truly comprehensive, empathic, dignity-conserving care.

ACKNOWLEDGMENTS

We gratefully acknowledge the work of our research nurse, Kathy Cullihall. This work was supported by grants from the National Cancer Institute of Canada, with funding from the Canadian Cancer Society. Dr. Chochinov is a Canada Research Chair in Palliative Care, funded by the Canadian Institutes for Health Research. Dr. Kristjanson is supported by The Cancer Council of Western Australia. Dr. Hack is a Dorothy J. Lamont Scientist, supported by the National Cancer Institute of Canada and the Canadian Institutes of Health Research.

REFERENCES

1. Chochinov HM, Hack T, McClement S, Harlos M, Kristjanson L: Dignity in the terminally ill: An empirical model. Soc Sci Med 2002;54:433–443.
2. Chochinov HM: Dignity conserving care: A new model for palliative care. JAMA 2002;287:2253–2260.
3. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M: Dignity in the terminally ill: A cross-sectional, cohort study. Lancet. 2002;360: 2026–2030.
4. Chochinov HM: Dignity and the eye of the beholder. J Clin Oncol 2004;22:1336–1340.
5. Chochinov HM: Defending dignity. J Support Palliat Care 2004;1:307–308.
6. Chochinov HM, Hack T, Hassard T, Kristjanson L, McClement S, Harlos M: Dignity and psychotherapeutic considerations in end of life care. J Palliat Care 2004;20:143–142.

7. Hack T, Chochinov H, Hassard H, Kristjanson L, McClement S, Harlos M: Defining dignity in terminally ill cancer patients: A factor-analytic approach. Psychooncology 2004;13:700–708.
8. Chochinov HM, Hack T, Hassard T, Kristjanson L, McClement S, Harlos M: Dignity therapy: A novel psychotherapeutic intervention for patients nearing death. J Clin Oncol 2005;23:5520–5525.
9. Wilson KG, Graham ID, Viola RA, Chater S, de Faye BJ, Weaver LA, Lachance JA: Structured interview assessment of symptoms and concerns in palliative care. Can J Psychiatry 2004;49:350–358.
10. Wilson KG, Curran D, McPherson CJ. A burden to others: A common source of distress for the terminally ill. Cogn Behav Ther 2005;34:115–123.
11. Filiberti A, Ripamonti C, Totis A, Ventafridda V, De Conno F, COntiero P, Tamburini M: Characteristics of terminal cancer patients who committed suicide during a home palliative care program. J Pain Symptom Manage 2001;22:544–553.
12. Kelly BJ, Burnett PC, Pelusi D, Badger SJ, Varghese FT, Robertson MM: Association between clinician factors and a patient's wish to hasten death: Terminally ill cancer patients and their doctors. Psychosomatics 2004;45:311–318.
13. O'Mahony S, Goulet J, Kornblith A, Abbatiello G, Clarke B, Kless-Siegal S, Breitbart W, Payne R: Desire for hastened death, cancer pain and depression: report of a longitudinal observational study. J Pain Symptom Manage 2005;29:446–457.
14. McClain CS, Rosenfeld B, Breitbart W: Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. Lancet 2003;361:1603–1607
15. Low J, Perry R, Wilkinson S: A qualitative evaluation of the impact of palliative care day services: the experiences of patients, informal carers, day unit managers and volunteer staff. Palliat Med 2005;19:65–70.

Address reprint requests to:
Harvey Max Chochinov, M.D., Ph.D.
CancerCare Manitoba
675 McDermot Avenue, Room 3021
Winnipeg, Manitoba R3E 0V9

E-mail: harvey.chochimov@cancercare.mb.ca

"HMC-11"

This is the exhibit marked "**HMC-11**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care

Kindness, humanity, and respect—the core values of medical professionalism—are too often being overlooked in the time pressured culture of modern health care, says **Harvey Chochinov**, and the A, B, C, and D of dignity conserving care can reinstate them

EDITORIAL, p 167

Harvey Max Chochinov
professor, department of psychiatry, University of Manitoba, CancerCare Manitoba, Winnipeg, MB, Canada R3E 0V9
harvey.chochinov@cancercare.mb.ca

Accepted: 15 May 2007

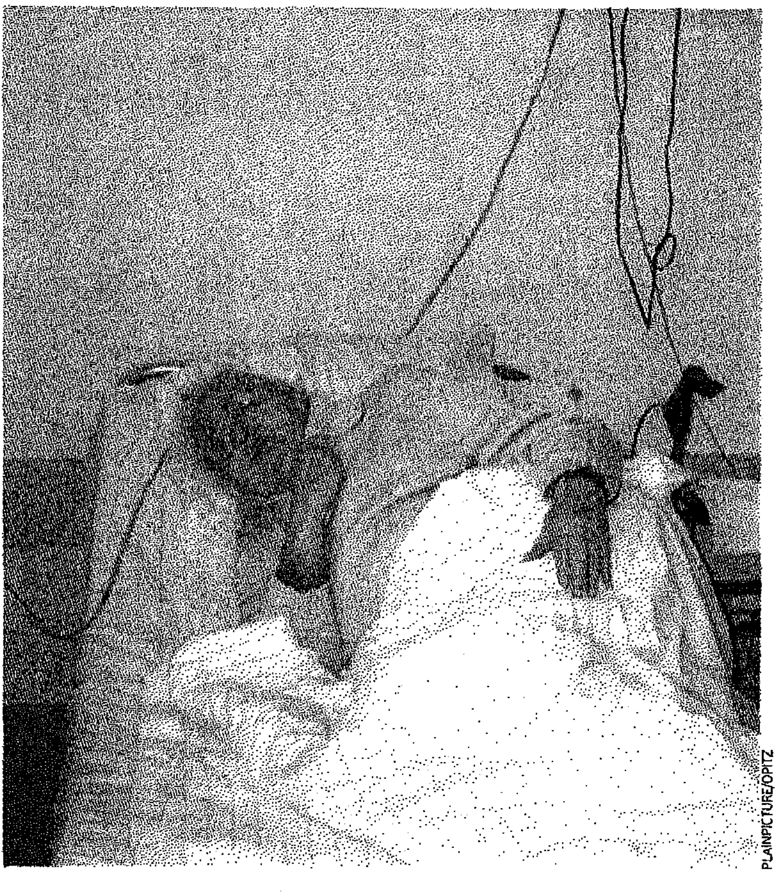
The late Anatole Broyard, essayist and former editor of the *New York Times Book Review*, wrote eloquently about the psychological and spiritual challenges of facing metastatic prostate cancer. "To the typical physician," he wrote, "my illness is a routine incident in his rounds while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity... I just wish he would... give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way."[1]

Broyard's words underscore the costs and hazards of becoming a patient. The word "patient" comes from the Latin patiens, meaning to endure, bear, or suffer, and refers to an acquired vulnerability and dependency imposed by changing health circumstances. Relinquishing autonomy is no small matter and can exact considerable costs.[2] These costs are sometimes relatively minor—for example, accepting clinic schedules or hospital routines. At other times, the costs seem incompatible with life itself. When patients experience a radical unsettling of their conventional sense of self[3] and a disintegration of personhood,[4] suffering knows few bounds. To feel sick is one thing, but to feel that who we are is being threatened or undermined—that we are no longer the person we once were—can cause despair affecting body, mind, and soul. How do healthcare providers influence the experience of patienthood, and what happens when this frame of reference dominates how they view people seeking their care?

Dignity and patienthood

Answering these questions begins with an examination of the relationship between patienthood and notions of dignity. Although the literature on dignity is sparse, it shows that "how patients perceive themselves to be seen" is a powerful mediator of their dignity.[5] [6] In a study of patients with end stage cancer, perceptions of dignity were most strongly associated with "feeling a burden to others" and "sense of being treated with respect."[7] As such, the more that healthcare providers are able to affirm the patient's value—that is, seeing the person they are or were, rather than just the illness they have—the more likely that the patient's sense of dignity will be upheld. This finding, and the intimate connection between care provider's affirmation and patient's self perception, underscores the basis of dignity conserving care.[8]

Yet, many healthcare providers are reticent to claim this particular aspect of care, which is variously referred to as spiritual care, whole person care, psychosocial care, or dignity conserving care.[9-12] This reluctance is often framed in terms of lack of expertise or concern about how much time this might consume. Yet, when personhood is not affirmed, patients are more likely to feel they are not being treated with dignity and respect.[13] Not being treated with dignity and respect can undermine a sense of value or worth.[5] Patients who feel that life no longer has worth, meaning, or purpose are more likely to feel they have become a burden to others, and patients



PLAINPICTURE/OPITZ

Box 1 | Attitudes

Questions to be asked

- How would I be feeling in this patient's situation?
- What is leading me to draw those conclusions?
- Have I checked whether my assumptions are accurate?
- Am I aware how my attitude towards the patient may be affecting him or her?
- Could my attitude towards the patient be based on something to do with my own experiences, anxieties, or fears?
- Does my attitude towards being a healthcare provider enable or disenable me to establish open and empathic professional relationships with my patients?

Actions to be taken

- Make a conscious effort to make these questions a part of your reflection on the care of each and every patient
- Discuss the issue of healthcare providers' attitudes and assumptions, and how they influence caring for patients, as a regular part of case reviews and clinical teaching
- Include ongoing professional development activities that have you challenge and question your attitudes and assumptions as they might affect patient care
- Create a culture among your colleagues and within your healthcare setting in which acknowledgement and discussion of these issues becomes a standard part of providing care

who feel they are little more than a burden may start to question the point of their continued existence.[14-16] Redressing the "incongruity" that Broyard raises—that is, the separation of humanity and compassion from healthcare delivery—requires that "treatment of disease takes its proper place in the larger problem of the care of the patient."[16]

The A, B, C, and D of dignity conserving care

The notion of dignity conserving care, while emerging primarily from palliative care, applies across the broad spectrum of medicine. Whether patients are young or old, and whatever their health problems, the core values of kindness, respect, and dignity are indispensable. Just as the simple "A, B, C" mnemonic (airway, breathing, and circulation) effectively summarises the fundamentals of critical care, an easily remembered core framework of dignity conserving care—the A, B, C, and D of dignity conserving care—may remind practitioners about the importance of caring for, as well as caring about, their patients.[16]

Attitude

"A"—attitude—underscores the need for healthcare providers first and foremost to examine their attitudes and assumptions towards patients. Attitude can be defined as an enduring, learnt predisposition to behave in a consistent way towards a given class of objects (or people), or a persistent mental or neural state of readiness to react to a certain class of objects (or people), not as they are but as they are conceived to be. The perceptions on which attitudes are based may or may not reflect the patient's reality. For instance, might an assumption of poor quality of life in a patient with longstanding disabilities lead to the withholding of life sustaining choices?[17] Might ageist assumptions mean that conversations about intimacy are rarely initiated?[18] Is a health worker more likely to assume intoxication in a confused, homeless patient, before considering whether they have a metabolic disorder? Do people with chronic mental illness provoke assumptions about malingering or somatoform disorders, even before an appropriate medical examination has been done?

Examining attitudes and assumptions is a deeply personal task, requiring approaches suited to the individual (box 1). At a minimum, healthcare providers must ask some basic questions, meant to help them understand how attitudes and assumptions can influence the way they deal with patients. They are reminded that "what they believe about patients and their potential may affect them profoundly. The attitude of an expert is contagious and can become limiting."[19] As a case in point, inordinately high suicide rates were reported among Scandinavian patients with advanced cancer, who were offered no further treatment or contact with the healthcare system.[20] While the rationale for this may have been based on considerations of resource allocation or medical futility, the psychological and spiritual fallout is clear: people who are treated like they no longer matter will act and feel like they no longer matter. In other words, patients look at healthcare providers as they would a mirror, seeking a positive image of themselves and their continued sense of worth. In turn, healthcare providers need to be aware that their attitudes and assumptions will shape those all-important reflections.

Box 2 | Behaviours

Disposition

- Treat contact with patients as you would any potent and important clinical intervention
- Professional behaviours towards patients must always include respect and kindness
- Lack of curative options should never rationalise or justify a lack of ongoing patient contact

Clinical examination

- Always ask the patient's permission to perform a physical examination
- Always ask the patient's permission to include students or trainees in the clinical examination
- Although an examination may be part of routine care, it is rarely routine for the patient, so always, as far as possible, take time to set the patient at ease and show that you have some appreciation for what they are about to go through (for example, "I know this might feel a bit uncomfortable"; "I'm sorry that we have to do this to you"; "I know this is an inconvenience"; "This should only hurt for a moment"; "Let me know if you feel we need to stop for any reason"; "This part of the examination is necessary because . . .")
- Limit conversations with patients during an examination (aside from providing them with instruction or encouragement) until they have dressed or been covered appropriately

Facilitating communication

- Act in a manner that shows the patient that he or she has your full and complete attention
- Always invite the patient to have someone from his or her support network present, particularly when you plan to discuss or disclose complex or "difficult" information
- Personal issues should be raised in a setting that attempts to respect the patient's need for privacy
- When speaking with the patient, try to be seated at a comfortable distance for conversation, at the patient's eye level when possible
- Given that illness and changing health status can be overwhelming, offer patients and families repeated explanations as requested
- Present information to the patient using language that he or she will understand; never speak about the patient's condition within their hearing distance in terms that they will not be able to understand
- Always ask if the patient has any further questions and assure them that there will be other opportunities to pose questions as they arise

Box 3 | Compassion

Getting in touch with one's own feelings requires the consideration of human life and experience

- Reading stories and novels and observing films, theatre, art that portray the pathos of the human condition
- Discussions of narratives, paintings, and influential, effective role models
- Considering the personal stories that accompany illness
- Experiencing some degree of identification with those who are ill or suffering

Ways to show compassion

- An understanding look
- A gentle touch on the shoulder, arm, or hand
- Some form of communication, spoken or unspoken, that acknowledges the person beyond their illness.

