Dignity in Care: A Virtual Workshop Sept 14, 21, 28, 2023

Harvey Max Chochinov OC OM MD PhD FRCPC FRSC FCAHS
Distinguished Professor of Psychiatry, University of Manitoba
Senior Scientist, CancerCare Manitoba Research Institute

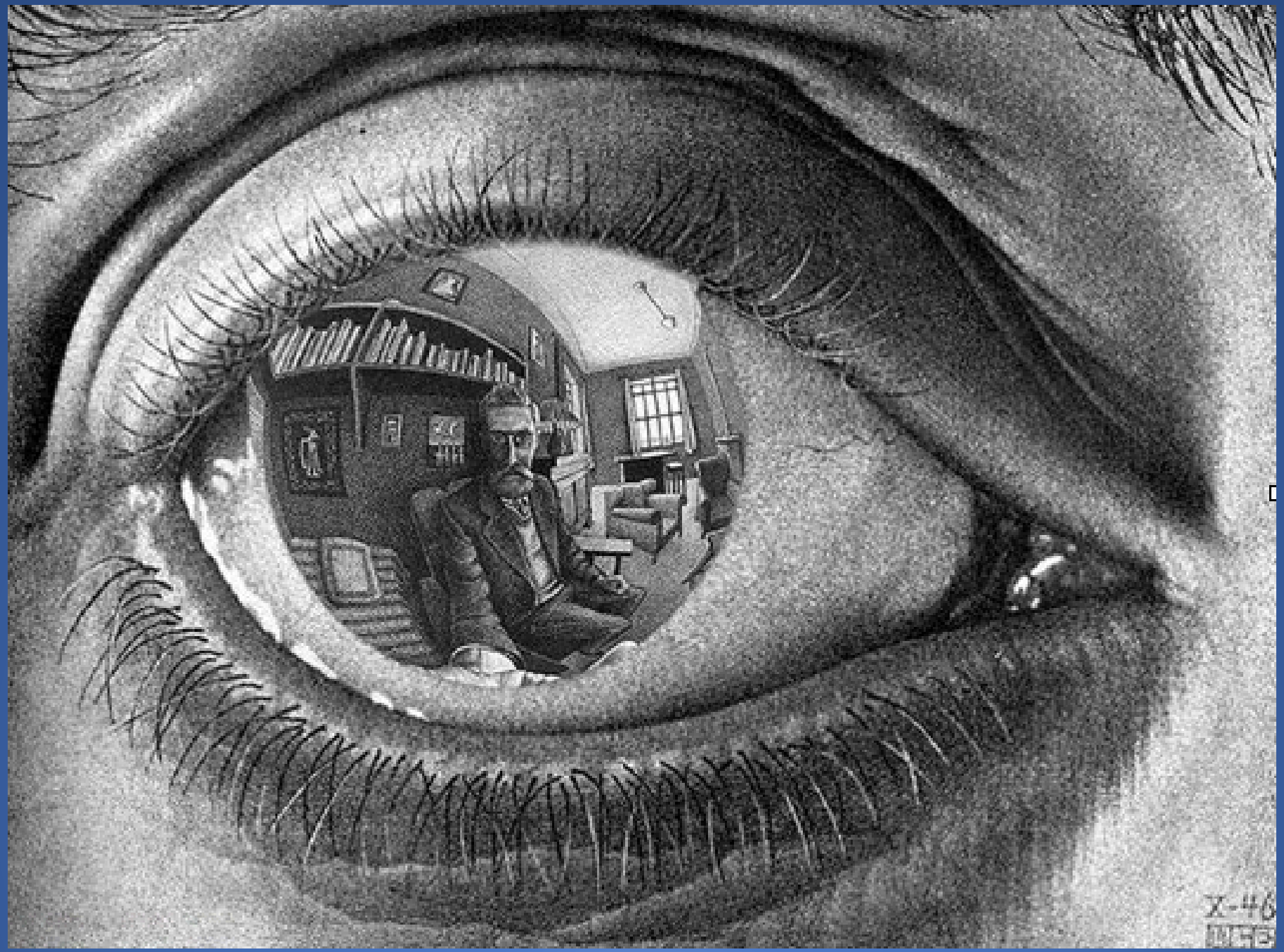
Lori Montross, Ph.D.
Associate Professor of Psychology
Franklin University Switzerland


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 Dutch Physicians, Why Patients Requested Euthanasia/PAS

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

Van der Maas Lancet 1991


X-46

PERGAMON

Social Science & Medicine 54 (2002) 433–443

SOCIAL SCIENCE & MEDICINE

www.elsevier.com/locate/socscimed

Dignity in the terminally ill: a developing empirical model

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

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

Abstract

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

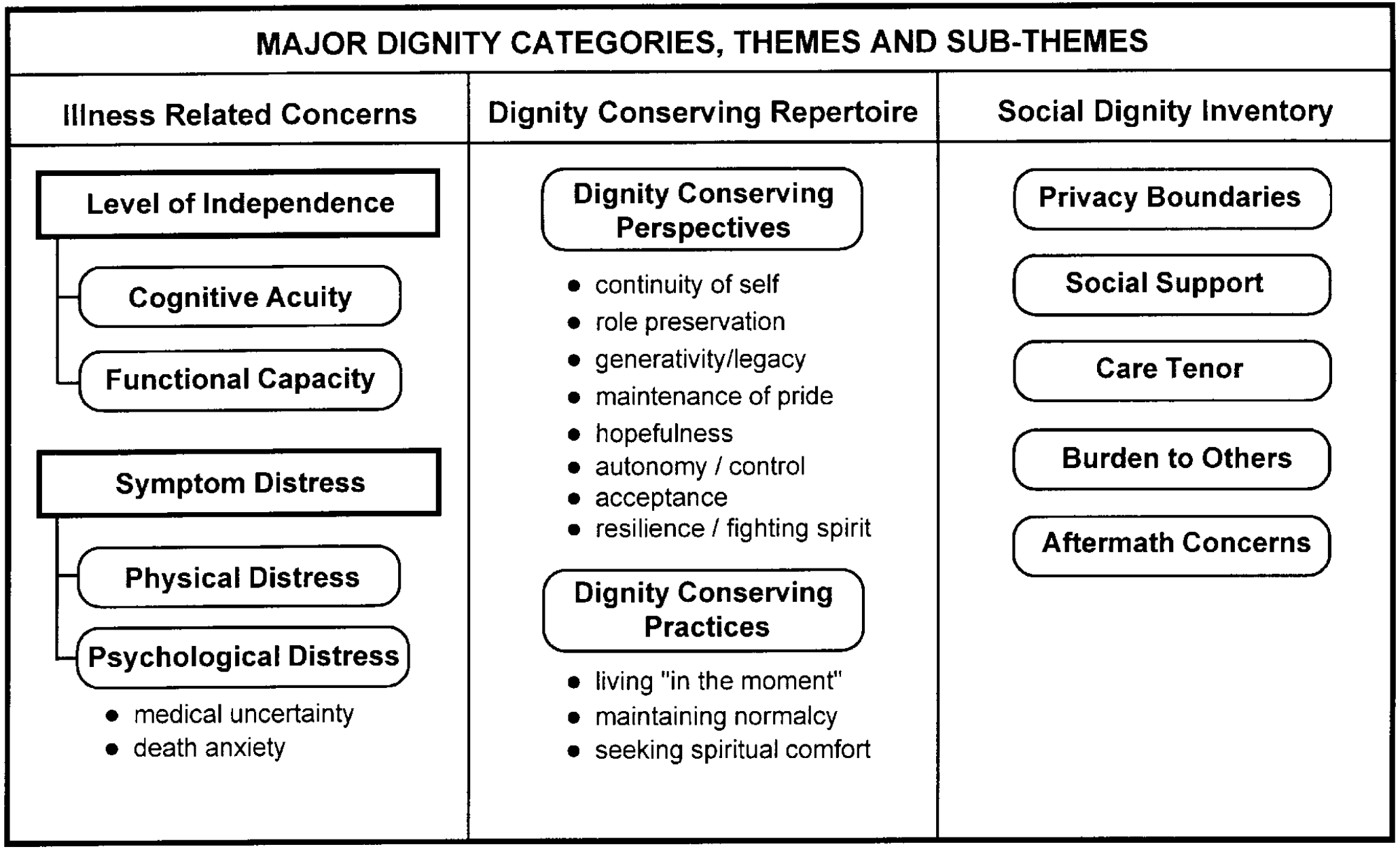
Keywords: Canada; Dignity; Palliative care; Cancer; Qualitative research

