The Platinum Rule

All that Glitters Isn't Gold

Palliative Care - Canada

BY

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Host and Moderator: Diana Vincze, Pallium Canada

Guest Speaker: Harvey Max Chochinov OC OM MD PhD FRCPC FRSC

Date: November 3rd, 2022

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Introductions

Host and Moderator

Diana Vincze, Palliative Care ECHO Project Manager
Pallium Canada

Guest Speaker

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

Conflict of Interest

Pallium Canada

- Non-profit
- Partially funded through a contribution by Health Canada
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Host/ Guest Speaker

- Diana Vincze: Nothing to disclose
- Harvey Chochinov: Nothing to disclose

Welcome and Reminders

- For comments, please use the chat function
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- This session is being recorded—this recording and slide deck will be emailed to registrants within the next week.

The Platinum Rule

All that Glitters Isn’t Gold

The Platinum Rule

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

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

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%)

Chochinov et al. Lancet. 1999;354:816-9

Intact versus Fracture Sense of Dignity

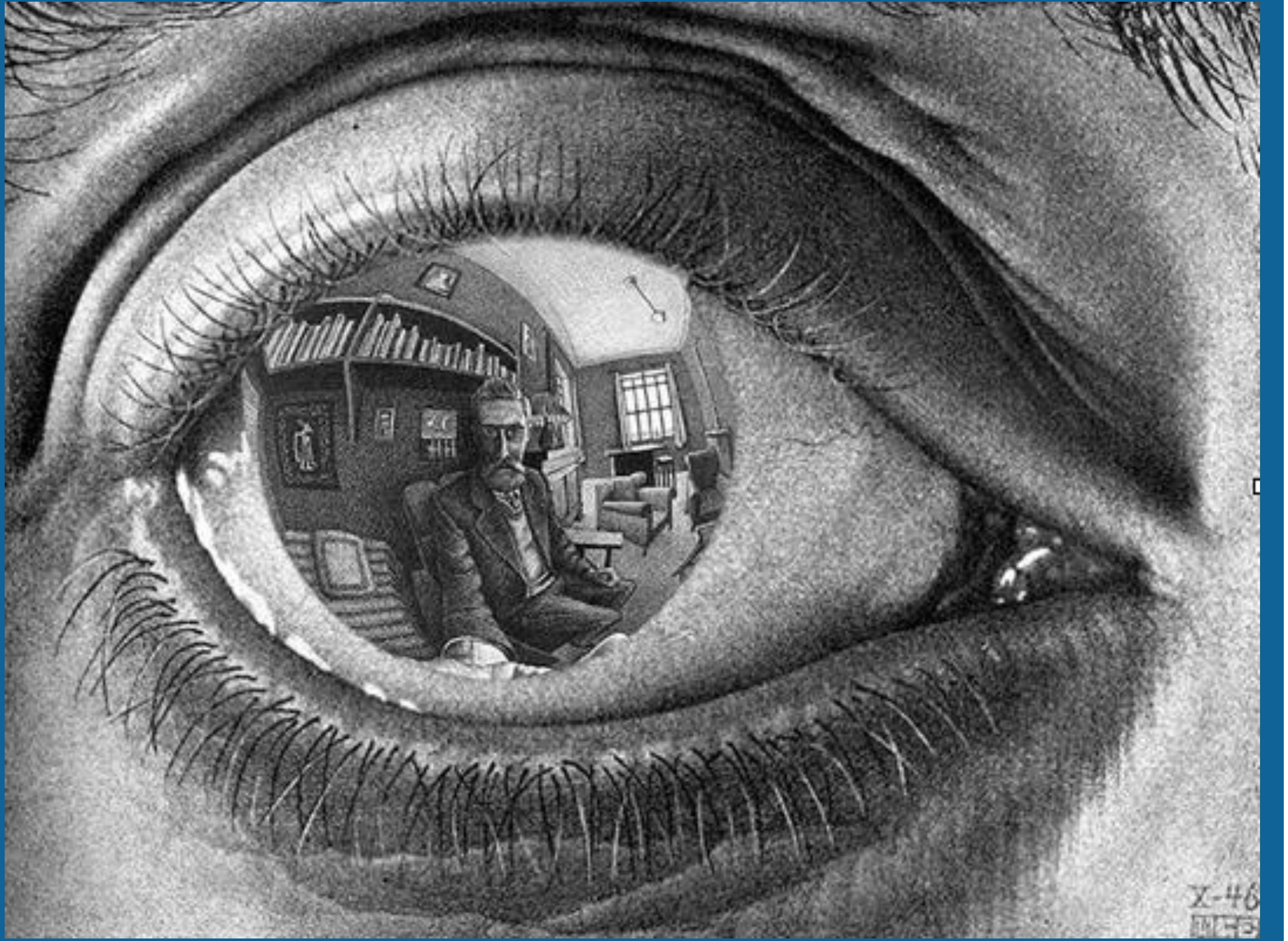
- Desire for death ($p < 0.0014$)
- Loss of will to live ($p < 0.013$)
- Depression ($p < 0.0084$)
- Hopelessness ($p < 0.020$)
- Anxiety ($p < 0.003$)

