

Dignity Therapy: Setting the Foundation for this Novel Palliative Care Psychotherapeutic Approach

Harvey Max Chochinov OC OM MD PhD FRSC

Distinguished Professor, Department of Psychiatry, Family Medicine & Community Health Sciences University of Manitoba

Senior Scientist, Research Institute on Oncology and Hematology (Patient Experience), CancerCare Manitoba





All human beings
are born free and equal
in dignity and rights.

Tous les êtres humains
naissent libres et égaux
en dignité et en droits.

Dignity-Conserving Care— A New Model for Palliative Care Helping the Patient Feel Valued

Harvey Max Chochinov, MD, PhD, FRCP(C)

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 loperamide, 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

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;287:2253-2263

www.jama.com

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.³⁻⁶ 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, FRCP(C), #2206, 771 Bannatyne Ave, Winnipeg, Manitoba, R3E 3N4 Canada (e-mail: chocho@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, Richard W. Rabow, MD, and Stuart Z. Perlman, MD; Amy L. Manaster, BA, is managing editor.
Perspectives on Care at the Close of Life Section Editor: Margaret A. Wilkie, MD, Deputy Editor, JAMA.



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

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 self³ 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

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

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



PAINPICTURE.COM

Is It Normal for Terminally Ill Patients to Desire Death?

James Henderson Brown, M.B., F.R.C.P.E., F.R.C.P.(C), Paul Hentleff, M.D.,
Samia Barakat, M.D., F.R.C.P.(C), and Cheryl June Rowe, M.D., F.R.C.P.(C)

Among 44 terminally ill patients, the majority (N=34) had never wished death to come early. Of the remainder, three were or had been suicidal and seven more had desired early death. All 10 patients who had desired death were found to be suffering from clinical depressive illness. The methodologic difficulties encountered by the authors were the lack of 1) a brief, efficient interview schedule suitable for debilitated patients and 2) criteria for depressive disorder that do not depend on suicidal thoughts or on symptoms that can also be caused by physical disease.

(Am J Psychiatry 143:208-211, 1986)

The prevalence of depression and suicidal thinking among terminally ill people has become an important topic because of the growth in recent years of a voluntary euthanasia movement, represented by organizations such as the Voluntary Euthanasia Society in the United Kingdom and the Hemlock Society in California. The basic assumption of this movement is that people facing serious life problems, especially people with painful, disfiguring, or disabling terminal illness, should be given encouragement and assistance in thinking of suicide as a rational solution. There is, however, a lack of data on whether people in such situations, in the absence of mental disorder, seriously consider suicide or otherwise wish to die.

Because the number of suicides increases as a result of publicity and imitative behavior (1-3), the publicity currently attracted by voluntary euthanasia may add to the number of suicides, but it is not clear whether any of the additional suicides will be rational. Some studies (4-7) have provided indirect evidence that suicide is highly dependent on mental disorder, and four retrospective studies (8-11) have provided direct evidence that almost all people who complete suicide have a mental disorder at the time; a prospective study (12) has suggested that few individuals

with no identifiable mental illness commit suicide. Depression, however, is underdiagnosed and often inadequately treated (13), and although most individuals who complete suicide are under medical care at the time of death, the doctors of many have failed to recognize the symptoms of depressive illness or have given inadequate treatment (11, 14).

In Finland, Achte and Vauhkonen (15) studied 100 persons affected by cancer and found none who expressed suicidal thoughts, although one man later committed suicide. On the other hand, using the Finnish cancer registry, Luohivuori and Hakama (16) found that the suicide rate was 1.3 times higher among male cancer patients and 1.9 times higher among female cancer patients than the rate in the general population. Farberow et al. (17), in an 8-year study of all suicides among patients in VA hospitals, found that 23% of 171 persons who had committed suicide had neoplastic disease. In another retrospective study, Farberow et al. (18) found that a group of cancer patients who had committed suicide had fewer psychosocial resources and showed a poorer adjustment to their illness than a control group of cancer patients who did not commit suicide. Silberfarb et al. (19) found that three of 146 breast cancer patients had suicidal thoughts, but all three were in the subgroup of patients with recurrent illness. In none of these studies was the relationship of suicide to major depression or other diagnosable mental disorder investigated.

Robins et al. (9, 20), in a retrospective study of 134 persons who had completed suicide, identified only five subjects with terminal medical illness and no accompanying psychiatric illness. In two of the five cases the relatives refused to give information about the subject and in a third the patient's wife was unable, or unwilling, to distinguish between her husband's medical and possible depressive symptoms.

METHODOLOGIC PROBLEMS

Suicidal thinking by itself does not justify a diagnosis of depression, but it is one of the criteria for depression in the major current research and statistical diagnostic schemes. For studies in which the relationship of suicide to depression is the focus, it would be desirable to have a set of criteria for depression that does not include suicide. Other criteria for depression also give

Received Jan. 25, 1985; revised June 27, 1985; accepted Oct. 1, 1985. From the Departments of Psychiatry and Social and Preventative Medicine, Faculty of Medicine, University of Manitoba. Address reprint requests to Dr. Brown, Department of Psychiatry, 770 Bannatyne Ave., Winnipeg, Man. R3E 0W3, Canada.

The authors thank Dr. J. Varsamis, who had previously devised the checklist for DSM-III depression for use by psychiatric nurses. Copyright © 1986 American Psychiatric Association.

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 cri-

teria 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).