Introduction

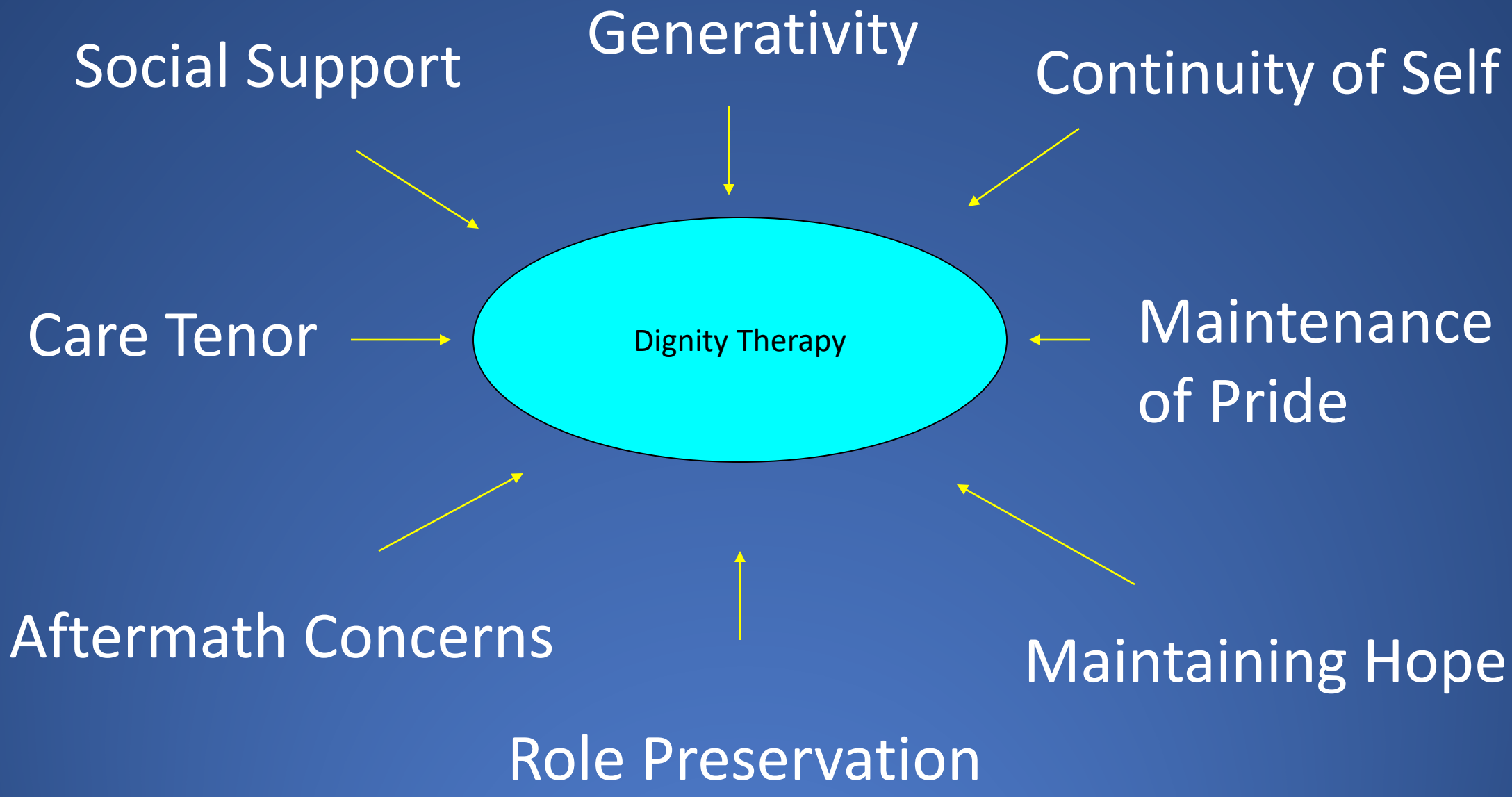
For many palliative cancer patients, their families, and caregivers, the term *dignity* conveys an inherent respect to be granted patients in preparation for death (Abiven, 1991; Council on Scientific Affairs, 1996; Kade, 2000; Pannuti & Tanneberger, 1993). Emphasis on the terminally ill individual has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

*Corresponding author. Department of Psychiatry-PX246, PsycHealth Centre, University of Manitoba, Winnipeg, Man., Canada R3T 2N2..
E-mail address: chochin@cc.umanitoba.ca (H.M. Chochinov).

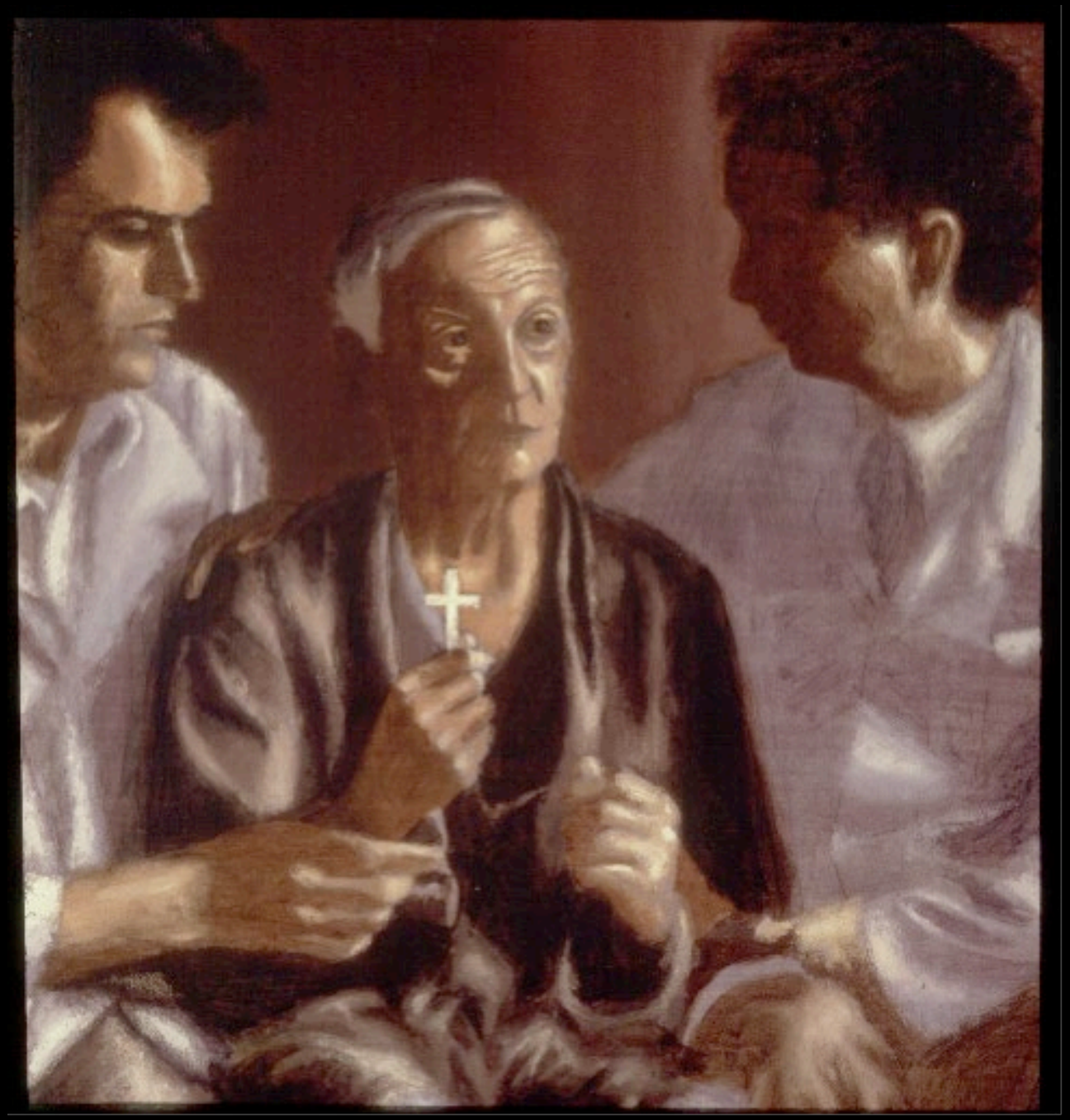
0277-9536/02/$ - see front matter
PII: S0277-9536(01)00084-3

