

An Introduction to Dignity Therapy

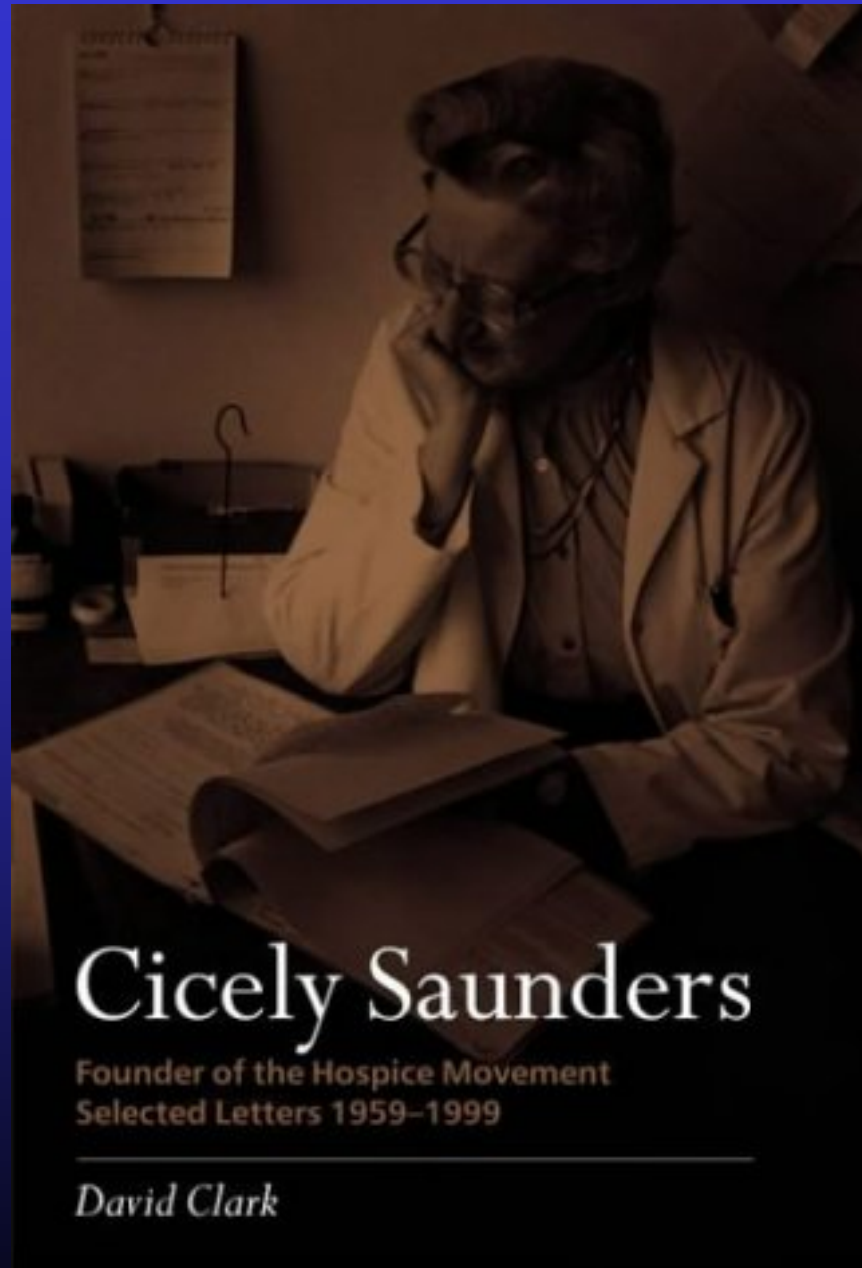
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Cicely Saunders

Founder of the Hospice Movement
Selected Letters 1959–1999

David Clark





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

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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



PHOTOGRAPH BY

D: Dialogue

Dignity Conserving Care



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

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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.

THE TORONTO STAR

CONTEXT

ANALYSIS • COMMENTARY • WORLD REPORT

Sunday, October 16, 1994 Section C

The Dutch way of death

Between the horror stories
of thousands of reluctant
deaths and the advocates
who see a lone refuge from
hypocrisy . . . lies the truth



FINAL DAYS: Seventy-year-old Jeanne Verheijen (right) knew she was dying and, fearing the pain, arranged for euthanasia if necessary. In the end, she didn't need it. Verheijen lived with her husband, Jan, died July 27th.