Chochinov et al. Lancet. 1999;354:816-9

Intact versus Fracture Sense of Dignity

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

Chochinov et al. Lancet. 1999;354:8169



VOLUME 22 · NUMBER 7 · APRIL 1 2004

JOURNAL OF CLINICAL ONCOLOGY

THE ART OF ONCOLOGY:
When the Tumor Is Not the Target

Dignity and the Eye of the Beholder

Harvey Max Chochinov

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

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

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

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

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Here's the Case

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

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

The Wish to Die

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

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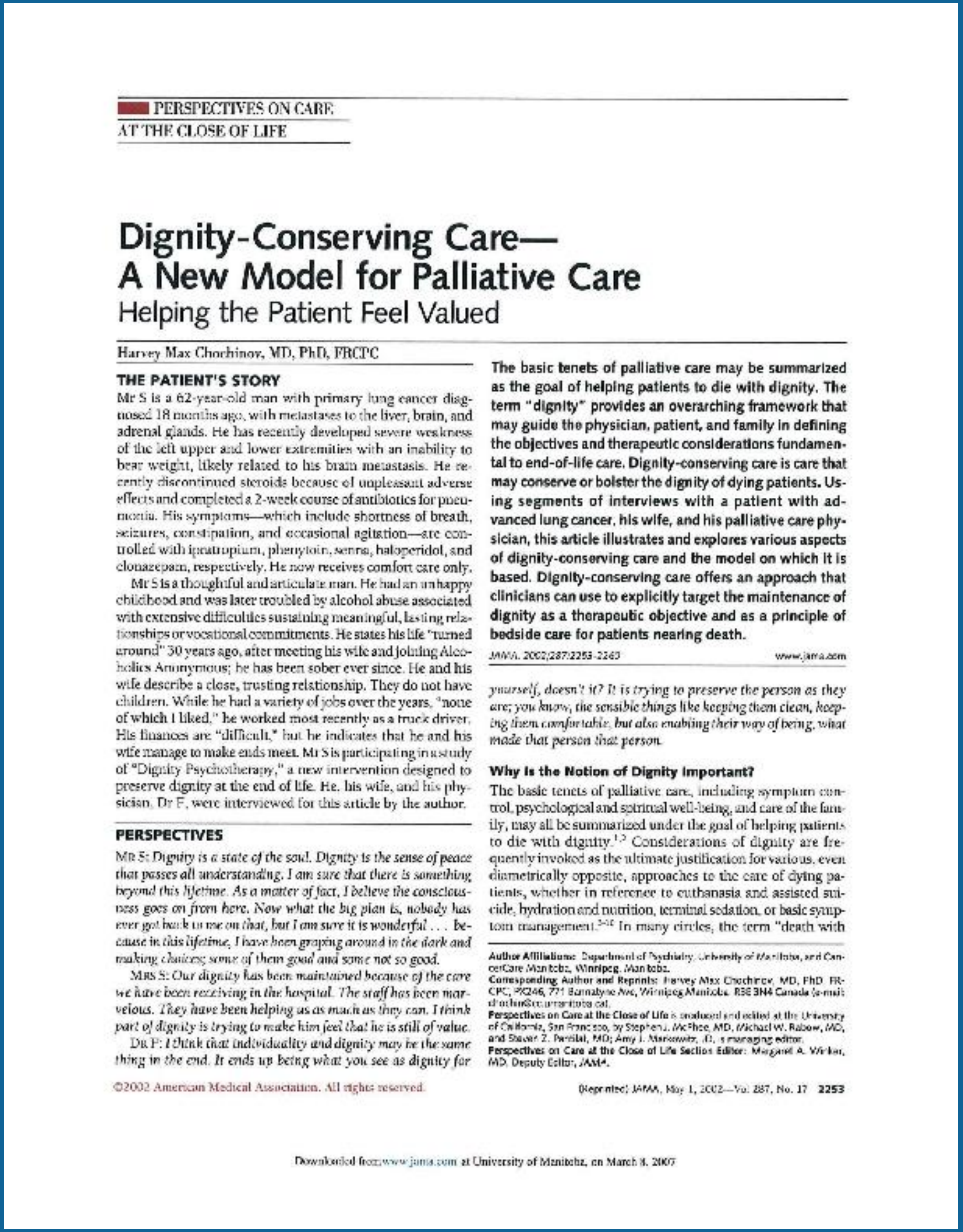

PERSPECTIVES ON CARE
AT THE CLOSE OF LIFE

Dignity-Conserving Care—A New Model for Palliative Care

Helping the Patient Feel Valued

Harvey Max Chochinov, MD, PhD, FRCPC

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

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

THE PATIENT'S STORY

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

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

PERSPECTIVES

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

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

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

Why Is the Notion of Dignity Important?