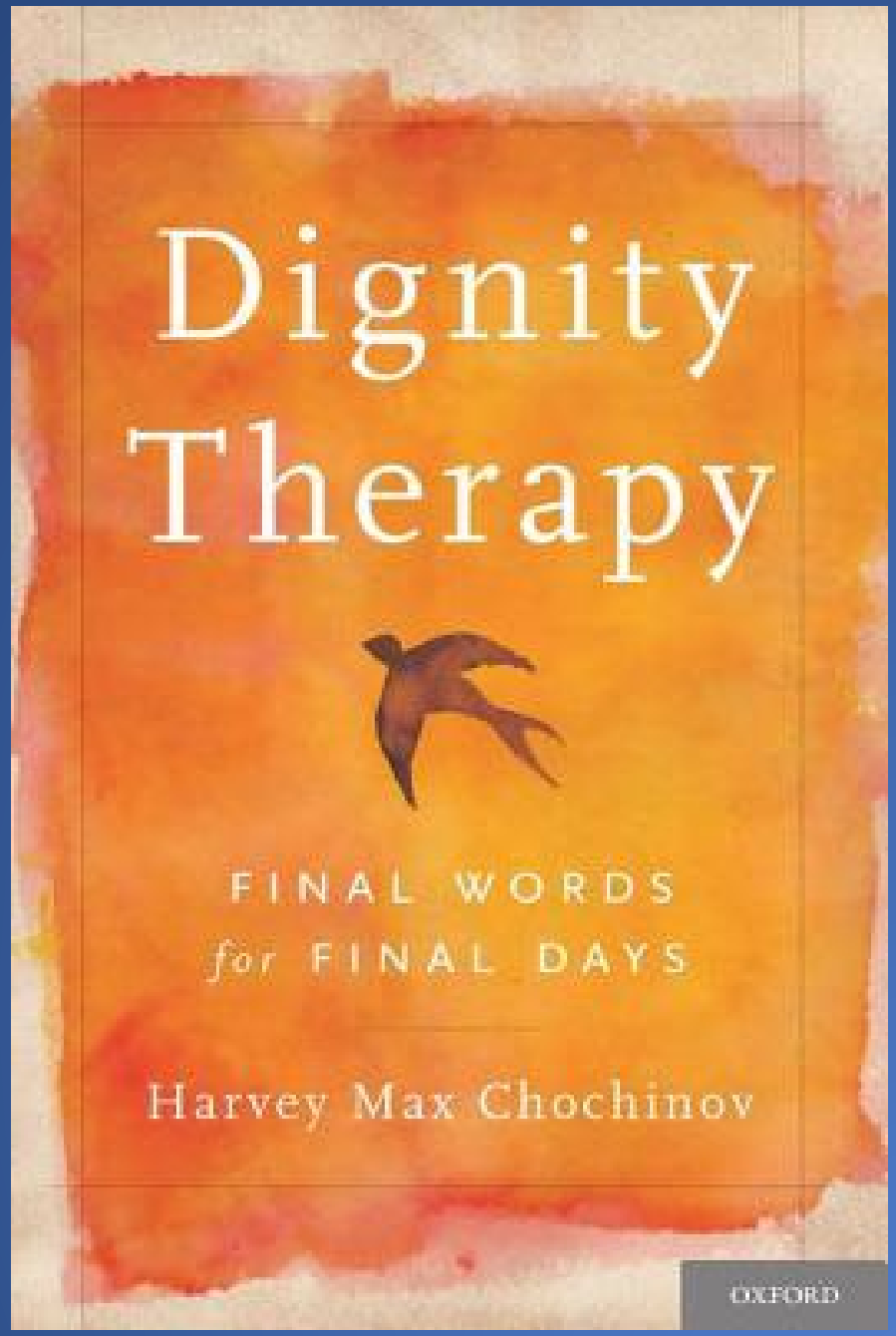


Chochinov et al. Social Science and Medicine 2002



Chochinov HM. Dignity-conserving care-a new model for palliative care. JAMA.2002





VOLUME 23 · NUMBER 24 · AUGUST 20 2005

JOURNAL OF CLINICAL ONCOLOGY | ORIGINAL REPORT

Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life

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

From the Department of Psychiatry, Family Medicine, Community Health Sciences, and Faculty of Nursing, University of Manitoba; Manitoba Palliative Care Research Unit and Patient and Family Support Services, CancerCare Manitoba; St Boniface General Hospital, Winnipeg, Manitoba, Canada; and Edith Cowan University, Perth, Australia.

Submitted December 15, 2004; accepted March 7, 2005.

Supported by the Cancer Council of Western Australia (L.J.K.) and grants from the American Foundation for Suicide Prevention and the National Cancer Institute of Canada, with funding from the Canadian Cancer Society. Dr Chochinov is a Canada Research Chair in palliative care, funded by the Canadian Institutes for Health Research.

This article reports original research; none of the results have been published previously, nor have they appeared in conference proceedings, abstracts, or reports. The outline of questions used for dignity therapy has appeared in *Journal of the American Medical Association* (Chochinov HM: Dignity-conserving care: A new model for palliative care. JAMA 287:2253-2260, 2002).

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

Address reprint requests to Harvey Max Chochinov, MD, PhD, CancerCare Manitoba Room, 3017-675 McDermot Ave, Winnipeg, Manitoba, Canada R3E 0V9; e-mail: harvey.chochinov@cancercare.mb.ca.

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

DOI: 10.1200/JCO.2005.08.391

ABSTRACT

Purpose
This study examined a novel intervention, dignity therapy, designed to address psychosocial and existential distress among terminally ill patients. Dignity therapy invites patients to discuss issues that matter most or that they would most want remembered. Sessions are transcribed and edited, with a returned final version that they can bequeath to a friend or family member. The objective of this study was to establish the feasibility of dignity therapy and determine its impact on various measures of psychosocial and existential distress.

Patients and Methods
Terminally ill inpatients and those receiving home-based palliative care services in Winnipeg, Canada, and Perth, Australia, were asked to complete pre- and postintervention measures of sense of dignity, depression, suffering, and hopelessness; sense of purpose, sense of meaning, desire for death, will to live, and suicidality; and a postintervention satisfaction survey.

Results
Ninety-one percent of participants reported being satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family. Postintervention measures of suffering showed significant improvement ($P = .023$) and reduced depressive symptoms ($P = .05$). Finding dignity therapy helpful to their family correlated with life feeling more meaningful ($r = 0.480$; $P = .000$) and having a sense of purpose ($r = 0.562$; $P = .000$), accompanied by a lessened sense of suffering ($r = 0.327$; $P = .001$) and increased will to live ($r = 0.387$; $P = .000$).

Conclusion
Dignity therapy shows promise as a novel therapeutic intervention for suffering and distress at the end of life.