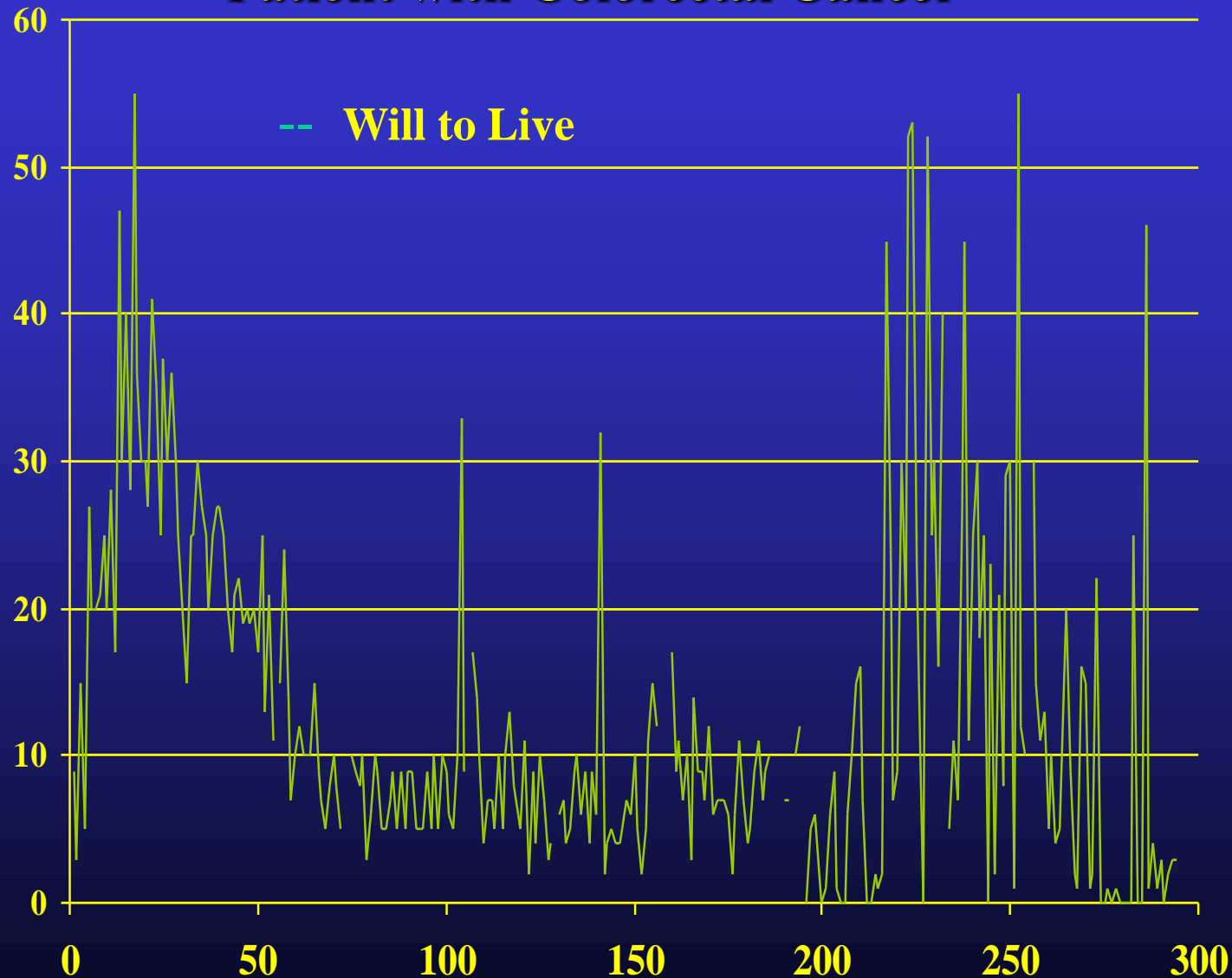
A second issue that requires clarification is the stability over time of the desire for death in patients who are

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.