The basic tenets of palliative care, including symptom control, psychological and spiritual well-being, and care of the family, may all be summarized under the goal of helping patients to die with dignity.[1,2] Considerations of dignity are frequently invoked as the ultimate justification for various, even diametrically opposite, approaches to the care of dying patients, whether in reference to euthanasia and assisted suicide, hydration and nutrition, terminal sedation, or basic symptom management.[3-16] In many circles, the term "death with

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

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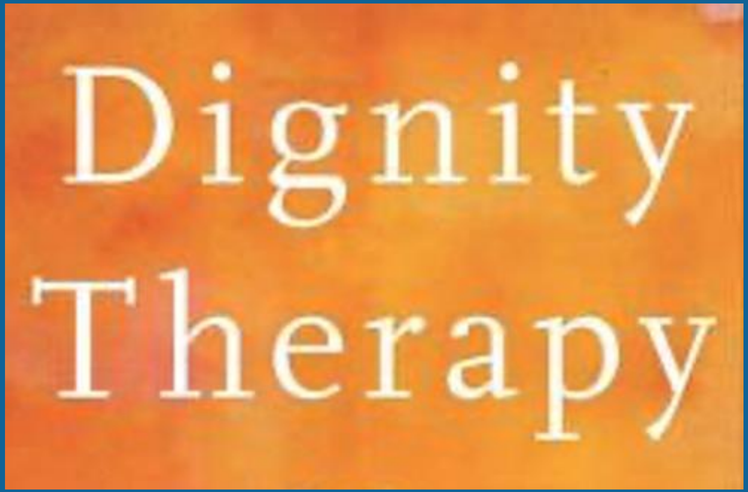

VOLUME 23 · NUMBER 24 · AUGUST 20 2005

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.

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

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.

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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

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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

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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[1], Jéssica Yumi Matuoka[2], Camila Cristófero Yamashita[3], Marina de Goés Salvetti[4]

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

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.

* 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.

[1] Universidade de São Paulo, Escola de Enfermagem, São Paulo, SP, Brazil.

[2] Universidade de São Paulo, Escola de Enfermagem, Programa de Pós-Graduação em Saúde do Adulto, São Paulo, SP, Brazil.

[3] Instituto do Câncer do Estado
Cuidados
Brazil.

ulo, Escola de
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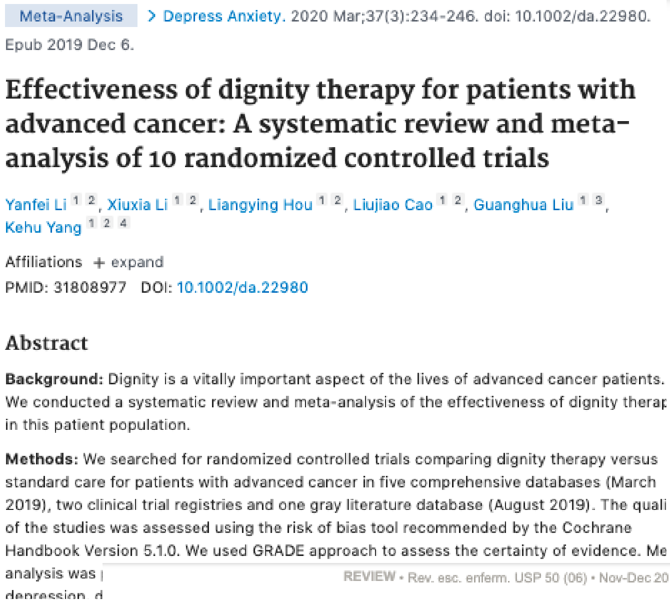
aulo, SP, Brazil.



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

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Check for updates

Research Article

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

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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 others, family, and friends. With the end goal of alleviating

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PALLIATIVE MEDICINE

Review Article

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

Palliative Medicine
2017, Vol. 31(6) 492–509
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Marina Martinez[1,2,3], María Arantzamendi[2,3], Alazne Belar[2,4], José Miguel Carrasco[2,3], Ana Carvajal[2,3,5], 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. Nonrandomised 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?