MAJOR DIGNITY CATEGORIES, THEMES AND SUB-THEMES

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

Therapeutic Pointers About Dignity Therapy

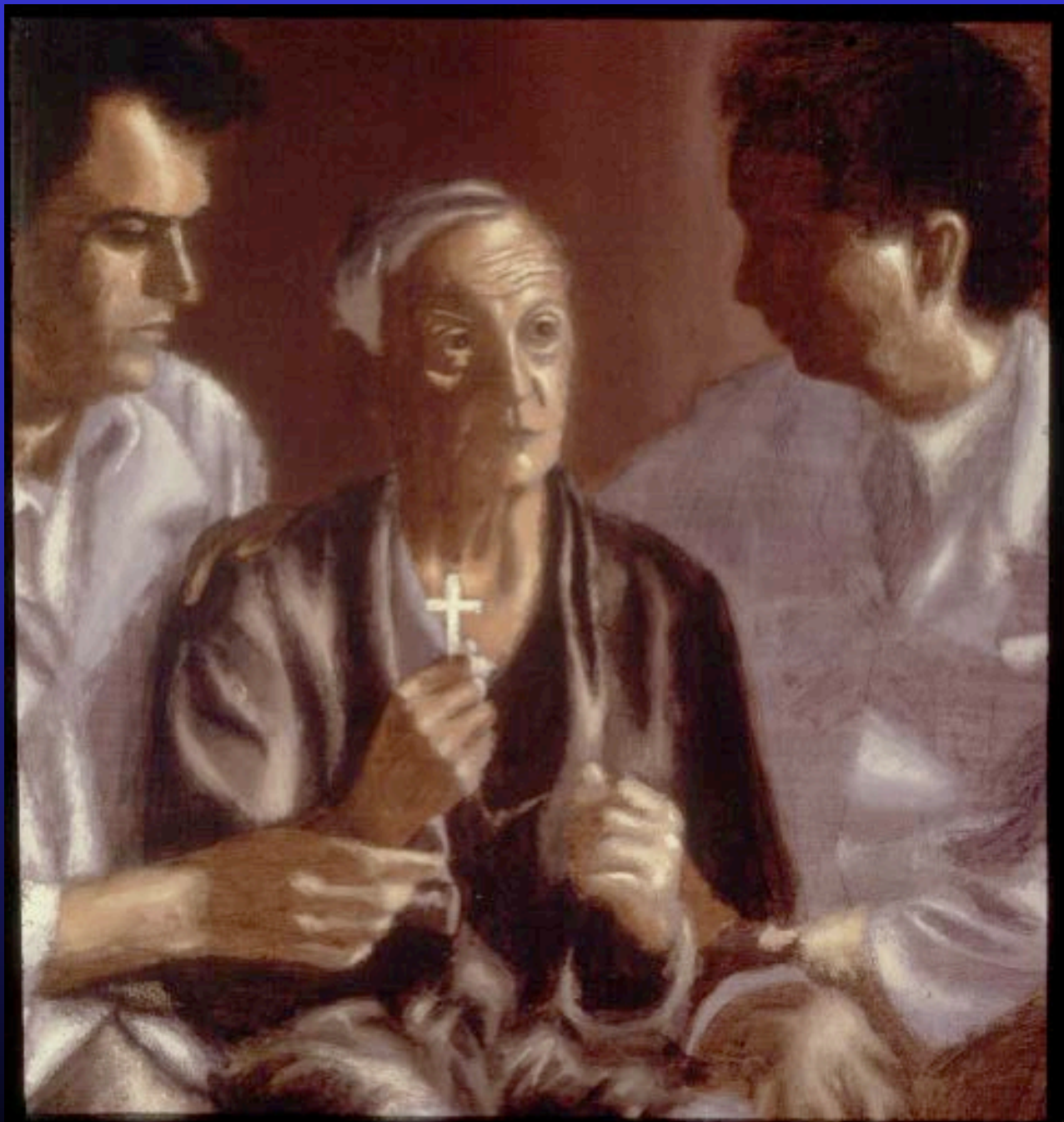
- Who is Dignity Therapy For?
- How to Introduce Dignity Therapy to Patients?
- Dignity Therapy Protocol Questions
- Tone
- Placing the Dots
- Photo Album Analogy