J Clin Oncol 23:5520-5525. © 2005 by American Society of Clinical Oncology

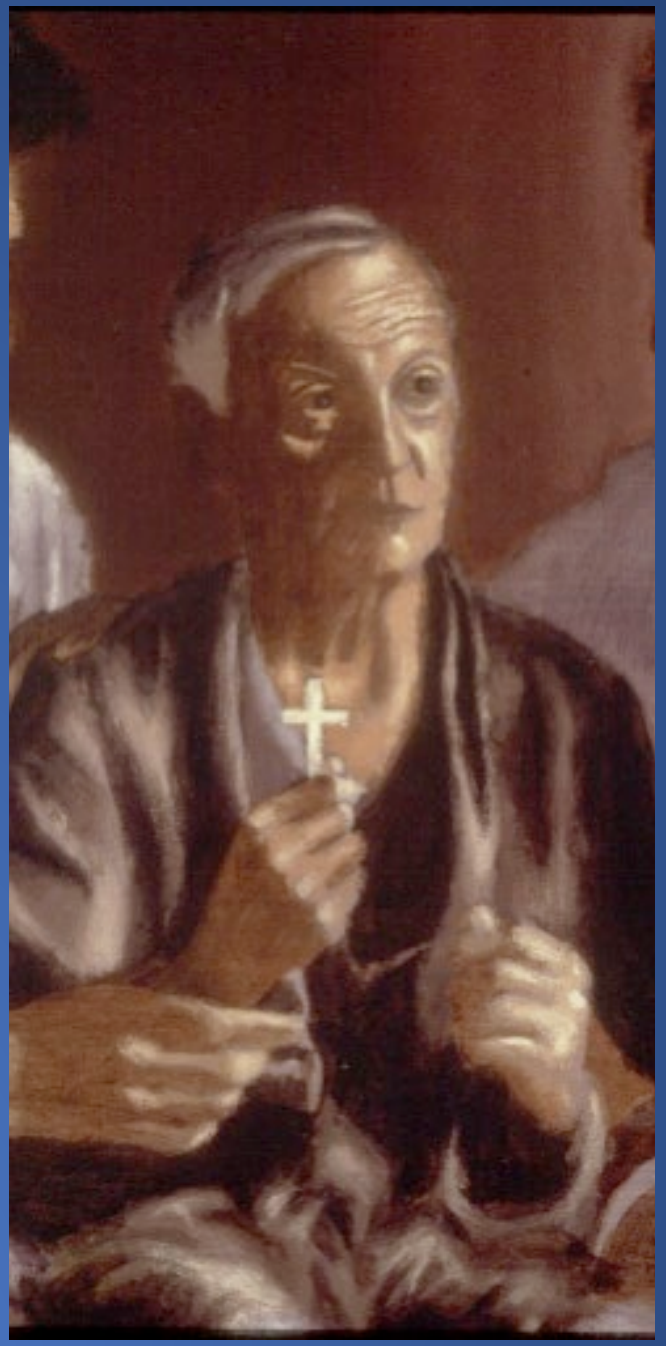
INTRODUCTION

One of the most confounding challenges faced by end-of-life care providers is helping patients achieve or maintain a sense of dignity. Our prior studies of dignity and end-of-life care have shown a strong association between an undermining of dignity and depression, anxiety, desire for death, hopelessness, feeling of being a burden on others, and overall poorer quality of life.[1-4] Yet, dying with dignity is usually only vaguely understood; hence, although the pursuit of dignity frequently underlies various approaches to end-of-life care, its therapeutic implications are frequently uncertain.

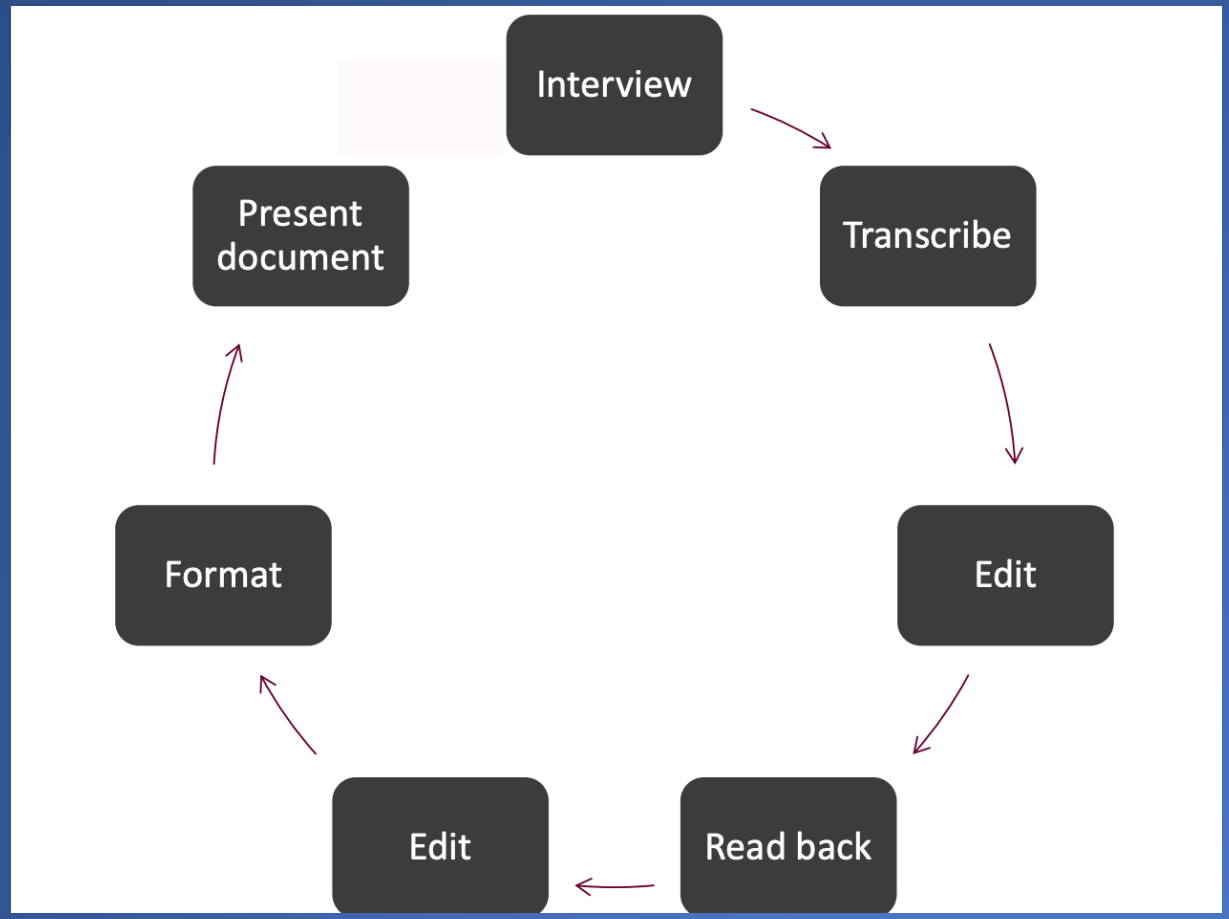
There is mounting evidence that suffering and distress are major issues facing dying patients. Some studies suggest that psychosocial and existential issues may be of even greater concern to patients than pain and physical symptoms.[5-7] The Institute of Medicine has identified overall quality of life and achieving a sense of spiritual peace and

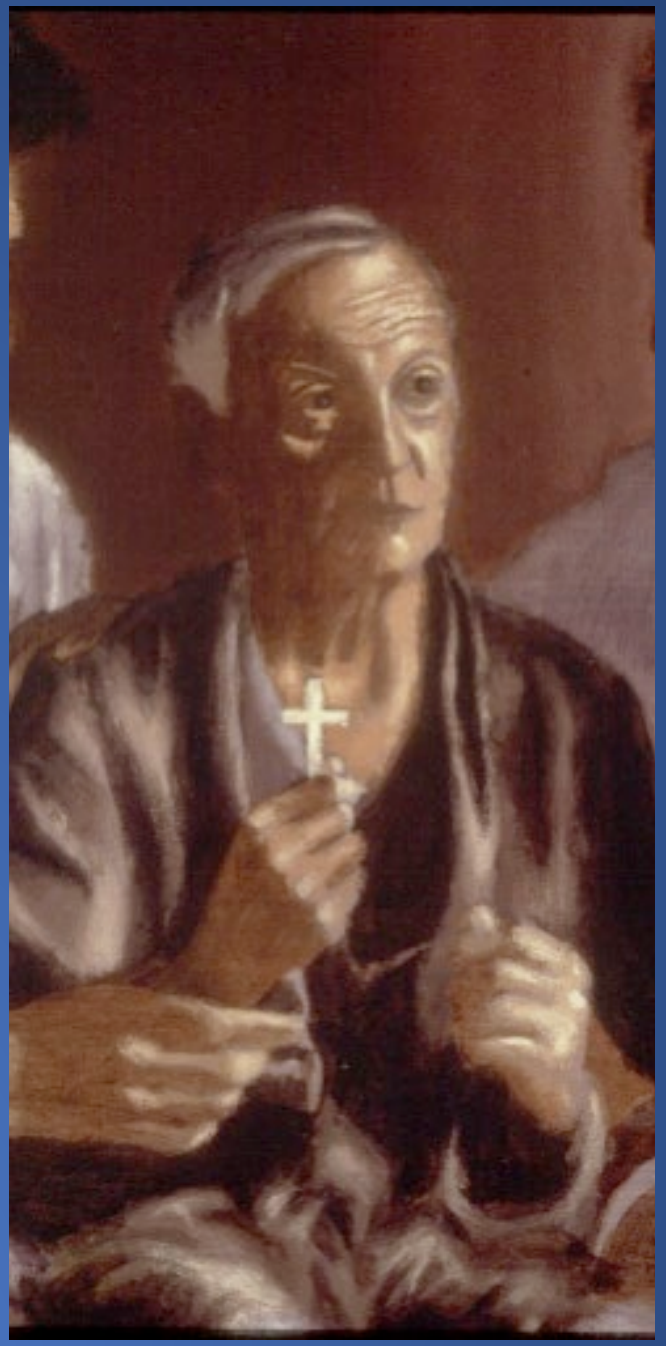
Dignity Therapy: Step by Step

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: Step by Step





Dignity therapy question protocol

1. Tell me a little bit about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?

2. 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?

