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## **Brief to the Select Committee on the issue of Dying with Dignity**

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### **Executive Summary**

Offering assisted suicide and/or euthanasia to some who want it would create a burden of proof for many other chronically or terminally ill individuals to prove that their lives are worth continuing. When some parts of society see the availability of euthanasia and or assisted suicide as a much cheaper and faster solution, it becomes more expedient to use it. This is also a question of how we want future generations to die: do we want to live in a culture that promotes death as medical treatment, or one that respects life and does not prolong it beyond its natural length, as current laws allow? To allow euthanasia and/or assisted suicide would also permanently damage the doctor/patient relationship for many patients who opt for life while their doctor offers death as their recommended treatment option.

Research shows that individuals who ask for assisted suicide or euthanasia rarely do so for physical reasons. The primary reasons are psychological and emotional, and these conditions are readily treatable today.

Canadians already have many rights at the end of their life. Under current law, they have the legal right to:

- refuse treatment
- withdraw treatment
- create a living will
- create a do not resuscitate order

These same laws already allow a certain level of autonomy and control. Euthanasia and assisted suicide are unnecessary legal entanglements. They foster concerns over individual's rights at the end of life, as if those rights listed above did not exist.

Finally, the international examples show us that no law surrounding these issues currently operating anywhere in the world can legislate against future abuses of that law. Switzerland and the Netherlands are examples of this.

Since many of the reasons why people ask for assisted suicide or euthanasia are themselves treatable, should we not make every effort to help people recover hope, so that they can die at peace with themselves and their families, when their natural last day arrives?

## **I. Why are assisted suicide and euthanasia not only issues of individual rights?**

If assisted suicide and/or euthanasia are made legal for the very few people who request it, the majority of patients who don't want to die a hastened death will face pressure to do so.

The case of Barbara Wagner in Oregon, where assisted suicide is legal, is instructive. Her health plan refused to pay for expensive cancer treatment at her request, instead offering to pay for the drugs she could take to die.<sup>1</sup>

This sends the message to those currently living with chronic or terminal illnesses that their lives are not worth living, such that they will have to justify expenses incurred to keep them alive when the cheaper alternative of a hastened death is available. As Baroness Campbell of Surbiton, a prominent disability rights campaigner, has stated: "Disabled people are fearful that when it becomes an option, it will gain a credibility that will erode the resolve of many people experiencing personal difficulties. "Not only will it enter our heads, it will also enter the heads of our families and friends, those who provide us with health and social care support and, ultimately, those holding the purse strings."<sup>2</sup>

Dr. Margaret Cottle, a palliative care physician and a clinical instructor at the University of British Columbia offers this observation which is pertinent to the committee's considerations of assisted suicide and euthanasia:

"'Euthanasia kills the patient twice.' The first time is when you look at the patient's life and say, 'Yeah, you're right. Your life really isn't worth living.' And the second time is when you actually do it."<sup>3</sup>

This is the opposite of compassion and choice.

Another question to answer is this: given that a change in the law will affect future generations, how do we want our grandchildren and great grandchildren to die? If assisted suicide and/or euthanasia are made legal, a cancer patient who wants to begin or continue treatment may feel or be challenged as to why they are costing the medical system so much when they could just take pills and die. Our elders, with life savings hanging in the balance, could be pressured by family members or caregivers to die early so that the inheritance will not be depleted. The medical community, with cost pressures already present today, may itself put its weight behind assisted suicide and/or euthanasia and, even by offering that option, add pressure to people who are chronically or terminally ill. If the choice is expensive treatments that may or may not extend

your life or a quick death, the cost of staying alive may itself be a burden to patients, pushing them to die early.

Ultimately, the medical system in Quebec and every other region of Canada is based on a relationship of trust between doctors and patients. Patients need to trust that their doctor is working in the best interests of their health. A study of cancer patients in Oregon and Washington found that “Patients with depression and psychological distress were significantly more likely to feel that discussions that included explicit mention of euthanasia or physician-assisted suicide would increase trust in their physician whereas patients with pain believed such discussions would not increase trust.”<sup>4</sup>

## **II. Why Do People Ask for Assisted Suicide?**

### ***Psychological and Emotional Needs***

Current research shows that those people who say that they would choose euthanasia or assisted suicide are most often suffering from other non-life threatening afflictions. In fact, when these issues are correctly diagnosed and treated, the patient no-longer wants to die. The most common issues are:

**Depression:** Multiple studies show that individuals are more likely to ask for assisted suicide or euthanasia when they are depressed.<sup>5</sup> A Dutch study found that almost 25 per cent of terminal cancer patients were suffering from depression.<sup>6</sup> This same study found that “the risk of a request for euthanasia by patients with depressed mood was 4.1 times higher than that of patients without depressed mood” when the study began.<sup>7</sup> A 1995 Canadian study found that “[t]he prevalence of diagnosed depressive syndromes was 58.8 per cent among patients with a desire to die and 7.7 per cent among patients without such a desire.”<sup>8</sup>

Another study found that “while oncology patients experiencing pain are unlikely to desire these interventions [euthanasia and assisted suicide] patients with depression are more likely to request assistance in committing suicide.”<sup>9</sup> Depression is treatable.

**Sense of Burden:** It is very common for individuals at the end of life to feel that they are a burden on others.<sup>10</sup>

In one study of patients with Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig’s Disease) in Oregon and Washington, “patients who discussed wanting assisted suicide were reported by their family caregivers to have... greater distress at being a burden in comparison to ALS patients who did not discuss wanting assisted suicide.”<sup>11</sup>

Whether they feel a burden to their loved ones

- emotionally (because they see the pain their deterioration is causing their loved ones).  
or
- physically (because of the physical burdens of caregiving)  
or
- they feel a burden to the hospital financially (due to the costs incurred in end of life care),

assisted suicide or euthanasia is seen as a way to stop the pain.

Loss of Control: A person diagnosed with a terminal illness loses almost all sense of control over their lives as they are unable to do anything to stop its progress. “Oregon physicians report that the most common reason patients request PAS (physical assisted suicide) is not pain or depression but a need for control. This need is usually related to patients’ fears of the future and presents the physician with an opportunity to address their specific concerns and to develop interventions that will relieve the anxiety of most patients.”<sup>12</sup>

Hopelessness: faced with no hope of recovery, individuals may lose any sense of meaning or purpose to their lives, and therefore desire to end it. One study found that “in the terminally ill, as with other populations, hopelessness is associated with suicidal ideation more strongly than is depression.”<sup>13</sup>

But hopefulness is recoverable, hopes for the future can be encouraged in even the terminally ill.<sup>14</sup>

Loss of Dignity: Something as basic as requiring help to use the bathroom and shower can cause a profound loss of dignity. But dignity lost is able to be recovered through therapeutic help. Dr. Harvey Chochinov, an internationally recognized palliative care specialist and professor at the University of Manitoba, has developed *Dignity-conserving care*:

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.<sup>15</sup>

Chochinov tested this therapy with terminally-ill patients and found that

Ninety-one per cent of participants were satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% 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.<sup>16</sup>

Death is not the solution to these real issues. Treatment is available for all these symptoms through palliative care teams. Death removes the option of healing in these important areas, even for patients who are terminally ill, and means that their lives end in real existential suffering, not in relief.

### **What rights do Quebecers and other Canadians currently have at the end of life?**

As in the rest of Canada, patients or their legal representatives in Quebec already have the right to:

- Refuse treatment. In Quebec, as in the rest of Canada, patients can say “no” to treatment. Whether a cancer patient refuses chemotherapy or a patient with Lou Gehrig’s Disease refuses to go on a respirator to allow them to breathe, such a decision is affirmed within provincial and federal law as legal
- Withdraw treatment. Patients can also withdraw treatment. A cancer patient can stop chemotherapy treatments. A person paralyzed from the neck down can have the respirator removed, or refuse food and drink
- Create a “mandate in anticipation of incapacity” which makes clear the patient’s desires as regards treatment. These documents describe the patient’s desire for treatment options: they may ask that everything possible be done to keep them alive, or they may ask that nothing be done. Yet again, these documents can describe desires for care for specific situations
- Create a do not resuscitate order. This document clearly states that a patient does not want medical personnel to engage in any form of Cardiopulmonary Resuscitation

These legal rights already allow a person to refuse drawn-out, painful treatment. As palliative care treatments become more widely available, individuals can control their treatment options, and move toward death in relative comfort due to advances in whole-person care.

For the most part, the main beneficiaries of a change in the law regarding euthanasia and/or assisted suicide are doctors, who would then be free from legal prosecution if they engaged in either of these activities.