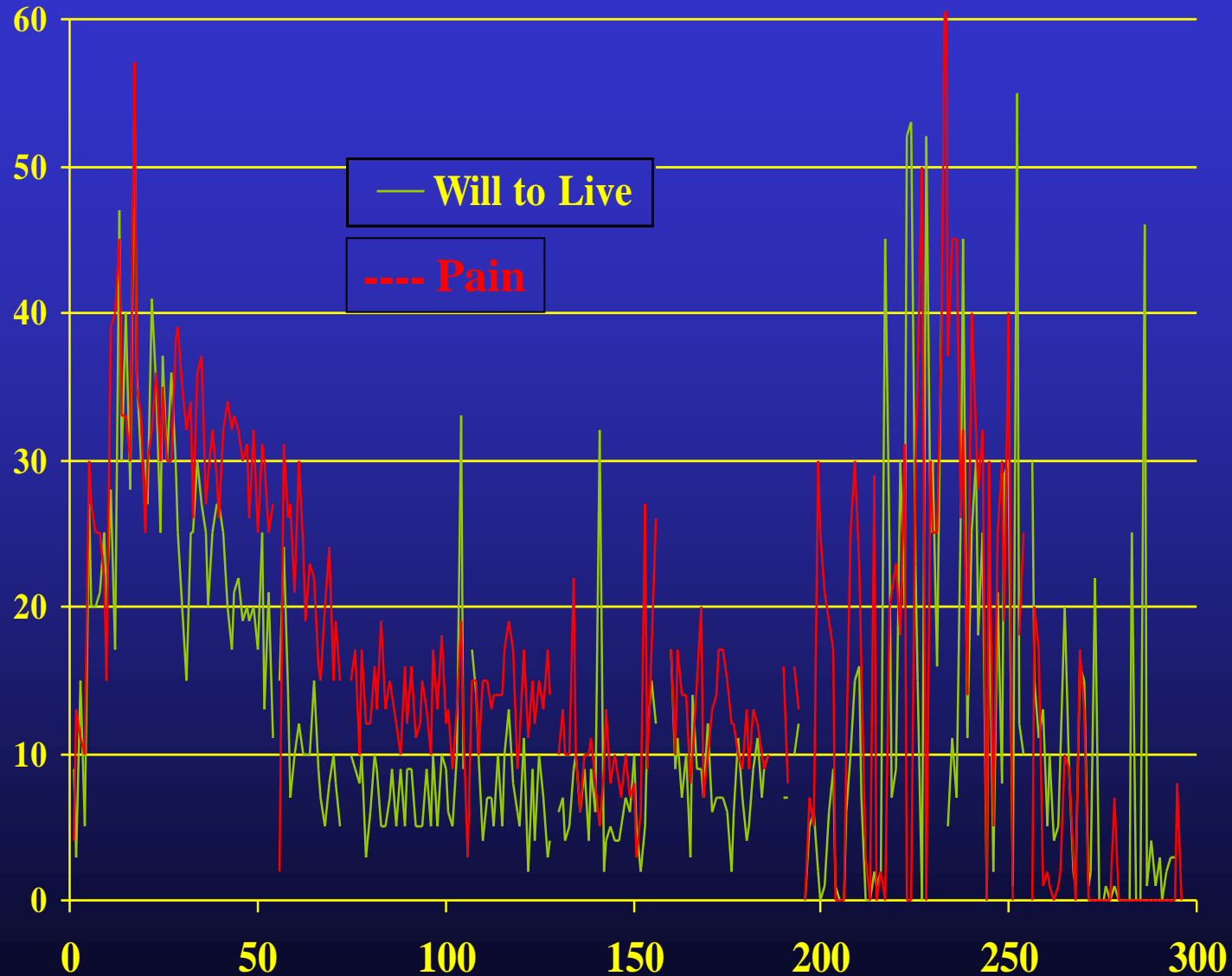
Stability of Will to Live with Pain in an 80 Year-old Patient with Colorectal Cancer



Observation Number (two per day)

Lancet. 1999;354:816-9.

Stability of Will to Live with Pain in an 80 Year-old Patient with Colorectal Cancer



Observation Number (two per day)

Lancet. 1999;354:816-9.

The Father of the Anti-Vaxxers

Newsweek

02.20.2015

DEATH BECOMES THEM

THE DUTCH
ARE CHOOSING
EUTHANASIA
IF THEY'RE
TIRED OF LIVING.
OTHERS MAY
SOON FOLLOW



Reasons - According to Physicians - Patients Requested Euthanasia/PAS

- Loss of Dignity - 57%
- Pain - 49%
- Unworthy Dying - 49%
- Being Dependent - 33%
- Tiredness of Life - 23%
- Pain Alone - 5%

Distribution of Sense of Dignity Responses

Responses	Prevalence
0 No sense of lost dignity	114 (53%)
1 Minimal sense of lost dignity	64 (30%)
2 Mild ; sense of lost dignity occasionally; regarded as minor problem	19 (9%)
3 Moderate sense of lost dignity; regards as significant problem	11 (5%)
4 Strong ; feels clear sense of lost dignity most of time	5 (2%)
5 Severe ; clear sense of lost dignity almost always present	0 (0%)
6 Extreme ; sense of lost dignity virtually constant	0 (0%)