Behaviour

A change, or at the very least an awareness, of one's attitudes can set the stage for modified behaviour—the "B" of dignity conserving care. Once healthcare providers are aware that they play an important role in mediating patients' dignity, several behaviours should logically follow (box 2). Healthcare providers' behaviour towards patients must always be predicated on kindness and respect. Small acts of kindness can personalise care and often take little time to perform.[21] Getting the patient a glass of water, helping them with their slippers, getting them their glasses or hearing aid, adjusting a pillow or their bed sheets, acknowledging a photograph, greetings card, or flowers—these behaviours convey a powerful message, indicating that the person is worthy of such attention. Such behaviour is particularly important when caring for patients with advanced disease "both because of the physical threats of dying and because of the challenge to our sense of self worth and self coherence."[22]

Box 4 | Dialogue

Acknowledging personhood

- "This must be frightening for you."
- "I can only imagine what you must be going through."
- "It's natural to feel pretty overwhelmed at times like these."

Knowing the patient

- "What should I know about you as a person to help me take the best care of you that I can?"
- "What are the things at this time in your life that are most important to you or that concern you most?"
- "Who else (or what else) will be affected by what's happening with your health?"
- "Who should be here to help support you?" (friends, family, spiritual or religious support network, etc)
- "Who else should we get involved at this point, to help support you through this difficult time?" (psychosocial services; group support; chaplaincy; complementary care specialists, etc)

Psychotherapeutic approaches

- Dignity therapy
- Meaning centred therapy
- Life review/reminiscence

One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient

Certain communication behaviours, as outlined in box 2, enhance the trust and connection between patients and their healthcare providers. Certain intimacies of care require special mention—taking the time to ask patients their permission to perform an examination will make them feel less like a specimen to be poked and prodded and more like a person whose privacy is theirs to relinquish under mutually agreed conditions. This quality of professionalism and connectedness also increases the likelihood that patients will be forthright in disclosing personal information, which so often has a bearing on their ongoing care.

Compassion

Attitude and behaviour can be examined within the realm of the intellectual, but compassion, the "C" of dignity conserving care, requires a discourse about the healthcare provider's feelings. Compassion refers to a deep awareness of the suffering of another coupled with the wish to relieve it. Compassion speaks to feelings that are evoked by contact with the patient and how those feelings shape our approach to care. Like empathy (identification with and understanding of another's situation, feelings, and motives),[23] compassion is something that is felt, beyond simply intellectual appreciation. Healthcare providers arrive at compassion through various channels (see box 3). For some, compassion may be part of a natural disposition that intuitively informs patient care. For others, compassion slowly emerges with life experience, clinical practice, and the realisation that, like patients, each of us is vulnerable in the face of ageing and life's many uncertainties. Compassion may develop over time, and it may also be cultivated by exposure to the medical humanities (http://medhum.med.nyu.edu/), including the interdisciplinary field of humanities (literature, philosophy, ethics, history, and religion), social sciences (anthropology, cultural studies, psychology, sociology), and the arts (literature, theatre, film, and visual arts). Each of these will not speak to every healthcare provider, but they can offer insight into the human condition and the pathos and ambiguity that accompany illness.

Although the process of arriving at compassion can be difficult or complex, showing compassion often flows naturally and can be as quick and as easy as a gentle look or a reassuring touch. In fact, compassion can be conveyed by any form of communication—spoken or unspoken—that shows some recognition of the human stories that accompany illness. As Broyard stated in his wonderful way, "I'd like my doctor to scan me, to grope for my spirit as well as my prostate. Without some such recognition, I am nothing but my illness."[1]

Dialogue

Dialogue, the "D" of dignity conserving care, may be the most—and the least—important component of this framework. Through a genuine examination of attitudes that shape patient care, a change in behaviour that draws from these insights, and the awakening of compassion, many fundamental aims of dignity conserving care will already have been achieved. The practice of medicine requires the exchange of extensive information, within a partnership whose tempo is set by gathering, interpreting, and planning according to new and emerging details. As such, dialogue is a critical element of dignity conserving care. At its most basic, such dialogue must acknowledge personhood beyond the illness itself and recognise the emotional impact that accompanies illness (box 4).

Several psychotherapeutic approaches (dignity therapy,[24] meaning centred therapy,[25] life review or reminiscence[26]) engage patients in more extensive, formatted dialogue, with the intent of bolstering their sense of meaning, purpose, and dignity (see further reading in box).[27] Dialogue should routinely be used to acquaint the healthcare provider with aspects of the patient's life that must be known to provide the best care possible. Treating a patient's severe arthritis and not knowing their core identity as a musician; providing care to a woman with metastatic breast cancer and not knowing she is the sole carer for two young children; attempting to support a dying patient and not knowing he or she is devoutly religious—each of these scenarios is equivalent to attempting to operate in the dark. Obtaining this essential context should be a standard and indispensable element of dignity conserving care. It will also foster a sense of trust, honesty, and openness, wherein personal information and medical facts are woven into a continuous and rich dialogue informing care.

Conclusions

In his 1927 landmark paper "The care of the patient" Francis Peabody wrote: "One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient."[16] The A, B, C, and D of dignity conserving care may provide clinicians with a framework to operationalise Peabody's sage insight and relocate humanity and kindness to their proper place in the culture of patient care. Easy to remember and empirically based, this framework may be readily applied to teaching, clinical practice, and standards at undergraduate and postgraduate levels and across all medical subspecialties, multidisciplinary teams, and allied health professions. For anyone privileged to look after patients, at whatever stage of the human life cycle, the duty to uphold, protect, and restore the dignity of those who seek our care embraces the very essence of medicine.

SUMMARY POINTS

Healthcare providers have a profound influence on how patients experience illness and on their sense of dignity

Dignity conserving care has an important effect on the experience of patienthood

The A, B, C, and D of dignity conserving care—attitude, behaviour, compassion, and dialogue—provide a framework to guide healthcare practitioners towards maintaining patients' dignity

This framework can be applied to teaching, clinical practice, and standards at undergraduate and postgraduate levels and across all medical subspecialties, multidisciplinary teams, and allied health professions

Funding: HMC is supported by funding from the Canadian Institutes of Health Research and the Canada Research Chairs programme; his work is also supported by CancerCare Manitoba Foundation.

Competing interests: None declared.

1 Broyard A. *Intoxicated by my illness: and other writings on life and death*. New York: Ballantine, 1992.
2 Murata H. Spiritual pain and its care in patients with terminal cancer: construction of a conceptual framework by philosophical approach. *Palliat Support Care* 2003;1:15-21.
3 Burt R. *Death is that man taking names: intersections of American medicine, law, and culture*. Berkeley: University of California Press, 2002.
4 Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med* 1982;306:639-45.
5 Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity in the terminally ill: a cross-sectional, cohort study. *Lancet* 2002;360:2026-30.
6 Chochinov HM. Dignity and the eye of the beholder. *J Clin Oncol* 2004;22:1336-40.
7 Chochinov HM, Krisjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Dignity in the terminally ill: revisited. *J Palliat Med* 2006;9:666-72.
8 Chochinov HM. Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *JAMA* 2002;287:2253-60.
9 Mount B. Whole person care: beyond psychosocial and physical needs. *Am J Hosp Palliat Care* 1993;10:28-37.
10 Safran DJ. Defining the future of primary care: what can we learn from patients? *Ann Intern Med* 2003;138:248-55.
11 Murillo M, Holland JC. Clinical practice guidelines for the management of psychosocial distress at the end of life. *Palliat Support Care* 2004;2:65-77.
12 Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol* 2005;23:5520-5.
13 Wilson KG, Curran D, McPherson CJ. A burden to others: a common source of distress for the terminally ill. *Cogn Behav Ther* 2005;34:115-23.
14 Chochinov HM. Burden to others in the terminally ill. *J Pain Symptom Manage* (in press).
15 McPherson CJ, Wilson KG, Murray MA. Feeling like a burden: exploring the perspectives of patients at the end of life. *Soc Sci Med* 2007;64:417-27.
16 Peabody FW. The care of the patient. *JAMA* 1927;88:876-82.
17 Stienstra D, Chochinov HM. Vulnerability, disability, and palliative end-of-life care. *J Palliat Care* 2006;22:166-74.
18 Lovell M. Caring for the elderly: changing perceptions and attitudes. *J Vasc Nurs* 2006;24:22-6.
19 Remen RN. The power of words: how the labels we give patients can limit their lives. *West J Med* 2001;175:353-4.
20 Louhivuori KA, Hakama J. Risk of suicide among cancer patients. *Am J Epidemiol* 1982;109:59-65.
21 Bollinger JL. Five dynamics in patienthood. *Bull Am Protestant Hosp Assoc* 1978;42:90-4.
22 Callahan D. Pursuing a peaceful death. *Hastings Center Report* 1993;23:33-8.
23 Spiro H. What is empathy and can it be taught? *Ann Int Med* 1992;116;843-6.
24 Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol* 2005;23(24):5520-5.
25 Breitbart W. Spirituality and meaning in supportive care: spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Support Care Cancer* 2002;10:272-80.
26 Bulter RN. The life review: an interpretation of reminiscence in the aged. *Psychiatry* 1963;26:65-76.
27 Chochinov HM, Cann B. Interventions to enhance the spiritual aspects of dying. *J Palliat Med* 2005;8:S103-15.

FURTHER READING

Block SD. Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA* 2001;285:2898-905.

Breitbart W, Gibson C, Poppito SR, Berg A. Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. *Can J Psychiatry* 2004;49:366-72.

Bauby J. *The diving bell and the butterfly: a memoir of life in death*. New York: Knopf, 1997.

Charon R. Narrative medicine: a model for empathy, reflection, profession, and trust. *JAMA* 2007;286:1897-1902.

Chochinov HM. Dying, dignity, and new horizons in palliative end-of-life care. *CA Cancer J Clin* 2006;56:84-103.

Lo B, Ruston D, Kates LW, Arnold RM, Cohen CB, Faber-Langendoen K, et al. Discussing religious and spiritual issues at the end of life: a practical guide for physicians. *JAMA* 2002;287:749-54.

Maguire P, Pitceathly C. Key communication skills and how to acquire them. *BMJ* 2002;325:697-700.

Sulmasy D. Spiritual issues in the care of dying patients: ". . . it's okay between me and God". *JAMA* 2006;296:1385-92.

Tulsky JA. Interventions to enhance communication among patients, providers, and families. *J Palliat Med* 2005;8(suppl 1):S95-102.

"HMC-12"

VOLUME 23 · NUMBER 24 · AUGUST 20 2005

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life

Harvey Max Chochinov, Thomas Hack, Thomas Hassard, Linda J. Kristjanson, Susan McClement, and Mike Harlos

From the Department of Psychiatry, Family Medicine, Community Health Sciences, and Faculty of Nursing, University of Manitoba; Manitoba Palliative Care Research Unit and Patient and Family Support Services, CancerCare Manitoba; St Boniface General Hospital, Winnipeg, Manitoba, Canada; and Edith Cowan University, Perth, Australia.

Submitted December 15, 2004; accepted March 7, 2005.

Supported by the Cancer Council of Western Australia (L.J.K.) and grants from the American Foundation for Suicide Prevention and the National Cancer Institute of Canada, with funding from the Canadian Cancer Society. Dr Chochinov is a Canada Research Chair in palliative care, funded by the Canadian Institutes for Health Research.

This article reports original research; none of the results have been published previously, nor have they appeared in conference proceedings, abstracts, or reports. The outline of questions used for dignity therapy has appeared in *Journal of the American Medical Association* (Chochinov HM: Dignity-conserving care: A new model for palliative care. JAMA 287:2253-2260, 2002).

Authors' disclosures of potential conflicts of interest are found at the end of this article.

Address reprint requests to Harvey Max Chochinov, MD, PhD, CancerCare Manitoba Room, 3017-675 McDermot Ave, Winnipeg, Manitoba, Canada R3E 0V9; e-mail: harvey.chochinov@cancercare.mb.ca.

0732-183X/05/2324-5520/$20.00

DOI: 10.1200/JCO.2005.08.391

ABSTRACT

Purpose
This study examined a novel intervention, dignity therapy, designed to address psychosocial and existential distress among terminally ill patients. Dignity therapy invites patients to discuss issues that matter most or that they would most want remembered. Sessions are transcribed and edited, with a returned final version that they can bequeath to a friend or family member. The objective of this study was to establish the feasibility of dignity therapy and determine its impact on various measures of psychosocial and existential distress.

Patients and Methods
Terminally ill inpatients and those receiving home-based palliative care services in Winnipeg, Canada, and Perth, Australia, were asked to complete pre- and postintervention measures of sense of dignity, depression, suffering, and hopelessness; sense of purpose, sense of meaning, desire for death, will to live, and suicidality; and a postintervention satisfaction survey.

Results
Ninety-one percent of participants reported being satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family. Postintervention measures of suffering showed significant improvement ($P = .023$) and reduced depressive symptoms ($P = .05$). Finding dignity therapy helpful to their family correlated with life feeling more meaningful ($r = 0.480$; $P = .000$) and having a sense of purpose ($r = 0.562$; $P = .000$), accompanied by a lessened sense of suffering ($r = 0.327$; $P = .001$) and increased will to live ($r = 0.387$; $P = .000$).