3. 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?

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

5. 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?

6. What are your hopes and dreams for your loved ones?

7. 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)?

8. Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?

9. In creating this permanent record, are there other things that you would like to include?

SOURCE: M. MARTÍNEZ *ET AL* / *PALLIATIVE MEDICINE* 2016

KNOWABLE MAGAZINE

Dignity therapy uses this standard set of nine questions as a starting point for discussion. The questions invite the dying person to evaluate their life and offer their wisdom to family and friends.

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%

Chochinov HM, et al. Dignity Therapy: A novel psychotherapeutic intervention for patients nearing death. JCO 2005; 23:5520-5525.

Family Dignity Follow-up Data (n=60)

Question	**Percentage**
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%***

McClement S, Hack T, Chochinov HM et al. Dignity Therapy: Family Member Perspectives. Journal of Palliative Medicine. 2007;10:1076-82.

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 (χ^2=35·50, df=2; p<0·0001), improve quality of life (χ^2=14·52; p=0·001), increase sense of dignity (χ^2=12·66; p=0·002), change how their family saw and appreciated them (χ^2=33·81; p<0·0001), and be helpful to their family (χ^2=33·86; p<0·0001). Dignity therapy was significantly better than client-centred care in improving spiritual wellbeing (χ^2=10·35; p=0·006), and was significantly better than standard palliative care in terms of lessening sadness or depression (χ^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 (χ^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.[6] 78% of patients' family members reported that the therapy enhanced the patient's dignity, and 72% that it heightened the meaning of life for the patient; 78% said the document from the therapy session was a comfort to them in their time of grief, and 95% that they would recommend dignity therapy to other patients and their families.[7] We therefore investigated

Published Online July 7, 2011 DOI:10.1016/S1470-2045(11)70153-X

See Online/Comment DOI:10.1016/S1470-2045(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 3062, 675 McDermot Avenue, Winnipeg, Manitoba R3E 0V9, Canada harvey.chochinov@cancercare.mb.ca

Dignity Therapy Significantly Outperformed other Trial Arms on:

- Being helpful to me
- As helpful as other aspects of my care
- Improved quality of life
- Sense of looking after unfinished business'
- Improved spiritual well being
- Lessened sadness and depression
- Feeling I'm able to carry out an important role
- Feel like I am still me
- Was satisfactory to me
- Made me feel life was more meaningful
- Heightened my sense of purpose
- Increased my sense of dignity
- Has or will be helpful to my family

Dignity Therapy Data Overview

- Over 100 papers on Dignity Therapy
- ~ 25 papers reporting primary data analyses
- ~ 10 systematic reviews
- Participants with higher base rates of distress show significant differences on primary outcome measures (depression, anxiety, demoralization)
- Most trials report positive self-reported patient satisfaction (perceived heightened sense of dignity, meaning, hope, purpose, will to live, generativity)
- Death acceptance, non-life prolonging treatment goals and choices
- Benefits for their families

JOURNAL OF PALLIATIVE MEDICINE
Volume 0, Number 0, 2023
Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2023.0336

Original Article

Open camera or QR reader and scan code to access this article and other resources online.

Engaging Mortality: Effective Implementation of Dignity Therapy

Diana J. Wilkie, PhD, RN,[1] George Fitchett, DMin, PhD,[2] Yingwei Yao, PhD,[1] Tasha Schoppee, PhD, RN,[1,3] Marvin O. Delgado Guay, MD,[4] Joshua Hauser, MD,[5] Sheri Kittelson, MD,[6] Sean O'Mahony, MD,[7] Michael Rabow, MD,[8] Tammie Quest, MD,[9] Sheldon Solomon, PhD,[10] George Handzo, MDiv, MA,[11] Harvey Max Chochinov, MD, PhD,[12] and Linda L. Emanuel, MD, PhD[13]

Abstract

Background: Patients consider the life review intervention, Dignity Therapy (DT), beneficial to themselves and their families. However, DT has inconsistent effects on symptoms and lacks evidence of effects on spiritual/existential outcomes.

Objective: To compare usual outpatient palliative care and chaplain-led or nurse-led DT for effects on a quality-of-life outcome, dignity impact.

Design/Setting/Subjects: In a stepped-wedge trial, six sites in the United States transitioned from usual care to either chaplain-led or nurse-led DT in a random order. Of 638 eligible cancer patients (age ≥55 years), 579 (59% female, mean age 66.4 ± 7.4 years, 78% White, 61% stage 4 cancer) provided data for analysis.

Methods: Over six weeks, patients completed pretest/posttest measures, including the Dignity Impact Scale (DIS, ranges 7–35, low-high impact) and engaged in DT+usual care or usual care. They completed procedures in person (steps 1–3) or via Zoom (step 4 during pandemic). We used multiple imputation and regression analysis adjusting for pretest DIS, study site, and step.

Results: At pretest, mean DIS scores were 24.3 ± 4.3 and 25.9 ± 4.3 for the DT ($n = 317$) and usual care ($n = 262$) groups, respectively. Adjusting for pretest DIS scores, site, and step, the chaplain-led ($\beta = 1.7$, $p = 0.02$) and nurse-led ($\beta = 2.1$, $p = 0.005$) groups reported significantly higher posttest DIS scores than usual care. Adjusting for age, sex, race, education, and income, the effect on DIS scores remained significant for both DT groups.

Conclusion: Whether led by chaplains or nurses, DT improved dignity for outpatient palliative care patients with cancer. This rigorous trial of DT is a milestone in palliative care and spiritual health services research. Clinicaltrials.gov: NCT03209440.

Fitchett et al. BMC Palliative Care (2015) 14:8
DOI 10.1186/s12904-015-0007-1

BMC Palliative Care

RESEARCH ARTICLE Open Access

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

George Fitchett[1], Linda Emanuel[2*], George Handzo[3], Lara Boyken[2] and Diana J Wilkie[4]

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

JOURNAL OF SCHOOL OF NURSING USP
REVISTA DA ESCOLA DE ENFERMAGEM DA USP

ARTICLE REVIEW DOI: http://dx.doi.org/10.1590/S0080-623420160000700019

Effects of dignity therapy on terminally ill patients: a systematic review*

Efeitos da terapia da dignidade para pacientes em fase final de vida: revisão sistemática
Efectos de la terapia dignidad para pacientes en fase final de vida: revisión sistemática

Suzana Cristina Teixeira Donato[I], Jéssica Yumi Matuoka[II], Camila Cristófero Yamashita[I], Marina de Goés Salvetti[I]

How to cite this article:
Donato SCT, Matuoka JY, Yamashita CC, Salvetti MG. Effects of dignity therapy on terminally ill patients: a systematic review. Rev Esc Enferm USP. 2016;50(6):1011-1021. DOI: http://dx.doi.org/10.1590/S0080-623420160000700019

* Extracted from the concluding residency work "Efeitos da terapia da dignidade para pacientes em fase final de vida: revisão sistemática", Programa de Residência em Enfermagem na Saúde do Adulto e Idoso, Escola de Enfermagem/Hospital Universitário, Universidade de São Paulo, 2016.

[I] Universidade de São Paulo, Escola de Enfermagem, São Paulo, SP, Brasil.
[II] Universidade de São Paulo, Escola de Enfermagem, Programa de Pós-Graduação em Saúde do Adulto, São Paulo, SP, Brasil.
[III] Instituto do Câncer do Estado
Cuidados
Brasil.
ão, Escola de
nto de Enfermagem
aulo, SP, Brasil.