Assisted suicide and euthanasia are not needed, as though Quebecers were without any rights at the end of their life. We have so many already, that these additions would allow one more option to a few individuals but would take away choice at the end of life for a vast number of individuals now and in the future (see above).

Canadian federal and provincial law does not force individuals to live beyond their natural course of death.

### **Further Abuses**

The international community gives ample evidence that no law legalizing euthanasia or assisted suicide can protect citizens of its country from further abuses unforeseen by the original law. Recently, an investigation by a Swiss newspaper suggests that Ludwig Minelli, the founder of Dignitas, has been made rich by Dignitas' operations. "Minelli declared that he had no taxable personal fortune in 1998, when he established Dignitas. Ten years la(t)er, he has an annual income of about US\$150,000 and a personal fortune of \$1.8 million. How did he become so wealthy"?<sup>17</sup> Recent news articles have also suggested a link between Dignitas and hundreds of urns filled with human ashes found at the bottom of a lake near the clinic.<sup>18</sup>

And in the Netherlands, a law which originally allowed euthanasia and/or assisted suicide only for competent, terminally ill adults with less than six months to live now allows doctors to kill newborns, with their parents' consent. Eligible newborns are those who have either:

- "no chance of survival. This group consists of infants who will die soon after birth, despite optimal care with the most current methods available locally." Instead of keeping the child comfortable until death arrives, doctors actively kill them.<sup>19</sup>
  - "a very poor prognosis and are dependent on intensive care. These patients may survive after a period of intensive treatment, but expectations regarding their future condition are very grim."<sup>20</sup> If the intensive treatment won't give a high return in terms of future health, the baby can be killed.
- or
- "a hopeless prognosis who experience what parents and medical experts deem to be unbearable suffering."<sup>21</sup> Once doctors judge that a child is experiencing "unbearable suffering", they can approach the parents for permission to kill them.

And a petition has been presented to the Dutch parliament by senior citizens attempt to make it legal for senior citizens who are simply tired of life to have assisted suicide when they want to die, regardless of the state of their health.<sup>22</sup>

The gradual and continuing broadening of those eligible for assisted suicide or euthanasia in the Netherlands clearly shows both the ethical and legal difficulties of containing these practices once they are made legal.

In short, the example of Dignitas, operating where assisted suicide cannot be offered for profit, and of the Netherlands, show us that no law can be crafted which will not be widened in the future to include more vulnerable people.

Ultimately, the question before all of us is this: since research shows that depression, hopelessness, lack of control and dignity as well as a sense of burden contribute to the desire for assisted suicide, should we not make every effort to restore or remove these things, as opposed to creating a nation where people are helped to die when they are most down and out?

### **Recommendations**

- That the committee recommend that euthanasia and assisted suicide remain illegal in the province of Quebec, and that the punishments laid out in the law be enforced in courts of law.
- That doctors be further trained to recognize and treat the suffering of patients for what it is (ie: depression, sense of burden, loss of control, hopelessness, loss of dignity) or refer patients for treatment, rather than offering death as the solution to their treatable problems
- That patients requesting assisted suicide or euthanasia be screened and treated for the aforementioned contributing factors so that they can continue life with renewed hope rather than dying in despair