Conclusion
Dignity therapy shows promise as a novel therapeutic intervention for suffering and distress at the end of life.

J Clin Oncol 23:5520-5525. © 2005 by American Society of Clinical Oncology

INTRODUCTION

One of the most confounding challenges faced by end-of-life care providers is helping patients achieve or maintain a sense of dignity. Our prior studies of dignity and end-of-life care have shown a strong association between an undermining of dignity and depression, anxiety, desire for death, hopelessness, feeling of being a burden on others, and overall poorer quality of life.[1-4] Yet, dying with dignity is usually only vaguely understood; hence, although the pursuit of dignity frequently underlies various approaches to end-of-life care, its therapeutic implications are frequently uncertain.

There is mounting evidence that suffering and distress are major issues facing dying patients. Some studies suggest that psychosocial and existential issues may be of even greater concern to patients than pain and physical symptoms.[5-7] The Institute of Medicine has identified overall quality of life and achieving a sense of spiritual peace and

This is the exhibit marked "**HMC-12**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at
this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

well-being among the key domains of quality end-of-life care. Similarly, patients deem a sense of spiritual peace, relieving burden, and strengthening relationships with loved ones among the most important facets of end-of-life care.[5] Several studies have linked these issues, including a loss of sense of dignity, loss of meaning, and a sense of being a burden on others, with heightened requests for a hastened death.[6-9] Clearly, palliative interventions must reach beyond the realm of pain and symptom management to be fully responsive to a broad and complex range of expressed needs.

The purpose of this study was to examine a brief, individualized psychotherapeutic intervention, dignity therapy, designed to address psychosocial and existential distress among terminally ill patients. Such distress has often been linked to the notion of suffering and described in terms of the challenges that threaten the intactness of a person.[10] Others have suggested that meaning, or a paucity of meaning, defines the essence of existential distress.[11] Dignity therapy builds on the foundation of this work by engaging patients in a brief, individualized intervention designed to engender a sense of meaning and purpose, thereby reducing suffering in patients nearing death.

Our empirically based dignity model of palliative care provides the framework for this novel intervention, informing its content and therapeutic tone (Table 1).[1-4] To decrease suffering, enhance quality of life, and bolster a sense of meaning, purpose, and dignity, patients are offered the opportunity to address issues that matter most to them or speak to things they would most want remembered as death draws near. An edited transcript of these sessions is returned to the patient for them to share with individuals of their choosing. This study was undertaken to establish the feasibility of dignity therapy and determine its impact on various measures of psychosocial and existential distress.

PATIENTS AND METHODS

The outline of the dignity-therapy interview guide is based on themes and subthemes that arise from the dignity model (Table 2). Therapy sessions are transcribed and edited, and the resulting "generativity document" is returned to patients to bequeath to a friend or family member. Therapeutic sessions, running between 30 and 60 minutes, were offered either at the patients' bedside for those in hospital or, for outpatients, in their residential setting (home or long-term care facility). A psychiatrist (H.M.C.) and palliative care nurse (in Winnipeg, Canada) or two palliative care nurses and a psychologist (in Perth, Australia) administered the manualized protocol. Before starting the study, pilot sessions were conducted to ensure intertherapist consistency in administering dignity therapy. To ensure protocol integrity, approximately one in four transcripts were selected randomly for review by the principal investigator (H.M.C.). Although no major breaches of the protocol were detected, this process enabled minor refinements and standardization of the interview format and editing process between therapists and across study sites.

Dignity therapy was offered to all patients meeting entry criteria who were registered with palliative care services in Perth or Winnipeg. In Australia, patients were recruited from two sites, including the Silver Chain Hospice Care Service (Osborne Park, Western Australia, Australia; Australia's largest in-home specialist palliative care service) and The Cancer Council Centre for Palliative Care Cottage Hospice (Shenton Park, Western Australia, Australia; a 26-bed palliative care unit). In Canada, patients were recruited from the Winnipeg Regional Health Authority Palliative Care Program (Winnipeg, Manitoba, Canada). Similar to the

Table 1. Dignity Themes, Definitions, and Dignity-Therapy Implications[1,2]

Dignity Theme	Definition	Dignity-Therapy Implication
Generativity	The notion that, for some patients, dignity is intertwined with a sense that one's life has stood for something or has some influence transcendent of death	Sessions are tape-recorded and transcribed, with an edited transcript or "generativity document" being returned to the patient to bequeath to a friend or family member
Continuity of self	Being able to maintain a feeling that one's essence is intact despite advancing illness	Patients are invited to speak to issues that are foundational to their sense of personhood or self
Role preservation	Being able to maintain a sense of identification with one or more previously held roles	Patients are questioned about previous or currently held roles that may contribute to their core identity
Maintenance of pride	An ability to sustain a sense of positive self-regard	Providing opportunities to speak about accomplishments or achievements that engender a sense of pride
Hopefulness	Hopefulness relates to the ability to find or maintain a sense of meaning or purpose	Patients are invited to engage in a therapeutic process intended to instill a sense of meaning and purpose
Aftermath concerns	Worries or fears concerning the burden or challenges that their death will impose on others	Inviting the patient to speak to issues that might prepare their loved ones for a future without them
Care tenor	Refers to the attitude and manner with which others interact with the patient that may or may not promote dignity	The tenor of dignity therapy is empathic, nonjudgmental, encouraging, and respectful

Table 2. Dignity Psychotherapy Question Protocol

Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc)? Why were they so important to you, and what do you think you accomplished in those roles?
What are your most important accomplishments, and what do you feel most proud of?
Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
What are your hopes and dreams for your loved ones?
What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, other[s])?
Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
In creating this permanent record, are there other things that you would like included?

Australian site's program, this program offers a broad range of inpatient and outpatient end-of-life care services.

Patient eligibility criteria were as follows: (1) a terminal illness associated with a life expectancy of $<$ 6 months; (2) minimum age of 18 years; (3) English speaking; (4) a commitment to three to four contacts over approximately 7 to 10 days; (5) no cognitive impairments, based on clinical consensus; and (6) willingness to provide verbal and written consent. The ethics review boards at both the University of Manitoba, Winnipeg (Winnipeg, Manitoba, Canada), and Edith Cowan University (Perth, Western Australia, Australia) approved this study.

Once consent was obtained, patients were asked to complete a psychometric battery covering a broad range of physical, psychological, and existential outcomes to discern possible areas of therapeutic influence. Because this was a feasibility study and we wished to examine possible areas of influence across a broad range of outcomes, these were confined to single-item screening instruments for depression, dignity, anxiety, suffering, hopefulness, desire for death, suicide, and sense of well-being (consisting of a seven-point ordinal scale: 0, not a source of distress; 1, minimal distress; 2, mild distress; 3, moderate distress; 4, strong distress; 5, severe distress; 6, extreme distress).[8] Wilson et al[8] have shown that such screening approaches yield excellent inter-rater (0.92 to 0.97) and test-retest (0.50 to 0.90) reliability and correlated highly with their visual analog equivalent (0.78 to 90).[6] The protocol also contained a two-item quality-of-life instrument[12] and a revised Edmonton Symptom Assessment Scale, which included a will-to-live visual analog scale.[13]

Once patients completed the baseline psychometrics, participants were reminded that the following session would consist of being asked to speak about things that mattered most to them, on audiotape, including things that they would want to say and be known to the people closest to them. They were provided the standard framework of questions (Table 2), thus giving them ample time to reflect on and shape their eventual responses. A time for the tape-recorded session was then scheduled at their earliest convenience, usually within 1 to 3 days.

The taped sessions began with the question, "Tell me a little about your life history, particularly the parts that you either remember most or think were most important"? The question framework provided a flexible guide for the therapist to shape the interview, based on the level of interest and elicited response. The therapist followed the patients' cues, helping them to structure and organize their thoughts (eg, by asking logical questions based on time sequences or how events were causally related to each other; facilitated disclosure of thoughts, feelings, and memories). Similarly, providing encouragement and asking for details enabled even patients particularly close to death to participate (eg, "Imagine that you and I are looking at a picture book of your life; tell me in as much detail as you can about some of the pictures we might see"). Most patients were able to complete this process with one recorded session; occasionally a second (and, rarely, a third) session was required to complete the generativity document.

Once the taped session was completed, over the course of the next 2 to 3 days, the patient's recorded dialogue was reshaped into a narrative. The interview was first transcribed verbatim. This transcript then underwent a formatted editing process, including (1) basic clarifications (eliminating colloquialisms, nonstarters, and portions of the transcript not related to generativity material [eg, needing to change a colostomy bag, interruptions that occurred during the course of the session such as visitors, care providers, and so on]); (2) chronological corrections (it was common for patients to say things out of sequence or present their thoughts in an illogical order); (3) tagging and editing any content that might inflict significant harm or suffering on the transcript's recipient(s) (these were always discussed and reviewed with the patient); and (4) finding a statement or passage within the transcript that provided an appropriate ending (given that this was a generativity, legacy-making exercise, the ending needed to be appropriate to the patient's overall message [eg, "Life has been good"; "I wish my family all God's blessings"; "I wouldn't have changed a thing"]), resulting in manuscripts that patients would feel captured their intent and achieved the appropriate final tone.

Once the edited transcript was completed, another session was arranged for the therapist to read the document in its entirety to the patient; this was often emotionally evocative, because patients heard their words, thoughts, and feelings spoken aloud. Patients were invited to make any editorial suggestions, including identifying errors of omission or commission. In some instances, these errors were minor in nature (eg, an elderly immigrant who stated "Not Bavaria. . .but Bulgaria!"); in other instances, the errors were major (eg, a middle-aged woman who felt she needed to say more about one of her two children). Depending on the patients' preference or health status, editorial changes were addressed within the transcript-review session or, occasionally, at the earliest possible follow-up time. Throughout the protocol, an ethos of immediacy and short time frames acknowledged the patients' limited life expectancy and reinforced the importance of what the patient needed to say and the significance of creating the generativity document. At the conclusion of the intervention, quantitative measures were readministered, along with a dignity-therapy satisfaction survey, which included an opportunity for patients to reflect on the experience of engaging in the therapy.

Pre- and postintervention comparisons and item correlations were tested by using Wilcoxon's signed rank-sum test and Spearman's rank correlation, respectively. Given the uniformly positive responses reported in the qualitative data and the lack of any significant adverse effects reported across the study sample, we hypothesized a postintervention improvement on all psychosocial measures; hence, in those instances, a one-tailed Wilcoxon test was carried out (the use of a one-tailed test provides more sensitivity and power than the corresponding two-tailed test, reducing the risk of a type II error while maintaining the risk of a type I error at .05). The results of a post–dignity-therapy intervention survey were also tabulated.

RESULTS

Over a 2-year period (2001 to 2003), 100 patients completed the study across both sites: 50 patients from Australia and 50 from Canada. One hundred eighty-one patients agreed to have their names released to the study nurse; of those, 21 either deteriorated or died before entering the study. Thirty-one patients (19.6%) subsequently refused to take part in the study. Within the remaining group of 129 participants, the study completion rate was 78% (14 patients died and 15 deteriorated before completing the protocol). There were no differences between those completing the protocol versus those not completing the protocol on dimensions of age, sex, or disease-site distribution. Of those completing the study, 18% had breast cancer, 17% had lung cancer, 15% had gastrointestinal cancer, 13% had genitourinary cancer, 5% had primary brain tumors, 5% had hematologic malignancies, 19% had various solid tumors, 5% had tumors of unknown primary, and 3% had nonmalignant conditions. The mean age of participants was 63.9 years (range, 22 to 95; standard deviation, 14.2), and 44 were women. Thirty-seven percent had less than a high school education, 23% had graduated from high school, and 39% had some college or postgraduate training. Sixty-four percent of the patients were married or cohabiting with someone, with the remainder being divorced (11%), never married (4%), widowed (14%), or separated (5%). The patients' religious affiliations were Protestant (34%), Catholic (23%), Jewish (2%), other (16%), and no religious affiliation (24%). The median length of survival from the time of the initial interview to the time of death was 51 days (range, 3 to 377), and the median survival from the time that the generativity document was received to the time of death was 40 days (range, 0 to 371).

Qualitative Findings

Of the 100 patients who completed the study, 91% reported feeling satisfied or highly satisfied with the intervention (a rating of ≥ 4 on a seven-point ordinal scale), with 86% reporting that the intervention was helpful or very helpful. Seventy-six percent indicated that it heightened their sense of dignity. With regard to the issue of hopefulness, 68% indicated that dignity therapy increased their sense of purpose, and 67% indicated that it heightened their sense of meaning. Forty-seven percent of participants indicated that dignity therapy increased their will to live; one 62-year-old woman with metastatic breast cancer went so far as to say, "I see [taking part in this study] as one reason why I am alive." It is particularly noteworthy that 81% of those who completed the protocol reported that this novel therapeutic intervention had already helped, or would help, their family.

The generativity documents contained innumerable affirmations of love and expressions of regret, and the foremost was the recounting of memories. Many patients raised issues related to the theme of generativity; for example one 36-year-old woman dying of metastatic breast cancer said, "I'm very happy to have participated in this project. It's helped bring my memories, thoughts, and feelings into perspective instead of all jumbled emotions running through my head. The most important thing has been that I'm able to leave a sort of 'insight' of myself for my husband and children and all my family and friends." Others spoke to issues that helped them reaffirm their sense of continued self-worth. For example, a 49-year-old woman with end-stage breast cancer stated that "dignity therapy was a lovely experience. Getting down on paper what I thought was a dull, boring life really opened my eyes to how much I really have done."