ABSTRACT

Objective: Analyzing the evidence of the effects of dignity therapy on terminally ill patients. **Method:** A Systematic review of the literature conducted using the search strategy in six databases. Inclusion criteria were primary studies, excluding literature reviews (systematic or not) and conceptual articles. **Results:** Ten articles were analyzed regarding method, results and evidence level. Dignity therapy improved the sense of meaning and purpose, will to live, utility, quality of life, dignity and family appreciation in studies with a higher level of evidence. The effects are not well established in relation to depression, anxiety, spirituality and physical symptoms. **Conclusion:** Studies with a moderate to high level of evidence have shown increased sense of dignity, will to live and sense of purpose. Further studies should be developed to increase knowledge about dignity therapy.

DESCRIPTORS

Palliative Care; Terminally Ill; Psychotherapy, Brief; Quality of Life; Holistic Nursing; Review.

Meta-Analysis > Depress Anxiety. 2020 Mar;37(3):234-246. doi: 10.1002/da.22980. Epub 2019 Dec 6.

Effectiveness of dignity therapy for patients with advanced cancer: A systematic review and meta-analysis of 10 randomized controlled trials

Yanfei Li [1 2], Xiuxia Li [1 2], Liangying Hou [1 2], Liujiao Cao [1 2], Guanghua Liu [1 3], Kehu Yang [1 2 4]

Affiliations + expand

PMID: 31808977 DOI: 10.1002/da.22980

Abstract

Background: Dignity is a vitally important aspect of the lives of advanced cancer patients. We conducted a systematic review and meta-analysis of the effectiveness of dignity therap in this patient population.

Methods: We searched for randomized controlled trials comparing dignity therapy versus standard care for patients with advanced cancer in five comprehensive databases (March 2019), two clinical trial registries and one gray literature database (August 2019). The quali of the studies was assessed using the risk of bias tool recommended by the Cochrane Handbook Version 5.1.0. We used GRADE approach to assess the certainty of evidence. Me analysis was depression, d

Check for updates

Research Article

Dignity Therapy for End-of-Life Care Patients: A Literature Review

Journal of Patient Experience
Volume 8: 1-12
© The Author(s) 2021
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/23743735211996951
journals.sagepub.com/home/jpx
SAGE

Pearl Ed Cuevas, PhD[1], Patricia Davidson, PhD, MEd[2], Joylyn Mejilla, MAN, RN[1], and Tamar Rodney, PhD[2]

Abstract

Dignity therapy as an intervention has been used for individuals receiving palliative care. The goal of this review is to explore the current state of empirical support to its use for end-of-life care patients. Data sources were articles extracted from search engines PubMed, Cochrane, Embase, CINAHL, Web of Science, and PsycINFO. The years searched were 2009 to 2019 (10-year period). The review process was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses. Results revealed the feasibility, acceptability, satisfaction, and effectiveness of dignity therapy for life-limiting cases/conditions of patients in different age groups. It also highlighted the importance of the therapy setting and the need to apply this in the cultural context. The meaning of dignity therapy to patients and their family care members also emerged. Findings showed most patients displayed the need to leave a legacy and from this their core values surfaced. In conclusion, this review highlighted the contribution of dignity therapy to the holistic care of patients who hope to leave a legacy. The therapy was also relevant to decrease the anxiety; depression, and burden of family members throughout the palliative care period of their loved ones.

Keywords
dignity, dignity therapy, end-of-life care, palliative care

Background/ Introduction

Dignity therapy was first developed as a way to assist patients in dealing with the approach to end of life (1). This intervention helped to conserve the dying patient's dignity by addressing the sources of psychosocial and existential distress. It gave patients a chance to record the meaningful therapeutic part was when the patient would be asked a series of questions about parts of their life that they remember the most and are most important about their life story. Answers to this were transcribed and returned to them for editing, going back and forth with the therapist for a polished documented result. This result can be given to their significant

Review Article

PALLIATIVE MEDICINE

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

Palliative Medicine
2017, Vol. 31(6) 492–509
© The Author(s) 2016
DOI:
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
journals.sagepub.com/home/pmj
SAGE

Marina Martínez[1,2,3], María Arantzamendi[2,3], Alazne Belar[2,4], José Miguel Carrasco[2,3], Ana Carvajal[1,3,5], María Rullán[2,4] and Carlos Centeno[1,2,3]

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.

Aim: 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 synthesised, 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 randomised 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. Non-randomised studies suggested statistically significant improvements in existential and psychosocial measurements. Patients, relatives and professionals perceived it improved end-of-life experience.

Conclusion: Evidence suggests that dignity therapy is beneficial. One randomised 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 most 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.

[1]Clínica Universidad de Navarra, Servicio de Cuidados Paliativos, Avenida Pío XII, 31080, Pamplona, España
[2]Universidad de Navarra, ICS, ATLANTES, Campus Universitario, 31080, Pamplona, España
[3]IdiSNA, Instituto de Investigación Sanitaria de Navarra, Pamplona, España
[4]Hospital Alto Mesmi, Arrosadia-Mendebaldea, España
[5]Departamento de Enfermería de la Persona Adulta, Facultad de Enfermería, Universidad de Navarra, Pamplona, España
[6]Complejo 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: marantz@unav.es

Meta-Analysis > Psychooncology. 2019 Sep;28(9):1791-1802. doi: 10.1002/pon.5162. Epub 2019 Jul 9.

Effects of dignity therapy on dignity, psychological well-being, and quality of life among palliative care cancer patients: A systematic review and meta-analysis

Jinnan Xiao [1], Ka Ming Chow [1], Yunhong Liu [1], Carmen W H Chan [1]

Affiliations + expand

PMID: 31243850 DOI: 10.1002/pon.5162

Abstract

Objectives: The review aims to identify available evidence related to the effects of dignity therapy on dignity, psychological well-being, and quality of life (QoL) among patients with cancer under palliative care.

Methods: Thirteen electronic databases were searched for published articles in English or Chinese from inception to May 2018. Methodological rigour was assessed through the Joann Briggs Institute (JBI) checklist for randomised controlled trials and quasi-experimental studies. Sufficient data from four trials were statistically pooled with Review Manager; otherwise, a narrative summary was used.

Results: Ten articles describing eight studies met the selection criteria and were included in the review. None of the studies met all JBI checklist criteria. Meta-analysis results revealed that dignity therapy significantly improved dignity-related distress in existential distress domain (mean differences [MD]: -0.26, 95% CI, -0.50 to -0.02, .03) and social support domain (MD: -0.23, 95% CI, -0.39 to -0.07, .004), but nonsignificant improved depression an anxiety. Narrative summaries indicated that dignity therapy exerted positive effects on patients' dignity, psychological well-being, and QoL.

Conclusions: Dignity therapy is a promising approach to improve psychological well-being among patients with cancer under palliative care. However, the effects of dignity therapy on dignity and QoL are inconsistent. Further extensive studies should measure the impact of dignity therapy through qualitative and quantitative approaches to establish outcomes in psychological well-being. Studies with sensitivity to the cultural context within which dignity therapy applied should be conducted to explore its effects on patients with cancer at the early stages of illness trajectory.

Keywords: cancer; dignity model; dignity therapy; oncology; palliative care; quality of life; systematic review.

REVIEW • Rev. esc. enferm. USP 50 (06) • Nov-Dec 2016 • https://doi.org/10.1590/S0080-623420160000700019 COPY

Effects of dignity therapy on terminally ill patients: a systematic review*

Efectos de la Terapia Dignidad Para Pacientes en Fase Final de Vida: Revisión Sistemática

Suzana Cristina Teixeira Donato Jéssica Yumi Matuoka Camila Cristófero Yamashita Marina de Goés Salvetti

ABOUT THE AUTHORS

Abstract

OBJECTIVE

Analyzing the evidence of the effects of dignity therapy onterminally ill patients.

METHOD

A Systematic review of the literature conducted using the search strategy in six databases. Inclusion criteria were primary studies, excluding literature reviews (systematic or not) and conceptual articles.

RESULTS

Ten articles were analyzed regarding method, results and evidence level. Dignity therapy improved the sense of meaning andpurpose, will to live, utility, quality of life, dignity and family appreciationin studies with a higher level of evidence. The effects are not well established in relation to depression, anxiety, spirituality and physical symptoms.