## Endnotes

- <sup>1</sup> James, S.D. (2008, August 6). Death Drugs Cause Uproar in Oregon: Terminally Ill Denied Drugs for Life, But Can Opt for Suicide. *ABC News*. Retrieved online July 12, 2010 from <http://abcnews.go.com/Health/story?id=5517492&page=1>
- <sup>2</sup> Campbell, J. (2010, June 3). Disabled people need help to live, not die. *guardian.co.uk*. Retrieved July 13, 2010 from <http://www.guardian.co.uk/commentisfree/2010/jun/03/disabled-people-assisted-suicide>
- <sup>3</sup> Stirk, F. (2006). A Natural Death: An Interview with Dr. Margaret Cottle. *IMFC Review*, Spring/Summer 2006. Retrieved online July 12, 2010 from [http://www.imfcanada.org/article\\_files/A\\_natural\\_death.pdf](http://www.imfcanada.org/article_files/A_natural_death.pdf)
- <sup>4</sup> Emmanuel, E.J., Fairclough, D.L., Daniels, E.R., et al. (1996). Euthanasia and physician-assisted suicide: attitudes and experience of oncology patients, oncologists, and the public. *Lancet* Vol. 347, Issue 9018, pp. 1805–1810.
- <sup>5</sup> Chochinov, H.M., Wilson, K.G., Enns, M., and Lander, S. (1998). Depression, Hopelessness, and Suicidal Ideation in the Terminally Ill. *Psychosomatics*, Vol. 39, pp. 366–370.
- <sup>6</sup> van der Lee, M., et al. (2005). Euthanasia and Depression: A Prospective Cohort Study Among Terminally Ill Cancer Patients. *Journal of Clinical Oncology*, Vol. 23 pp. 6607-6612. Retrieved July 14, 2010 from <http://jco.ascopubs.org/cgi/reprint/23/27/6607>
- <sup>7</sup> *Ibid.*
- <sup>8</sup> Chochinov, H.M. Kristjanson, L. J, Hack, T. F., Hassard, T., McClement, S., and Harlos, M. (1995). Desire for Death in Terminally Ill Patients. *American Journal of Psychiatry*, Vol. 152, pp. 1185-1191.
- <sup>9</sup> Emmanuel, E.J et al. (1996).
- <sup>10</sup> Chochinov, H.M. et al. (2007). Burden to Others and the Terminally Ill. *Journal of Pain and Symptom Management*, Vol. 34, pp. 463-471.
- <sup>11</sup> Ganzini L, Silveira M.J., Johnston, W.S. (2002). Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. *Journal of Pain and Symptom Management*. Vol. 24, pp. 312-317.
- <sup>12</sup> Hendin, H., Foley, K. (2008). Physician assisted suicide in Oregon. *Michigan Law Review*, Vol. 106 , pp. 1613-1640. Retrieved July 9, 2010 from [http://www.spiorg.org/publications/HendinFoley\\_MichiganLawReview.pdf](http://www.spiorg.org/publications/HendinFoley_MichiganLawReview.pdf)
- <sup>13</sup> Chochinov, H.M. et al. (1998). Depression, Hopelessness, and Suicidal Ideation in the Terminally Ill.
- <sup>14</sup> Hudson, P.L. et al. (2006). Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review. *Palliative Medicine*, Vol. 20, pp. 693-701.
- <sup>15</sup> Chochinov, H.M., Hack, T., Hassard, T., Kristjanson, L.J., McClement, S., Harlon, M. (2005) Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life. *Journal of Clinical Psychology*, Vol. 23, pp. 5520-5525.
- <sup>16</sup> *Ibid.*
- <sup>17</sup> Cook, M. (July 3, 2010). Has assisted suicide made the founder of Dignitas a millionaire? *Bioedge.org*. Retrieved July 8, 2010 from [http://www.bioedge.org/index.php/bioethics/bioethics\\_article/9088/](http://www.bioedge.org/index.php/bioethics/bioethics_article/9088/)
- <sup>18</sup> Boyes, R. (April 28, 2010). Ashes dumped in Lake Zurich put Dignitas back in the spotlight. London: The Times. Retrieved July 8, 2010 from <http://www.timesonline.co.uk/tol/news/world/europe/article7109939.ece>
- <sup>19</sup> Verhagen, E., Sauer, P. (2005). The Groningen Protocol — Euthanasia in Severely Ill Newborns. *New England Journal of Medicine*, Vol. 352, pp. 959-962. Retrieved July 12, 2010 from <http://content.nejm.org/cgi/content/full/352/10/959/T2>
- <sup>20</sup> *Ibid.*
- <sup>21</sup> *Ibid.*

## 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

### A B S T R A C T

#### 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.

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### 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.<sup>1-4</sup> Yet, dying with dignity is usually only vaguely un-

derstood; 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.<sup>5-7</sup> The Institute of Medicine has identified overall quality of life and achieving a sense of spiritual peace and

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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).

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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.<sup>5</sup> 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.<sup>6-9</sup> 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.<sup>10</sup> Others have suggested that meaning, or a paucity of meaning, defines the essence of existential distress.<sup>11</sup> 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).<sup>1-4</sup> 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<sup>1,2</sup>

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).<sup>8</sup> Wilson et al<sup>8</sup> 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 0.90).<sup>6</sup> The protocol also contained a two-item quality-of-life instrument<sup>12</sup> and a revised Edmonton Symptom Assessment Scale, which included a will-to-live visual analog scale.<sup>13</sup>

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  $\geq 4$  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 life 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.<sup>14,15</sup> 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."<sup>16</sup> 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.

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#### 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, Earmons 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, Graham 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, 1982
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