A 61-year-old woman with a recurrent rectal cancer captured the essence of hopefulness as it relates to issues of ongoing meaning and purpose: "This experience has helped me to delve within myself and see more meaning to my life. I really look forward to sharing it with my family. I have no doubt that it will be enlightening to them." The wife of a 72-year-old man with end-stage lung cancer described the transcript as "magnificent," indicating that her husband "wanted to contribute; the interview gave him a 'second chance' to do something to help."

Quantitative Outcomes

Postintervention measures of suffering showed significant improvement ($z = -2.00$; $P = .023$ [one-tailed Wilcoxon test]), as did self-reports of depressed mood ($z = -1.64$; $P = .05$ [one-tailed Wilcoxon test]); the postintervention improvement in dignity approached significance ($z = -1.37$; $P = .085$ [one-tailed Wilcoxon test]). Hopelessness, desire for death, anxiety, will to live, and suicide all showed nonsignificant changes favoring improvement. It is not surprising that, given that patients were moving toward death, the level of well-being and current quality of live diminished slightly, albeit nonsignificantly.

Patients reporting more initial psychosocial despair seemed to especially benefit from dignity therapy. Specifically, preintervention distress on measures of current quality of life ($r = -0.198$; $P = .049$), satisfaction with quality of life ($r = -0.203$; $P = .042$), and level of dignity ($r = 0.230$; $P = .021$), suffering ($r = 0.226$; $P = .025$), and suicidality ($r = 0.250$; $P = .012$) all correlated significantly with finding the intervention helpful and/or satisfactory. Even patients reporting less satisfaction with pain relief before the intervention were more likely to report that dignity therapy yielded an increased sense of purpose ($r = -0.254$; $P = .04$); this finding could not be accounted for by any changes in pain reports before versus after the intervention.

Initial psychosocial distress, reflected by scores on measures of quality of life ($r = -0.220$; $P = .028$), satisfaction with quality of life ($r = -0.237$; $P = .018$), and desire for death ($r = 0.192$; $P = .055$) were significantly correlated with reports of finding that the intervention increased their sense of meaning. Consistent with the latter finding, patients who indicated that dignity therapy had increased their will to live were significantly more likely to report a heightened sense that their current life was more meaningful ($r = 0.480$; $P < .0001$) and an enhanced sense of purpose ($r = 0.452$; $P < .0001$).

Finding dignity therapy helpful was significantly correlated with reporting that it had made life currently feel more meaningful ($r = 0.566$; $P < .0001$), heightening sense of purpose ($r = 0.547$; $P < .0001$), lessening suffering ($r = 0.267$; $P = .008$), and increasing will to live ($r = 0.290$; $P = .004$). The latter was also significantly correlated with a sense that the intervention had engendered a sense of heightened purpose ($r = 0.444$; $P < .0001$) and diminished suffering ($r = 0.401$; $P < .0001$); the effect of dignity therapy on sense of purpose and suffering were also highly correlated ($r = 0.444$; $P < .0001$). A lessened sense of suffering resulting from the intervention correlated highly with finding life more meaningful ($r = 0.343$; $P = .001$) and having a heightened sense of purpose ($r = 0.444$; $P < .0001$). Finally, a belief that dignity therapy had helped or would be of help to their family correlated significantly with life feeling more meaningful ($r = 0.480$; $P < .0001$) and having a sense of purpose ($r = 0.562$; $P < .0001$) and was accompanied by a lessened sense of suffering ($r = 0.327$; $P = .001$) and increased will to live ($r = 0.387$; $P < .0001$).

DISCUSSION

There are few nonpharmacologic interventions specifically designed to lessen the suffering or existential distress that often accompanies patients toward the end of life. The rationale of most interventions is to make the sufferer less aware of his or her suffering. Thus, strategies are invoked to render patients less aware of their suffering or distress until it either improves or, more commonly, death ensues. As such, they offer the equivalent of emotional analgesia without necessarily addressing the source or cause of the underlying psychic pain.

Dignity therapy introduces a novel, brief, psychotherapeutic approach based on an empirically validated model of dignity in the terminally ill. This model informs the structure, content, and tone of its delivery, thus ensuring its feasibility at the bedside of patients nearing death. Unlike most other symptom-focused interventions, the beneficial effects of dignity therapy reside in being able to bolster a sense of meaning and purpose while reinforcing a continued sense of worth within a framework that is supportive, nurturing, and accessible, even for those proximate to death.

The low refusal rate (19.6%) and similarly low withdrawal rate (22%; the latter primarily because of deterioration or death before protocol completion) speak to the feasibility and value of this intervention for patients with advanced, life-limiting diseases. One of the patients most proximate to death, a 55-year-old woman with end-stage liver cancer, died within days of completing her generativity document. Despite profound illness and severely compromised respiratory status, she was able to "whisper" the derivation of her child's name, based on a beloved character from a favorite foreign film.

The survey responses indicate how favorably the vast majority of participants received dignity therapy. These clear endorsements on measures of satisfaction (93%), helpfulness (91%), sense of dignity (76%), purpose (68%), and meaning (67%), suggest that beneficial effects were obtained irrespective of whether patients indicated initial significant psychosocial/existential distress. This explains one of the challenges of trying to document quantitative improvements, given that even in the context of low initial distress, patients almost invariably reported having benefited from the intervention. It is also interesting to note that 81% of patients felt that dignity therapy had helped, or would be of help to, their families and that this perception was related to a heightened sense of purpose and meaning along with a diminished sense of suffering and heightened will to live. This distinguishes dignity therapy as a unique end-of-life care intervention in that it benefits the patients and their family members—with real potential for multigenerational impact.

In reflecting on the quantitative findings, it is important to note that we selected a broad range of outcomes to detect areas of possible therapeutic influence. As such, many brief measures were applied rather than selecting fewer, more detailed, and lengthy measures. It should also be borne in mind that patients were moving closer toward death during the study, thus making the task of showing improvement on measures of distress even more challenging. Nonetheless, depressed mood and suffering seem particularly responsive to dignity therapy. This is noteworthy, given that other studies have shown that distress usually worsens as death draws near.[14,15] However, the role of dignity therapy as a treatment, or adjunctive treatment, for major depression has not been explored yet.

Patients who are initially more distressed (as reflected on measures of quality of life, dignity, suffering, and suicidality) seemed to be those most likely to find the intervention beneficial. The data also suggest that although quality of life and sense of well-being inevitably deteriorate as physical decline ensues, suffering, depression, and sense of dignity (all facets of the patient's internal psychological and spiritual life) may have a resilience, or the capacity to improve, independent of bodily deterioration.

It is interesting to examine the ways in which therapeutic improvement seems to be mediated. For example, the beneficial effects of dignity therapy are associated with an enhanced sense of meaning and purpose, both of which are intertwined with a diminished sense of suffering, lessening desire for death, and increased will to live. In palliative care, the patient and family are often referred to as the "unit of care."[16] With that in mind, it is noteworthy that patients who felt that the intervention had or might have some benefit for their family were most likely to report a heightened sense of meaning and purpose, along with a lessening of suffering, and a heightened sense of will to live. For dying patients, the salutary effects of safeguarding the well-being of those who they are about to leave behind seems to extend to the end of life itself.

We recognize several limitations of the study. This study took place primarily among older patients with end-stage malignancies. It would be premature to assume that this intervention could be applied successfully within all age groups and across all terminal conditions. (We are currently conducting a small study of dignity therapy in patients with amyotrophic lateral sclerosis; although this group presents special logistical challenges in terms of protocol administration, it seems to be enjoying a highly favorable response.) Most importantly, this trial was conducted as a feasibility study.

Despite these limitations, it would seem that dignity therapy is a feasible and effective new approach to address suffering and distress in patients toward the end of life. As evidence mounts (and with appropriate training), we envision this being a form of treatment that could be administered by individuals with skill and expertise in psychosocial oncology. Health care practitioners should also note that evidence from this trial speaks to the importance of using every clinical encounter as an opportunity to acknowledge, reinforce, and, where possible, reaffirm the personhood of patients charged to their care. An international randomized controlled trial of dignity therapy, which will take place in Winnipeg, New York, and Perth has recently been funded by the National Institutes of Health. We hope that this randomized controlled trial will generate additional evidence to support the application of this novel therapeutic approach to suffering and distress, so commonly seen in patients nearing death.

◆ ◆ ◆

Acknowledgment

We thank our research nurses Kathy Cullihall, Joanne Hale, Jenny Clarke, and Lynn Oldham.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

REFERENCES

1. Chochinov HM, Hack T, McClement S, et al: Dignity in the terminally ill: An empirical model. Soc Sci Med 54:433-443, 2002

2. Chochinov HM, Hack T, Hassard T, et al: Dignity in the terminally ill: A cross-sectional cohort study. Lancet 360:2026-2030, 2002

3. Chochinov HM: Dignity-conserving care: A new model for palliative care. JAMA 287:2253-2260, 2002

4. Chochinov HM: Dignity and the eye of the beholder. J Clin Oncol 22:1336-1340, 2004

5. Field MJ, Cassel CK (eds). Approaching Death: Improving Care at the End of Life. Washington DC, National Academy Press, 1997

6. Breitbart W, Rosenfeld BD, Passik SD: Interest in physician-assisted suicide among ambulatory HIV-infected patients Am J Psychiatry 153:238-242, 1996

7. Meier DE, Eammons CA, Wallenstein S, et al: A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 338:1193-1201, 1998

8. Wilson KG, Grahan ID, Viola RA, et al: Structured interview assessment of symptoms and concerns in palliative care. Can J Psychiatry 49:350-358, 2004

9. Van der Maas PJ, Van Delden JJM, Pijnenborg L, et al: Euthanasia and other medical decisions concerning the end of life. Lancet 338:669-674, 1991

10. Cassel EJ: The nature of suffering and the goals of medicine. N Engl J Med 306:639-645, 1982

11. Frankl VF: Man's Search for Meaning (ed 4). Boston, MA, Beacon Press, 1992

12. Graham KY, Longman AJ: Quality of life in persons with melanoma: Preliminary model testing. Cancer Nurs 10;338-346, 1987

13. Bruera E, Kuehn N, Miller MJ, et al: The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. J Palliat Care 7:6-9, 1991

14. Hwang SS, Chang VT, Fairclough DL, et al: Longitudinal quality of life in advanced cancer patients: Pilot study results from a VA medical cancer center. J Pain Symptom Manage 25:225-235, 2003

15. Kornblith AB, Thaler HT, Wong G, et al: Quality of life of women with ovarian cancer. Gynecol Oncol 59:231-242, 1995

16. McIntyre R: Support for family and carers, in Lugton J, Kindlen M (eds): Palliative Care: The Nursing Role. Edinburgh, Scotland, Churchill Livingstone, 1999, pp 193-215

"HMC-13"

This is the exhibit marked "**HMC-13**" referred to in the affidavit of **Harvey Max Chochinov** affirmed at
this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial

Harvey Max Chochinov, Linda J Kristjanson, William Breitbart, Susan McClement, Thomas F Hack, Tom Hassard, Mike Harlos

Summary

Background Dignity therapy is a unique, individualised, short-term psychotherapy that was developed for patients (and their families) living with life-threatening or life-limiting illness. We investigated whether dignity therapy could mitigate distress or bolster the experience in patients nearing the end of their lives.

Methods Patients (aged ≥18 years) with a terminal prognosis (life expectancy ≤6 months) who were receiving palliative care in a hospital or community setting (hospice or home) in Canada, USA, and Australia were randomly assigned to dignity therapy, client-centred care, or standard palliative care in a 1:1:1 ratio. Randomisation was by use of a computer-generated table of random numbers in blocks of 30. Allocation concealment was by use of opaque sealed envelopes. The primary outcomes—reductions in various dimensions of distress before and after completion of the study—were measured with the Functional Assessment of Chronic Illness Therapy Spiritual Well-Being Scale, Patient Dignity Inventory, Hospital Anxiety and Depression Scale, items from the Structured Interview for Symptoms and Concerns, Quality of Life Scale, and modified Edmonton Symptom Assessment Scale. Secondary outcomes of self-reported end-of-life experiences were assessed in a survey that was undertaken after the completion of the study. Outcomes were assessed by research staff with whom the participant had no previous contact to avoid any possible response bias or contamination. Analyses were done on all patients with available data at baseline and at the end of the study intervention. This study is registered with ClinicalTrials.gov, number NCT00133965.

Findings 165 of 441 patients were assigned to dignity therapy, 140 standard palliative care, and 136 client-centred care. 108, 111, and 107 patients, respectively, were analysed. No significant differences were noted in the distress levels before and after completion of the study in the three groups. For the secondary outcomes, patients reported that dignity therapy was significantly more likely than the other two interventions to have been helpful ($\chi^2=35\cdot50$, df=2; $p<0\cdot0001$), improve quality of life ($\chi^2=14\cdot52$; $p=0\cdot001$), increase sense of dignity ($\chi^2=12\cdot66$; $p=0\cdot002$), change how their family saw and appreciated them ($\chi^2=33\cdot81$; $p<0\cdot0001$), and be helpful to their family ($\chi^2=33\cdot86$; $p<0\cdot0001$). Dignity therapy was significantly better than client-centred care in improving spiritual wellbeing ($\chi^2=10\cdot35$; $p=0\cdot006$), and was significantly better than standard palliative care in terms of lessening sadness or depression ($\chi^2=9\cdot38$; $p=0\cdot009$); significantly more patients who had received dignity therapy reported that the study group had been satisfactory, compared with those who received standard palliative care ($\chi^2=29\cdot58$; $p<0\cdot0001$).