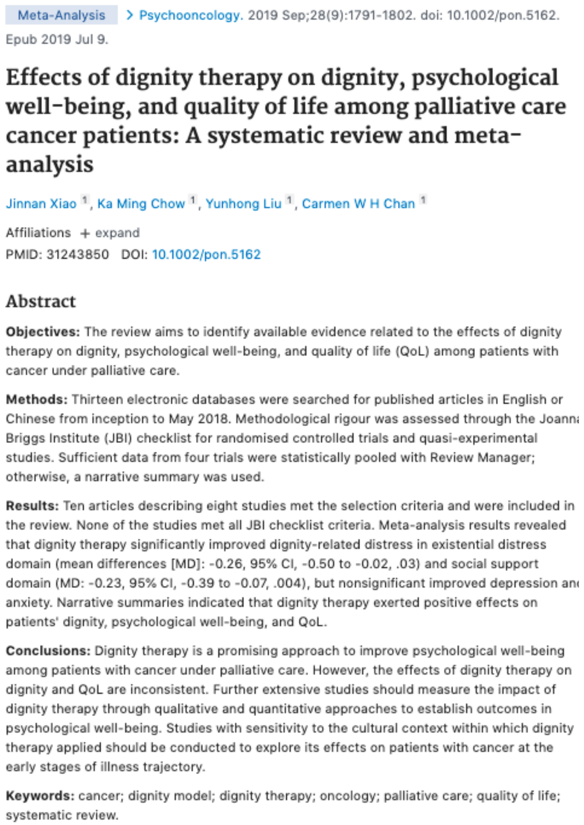
- DT was recently developed to relieve psychological and existential distress in patients at end of life. Originally was conceived for patients with low levels of distress.
- DT seems to affect several dimensions of patients but the process and the way of measuring the impact of the intervention are 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, 31008, 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 Deba, Arrasate-Mondragón, 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 Joanna 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 anc 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.

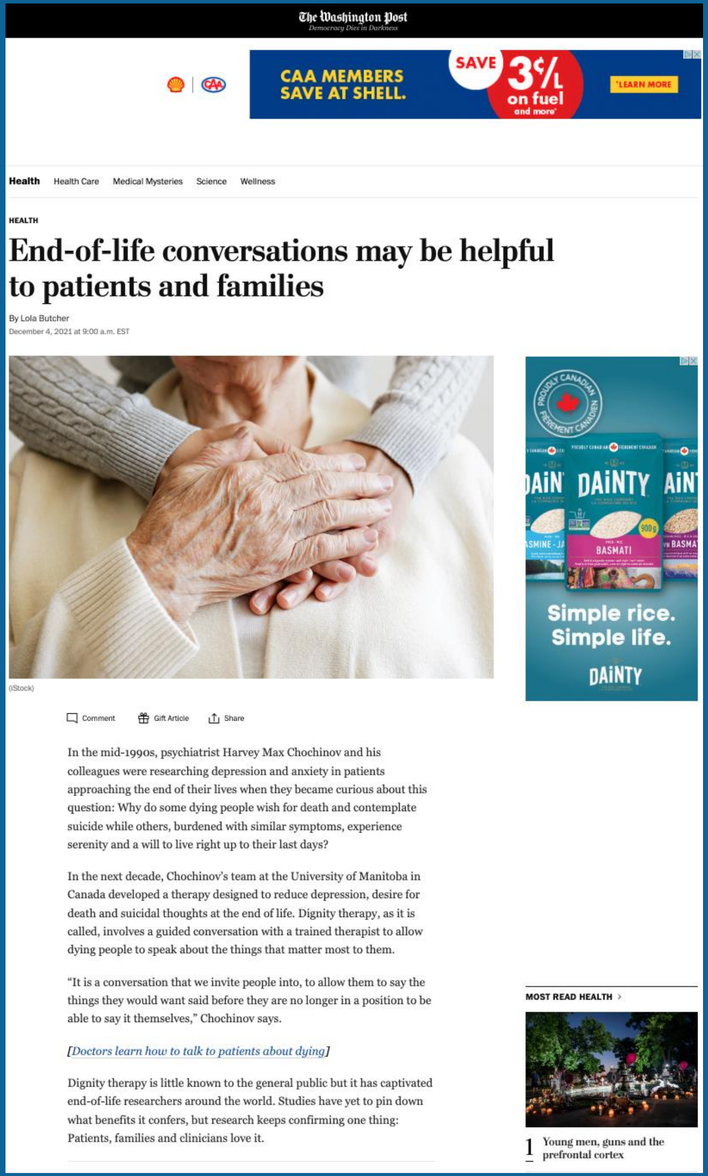
RESULTS

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



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HEALTH

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

By Lola Butcher

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

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PROUDLY CANADIAN
DAiNTY
BASMATI
Simple rice. Simple life.
DAiNTY

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.