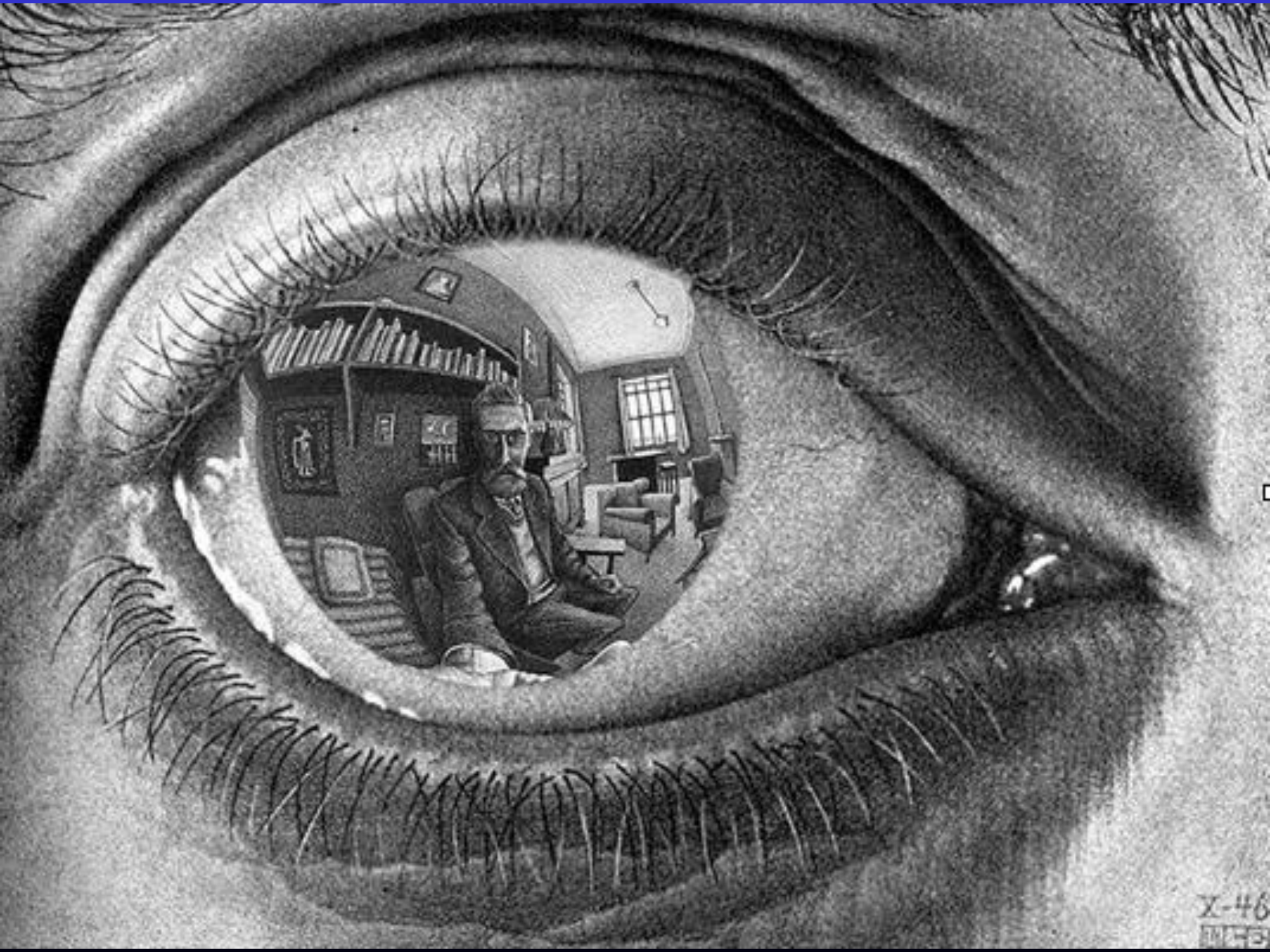
- Desire for death ($p < 0.0014$)
- Loss of will to live ($p < 0.013$)
- Depression ($p < 0.0084$)
- Hopelessness ($p < 0.020$)
- Anxiety ($p < 0.003$)



- Pain ($p < 0.048$)
- Difficulty with bowel functioning ($p < 0.026$)
- Physical appearance ($p < 0.002$)



- **Bathing** (OR = 8.45 [1.50 to 47.70]; $p < 0.016$)
- **Dressing** (OR = 2.79 [0.95 - 8.15]; $p < 0.061$)
- **Incontinence** (OR = 3.47 [1.27 - 9.51]; $p < 0.016$)



MAJOR DIGNITY CATEGORIES, THEMES AND SUB-THEMES

Illness Related Concerns	Dignity Conserving Repertoire	Social Dignity Inventory
<div data-bbox="125 406 633 489">Level of Independence</div> <div data-bbox="150 525 585 596">Cognitive Acuity</div> <div data-bbox="150 632 585 704">Functional Capacity</div> <div data-bbox="125 753 633 836">Symptom Distress</div> <div data-bbox="150 872 585 943">Physical Distress</div> <div data-bbox="150 979 585 1051">Psychological Distress <ul style="list-style-type: none"> • medical uncertainty • death anxiety </div>	<div data-bbox="759 406 1163 506">Dignity Conserving Perspectives <ul style="list-style-type: none"> • continuity of self • role preservation • generativity/legacy • maintenance of pride • hopefulness • autonomy / control • acceptance • resilience / fighting spirit </div> <div data-bbox="759 903 1163 1003">Dignity Conserving Practices <ul style="list-style-type: none"> • living "in the moment" • maintaining normalcy • seeking spiritual comfort </div>	<div data-bbox="1352 406 1748 478">Privacy Boundaries</div> <div data-bbox="1352 514 1748 585">Social Support</div> <div data-bbox="1352 621 1748 692">Care Tenor</div> <div data-bbox="1352 728 1748 799">Burden to Others</div> <div data-bbox="1352 835 1748 906">Aftermath Concerns</div>



Dignity IN CARE



Manitoba Palliative Care Research Unit
mpcru@cancercare.mb.ca

Patient Dignity Inventory

Chochinov et al JPSM 2008

For each item, please indicate how much of a problem or concern these have been for you within the last few days.

1 = NOT A PROBLEM 3 = A PROBLEM 5 = AN OVERWHELMING PROBLEM
2 = A SLIGHT PROBLEM 4 = A MAJOR PROBLEM

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

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;■:■–■. © 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. 5021, 675 McDermot Avenue, Winnipeg, Manitoba R3E 0V9, Canada. E-mail: harvey.chochinov@cancercare.mb.ca

Accepted for publication: April 1, 2009

The Patient Dignity Inventory: Applications in the Oncology Setting

Harvey Max Chochinov, M.D., Ph.D.,^{1,2,4} Susan E. McClement, R.N., Ph.D.,^{2,3}
Thomas F. Hack, Ph.D., Psych,^{3,4} Nancy A. McKeen, R.N., Ph.D.,^{1,2} Amanda M. Rach, B.A.,²
Pierre Gagnon, M.D.,⁵ Shane Sinclair, B.A., MDiv, Ph.D.,⁶ and Jill Taylor-Brown, M.S.W., R.S.W.⁴