CONCLUSION

Studies with a moderate to high level of evidence have shown increased sense of dignity, will to live and sense of purpose. Further studies should be developed to increase knowledge about dignity therapy.

Descriptors
Palliative Care; Terminally Ill; Psychotherapy, Brief;Quality of Life; Holistic Nursing; Review

behavioral sciences

MDPI

Article

The Value of Dignity in Prison: A Qualitative Study with Life Convicts

Ines Testoni [1,2,*], Francesca Marrella [1], Gianmarco Biancalani [1], Paolo Cottone [1], Francesca Alemanno [3], David Mamo [4] and Luigi Grassi [5]

1 Department of Philosophy, Sociology, Education and Applied Psychology (FISPPA), University of Padova, 35122 Padova, Italy; francescamarrella@outlook.it (F.M.); gianmarco.biancalani@unipd.it (G.B.); paolo.cottone@unipd.it (P.C.)
2 Emili Sagol Creative Arts Therapies Research Center, University of Haifa, Haifa 3498838, Israel
3 European and Mediterranean Cultures (DiCEM) Department, University of Basilicata, 85100 Potenza, Italy; francesca.alemanno@unibas.it
4 General Adult & Geriatric Psychiatry, Faculty of Medicine, University of Malta, 2080 Msida MSD, Malta; david.mamo1@gmail.com
5 Institute of Psychiatry, Department of Biomedical and Specialty Surgical Sciences—Università di Ferrara, 44121 Ferrara, Italy; luigi.grassi@unife.it
* Correspondence: ines.testoni@unipd.it; Tel.: +39-049-827-6646

Received: 11 April 2020; Accepted: 26 May 2020; Published: 28 May 2020

check for updates

Abstract: Background: This research is based on the perspective of dignity according to Chochinov; thus, the life imprisonment of detainees is assimilated to a severe disease. Methods: Ten male prisoners were interviewed trough Chochinov's Dignity Therapy, and the results were analysed using thematic analysis. Results: Two areas of thematic prevalence emerged, namely, value of freedom, self-consciousness and education and their failure in jail, and life sentence as annihilation of life meaning and of the values of generativity and family. Conclusions: Life imprisonment has been described in its negativity by several respondents as a punishment worse than the death penalty. It has been compared to death itself, to a terminal illness, to torture and to a pain that grows over the years, with the awareness that despite the passing of time, you will not have the opportunity to return to your loved one and to a free life. In fact, prisoners live out their condition within a space in which any value that gives meaning to life risks being destroyed.

Keywords: dignity; prisoners; men; life sentence; personal values

1. Introduction

Life imprisonment is the punishment of being put in prison without any release arrangements or until death. The Grand Chamber of the European Court of Human Rights (ECHR) affirmed that the very essence of the ECHR is to recognise and protect human dignity [1]. In relation to prisoners sentenced for life, this involves providing a realistic possibility of release [2,3]. In keeping with this, the European Prison Rules underlined that prison regimes should be designed to enable all sentenced prisoners to lead a responsible and crime-free life [4]. The ECHR has emphasised the importance of giving every offender the opportunity to rehabilitate whilst serving his/her sentence, with the prospect of eventually functioning as a responsible member of free society [2]. According to Shannon [5], dignity is a quality or state of being worthy, honoured or esteemed, and it is 'realized through individual freedom that is brought to bear in the course of the self's participation in meaningful decision making and exercise of individual responsibility' [5] (p. 17).

The concept of dignity has been used in many human studies. In philosophy, the concept of dignity and respect of person is highlighted in the second categorical imperative theorised by Kant:

Received: 15 October 2021 Revised: 12 February 2022 Accepted: 24 February 2022

DOI: 10.1002/pon.5913

CLINICAL CORRESPONDENCE

WILEY

A comparison of Dignity Therapy narratives among people with severe mental illness and people with cancer

Luigi Grassi[1] | Maria Giulia Nanni[1] | Rosangela Caruso[1] | Heifa Ounalli[1] | Harvey M. Chochinov[2,3] | Bruno Biancosino[4] | Ines Testoni[5,6] | Martino Belvederi Murri[1] | Tatiana Bertelli[7] | Laura Palagini[1] | Silvia De Padova[7] | Elisa Tiberto[1]

[1]Institute of Psychiatry, Department of Neuroscience and Rehabilitation, University of Ferrara, Ferrara, Italy

[2]Department of Psychiatry, University of Manitoba, Winnipeg, Manitoba, Canada

[3]CancerCare Manitoba Research Institute, CancerCare Manitoba, Winnipeg, Manitoba, Canada

[4]Integrated Department of Mental Health and Pathological Addictions, Ferrara Local Health Trust, Ferrara, Italy

[5]Department of Philosophy. Sociology, Pedagogy and Applied Psychology (FISPPA) University of Padua, Padova, Italy

[6]Emili Sagol Creative Arts Therapies Research Center, University of Haifa, Haifa, Israel

[7]Psycho-Oncology Unit, Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori "Dino Amadori" (IRST), IRCCS, Meldola, Italy

Correspondence
Luigi Grassi, Institute of Psychiatry, University of Ferrara Via Fossato di Mortara 64a - 44121, Ferrara, Italy.
Email: luigi.grassi@unife.it

Funding information
Università degli Studi di Ferrara

Abstract

Objective: To examine Dignity Therapy (DT) narratives in patients with severe mental illness (SMI) and a control group of cancer patients.

Methods: 12 patients with SMI (schizophrenia, bipolar disorders, sever personality disorders) and 12 patients with non-advanced cancer individually participated to DT interviews. DT was tape-recorded, transcribed verbatim and shaped into a narrative through a preliminary editing process. A session was dedicated to the final editing process along with the participant, with a final written legacy (generativity document) provided to the participant. Interpretative Phenomenological Analysis was used to qualitatively analyze the generativity documents.

Results: Patients with SMI and patients with cancer presented similar main narrative categories relative to dignity, such as "Meaning making", "Resources", "Legacy", "Dignity"; in addition, inpatients with SMI "Stigma" and inpatients with cancer "Injustice" emerged as separate categories. Patients in both groups strongly appreciated DT as an opportunity to reflect on their life story and legacy.

Conclusions: The study showed that DT is a valuable intervention for people with SMI, grounded in a practical, person-centered approach. All patients found DT as an opportunity to describe their past and present, highlighting changes in the way they relate to themselves and others. These results can guide implementation of DT in mental health settings for people with SMI, as it is for people with cancer.

KEYWORDS
bipolar disorders, cancer, Dignity Therapy, psycho-oncology, schizophrenia

Key points

- This study analyzed the narratives in patients with severe mental illness (SMI) and a control group of cancer patients
- All patients completed Dignity Therapy (DT), including creating a generativity document
- Patients with SMI and patients with cancer presented similar main narrative categories relative to dignity, such as "Meaning making", "Resources", "Legacy", "Dignity"; in addition, patients with SMI included "Stigma" and patients with cancer "Injustice"
- Results can guide implementation of DT in mental health settings for people with SMI

International Journal of Older People Nursing

ORIGINAL ARTICLE

Living well with dementia: enhancing dignity and quality of life, using a novel intervention, Dignity Therapy

Bridget Johnston BN (Hons), RGN, PGCE(FE), PhD
Professor, Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care, The University of Nottingham, Nottingham, UK

Sally Lawton RGN, NDN cert, RCNT, RDNT, MA, PhD, LLM
Senior Lecturer and Honorary Professor, NHS Grampian and Robert Gordon University, Aberdeen, UK

Catriona McCaw BSc, RMN
Clinical Studies Officer, Scottish Dementia Clinical Research Network, Murray Royal Hospital, Perth, UK

Emma Law RN, MPH
Scottish Dementia Clinical Research Network manager, Scottish Dementia Clinical Research Network, Murray Royal Hospital, Perth, UK

Joyce Murray RGN, SCM
Early Stage Dementia Co-ordinator, Angus Council Social Work and Health, Angus, UK

John Gibb RMN
Post Diagnostic Dementia Practitioner, Community Mental Health Team, NHS Tayside, Angus, UK

Jan Pringle RGN, BSc (Hons), PhD
Research fellow, School of Nursing and Midwifery, University of Dundee, Dundee, UK and University of Nottingham, Nottingham, UK