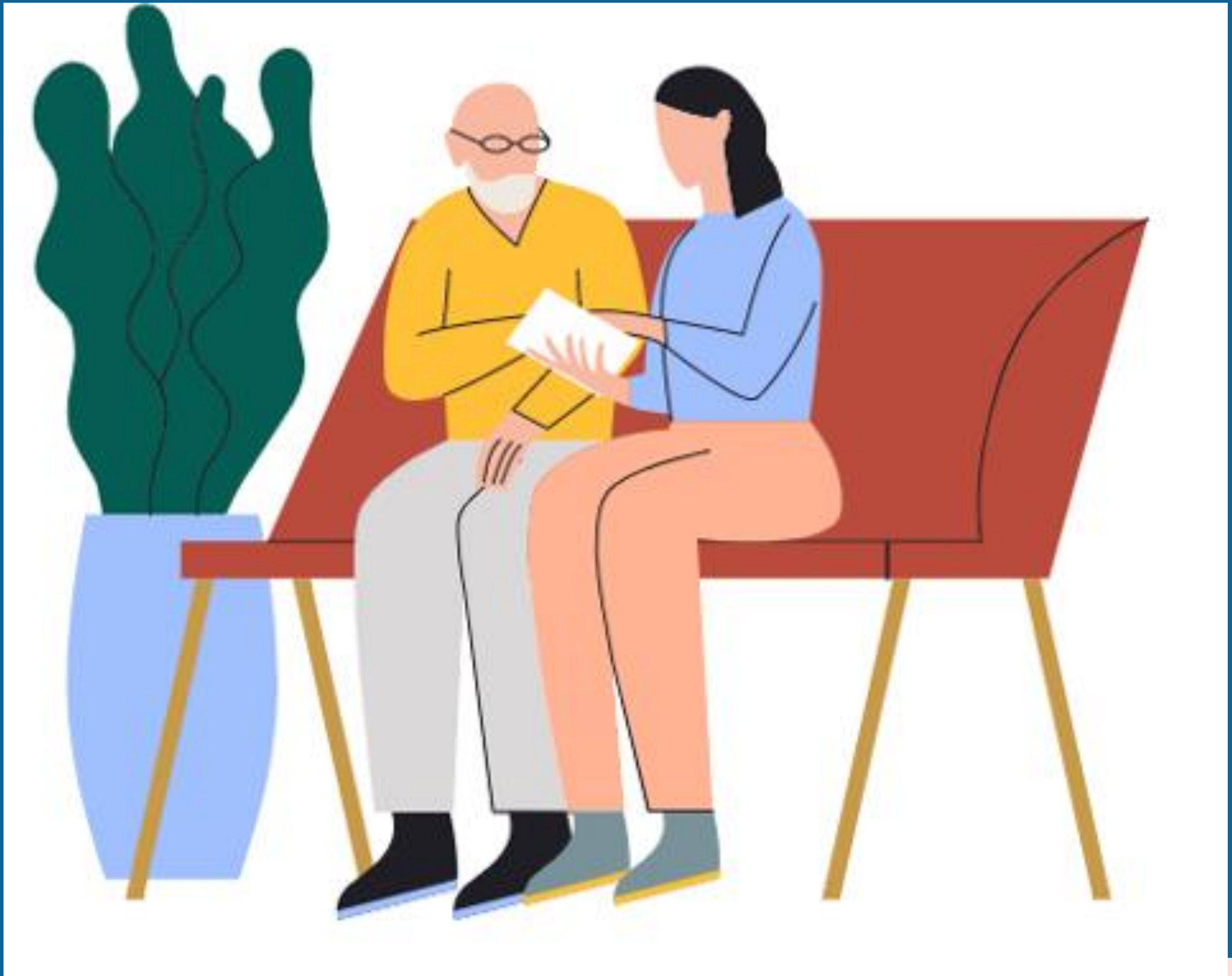
"It is a conversation that we invite people into, to allow them to say the things they would want said before they are no longer in a position to be able to say it themselves," Chochinov says.

[*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



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Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care

Kindness, humanity, and respect—the core values of medical professionalism—are too often being overlooked in the time pressured culture of modern health care, says **Harvey Chochinov**, and the A, B, C, and D of dignity conserving care can reinstate them

EDITORIAL, p 167

Harvey Max Chochinov
professor, department of psychiatry, University of Manitoba, CancerCare Manitoba, Winnipeg, MB, Canada R3E 0V9
harvey.chochinov@cancercare.mb.ca

Accepted: 15 May 2007

The late Anatole Broyard, essayist and former editor of the *New York Times Book Review*, wrote eloquently about the psychological and spiritual challenges of facing metastatic prostate cancer. "To the typical physician," he wrote, "my illness is a routine incident in his rounds while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity… I just wish he would… give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way."[1]

Broyard's words underscore the costs and hazards of becoming a patient. The word "patient" comes from the Latin patiens, meaning to endure, bear, or suffer, and refers to an acquired vulnerability and dependency imposed by changing health circumstances. Relinquishing autonomy is no small matter and can exact considerable costs.[2] These costs are sometimes relatively minor—for example, accepting clinic schedules or hospital routines. At other times, the costs seem incompatible with life itself. When patients experience a radical unsettling of their conventional sense of self[3] and a disintegration of personhood,[4] suffering knows few bounds. To feel sick is one thing, but to feel that who we are is being threatened or undermined—that we are no longer the person we once were—can cause despair affecting body, mind, and soul. How do healthcare providers influence the experience of patienthood, and what happens when this frame of reference dominates how they view people seeking their care?