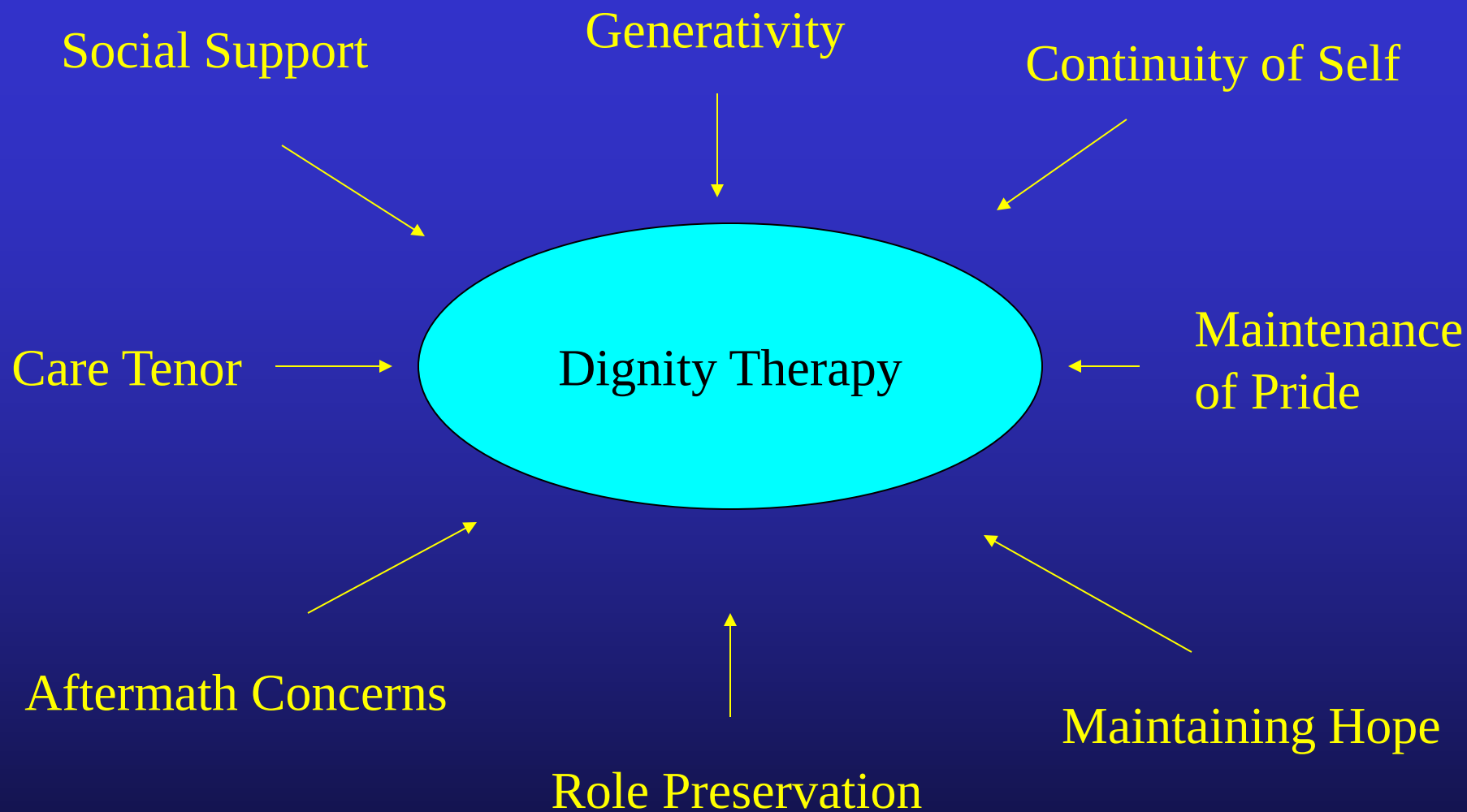


Therapeutic Pointers About Dignity Therapy

- Good, Sad and Ugly Stories
- Clarity
- Not about promoting psychological insight







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 23:5520-5526. © 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

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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.