Gillian Munro BSc, BD
Head of Spiritual Care, Wellbeing Centre, NHS Tayside, Royal Victoria Hospital, Dundee, UK

Cesar Rodriguez MD
Associate Medical Director (Older People), Consultant in Old Age Psychiatry, NHS Tayside Angus, Angus, UK

Submitted for publication: 12 January 2015
Accepted for publication: 7 October 2015

Correspondence:
Bridget Johnston
Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care, The University of Nottingham, Nottingham, UK and Queen's Medical Centre, Nottingham, UK
Telephone: +44 0 115 823 08 17
E-mail: Bridget.Johnston@nottingham.ac.uk

JOHNSTON B., LAWTON S., MCCAW C., LAW E., MURRAY J., GIBB J., PRINGLE J., MUNRO G., RODRIGUEZ C. (2016) Living well with dementia: enhancing dignity and quality of life, using a novel intervention, Dignity Therapy. *International Journal of Older People Nursing* **11**, 107–120. doi: 10.1111/opn.12103

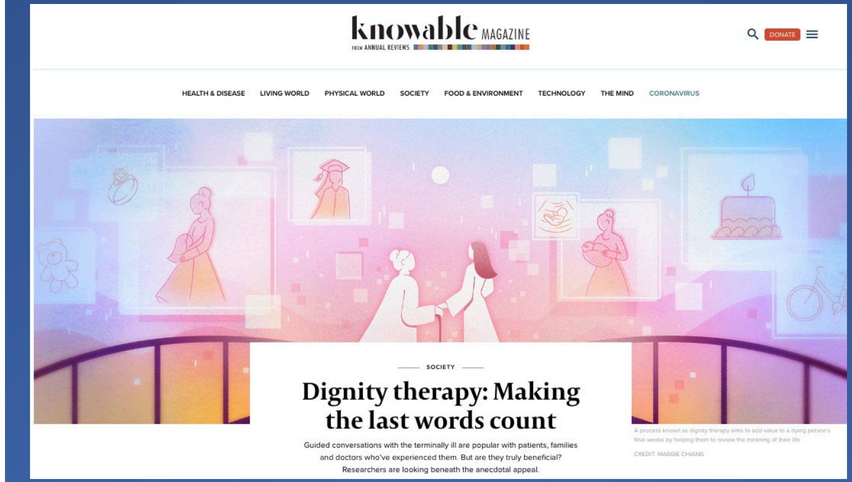
Aims and objectives. To assess the feasibility, acceptability and potential effectiveness of Dignity Therapy to improve the quality of life and reduce psychological and spiritual distress in older people with early stage dementia.
Background. Dementia is a syndrome with several causes that leads to a progressive decline in multiple areas of functioning. The maintenance of dignity and enhancement of

38 weekend extra

The final chapter

A Geelong program is helping the terminally ill to die with dignity, knowing their story will live on after their death, writes MANDY SQUIRES

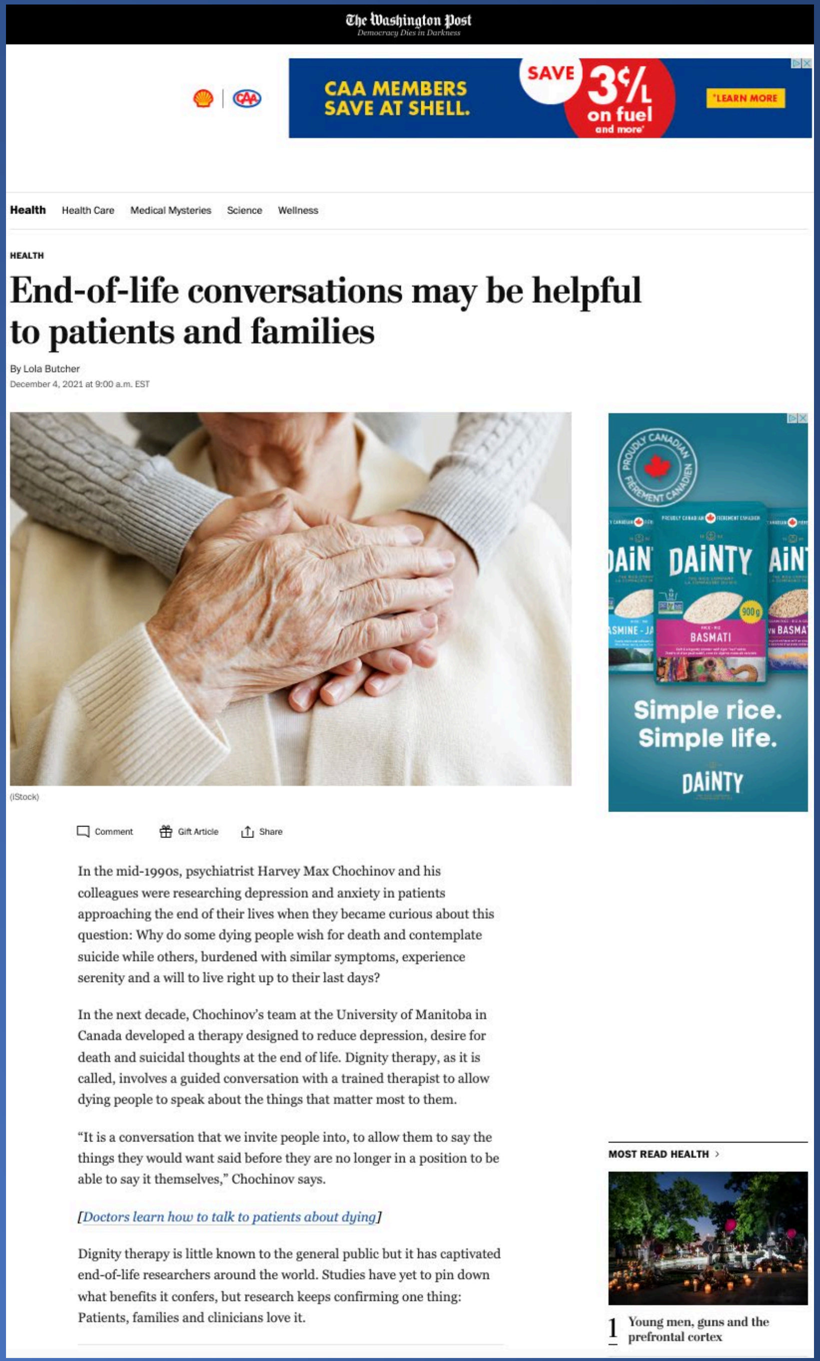
"God, I think it's so unfair. I get the most beautiful little girl and then I'm not going to be able to be around her. I know I'll watch over her, and I will. I won't let her out of my sight.



SOCIETY

Dignity therapy: Making the last words count

Guided conversations with the terminally ill are popular with patients, families and doctors who've experienced them. But are they truly beneficial? Researchers are looking beneath the anecdotal appeal.



HEALTH

End-of-life conversations may be helpful to patients and families

By Lola Butcher
December 4, 2021 at 9:00 a.m. EST

(iStock)

In the mid-1990s, psychiatrist Harvey Max Chochinov and his colleagues were researching depression and anxiety in patients approaching the end of their lives when they became curious about this question: Why do some dying people wish for death and contemplate suicide while others, burdened with similar symptoms, experience serenity and a will to live right up to their last days?

In the next decade, Chochinov's team at the University of Manitoba in Canada developed a therapy designed to reduce depression, desire for death and suicidal thoughts at the end of life. Dignity therapy, as it is called, involves a guided conversation with a trained therapist to allow dying people to speak about the things that matter most to them.

"It is a conversation that we invite people into, to allow them to say the things they would want said before they are no longer in a position to be able to say it themselves," Chochinov says.

[*Doctors learn how to talk to patients about dying*]

Dignity therapy is little known to the general public but it has captivated end-of-life researchers around the world. Studies have yet to pin down what benefits it confers, but research keeps confirming one thing: Patients, families and clinicians love it.

MOST READ HEALTH

1 Young men, guns and the prefrontal cortex

Harvey.chochinov@cancercare.mb.ca

#dignityincare22

Twitter: @HMChochinov

LinkedIn: Harvey Max Chochinov

DignityinCare.ca

VirtualHospice.ca