Dignity and patienthood

Answering these questions begins with an examination of the relationship between patienthood and notions of dignity. Although the literature on dignity is sparse, it shows that "how patients perceive themselves to be seen" is a powerful mediator of their dignity.[5 6] In a study of patients with end stage cancer, perceptions of dignity were most strongly associated with "feeling a burden to others" and "sense of being treated with respect."[7] As such, the more that healthcare providers are able to affirm the patient's value—that is, seeing the person they are or were, rather than just the illness they have—the more likely that the patient's sense of dignity will be upheld. This finding, and the intimate connection between care provider's affirmation and patient's self perception, underscores the basis of dignity conserving care.[8]

Yet, many healthcare providers are reticent to claim this particular aspect of care, which is variously referred to as spiritual care, whole person care, psychosocial care, or dignity conserving care.[9-12] This reluctance is often framed in terms of lack of expertise or concern about how much time this might consume. Yet, when personhood is not affirmed, patients are more likely to feel they are not being treated with dignity and respect.[13] Not being treated with dignity and respect can undermine a sense of value or worth.[5] Patients who feel that life no longer has worth, meaning, or purpose are more likely to feel they have become a burden to others, and patients

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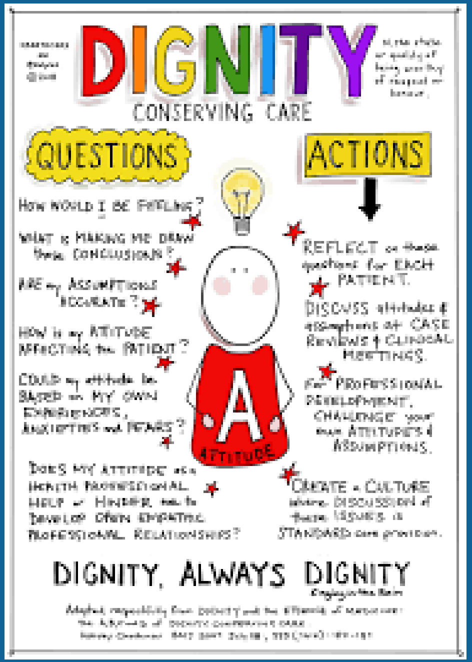

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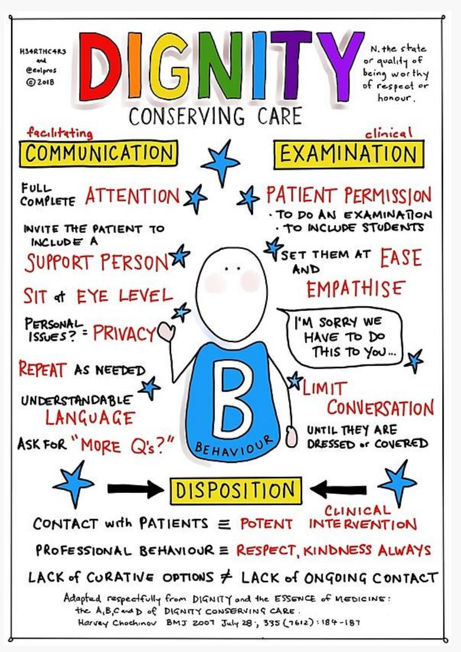

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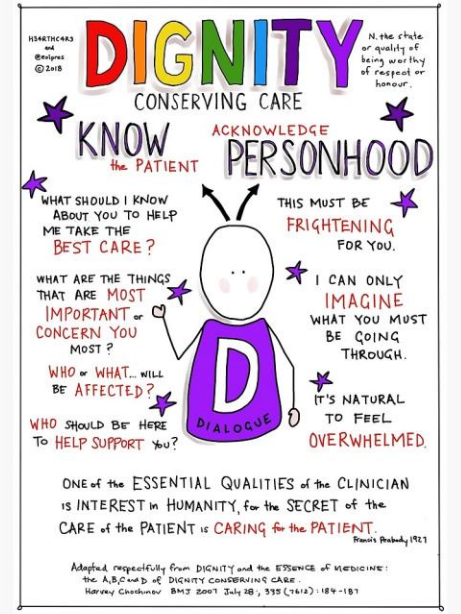
"I'D LIKE MY DOCTOR TO SCAN ME, TO GROPE FOR MY SPIRIT AS WELL AS MY PROSTATE. WITHOUT SUCH RECOGNITION I AM NOTHING BUT MY ILLNESS" Anatole Broyard