Abstract

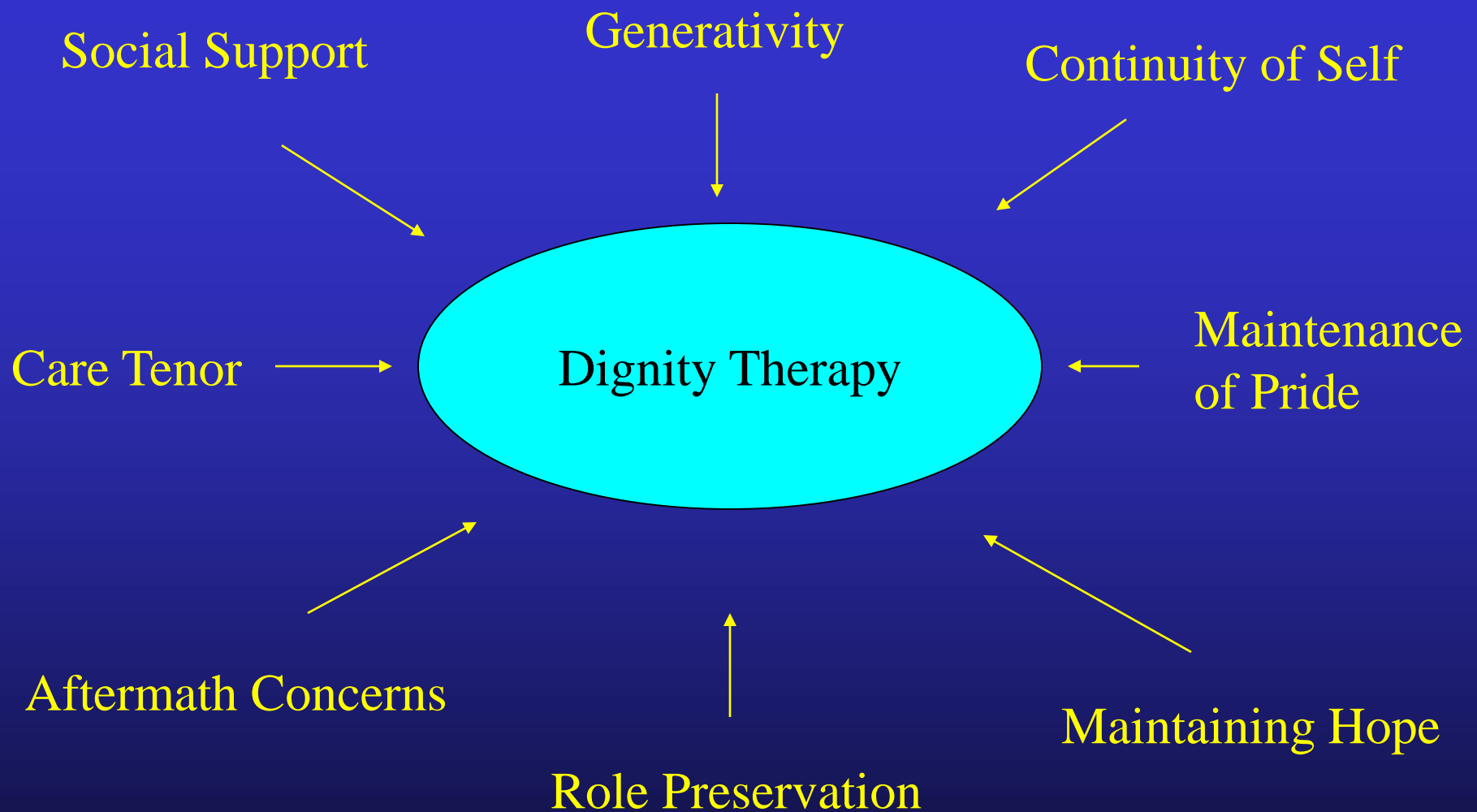
Background: The Patient Dignity Inventory (PDI) is a novel 25-item psychometric instrument, designed to identify multiple sources of distress (physical, functional, psychosocial, existential, and spiritual) commonly seen in patients who are terminally ill. It was also designed to help guide psychosocial clinicians in their work with patients. While its validity and reliability have been studied within the context of palliative care, its utility in clinical settings has not as yet been examined.

Purpose: The purpose of this study was to determine how psychosocial oncology professionals would use the PDI with within their practice and what utility it might have across the broad spectrum of cancer.

Methods: Between October 2008 and January 2009, psychosocial oncology clinicians from across Canada were invited to use the PDI to determine their impressions of this approach in identifying distress and informing their practice.

Results: Ninety participants used the PDI and submitted a total of 429 feedback questionnaires detailing their experience with individual patients. In 76% of instances, the PDI revealed one or more previously unreported concerns; in 81% of instances, clinicians reported that the PDI facilitated their work. While it was used in a wide range of circumstances, clinicians were more inclined to apply the PDI to patients engaged in active treatment or palliation, rather than those in remission, having recently relapsed, or newly diagnosed. Besides its utility in identifying distress, the PDI enabled clinicians to provide more targeted therapeutic responses to areas of patient concern.

Conclusions: While this study suggests various clinical applications of the PDI, it also provides an ideal forerunner for research that will directly engage patients living with cancer.



Dignity Therapy



FINAL WORDS
for FINAL DAYS

Harvey Max Chochinov

OXFORD

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

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 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.⁵⁻⁷ The Institute of Medicine has identified overall quality of life and achieving a sense of spiritual peace and

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 and author contributions are found at the end of this article.