Interpretation Although the ability of dignity therapy to mitigate outright distress, such as depression, desire for death or suicidality, has yet to be proven, its benefits in terms of self-reported end-of-life experiences support its clinical application for patients nearing death.

Funding National Cancer Institute, National Institutes of Health.

Lancet Oncol 2011; 12: 753–62

DOI:10.1016/S1470-2045(11)70153-X

See Comment page 712

Department of Psychiatry (Prof H M Chochinov MD), Faculty of Nursing (Prof S McClement PhD, Prof T F Hack PhD), and Community Health Sciences (Prof H M Chochinov, Prof T Hassard PhD), University of Manitoba, Winnipeg, MB, Canada; Manitoba Palliative Care Research Unit, CancerCare Manitoba, Winnipeg, MB, Canada (Prof H M Chochinov, Prof S McClement); Department of Patient Support and Family Services, CancerCare Manitoba, Winnipeg, MB, Canada (Prof T F Hack); Swinburne University of Technology, Melbourne, VIC, Australia (Prof L J Kristjanson PhD); Curtin University, Perth, WA, Australia (Prof L J Kristjanson); Edith Cowan University, Perth, WA, Australia (Prof L J Kristjanson); Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, NY, USA (Prof W Breitbart MD); and Winnipeg Regional Health Authority, St Boniface General Hospital, Winnipeg, MB, Canada (Prof M Harlos MD)

Correspondence to:
Prof Harvey Max Chochinov,
Department of Psychiatry,
University of Manitoba,
CancerCare Manitoba,
Palliative Care Research Unit,
Room 3017, 675 McDermot
Avenue, Winnipeg,
Manitoba R3E 0V9, Canada
harvey.chochinov@cancercare.mb.ca

Introduction

Research into methods to understand and support patients who are nearing the end of their lives is increasing.[1-3] Dignity therapy, a unique, individualised, brief psychotherapy, was developed for the purpose of relieving distress and enhancing the end-of-life experiences of terminally ill patients. It provides these patients with an opportunity to reflect on things that matter most to them or that they would most want remembered. The therapeutic process begins with a framework of questions (panel 1) that are based on an empirical model of dignity in the terminally ill patient.[4,5] These conversations, guided by a trained therapist, are flexible to accommodate the patients' needs and choices about what they specifically wish to address. Dignity therapy is audiorecorded and transcribed, with an edited version of the transcript given to patients to share or bequeath to individuals of their choice.

In a phase 1 trial with 100 terminally ill patients, 91% were satisfied with dignity therapy, and 76% reported a heightened sense of dignity, 68% an increased sense of purpose, 67% a heightened sense of meaning, 47% an increased will to live, and 81% that it had been or would be of help to their family.[6] Post-intervention assessments of suffering and depressive symptoms showed small, but significant improvements.[6] 78% of patients' family members reported that the therapy enhanced the patient's dignity, and 72% that it heightened the meaning of life for the patient; 78% said the document from the therapy session was a comfort to them in their time of grief, and 95% that they would recommend dignity therapy to other patients and their families.[7] We therefore investigated

Panel 1: Protocol for questions about dignity therapy

- Tell me a little about your life history, particularly the parts that you either remember most or think are the most important? When did you feel most alive?
- Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- What are the most important roles you have had in life (eg, family roles, vocational roles, community-service roles)? Why were they so important to you and what do you think you accomplished in those roles?
- What are your most important accomplishments, and what do you feel most proud of?
- Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your son, daughter, husband, wife, parents, or other(s)?
- Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
- In creating this permanent record, are there other things that you would like included?

whether this novel psychotherapeutic approach would be better than standard palliative care and client-centred care (which focused on non-generativity—ie, here and now issues) in terms of reducing psychological, existential, and spiritual distress in patients who are terminally ill.

Methods

Participants

Individuals were eligible for participation in the study if they had a terminal prognosis with a life expectancy of 6 months or less, according to their treating physician; were receiving palliative care in a hospital or community setting (hospice or home) through an affiliated recruitment site in Canada, USA, and Australia; were aged 18 years or older; were willing to commit to three or four contacts over about 7–10 days; and were able and willing to provide written informed consent. Patients were excluded if they were delirious or otherwise cognitively impaired (based on clinical consensus and post-randomisation Blessed Orientation Memory Concentration test),[8] too ill to complete the requirements of the protocol, or unable to speak and read English.

This trial was coordinated by the Manitoba Palliative Care Research Unit at CancerCare Manitoba, Winnipeg, MB, Canada. Other participating centres were Curtin University, Perth, WB, Australia, and Memorial Sloan Kettering Cancer Center, New York, NY, USA. Approval was obtained from the ethics committees of all participating centres. All participants provided written informed consent.

Generativity
or the ability to guide the next generation, encompasses how patients might find strength or comfort in knowing that they will leave behind something lasting and transcendent after death

Randomisation and masking

After providing consent, all participants were randomly assigned in a 1:1:1 ratio to one of three study groups—dignity therapy, standard palliative care, or client-centred care—and asked to complete baseline psychosocial questionnaires. The study statistician used a computer-generated table of random numbers in blocks of 30 to allocate patients. Allocation concealment was by use of opaque sealed envelopes. The envelopes were sent to each site and opened sequentially by study staff after consent had been obtained from the patient. To avoid any possible response bias or contamination, research staff with whom the participant had no previous contact administered the final psychometric battery of questionnaires. Recordings from the dignity therapy and client-centred care groups were reviewed by the study coordinator to ensure protocol adherence and prevent cross-contamination.

Study groups

Dignity therapy was provided by a psychologist, psychiatrist, or experienced palliative-care nurse. All therapists took part in a 3-day training workshop, led by the principal investigator (HMC). Continuous supervision of the therapy was provided by the site investigator (HMC, LJK, WB), initially for every case and then varied, until each therapist was fully competent. Group supervision, led by the principal investigator, took place every 6–8 weeks throughout the study, with videoconferencing to connect all three study sites. The principal investigator also reviewed a random sample (about one in six) of transcripts from all study sites to identify any difficulties or therapeutic improvements. Feedback from this review was offered either individually or, when more broadly applicable, within group supervision.

Patients were shown the framework of questions for dignity therapy (panel 1) and asked to consider what they might wish to speak about during their session(s); this initial introduction to, and explanation of, dignity therapy took about 30 min. Within a few days, or as soon as a second meeting could be arranged, the therapist used the question framework to help elicit patients' recollections, hopes, wishes for loved ones, lessons learned, and things they wanted remembered by those they were about to leave behind. Dignity therapy is flexible enough to accommodate participant's preferences and choices about content, but the ethos of questioning targets those things that might enhance a sense of meaning, purpose, continued sense of self, and overall sense of dignity. All therapy sessions were audiotaped; these sessions usually took about 60 min. On completion, the audiorecording was transcribed verbatim and the transcript edited, to provide a clear and readable narrative. This transcript or generativity document was returned to the patient within about 4 working days from their previous session, read to them in its entirety to ensure that no errors of omission or commission needed to be addressed (this final session usually took about 30 min). The final version of the **generativity** document was given to the patient, to be passed along to a recipient of the patient's choice, from whom follow-up data were later obtained (the effect of dignity therapy on family members given the generativity documents will be reported separately). At the conclusion

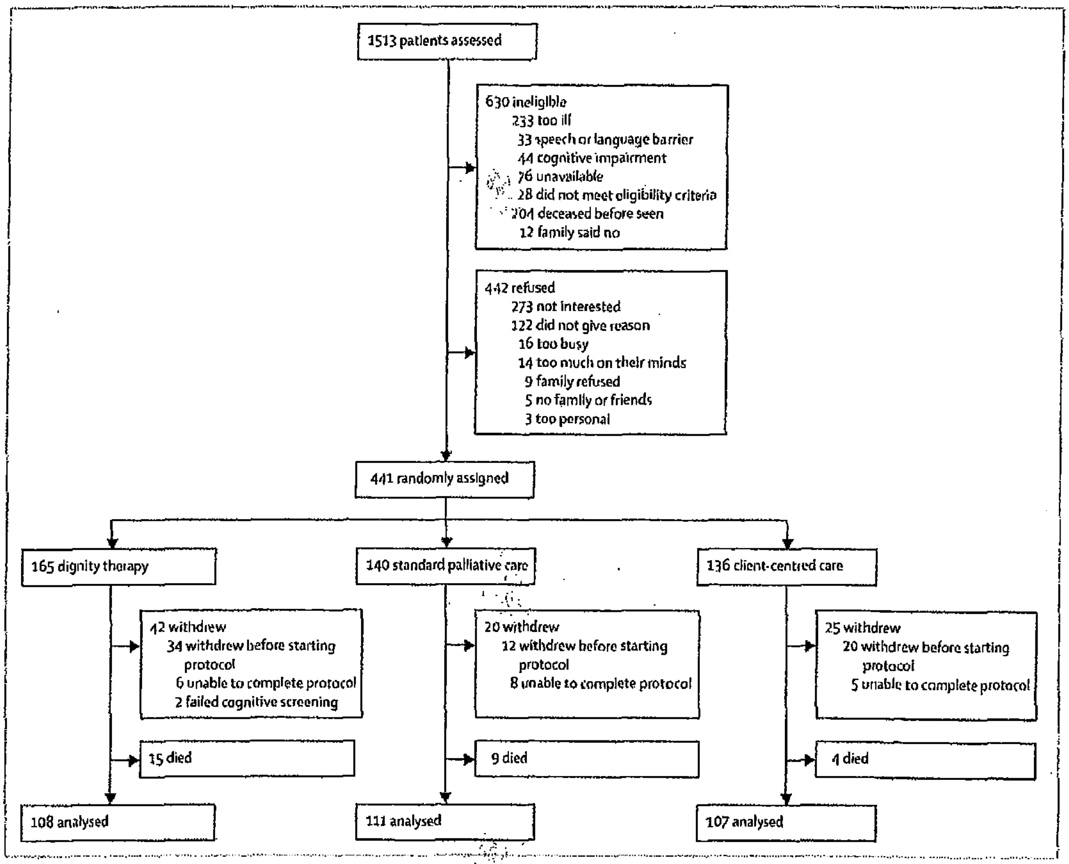


Figure: Trial profile

of this session, participants were asked to complete a psychometric follow-up battery described in the outcome measurements section below.

Client-centred care is a supportive psychotherapeutic approach, in which the research nurse therapist guides the patient through discussions that focus on here-and-now issues—ie, participants are asked about their illness, associated symptoms, and what is being done to address their distress. The content of client-centred care was kept as distinct from dignity therapy as much as possible and did not focus on issues of generativity, meaning, or purpose. If these issues were raised, the therapist did not probe for additional detail, allowing the interview to gently return to illness-related inquiry. Although these sessions were audiorecorded for purposes of auditing protocol adherence, no permanent record of these conversations was provided to the patient or the patient's family. The number of contacts for client-centred care and dignity therapy were identical, with the initial, middle, and final meetings designed to take about the same time in both groups. During the final meeting, 7–10 days later, the participants completed the psychometric battery.

Participants assigned to standard palliative care had access to the complete range of palliative-care-support services that were available to all study patients, including specialist palliative-care physicians and nurses (ie, experts in the management of pain and symptoms), social workers, chaplains, and psychologists or psychiatrists. No participating site provided a formal approach to addressing generativity issues; therefore, a programme similar to dignity therapy was not available to patients who were not randomly assigned to this group. Patients were asked to complete the battery of psychometric questionnaires as soon as they were assigned to standard palliative care and then 7–10 days later—a timeframe roughly corresponding to the time between the first and last contact in the other two study groups.

Outcome measurements

The primary outcomes—reductions in various dimensions of distress—consisted of mean changes between baseline and end of intervention in measurements of psychosocial, spiritual, and existential distress. The primary measurements were the Palliative Performance Scale (for physical

See Online for webappendix

performance; 100%=healthy, 0%=death),[9] Functional Assessment of Chronic Illness Therapy Spiritual Well-Being Scale (spiritual wellbeing with two subscales—meaning or peace and faith),[10] Patient Dignity Inventory,[11] and Hospital Anxiety and Depression Scale.[12] We also administered items from the Structured Interview for Symptoms and Concerns,[13] including dignity, desire for death, suffering, hopelessness, depression, suicidal ideation, and sense of burden to others. Additional measurements were a two-item Quality of Life Scale[14] and an Edmonton Symptom Assessment Scale, modified to include a will-to-live visual analogue scale.[15] All scales were administered at baseline and immediately after study completion. Secondary outcomes, addressing to what extent the intervention might have affected the participants' end-of-life experiences, were measured with a survey done after study completion, with detailed questions about their experience of participation in the study and how it had affected them and their family (for the questionnaire see webappendix pp 1–18).