Adapted respectfully from DIGNITY and the ESSENCE of MEDICINE: the A, B, C and D of DIGNITY CONSERVING CARE. Harvey Chochinov BMJ 2007 July 28; 335 (7612): 184-187



ONE of the ESSENTIAL QUALITIES of the CLINICIAN is INTEREST in HUMANITY, for the SECRET of the CARE of the PATIENT is CARING for the PATIENT. Francis Peabody 1927

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Project ECHO Palliative Care - Canada BY Pallium Canada

The Patient Dignity Question (PDQ)

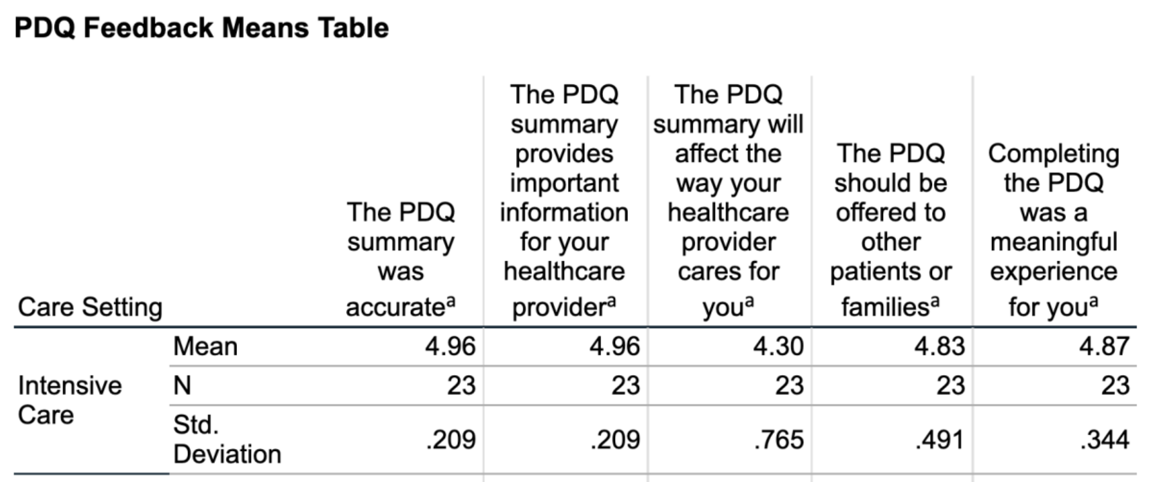
What should I know about you as a person to help me take the best care of you that I can?

Patient and Family Response to PDQ

Patient/Family Perception	**Number of PDQs**	**Percentage**
The PDQ accurate	121	97%
Permission to place on chart	124	99%
Wanted a copy	95	76%
Information Important for HCP	107	93%
Could affect my care	78	81%
Would recommend it for others	117	99%

Effect of PDQ on Health Care Provider

Effect of PDQ on Health Care Provider	**Not Influenced**	**Neutral**	**Influenced**
Learn something new from PDQ	24 (8.3%)	4 (1.4%)	262 (90%)
Was emotionally affected by PDQ	40 (13.7%)	66 (23.0%)	187 (63.8%)
PDQ influenced attitude	56 (19.3%)	73 (25.2%)	161 (55.5%)
PDQ influenced care	75 (26.6%)	82 (29.1%)	125 (44.3%)
PDQ influence respect	52 (18.3%)	96 (33.8%)	136 (47.9%)
PDQ influenced empathy	37 (13.2%)	78 (27.9%)	165 (58.9%)
PDQ affected connectedness	29 (10.4%)	74 (26.5%)	176 (63.1%)



PDQ Feedback Means Table

Care Setting		The PDQ summary was accurate[a]	The PDQ summary provides important information for your healthcare provider[a]	The PDQ summary will affect the way your healthcare provider cares for you[a]	The PDQ should be offered to other patients or families[a]	Completing the PDQ was a meaningful experience for you[a]
Intensive Care	Mean	4.96	4.96	4.30	4.83	4.87
	N	23	23	23	23	23
	Std. Deviation	.209	.209	.765	.491	.344

Terri wants the healthcare team to know that her mother is not any ordinary patient but is a very special woman. “Since my mother was admitted, I have been struggling to find a way to share my mother’s story with the staff, but my heart is so happy that this PDQ will now allow me to do so. I hope the staff read my mother’s story and appreciate the life she lived”.