Address reprint requests to Harvey Max Chochinov, MD, PhD, CancerCare Manitoba Room, 2017-675 McDermot Ave, Winnipeg, Manitoba, Canada R3E 0V9; e-mail: harvey.chochinov@cancercare.mb.ca.

© 2005 by American Society of Clinical Oncology

0732-183X/05/2324-5520/\$20.00

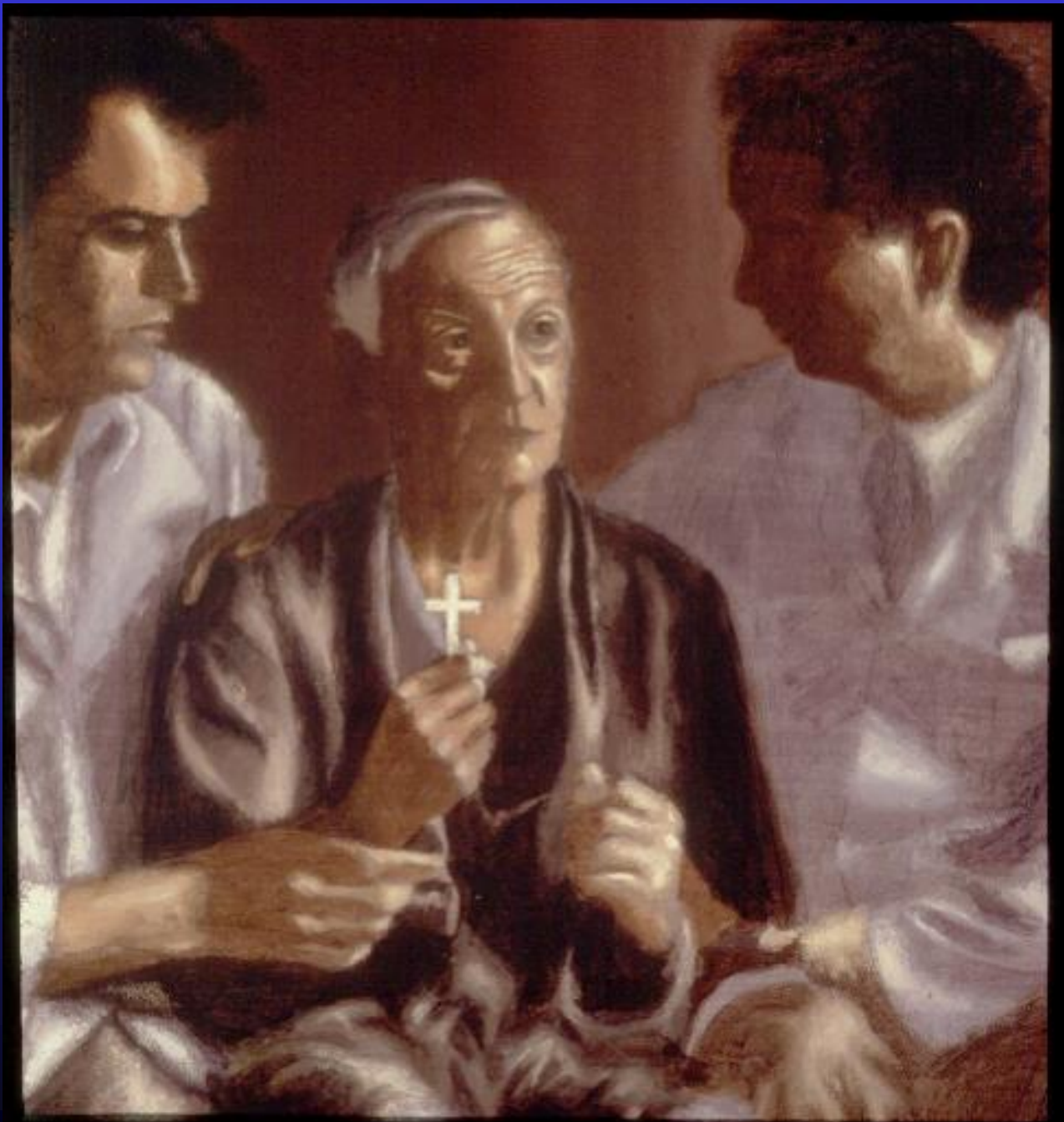
DOI: 10.1200/JCO.2005.08.391

Dignity Therapy: Step by Step

1. Identify eligible patient;
2. Provide full explanation of Dignity Therapy;
3. Share Dignity Therapy Question Framework;
4. Obtain 'framing' history for Dignity Therapy;
5. Arrange Dignity Therapy session;
6. Conduct Dignity Therapy session;
7. Follow editing protocol to create generativity document;
8. At follow-up session, read document to patient; address any final editing issues;
9. Provide patient final generativity document.

Dignity Therapy Question Framework

- “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, others)?”
- “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?”