	Dignity therapy (n=108)	Standard palliative care (n=111)	Client-centred care (n=107)
Age (years)	64·2 (14·6)	66·7 (14·2)	64·3 (14·3)
PPS score	44·2 (15·2)	44·2 (15·9)	44·4 (14·4)
Sex (male)	56 (52%)	50 (45%)	55 (51%)
Marital status			
Married	60 (56%)	65 (59%)	67 (63%)
Other	48 (44%)	46 (41%)	40 (37%)
Religion*			
Catholic	31 (29%)	26 (23%)	29 (27%)
Protestant	22 (20%)	30 (27%)	16 (15%)
Jewish	17 (16%)	11 (10%)	15 (14%)
Anglican	17 (16%)	16 (14%)	18 (17%)
Other	11 (10%)	18 (16%)	14 (13%)
None	9 (8%)	10 (9%)	14 (13%)
Living arrangements			
Alone	30 (28%)	29 (26%)	27 (25%)
Spouse	37 (34%)	50 (45%)	51 (48%)
Others	18 (17%)	21 (19%)	13 (12%)
Combination	23 (21%)	11 (10%)	16 (15%)
Education			
None or primary	11 (10%)	11 (10%)	8 (7%)
High school	38 (35%)	36 (32%)	33 (31%)
College	43 (40%)	47 (42%)	45 (42%)
Postgraduate	16 (15%)	17 (15%)	20 (19%)
Terminal illness			
Primary cancer site			
Lung	15 (14%)	15 (14%)	18 (17%)
Breast	10 (9%)	8 (7%)	11 (10%)
Gastrointestinal	30 (28%)	48 (43%)	29 (27%)
Genitourinary	12 (11%)	9 (8%)	8 (2%)
Gynaecological	3 (3%)	3 (3%)	5 (5%)
Haematological	5 (5%)	6 (5%)	3 (3%)
Brain	4 (4%)	2 (2%)	3 (3%)
Other solid tumours	23 (21%)	20 (18%)	24 (22%)
Non-malignant	5 (5%)	2 (2%)	5 (5%)
Missing	1 (<1%)	1 (<1%)	1 (<1%)
Ethnic origin			
White	98 (91%)	99 (89%)	94 (88%)
Other	10 (9%)	12 (11%)	13 (12%)
Care setting			
Palliative care unit	25 (23%)	21 (22%)	24 (22%)
Inpatient palliative care service	7 (6%)	9 (9%)	13 (12%)
Outpatient or home	64 (59%)	70 (60%)	61 (57%)
Hospice	12 (11%)	11 (9%)	9 (8%)

Data are number (%) or mean (SD). PPS=Palliative Performance Scale. *Two individuals (one in dignity therapy group and one in client-centred care group) did not provide an answer to the question about religious affiliation.

Table 1: Demographic characteristics of patients at baseline

Statistical analysis

Analyses were done on all patients with available data at baseline and at the end of the study intervention. The data were summarised with standard descriptive measurements. Two group comparisons were undertaken—*t* tests when the data approximated a normal distribution and Mann Whitney *U* tests when the data were ordinal. Three group comparisons were undertaken by use of ANOVA when a normal distribution was reasonably approximated and Kruskal-Wallis tests when it was not. With an α set at 0·05, desired power set at 80%, and small-to-medium effect size with Cohen's value for such an effect size of 0·15, the estimated recruitment target was 120 patients per group.[16] The effect size here refers to the standard deviation of the group means divided by the postulated common standard deviation. With three groups, an effect size of 0·15 would imply that at least one group mean is at least a third of a standard deviation away from the other two. SPSS (version 18.0) was used for the statistical analysis.

When a significant result was obtained in a multigroup comparison, the precise nature of the group differences was investigated with Tukey's test (if ANOVA had been used) or a series of Mann-Whitney *U* tests (if the Kruskal-Wallis test had been used). Comparisons of before and after therapy were undertaken by use of the paired *t* test if the data were roughly normal or the Wilcox signed-rank test if they were not. All comparisons were done on a two-tailed basis. Since the number of comparisons was large and the risk of type 1 errors was increased, a probability of less than 0·01 was prespecified as the minimum acceptable designation of significance.

This study is registered with ClinicalTrials.gov, number NCT00133965.

Role of the funding source

The funders had no role in the study design, data collection, analysis or interpretation of the data, or in writing the final report. The corresponding author had full access to all the data and final responsibility to submit for publication.

	Dignity therapy (n=108)		Standard palliative care (n=111)		Client-centred care (n=107)	
	Baseline	Study completion	Baseline	Study completion	Baseline	Study completion
Not able to continue usual routines	2·47 (1·28)	2·33 (1·25)	2·70 (1·32)	2·42 (1·25)	2·51 (1·14)	2·28 (1·14)
Physically distressing symptoms	2·32 (1·29)	2·37 (1·24)	2·28 (1·21)	2·22 (1·14)	2·57 (1·33)	2·35 (1·20)
Not able to carry out important roles	1·88 (1·15)	1·88 (1·24)	2·11 (1·22)	2·05 (1·17)	2·02 (1·17)	2·02 (1·17)
No longer feeling like who I was	2·20 (1·29)	2·09 (1·27)	2·00 (1·27)	2·02 (1·15)	2·21 (1·34)	2·06 (1·26)
Not able to perform tasks of daily living	1·79 (1·08)	2·11 (1·25)	1·74 (1·15)	1·84 (1·15)	1·84 (1·11)	1·88 (1·21)
Feeling of not having control	2·15 (1·29)	2·00 (1·12)	2·08 (1·12)	2·00 (1·05)	2·15 (1·23)	2·22 (1·22)
Feeling uncertain	2·10 (1·18)	2·21 (1·22)	2·08 (1·24)	1·88 (1·09)	2·05 (1·16)	2·07 (1·23)
Not able to attend to bodily functions	1·42 (0·93)	1·82 (1·56)	1·40 (0·95)	1·64 (1·12)	1·56 (1·06)	1·61 (1·02)
Feeling anxious	1·93 (1·09)	1·90 (1·09)	1·73 (1·01)	1·80 (1·02)	1·93 (1·11)	1·92 (1·08)
Feeling of reduced privacy	1·82 (1·13)	1·84 (1·18)	1·87 (1·13)	1·73 (1·01)	1·66 (1·04)	1·83 (1·08)
Feeling a burden to others	1·90 (1·08)	1·91 (1·02)	1·99 (1·08)	1·92 (1·11)	2·07 (1·13)	2·11 (1·14)
Feeling how you look has changed	1·83 (1·12)	1·72 (1·08)	1·79 (1·11)	1·69 (1·08)	1·64 (1·04)	1·71 (0·99)
Feeling depressed	1·84 (1·12)	1·81 (1·07)	1·69 (0·95)	1·74 (0·99)	1·76 (1·00)	1·79 (1·06)
Worried about future	2·08(1·30)	2·03 (1·26)	2·13 (1·22)	1·76 (1·03)	2·15(1·24)	1·94 (1·17)
Not being able to think clearly	1·74 (0·93)	1·79 (1·12)	1·66 (1·04)	1·69 (0·98)	1·92 (1·12)	1·85 (1·10)
Feeling of unfinished business	1·91 (1·11)	1·79 (1·02)	1·95 (1·10)	1·86 (1·15)	2·03 (1·15)	1·91 (1·07)
Feeling life no longer has meaning or purpose	1·58 (0·98)	1·46 (0·85)	1·56 (1·05)	1·48 (0·92)	1·54 (1·01)	1·64 (1·03)
Not feeling worthwhile or valued	1·50 (0·93)	1·57 (1·15)	1·42 (0·86)	1·44 (0·91)	1·61 (1·09)	1·58 (1·06)
Feeling have not made meaningful contribution	1·33 (0·71)	1·36 (0·86)	1·30 (0·74)	1·23 (0·67)	1·39 (0·80)	1·44 (0·89)
Not feeling able to mentally fight illness	1·43 (0·84)	1·46 (0·88)	1·40 (0·79)	1·44 (0·93)	1·56 (0·90)	1·58 (0·95)
Not being able to accept things as they are	1·57 (1·02)	1·54 (0·94)	1·48 (0·86)	1·48 (0·95)	1·55 (0·91)	1·50 (0·85)
Concerns about spiritual life	1·30 (0·73)	1·37 (1·26)	1·18 (0·51)	1·23 (0·67)	1·36 (0·76)	1·24 (0·61)
Not being treated with respect	1·19 (0·59)	1·20 (0·62)	1·12 (0·40)	1·20 (0·59)	1·18 (0·53)	1·23 (0·68)
Not feeling supported by health-care providers	1·20 (0·68)	1·11 (0·42)	1·18 (0·49)	1·13 (0·49)	1·45 (0·95)	1·26 (0·76)
Not feeling supported by friends or family	1·23 (0·73)	1·08 (0·39)	1·07 (0·29)	1·14 (0·55)	1·18 (0·64)	1·23 (0·71)

Data are mean (SD). Score of 1 indicates that the treatment was not a problem, 2 a slight problem, 3 a problem, 4 a major problem, and 5 an overwhelming problem.

Table 2: Distress measured with the Patient Dignity Inventory[5] at baseline and after study completion

Results

The figure shows the trial profile. 1513 patients were assessed for eligibility by use of a consecutive sampling approach between April, 2005, and October, 2008. After randomisation, 28 patients died, 85 withdrew because of declining health, and two failed Blessed Orientation Memory Concentration screening. These individuals were excluded from the analysis because we had either no or only incomplete data for them. Therefore, 326 participants—108 (33%) assigned to dignity therapy, 111 (34%) to standard palliative care, and 107 (33%) to client-centred care—completed the study. Recruitment was fairly even across the three study sites (Winnipeg [n=119], Perth [n=99], and New York [n=108]), with the number of participants at each site balanced across the study groups.

Table 1 shows that the baseline demographic characteristics of participants assigned to the three groups were well balanced. 161 (49%) of 326 participants were men (table 1). The mean age of the participants was 65·1 years (SD 14·4; range 22–102). 192 (59%) participants were married or living in common-law partnerships, and the rest were widowed, divorced, or not married. 138 (42%) were living with their spouse or partner, 86 (26%) were living alone, 70 (21%) were living with children, and the rest were living with others, such as friends or other relatives. 196 (60%) were receiving home-based palliative care, 72 (22%) palliative care in an inpatient unit, 31 (10%) acute care in an inpatient unit (followed by palliative care on a non-palliative-care unit), and 27 (8%) freestanding hospice care. 68 (21%) participants were Protestant, 86 (26%) Catholic, 43 (13%) Jewish, 51 (16%) Anglican, 43 (13%) other, 33 (10%) no religious affiliation, and two individuals did not provide an answer to the question about religious affiliation. 30 (9%) individuals had less than high school education, 107 (33%) had completed high school, and 188 (58%) had completed college or postgraduate training (one individual was unable to answer). Cancer sites were gastrointestinal (108 [33%]), genitourinary (26 [8%]), lung (48 [15%]), breast (29 [9%]), gynaecological (11 [3%]), miscellaneous solid tumours (67 [21%]), haematological (14 [4%]), and brain (nine [3%]), and 12 [4%] patients had non-malignant terminal illness (ie, end-stage organ failure and amyotrophic lateral sclerosis). The mean Palliative Performance Scale rating for all participants at baseline was 44·3% (SD 15·1).

134 (41%) participants reported that they had lived with their life-limiting illness for less than 1 year, 104 (32%) for

	Dignity therapy (n=108)		Standard palliative care (n=111)		Client-centred care (n=107)	
	Baseline	Study completion	Baseline	Study completion	Baseline	Study completion
Structured Interview for Symptoms and Concerns*						
Loss of Dignity	0·58 (1·00)	0·67 (1·19)	0·35 (0·81)	0·51 (0·94)	0·68 (1·09)	0·47 (0·96)
Desire for Death	0·44 (0·87)	0·53 (0·88)	0·60 (1·19)	0·65 (1·29)	0·64 (1·18)	0·68 (1·18)
Sense of Suffering	1·63 (1·57)	1·34 (1·40)	1·46 (1·53)	1·41 (1·38)	1·52 (1·35)	1·46 (1·35)
Hopelessness	0·90 (1·17)	0·86 (1·27)	0·78 (1·08)	0·68 (1·31)	0·87 (1·24)	0·80 (1·17)
Depression	1·22 (1·26)	1·23 (1·23)	1·14 (1·31)	1·06 (1·38)	1·25 (1·19)	1·06 (1·25)
Suicidality	0·29 (0·72)	0·27 (0·73)	0·21 (0·66)	0·30 (1·02)	0·38 (0·86)	0·32 (0·96)
Burden to Others	1·47 (1·55)	1·33 (1·40)	1·54 (1·45)	1·24 (1·50)	1·53 (1·56)	1·43 (1·38)
Edmonton Symptom Assessment Scale†						
Pain	2·72 (2·79)	2·79 (2·61)	2·76 (2·80)	2·87 (2·80)	3·13 (2·84)	3·18 (2·94)
Nausea	1·52 (2·18)	1·57 (2·42)	1·62 (2·44)	1·59 (2·61)	1·30 (2·34)	1·55 (2·42)
Drowsiness	3·61 (2·96)	3·65 (2·91)	2·89 (2·71)	3·07 (2·84)	3·31 (2·92)	3·54 (2·96)
Shortness of Breath	1·98 (2·59)	2·52 (2·85)	1·70 (2·33)	1·75 (2·50)	2·35 (2·92)	2·51 (3·11)
Will to Live‡	9·08 (1·94)	8·99 (1·62)	9·05 (2·02)	8·84 (2·40)	9·00 (2·00)	9·00 (2·19)
Appetite	6·59 (3·13)	6·24 (3·04)	5·91 (3·03)	6·05 (3·18)	6·93 (2·65)	7·05 (3·00)
Level of Activity	4·59 (2·97)	4·24 (2·92)	4·59 (2·66)	4·45 (2·81)	4·80 (2·69)	4·42 (2·78)
Sense of Well Being‡	6·67 (2·67)	6·62 (2·66)	6·65 (2·64)	6·44 (2·89)	6·74 (2·62)	6·50 (2·88)
Quality of life§						
Rating	6·48 (2·69)	6·39 (2·54)	6·27 (2·70)	6·34 (2·47)	6·29 (2·50)	6·64 (2·55)
Satisfaction	6·34 (3·06)	6·04 (2·94)	6·10 (3·09)	6·05 (2·99)	5·83 (3·16)	6·05 (2·88)
Functional Assessment of Chronic Illness Therapy (FACIT)¶ (48)						
Total	34·70 (9·59)	33·97 (10·29)	33·82 (9·56)	34·44 (10·13)	32·86 (9·61)	32·43 (10·37)
FACIT-Secular (32)	24·50 (5·85)	23·88 (6·27)	23·65 (6·30)	24·04 (6·76)	23·05 (6·26)	22·80 (7·19)
FACIT-Faith (16)	10·20 (5·22)	10·09 (5·13)	10·00 (5·07)	10·40 (4·72)	9·81 (5·10)	9·63 (5·05)
Hospital Anxiety and Depression Scale (HADS)‖ (56)						
Total	11·08 (6·76)	11·45 (6·84)	11·36 (6·76)	11·39 (7·43)	12·06 (7·28)	11·76 (7·80)
HADS-Depression (28)	5·86 (3·86)	5·64 (4·07)	6·03 (4·02)	6·19 (4·21)	6·30 (4·04)	6·38 (4·30)
HADS-Anxiety (28)	5·22 (4·20)	5·81 (3·80)	5·34 (3·79)	5·20 (4·05)	5·76 (4·26)	5·38 (4·40)