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

DOI: 10.1200/JCO.2005.06.391

Dignity Therapy Study: Preliminary Data

(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%

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.¹⁻³ Dignity therapy, a unique, individualised, brief psychotherapy, was developed for the purpose of relieving distress and enhancing the end-of-life experiences of terminally ill patients. It provides these patients with an opportunity to reflect on things that matter most to them or that they would most want remembered. The therapeutic process begins with a framework of questions (panel 1) that are based on an empirical model of dignity in the terminally ill patient.^{4,5} These conversations, guided by a trained therapist, are flexible to accommodate the patients' needs and choices about what they specifically wish to address. Dignity therapy is audiorecorded and transcribed, with an edited

version of the transcript given to patients to share or bequeath to individuals of their choice.

In a phase 1 trial with 100 terminally ill patients, 91% were satisfied with dignity therapy, and 76% reported a heightened sense of dignity, 68% an increased sense of purpose, 67% a heightened sense of meaning, 47% an increased will to live, and 81% that it had been or would be of help to their family.⁶ Post-intervention assessments of suffering and depressive symptoms showed small, but significant improvements.⁷ 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.⁸ We therefore investigated

Published Online

July 7, 2011

DOI:10.1016/S1473-2045(11)70153-X

See Online/Comment

DOI:10.1016/S1473-2045(11)70185-1

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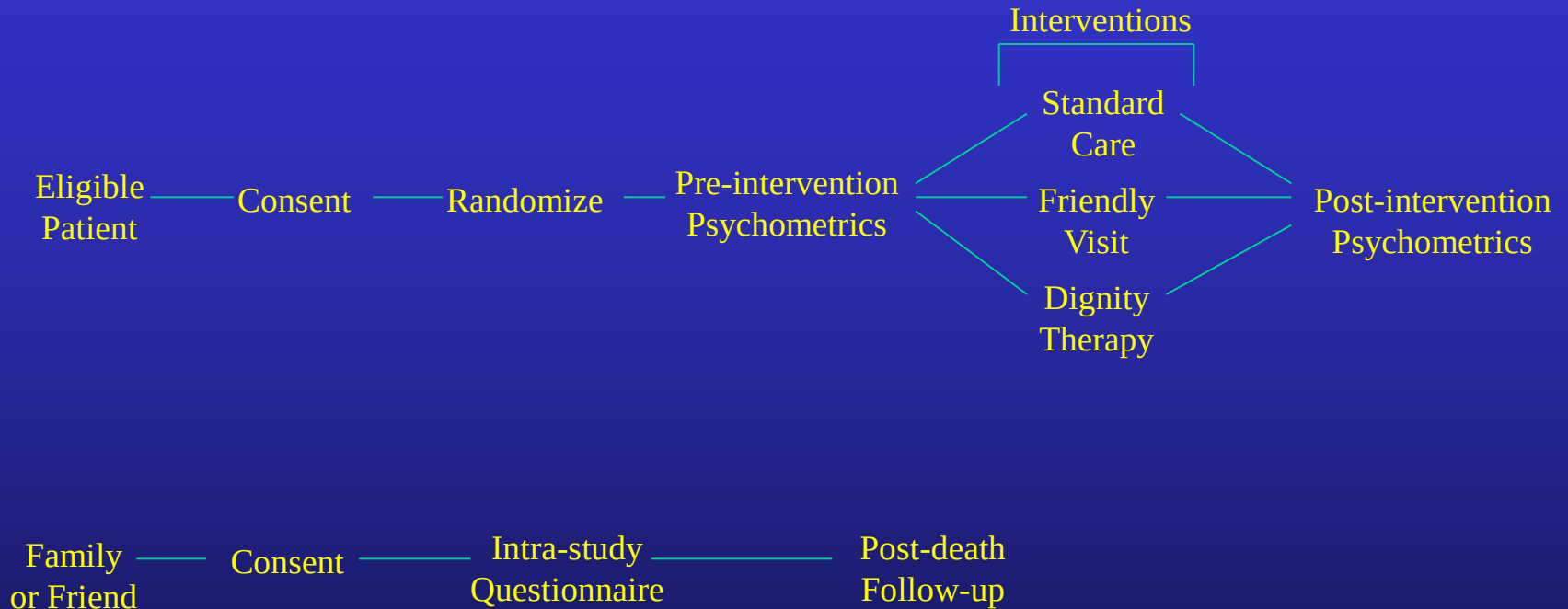
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Palliative Care Support Study



Randomized Controlled Trial

Palliative Care Support Study

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

Palliative Care Support Study

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 Knowledge Translation

TRIALS

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

TRAINING

- China
- Japan
- Portugal
- Switzerland
- Israel
- Winnipeg