Dignity Therapy Study: Phase I Trial

(n=100)

Satisfied or highly satisfied	91%
Helpful or very helpful	86%
Increased Sense of Dignity	76%
Increased sense of purpose	68%
Heightened sense of meaning	67%
Increased will to live	47%
Believed it had or would help their family	81%

Finding the Dignity Intervention Helpful to ones Family

*Finding life more meaningful
($r = .489$; $p < .000$)

*Having a heightened sense of
purpose ($r = .562$; $p < .000$)

*A lessened sense of suffering
($r = .327$; $p = .001$)

*An increased will to live
($r = .389$; $p < .000$)



Family Dignity Follow-up Data (n=60)

<u>Question</u>	<u>Percentage</u>
Helped patient	95%
Gave patient heightened sense of purpose	71.7%
Heightened patient's sense of dignity	78.3%
Helped patient prepare for death	65%
Was as important as any other aspect of patient's care	64.6%
Reduced patient's suffering	43.3%
Helped surviving family during time of grief	78%
Will continue to comfort family	76.7%
Recommend it to other patients and families	95%

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 ($\chi^2=35.50$, $df=2$; $p<0.0001$), improve quality of life ($\chi^2=14.52$; $p=0.001$), increase sense of dignity ($\chi^2=12.66$; $p=0.002$), change how their family saw and appreciated them ($\chi^2=33.81$; $p<0.0001$), and be helpful to their family ($\chi^2=33.86$; $p<0.0001$). Dignity therapy was significantly better than client-centred care in improving spiritual wellbeing ($\chi^2=10.35$; $p=0.006$), and was significantly better than standard palliative care in terms of lessening sadness or depression ($\chi^2=9.38$; $p=0.009$); significantly more patients who had received dignity therapy reported that the study group had been satisfactory, compared with those who received standard palliative care ($\chi^2=29.58$; $p<0.0001$).

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.

Introduction

Research into methods to understand and support patients who are nearing the end of their lives is increasing.^{1,2} 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.³ 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.⁴ Post-intervention assessments of suffering and depressive symptoms showed small, but significant improvements.⁴ 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.⁵ We therefore investigated

Published Online

July 2, 2011

DOI:10.1016/S1473-0459(11)70153-X

See Online/Comment
DOI:10.1016/S1473-0459(11)70185-1

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 3012, 675 McDermott Avenue, Winnipeg, Manitoba R3E 0V9, Canada. harvey.chochinov@cancercare.mb.ca



Dignity Therapy RCT

Patient Data

Post Study Survey Questions The study arm has...	Standard Care (SC)	Client Centered Care (CCC)	Dignity Therapy (DT)	χ^2 2 df	p- value
...been as helpful as any other aspect of my health care	3.27	3.12	3.63	6.386	0.041
...given me a sense of looking after unfinished business	2.86	2.93	3.35	6.874	0.032
...made me feel like I am still me	3.59	3.40	3.81	5.906	0.052
...made me feel that I am still able to carry out important tasks or fill an important role	3.48	3.02	3.62	8.963	0.011
...made me feel that life was more meaningful	3.19	3.31	3.55	6.731	0.035
...given me a heightened sense of purpose	3.20	3.15	3.49	6.858	0.032
In general, I am satisfied with my psychosocial care	4.14	3.99	4.25	5.969	0.051

Dignity Therapy RCT

Patient Data

Post Study Survey Questions	Standard Care (SC)	Client Centered Care (CCC)	Dignity Therapy (DT)	χ^2	p-value	Arms DT Significantly Outperformed
The study arm has...						
...improved my spiritual well being	3.00	2.56	3.27	10.354	0.006	CCC
...lessened my sense of sadness and depression	2.57	2.65	3.11	9.379	0.009	SC
...been satisfactory	3.80	4.17	4.26	29.583	0.000	SC
...been helpful to me	3.50	3.72	4.23	35.501	0.000	CCC, SC
...improved my quality of life	2.96	2.84	3.54	14.520	0.001	CCC, SC
...increased my sense of dignity	3.09	3.11	3.52	12.655	0.002	CCC, SC
...or will be of help to my family	3.20	3.29	3.93	33.864	0.000	CCC, SC
...or could change way my family sees of appreciates me	2.85	2.85	3.58	33.811	0.000	CCC, SC

'Dignity therapy', a promising intervention in palliative care: A comprehensive systematic literature review

Palliative Medicine
2017, Vol. 31(3) 492–509
© The Author(s) 2016



Reprints and permissions:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/0898010116644114
journals.sagepub.com/home/pmj



Marina Martínez^{1,2,3}, María Arantzamendi^{1,3}, Alazne Belar^{1,4},
José Miguel Carrasco^{1,3}, Ana Carvajal^{1,3,5}, María Ruilán^{1,4} and Carlos Centeno^{1,3,3}

Abstract

Background: Dignity therapy is psychotherapy to relieve psychological and existential distress in patients at the end of life. Little is known about its effect.

Aims: To analyse the outcomes of dignity therapy in patients with advanced life-threatening diseases.

Design: Systematic review was conducted. Three authors extracted data of the articles and evaluated quality using Critical Appraisal Skills Programme. Data were synthesized, considering study objectives.

Data sources: PubMed, CINAHL, Cochrane Library and PsycINFO. The years searched were 2002 (year of dignity therapy development) to January 2016. 'Dignity therapy' was used as search term. Studies with patients with advanced life-threatening diseases were included.

Results: Of 121 studies, 28 were included. Quality of studies is high. Results were grouped into effectiveness, satisfaction, suitability and feasibility, and adaptability to different diseases and cultures. Two of five randomized control trials applied dignity therapy to patients with high levels of baseline psychological distress. One showed statistically significant decrease on patients' anxiety and depression scores over time. The other showed statistical decrease on anxiety scores pre-post dignity therapy, not on depression. Nonrandomized studies suggested statistically significant improvements in existential and psychosocial measurements. Patients, relatives and professionals perceived it improved end-of-life experience.