The parenthesised numbers besides the scales and subscales represent the maximum scores. *0=none, 1=minimum, 2=mild, 3=moderate, 4=strong, 5=severe, and 6=extreme. †1=no or poor, 10=worst. ‡Reverse scoring—higher scores represent better outcomes. §1=poor or not satisfied, 10=excellent or very satisfied. ¶High score indicates better spiritual wellbeing. ‖High score indicates more intense depression.

Table 3: Distress according to the Structured Interview for Symptoms and Concerns,[8,9] Edmonton Symptom Assessment Scale,[10,11] Quality of Life Scale,[3,20] Functional Assessment of Chronic Illness Therapy,[18] and Hospital Anxiety and Depression Scale[22,23] at baseline and study completion

1–3 years, and 88 (27%) for more than 3 years. The median survival time was 110 days (IQR <56 to <235); 213 [65%] patients had died by the time the study ended; the proportion of patients surviving in each of the study groups was not significantly different between groups (62 [57%] of 108 in dignity therapy group, 78 [70%] of 111 in standard palliative care group, and 73 [68%] of 107 in client-centred care group; p=0·1). No difference was noted in the survival times after study completion between the three groups (81 days [IQR 48–249] in dignity therapy group, 109 days [61–222] in standard palliative care group, and 128 days [67–233] in client-centred care group; p=0·51). Age and sex distribution, Palliative Performance Scale ratings, and dropout rate (death and withdrawal because of deterioration in health), in all three study groups showed no significant differences at completion of the study.

Because no initial threshold level of distress was stipulated as an entry criterion, the sample was most noteworthy for its paucity of distress at baseline (table 2; table 3). In most instances, patients were not greatly distressed, as indicated by the average Patient Dignity Inventory item scores and other baseline psychometric scores (table 2; table 3). Differences between before and after study measurements were calculated for Patient Dignity Inventory and Structured Interview for Symptoms and Concerns items, modified Edmonton Symptom Assessment Scale individual subscale scores, Quality of Life Scale, Functional Assessment of Chronic Illness Therapy, and Hospital Anxiety and Depression Scale; no significant differences were noted between the three groups (table 2 and table 3). The survey after the study, however, showed differences between the three study groups (table 4). Patients given dignity therapy were significantly more likely than were those in either of the two other groups to report that the treatment was helpful to them, improved their quality of life, and sense of dignity (table 4). The patients in the dignity therapy group, compared with the other study

	Dignity therapy (n=108)	Standard palliative care (n=111)	Client-centred care (n=107)	χ^2 (2 df)	p value
The study group has been helpful to me	4·23 (0·64)	3·50 (1·01)	3·72 (0·89)	35·50	<0·0001*
The study group has been as helpful as any other aspect of my health care	3·63 (1·04)	3·27 (1·04)	3·12 (1·04)	6·39	0·041
The study group has improved my quality of life	3·54 (0·95)	2·96 (0·96)	2·84 (1·05)	14·52	0·001*
The study group has given me a sense of looking after unfinished business	3·35 (1·01)	2·86 (1·60)	2·93 (1·16)	6·87	0·032
The study group has improved my spiritual wellbeing	3·27 (1·09)	3·00 (1·11)	2·56 (0·98)	10·35	0·006†
The study group has lessened my sense of sadness and depression	3·11 (1·02)	2·57 (0·92)	2·65 (1·04)	9·38	0·009‡
The study group has lessened my sense of feeling a burden to others	2·81 (0·98)	2·58 (0·95)	2·53 (0·96)	2·71	0·258
The study group has made me feel more worthwhile or valued	3·38 (0·93)	3·35 (1·00)	3·02 (1·01)	3·75	0·153
The study group has made me feel like I am still me	3·81 (0·85)	3·59 (0·92)	3·40 (0·98)	5·91	0·052
The study group has given me a greater sense of having control over my life	3·02 (1·02)	3·16 (1·00)	2·81 (1·05)	2·74	0·255
The study group has helped me to accept the way things are	3·39 (1·062)	3·31 (1·01)	3·19 (1·12)	0·92	0·630
The study group has made me feel more respected and understood by others	3·16 (0·90)	3·04 (0·98)	2·79 (0·98)	3·85	0·146
The study group has made me feel that I am still able to carry out important tasks or fill an important role	3·62 (0·97)	3·48 (1·00)	3·02 (1·05)	8·96	0·011
The study group has been satisfactory	4·26 (0·63)	3·80 (0·74)	4·17 (0·56)	29·58	<0·0001‡
The study group has made me feel that life was more meaningful	3·55 (1·05)	3·19 (1·70)	3·31 (1·02)	6·73	0·035
The study group has given me a heightened sense of purpose	3·49 (1·04)	3·20 (0·98)	3·15 (1·03)	6·86	0·032
The study group has increased my sense of dignity	3·52 (1·04)	3·09 (1·02)	3·11 (0·97)	12·66	0·002*
The study group has lessened my sense of suffering	2·86 (1·04)	2·70 (1·02)	2·77 (0·98)	1·06	0·588
The study group has increased my will to live	2·94 (1·11)	2·76 (1·04)	2·92 (0·97)	1·73	0·422
The study group has or will be of help to my family	3·93 (0·80)	3·20 (1·00)	3·29 (0·99)	33·86	<0·0001*
The study group has or could change way my family sees or appreciates me	3·58 (1·01)	2·85 (1·00)	2·85 (1·04)	33·81	<0·0001*
In general, I am satisfied with my psychosocial care	4·25 (0·77)	4·14 (0·65)	3·99 (0·89)	5·97	0·051

Data are mean (SD). Score 1 is strongly disagree, 2 disagree, 3 neither agree nor disagree, 4 agree, and 5 strongly agree. NA=not applicable (detailed group comparisons only undertaken if $p<0·01$). *Dignity therapy was significantly better than client-centred care and standard palliative care. †Dignity therapy was significantly better than client-centred care. ‡Dignity therapy was significantly better than standard palliative care.

Table 4: Results of survey done after study completion

groups, were also significantly more likely to report that the study treatment changed how their family saw and appreciated them, and that it had or would be of help to their family (table 4). Dignity therapy was significantly better than the client-centred care in improving spiritual wellbeing, and was significantly better than standard palliative care in terms of lessening sadness or depression; significantly more patients who had received dignity therapy reported that the study group had been satisfactory than did those who received standard palliative care (table 4).

Discussion

Although floor effects precluded our ability to show significant differences between the study groups in terms of the primary outcomes, our secondary outcomes showed substantive benefits of dignity therapy, a novel psychotherapeutic approach, over standard palliative care and client-centred care. Patients in this group, when surveyed after the study, were significantly more likely to report benefits in terms of finding the treatment helpful; improving their quality of life, their sense of dignity; changing how their family saw or appreciated them, and helping their family than did those in the standard palliative care and client-centred care groups (panel 2).

Comprehensive palliative care requires that careful attention be paid to the physical, psychosocial, existential, and spiritual sources of end-of-life distress. Restricting the clinical focus on any of these domains to the exclusion of others does not achieve standards of palliative care as specified by WHO[20] and the US Institute of Medicine.[21] In describing factors associated with a good death, the Institute of Medicine includes preparation for death and opportunities for closure or sense of completion of the life.[21] Yet, although much progress has been made in our ability to achieve physical comfort for patients who are dying, few novel interventions have been designed to address the psychosocial, existential, and spiritual dimensions of end-of-life care.

Dignity therapy was developed for the purpose of lessening distress and enhancing end-of-life experience for patients nearing death. In our phase 1 trial,[4] nearly all patients reported that dignity therapy was helpful, whether they had disclosed substantial initial distress or not. On the basis of that finding, baseline distress was not specified as an entry criterion for the randomised controlled trial. Because the base rates of distress within our sample were quite low, it is perhaps unsurprising that we were unable to measure any significant changes in distress in the three study groups. Improvement in

Panel 2: **Research in context**

Systematic review

This study is the first randomised trial of dignity therapy. The systematic review that accompanied the application for funding of this randomised controlled trial was incorporated into two reports.[17–19]

Interpretation

Based on the findings of this study, clinicians should consider dignity therapy a viable therapeutic approach, which can enhance end-of-life experience for patients and families confronting death.

indicators of depression, will to live, and quality of life, presupposes that patients' initially consider these a problem. In the absence of such initial distress, little room exists for improvement.

Perhaps the scales we used for assessment of our primary outcome were less responsive and less sensitive to changes than were those used for the secondary outcome, whereby patients reported their experiences in the survey undertaken after study completion. The difficulty in showing end-of-life psychosocial change with self-reported measurements has been well documented. Unlike a trial of chemotherapy, in which survival time, tumour load, and overall mortality provide readily measurable and objective outcomes, defining outcomes for dignity therapy is a greater challenge. Dignity therapy was designed to positively affect the experience of people who are dying. Measurements of overt distress, with indicators of psychosocial, existential, and spiritual effect, were incorporated into the study protocol. In a recent review of quality of life measurements that are suitable for use in palliative care, none of the items could be identified as having an established responsiveness to change.[22] The conclusion drawn from the results of a meta-analysis is that distress before the intervention is a critical moderator of efficacy of psychosocial interventions in patients with cancer.[23] Murray and colleagues[24] have suggested that a more successful approach might be to have serial qualitative interviews. This approach, however, would not be well suited to a randomised, controlled trial.

With the lack of significant difference for the three study groups for the primary outcome measurements, we also considered whether our trial might have been underpowered. A post-hoc power calculation, based on the actual number of trial participants, determined that with 326 patients, this study had a power of 0·72–0·95 to detect an effect size of 0·15–0·30.

Patients in the dignity therapy group were significantly more likely than were those assigned to the other groups to report that this approach was helpful, improved their quality of life, enhanced their sense of dignity, and provided benefits to their family. Although they reported their initial state of psychosocial or existential wellbeing as satisfactory, patients given dignity therapy often had an enhanced quality-of-end-of-life experience that they simply could not have expected. The effect, although difficult to assess, was often poignant and profound. For example, a 72-year-old woman with bowel cancer stated that "[dignity therapy] brought to the forefront that I have to prepare my family to the best of my ability". A 56-year-old woman said, "Mostly I want my family to know that I'm okay with dying and they must move on". She went on to say that "the therapy showed me I am not the cancer, I am still in here. I am so grateful for that because I lost myself....it really helped me remember who I am".

With hindsight, the argument could be that we should have screened patients for some baseline critical distress. That might have improved the likelihood of showing differences, based on changes reported in the questionnaires before and after the intervention, in the three study groups. Our disinclination to do so, however, was based on previous findings, showing the beneficial effects of dignity therapy for nearly all patients nearing death, whether overtly distressed or not. Introduction of critical thresholds of distress for study inclusion would have excluded most patients who were most likely to participate in this study. Another consideration might have been a crossover study design, in which patients could experience and thus compare dignity therapy with other possible study treatments. However, such a design would not have been feasible, with many patients either deteriorating or dying before a comparison of the groups was possible.

Notably, of the 1513 patients who were assessed for eligibility, 42% were ineligible, mainly because they were too ill to take part in the study. Of the patients who met the eligibility criteria, half consented to participate, and nearly three-quarters of these completed the protocol. For palliative care protocols that require participants who do not have any cognitive impairment, this recruitment pattern is not at all atypical.[25] The nature of dignity therapy is such that only patients who are mentally capable of providing personally meaningful responses are those who will be approached to take part. Therefore, generalisability should be defined in terms of patients who maintain their cognitive capacity while they are nearing death. Although in this trial we mainly enrolled patients with cancer, the application of dignity therapy in non-cancer populations has been investigated in other studies.[26]

We are not aware of any instance in which patients withdrew from dignity therapy because of feeling upset or distressed. Many patients, however, indicated moments during therapy that were emotionally evocative—eg, talking about hopes or wishes for family members in anticipation of a time after their death. Mostly, however, patients appreciated the opportunity to articulate these issues. The only safety issue, which will be reported fully in a separate report of families' experiences of dignity therapy, was that on a few occasions family members were dissatisfied with the generativity document. The family members felt the patient had become too ill to give fulsome responses, or that the answers provided a distorted image of the participant. Therefore, patients who are delirious or otherwise cognitively impaired should not be given dignity therapy.

Several studies have been done to assess dignity therapy under different circumstances. The conclusions drawn from a phase 1 Danish study[27] of ten health-care professionals and 20 patients was that, with minor cultural adaptations, dignity therapy was "a manageable, acceptable and relevant intervention for Danish patients admitted to palliative care". The results of a pilot study of eight patients in rural Kentucky, USA, with end-stage cancer showed that dignity therapy could be delivered by videophone, and achieve overall benefit and high patient satisfaction.[28] In a phase 1 study of a cohort of 33 terminally ill patients that was done in French-speaking Canada, relevance and satisfaction were high for patients and their families.[29]

Despite the beneficial effects of dignity therapy, its ability to mitigate outright distress (eg, depression, desire for death or suicidality) has not yet been proven. Future research in more severely distressed patients might indeed establish its role in such circumstances. However, the purpose and potential benefit of individual psychotherapy for patients with advanced or terminal disease is not solely the symptomatic relief of stress.[30] Psychotherapy is also offered for the prevention of distress, promotion of wellbeing, and establishment of a sense of personal meaning and life purpose. Psychotherapeutic support can help patients cope with disappointments, process the reality of leaving behind loved ones, deal with feelings of sadness, loss, isolation, and a damaged sense of identity and personal value. It can also help patients consider personal priorities in terms of relationships, religious and spiritual beliefs, and deal with the urgency of resolving conflicts or achieve personally meaningful goals.[30–31] Palliative care must offer patients opportunities to engage in these complex issues, and dignity therapy is a means by which it might do so. Future research exploring the beneficial effects of dignity therapy will help to unravel the psychological, spiritual, and existential complexities for an individual facing death, and the best way to support patients with advanced and terminal illness and their families.

Contributors

HMC was responsible for retrieving funding for the study, overseeing the study, contributing to the data analysis, writing the initial draft of the report, and revising the report based on the recommendations of the other authors. LJK and WB were site coordinators; they oversaw patient recruitment and local staff. SM, TFH, and MH helped in the design of the protocol; they participated in monitoring the study and maintaining protocol adherence. TH oversaw the randomisation process and supervised the data analysis. All coauthors contributed to writing the final study report.

Conflicts of interest

We declare that we have no conflicts of interest.

Acknowledgments

This study is funded by the National Cancer Institute, National Institutes of Health (grant number R01CA102201). HMC is a Canada Research Chair in Palliative Care, funded by the Canadian Institutes for Health Research. We thank our research staff, including Sheila Lander, Kathy Cullihall, Beverley Cann (Winnipeg); Joanne Hale, Jenny Clarke, Sky Dawson, and Lynn Oldham (Perth); and Shannon Poppito, Wendy Lichtenthal, Amy Berg, Kimberly Pitrelli (New York).

References

1 Steinhauser KE, Christakis NA, Clipp EC, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage* 2001; 22: 727–37.

2 Lynn J. Perspectives on care at the close of life. Serving patients who may die soon and their families: the role of hospice and other services. *JAMA* 2001; 285: 925–32.

3 Emanuel L, Bennett K, Richardson VE. The dying role. *J Palliat Med* 2007; 10: 159–68.

4 Chochinov HM, Hack T, McClement S, Harlos M, Kristjanson L. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med* 2002; 54: 433–43.

5 Chochinov HM. Dignity conserving care: a new model for palliative care. *JAMA* 2002; 287: 2253–60.

6 Chochinov HM, Hack T, Hassard T, Kristjanson L, McClement S, Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients nearing death. *J Clin Oncol* 2005; 23: 5520–25.

7 McClement S, Hack T, Chochinov HM, Hassard T, Kristjanson L, Harlos M. Dignity therapy: family member perspectives. *J Palliat Med* 2007; 10: 1076–82.

8 Brooke P, Bullock R. Validation of a 6 item cognitive impairment test with a view to primary care usage. *Int J Geriatr Psychiatry* 1999; 14: 936–40.

9 Anderson F, Downing GM, Hill J, Casorso L, Lerch N. Palliative Performance Scale (PPS): a new tool. *J Palliat Care* 1996; 12: 5–11.

10 Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy—spiritual well-being scale (FACIT-sp). *Ann Behav Med* 2002; 24: 49–58.

11 Chochinov HM, Hassard T, McClement S, et al. The Patient Dignity Inventory: a novel way of measuring dignity related distress in palliative care. *J Pain Symptom Manage* 2008; 36: 559–71.

12 Moorey S, Greer S, Watson M, et al. The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. *Br J Psychiatry* 1991; 158: 2555–59.

13 Wilson KG, Graham ID, Viola RA, et al. Structured interview assessment of symptoms and concerns in palliative care. *Can J Psychiatry* 2004; 49: 350–58.

14 Graham KY, Longman AJ. Quality of life in persons with melanoma: preliminary model testing. *Cancer Nursing* 1987; 10: 338–46.

15 Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991; 7: 6–9.

16 Cohen J. Statistical power analysis for the behavioral sciences (revised edition). New York: Academic Press, 1977.

17 Chochinov HM, Hack T, Hassard T, et al. Dignity and psychotherapeutic considerations in end of life care. *J Palliat Care* 2004; 20: 142–43.

18 Chochinov HM. Dying, dignity and new horizons in palliative end-of-life care. *CA Cancer J Clin* 2006; 56: 84–103.

19 Chochinov HM. Dignity therapy: final words for final days. New York: Oxford University Press (in press).

20 WHO. Cancer pain relief and palliative care: report of a WHO Expert Committee (technical bulletin 804). Geneva: World Health Organization, 1990.

21 Field MJ, Cassel CK. Approaching death: Improving care at the end of life. Washington DC: National Academy Press, 1997.

22 Albers G, Echteld MA, de Vet HCW, Onwuteaka-Philipsen BD, van der Linden MHM, Deliens L. Evaluation of quality-of-life measures for use in palliative care: a systematic review. *Palliat Med* 2010; 24: 17–37.

23 Schneider S, Moyer A, Knapp-Oliver, Sohl S, Cannella D, Targhella V. Pre-intervention distress moderates the efficacy of psychosocial treatment for cancer patients: a meta-analysis. *J Behav Med* 2010; 33: 1–14.

24 Murray SA, Kendall M, Carduff E, et al. Use of serial qualitative interviews to understand patients' evolving experiences and needs. *BMJ* 2009; 339: b3702.

25 Wilson KG, Chochinov HM, McPherson CJ, et al. Desire for euthanasia or physician-assisted suicide in palliative cancer care. *Health Psychol* 2007; 26: 314–23.

26 Chochinov HM, Cann B, Cullihall K, et al. Dignity therapy: a feasibility study of elders in long-term care. *J Palliat Support Care* (in press).

27 Houmann LJ, Rydahl-Hansen S, Chochinov HM, Kristjanson LJ, Groenvold M. Testing the feasibility of the dignity therapy interview: adaptation for the Danish culture. *BMC Palliat Care* 2010; 9: 21.

28 Passik SD, Kirsh KL, Leibee S, et al. A feasibility study of dignity psychotherapy delivered via telemedicine. *Palliat Support Care* 2004; 2: 149–55.

29 Gagnon P, Chochinov HM, Cochrane J, Le Moignan Moreau J, Fontaine R, Croteau L. Psychothérapie de la dignité: une intervention pour réduire la détresse psychologique chez les personnes en soins palliatifs. *Psycho-Oncologie* 2010; 4: 169–75.

30 Rodin G. Individual psychotherapy for the patient with advanced disease individual psychotherapy for the patient with advanced disease. In: Chochinov HM, Breitbart W, eds. Handbook of psychiatry and palliative medicine. New York: Oxford University Press, 2006.

31 Cordova MJ, Cunningham LL, Carlson CR, Andrykowski MA. Posttraumatic growth following breast cancer: a controlled comparison study. *Health Psychol* 2001; 20: 176–85.

32 Block SD. Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA* 2001; 285: 2898–905.

33 Tedeschi RG, Calhoun LG. Trauma and the transformation of suffering. Thousand Oaks, CA: Sage Publications, 1995.

"HMC-14"

This is the exhibit marked **"HMC-14"** referred to in the affidavit of **Harvey Max Chochinov** affirmed at
this day of May 2015 before me:

A person duly authorised to administer oaths by the law of Canada

Dignity-Conserving Care at the End of Life

To the Editor: Dr Chochinov's article[1] on dignity-conserving care at the end of life provides a model for how people should treat each other. Its elements, which generally can be found in hospice care, enable most patients to die with dignity.

Unfortunately, this model is not practiced in most hospital or nursing home settings, and is demanding for the average caregiver. Still, if most individuals with a terminal illness were treated this way, the incentive to end their lives would be greatly reduced. Nonetheless, there would still be other reasons arising from suffering, physical deterioration, and personal choice.

Those of us who defend a person's right to choose a peaceful, quick, and certain death, preferably with the help of a physician, do not mean to imply that a hastened death is the only way to achieve dignity at the end of life. But the dignity of all individuals is minimized if they are not allowed to make their own choices. Why not use this compassionate model and provide access to a gentle death if that is still what is wanted by the patient? Why compromise people's dignity by insisting that they must live, when they are ready to die and would prefer to do so?

Faye Girsh, EdD
The Hemlock Society USA
Denver, Colo

1. Chochinov, HM. Dignity-conserving care: a new model for palliative care. *JAMA*. 2002;287:2253-2260.

In Reply: I am delighted by the Hemlock Society's endorsement of the dignity-conserving model of care. I was particularly taken by Dr Girsh's unequivocal statement that, "if most individuals with a terminal illness were treated this way [according to the dignity-conserving model of care], the incentive to end their lives would be greatly reduced."

If she is correct, one cannot help but wonder how many fewer patients, in anticipation of dying, would feel compelled to consider or seek the option of a hastened death. It is known that patients who are free of pain, clinical depression, and social isolation are less vulnerable to considerations of euthanasia or assisted suicide.[1-3] Similarly, patients who do not feel abandoned by their health care providers are less likely to consider or commit suicide.[4] Data from Oregon suggest that the number of patients who died of physician-assisted suicide is relatively small, about 9 per 10000 deaths annually.[5] In the context of a dignity-conserving care model, would the correspondent's predication of substantial, further reductions in the incentive to die be realized?

Successful end-of-life care should not be measured in days of life endured, but rather in quality of life lived. There will likely always be a small number of patients who will wish to control the specific timing and exact circumstances of their dying. Finding compassionate and moral ways to address their needs will remain a challenge for policy makers and caregivers alike. However, with improving end-of-life care, it is conceivable that fewer patients will request the services and supports available through groups such as the Hemlock Society. Perhaps the time is nearing when these organizations could turn their attention to the broader range of end-of-life care issues that face the many hospitals and nursing homes that Girsh says would do well to embrace a dignity-conserving model of care.

Harvey Max Chochinov, MD, PhD, FRCPC
Department of Psychiatry and Family Medicine
University of Manitoba
CancerCare Manitoba
Winnipeg

1. Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry*. 1995;152:1185-1191.
2. Wilson KG, Scott JF, Graham ID, et al. Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide. *Arch Intern Med*. 2000;160:2454-2460.
3. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284:2907-2911.
4. Bolund C. Suicide and cancer, I: demographic and social characteristics of cancer patients who committed suicide in Sweden, 1973-1976. *J Psychosoc Oncol*. 1985;3:17-30.
5. Sullivan AD, Hedberg K, Fleming DW. Legalized physician-assisted suicide in Oregon: the second year. *N Engl J Med*. 2000;342:598-604.

RESEARCH LETTERS

Loss of HIV-1–Specific Immunity During Treatment Interruption in 2 Chronically Infected Patients

To the Editor: Human immunodeficiency virus 1 (HIV-1) antigen-specific proliferative $CD4^+$ T cell responses are typically absent in patients with chronic HIV-1 infection.[1] However, these responses are present in so-called long-term nonprogressors who experience control of viremia even without treatment[1-3] and in patients treated with highly active antiretroviral therapy (HAART) during acute seroconversion who are subsequently

GUIDELINES FOR LETTERS. Letters discussing a recent *JAMA* article should be received within 4 weeks of the article's publication and should not exceed 400 words of text and 5 references. Letters reporting original research should not exceed 500 words and 6 references. All letters should include a word count. Letters must not duplicate other material published or submitted for publication. Letters will be published at the discretion of the editors as space permits and are subject to editing and abridgment. A signed statement for authorship criteria and responsibility, financial disclosure, copyright transfer, and acknowledgment is required for publication. Letters not meeting these specifications are generally not considered. Letters will not be returned unless specifically requested. Also see Instructions for Authors (July 3, 2002). Letters may be submitted by surface mail: Letters Editor, *JAMA*, 515 N State St, Chicago, IL 60610; e-mail: JAMA-letters@ama-assn.org; or fax (please also send a hard copy via surface mail): (312) 464-5225.

Letters Section Editor: Stephen J. Lurie, MD, PhD, Senior Editor.