Conclusions: Evidence suggests that dignity therapy is beneficial. One randomized controlled trial with patients with high levels of psychological distress shows DT efficacy in anxiety and depression scores. Other design studies report beneficial outcomes in terms of end-of-life experience. Further research should understand how dignity therapy functions to establish a means for measuring its impact and assessing whether high level of distress patients can benefit more from this therapy.

Keywords

Dignity therapy, end of life, terminal, palliative care, psychotherapy

What is already known about the topic?

- DT was recently developed to relieve psychological and existential distress in patients at end of life. Originally was conceived for patients with low levels of distress.
- DT seems to affect several dimensions of patients but the process and the way of measuring the impact of the intervention are not clear.

What this paper adds

- This paper provides a critical and comprehensive view about DT including primary and secondary study results, which is key to have an overview of the therapy.

¹Clinica Universidad de Navarra, Servicio de Cuidados Paliativos, Avenida Pio XII, 11006, Pamplona, España

²Universidad de Navarra, ICS, ATLANTES, Campus Universitario, 31006, Pamplona, España

³IdiSNA, Instituto de Investigación Sanitaria de Navarra, Pamplona, España

⁴Hospital Alta Mendi, Arreaza-Piedrabuena, España

⁵Departamento de Enfermería de la Persona Adulta, Facultad de Enfermería, Universidad de Navarra, Pamplona, España

⁶Complejo Hospitalario de Navarra, Departamento de Gastroenterología, Pamplona, España

Corresponding author

María Arantzamendi, ATLANTES, Instituto Cultura y Sociedad (ICS), Universidad de Navarra, Campus Universitario, Edificio de Bibliotecas, 31009 Pamplona, Navarra, España.
Email: maraen@unav.es

RESEARCH ARTICLE

Open Access

Care of the human spirit and the role of dignity therapy: a systematic review of dignity therapy research

George Fitchett¹, Linda Emanuel^{2*}, George Handzo³, Lara Boyken² and Diana J Wilkie⁴

Abstract

Background: Dignity Therapy (DT), an intervention for people facing serious illness, focuses on dignity conservation tasks such as settling relationships, sharing words of love, and preparing a legacy document for loved ones. Research on DT began more than a decade ago and has been conducted in 7 countries, but a systematic review of DT research has not been published.

Methods: Using a PubMed search with key terms of 'dignity therapy', 'dignity psychotherapy', 'Chochinov', and 'dignity care', we found 29 articles on DT and retained 25 after full-text review.

Results: Of these, 17 articles representing 12 quantitative studies establish that patients who receive DT report high satisfaction and benefits for themselves and their families, including increased sense of meaning and purpose. The effects of DT on physical or emotional symptoms, however, were inconsistent.

Conclusions: Conclusions point to three areas for future research on DT, to determine: (1) whether the DT intervention exerts an impact at a spiritual level and/or as a life completion task; (2) how DT should be implemented in real world settings; and (3) if DT has an effect on the illness experience within the context of not only the patient, but also the family and community. Building on this body of DT research, investigators will need to continue to be sensitive as they involve participants in DT studies and innovations to facilitate the generation and delivery of legacy documents to participants near the end of life.

Keywords: Dignity therapy, Literature review, Spiritual care, End-of-life care

Background

Care of the psychological and spiritual aspects of a person during illness are recognized as essential components of patient-centered care. That the achievement of well-being in the face of incurable illness depends on these aspects of a person's experience is particularly well acknowledged [1,2]. Research addressing social and psychological needs during physical illness has become more substantial in recent decades [1,3]. However, systematically developed, manualized, and well-studied interventions for these dimensions lag behind those for physical aspects of illness [4,5]. This paucity is even more pronounced for spiritual care than it is in

psychological and social care, despite growing evidence for its importance [6-13].

Chochinov proposed Dignity Therapy (DT) as a psychotherapeutic intervention for people facing serious illness [14]. DT focuses on dignity conservation tasks such as settling relationships, sharing words of love, and preparing legacies of memory and shared values, all of which take on a heightened importance at the end of life. DT has some similarities with Butler's Life Review [15], which Butler understood as part of a life-cycle task and developed as an antidote to depression in older adults. Both DT and Life Review are conceptualized as multi-dimensional psychosocial interventions for patient-centered care [14,15]. Perceiving that dignity depends on experiences of generativity and the pursuit of purpose and meaning, Chochinov [16] identified aspects of dignity-conserving care and proposed a model for its development,

* Correspondence: l.emanuel@northwestern.edu
²Bushnell Center on Health, Aging & Society, Northwestern University, 750 N. Lake Shore Dr. Suite 603, Chicago, IL 60611, USA
Full list of author information is available at the end of the article



© 2015 Fitchett et al.; licensee BioMed Central. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly credited. The Creative Commons Public Domain Dedication waiver (<http://creativecommons.org/publicdomain/zero/1.0/>) applies to the data made available in this article, unless otherwise stated.

Dignity Therapy Data Overview

- Establish high satisfaction; high acceptability
- Benefits for themselves and their families
- Increased sense of meaning and purpose.
- Studies with higher base rates of distress indicate lower depression, anxiety; and increased hopefulness
- Multiple adaptations i.e. different populations and settings

Dignity Therapy Knowledge Translation

TRIALS

- Sweden
- Denmark
- Spain
- Portugal
- Italy
- Scotland
- England
- Australia
- Canada (Hamilton, Ottawa, Quebec City)

TRAINING

- USA
- Australia
- China
- Portugal
- Switzerland
- Israel
- Germany
- Winnipeg



Dignity IN CARE