The Golden Rule

Limitations of Golden Rule

- Imposes an external standard
- May lead to therapeutic nihilism
- May lead to advice based on avoiding a future that the care provider would find untenable
- May lead to discordance regarding goals of care

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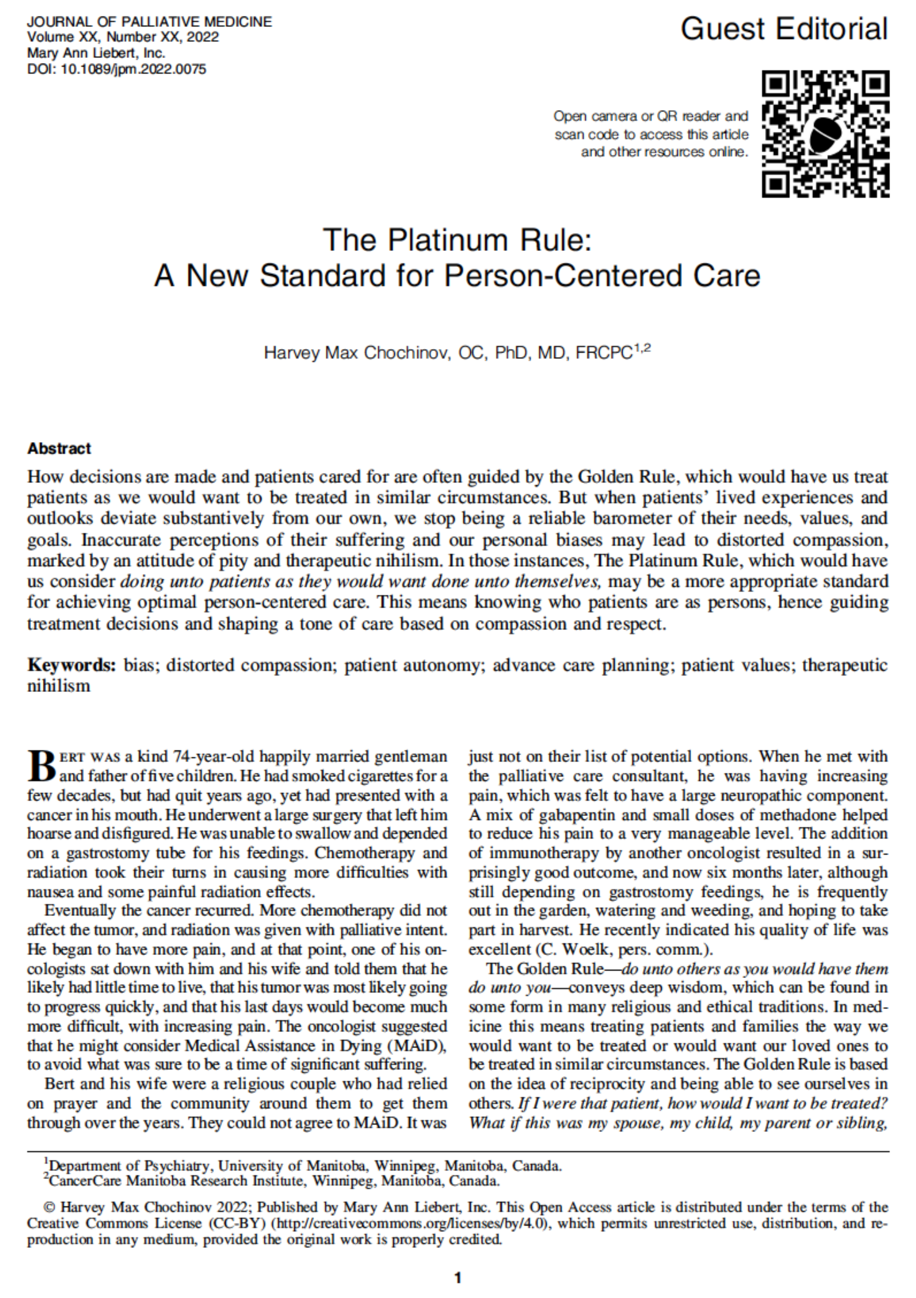

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Guest Editorial

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The Platinum Rule: A New Standard for Person-Centered Care

Harvey Max Chochinov, OC, PhD, MD, FRCPC[1,2]

Abstract

How decisions are made and patients cared for are often guided by the Golden Rule, which would have us treat patients as we would want to be treated in similar circumstances. But when patients' lived experiences and outlooks deviate substantively from our own, we stop being a reliable barometer of their needs, values, and goals. Inaccurate perceptions of their suffering and our personal biases may lead to distorted compassion, marked by an attitude of pity and therapeutic nihilism. In those instances, The Platinum Rule, which would have us consider *doing unto patients as they would want done unto themselves,* may be a more appropriate standard for achieving optimal person-centered care. This means knowing who patients are as persons, hence guiding treatment decisions and shaping a tone of care based on compassion and respect.

Keywords: bias; distorted compassion; patient autonomy; advance care planning; patient values; therapeutic nihilism

Bert was a kind 74-year-old happily married gentleman and father of five children. He had smoked cigarettes for a few decades, but had quit years ago, yet had presented with a cancer in his mouth. He underwent a large surgery that left him hoarse and disfigured. He was unable to swallow and depended on a gastrostomy tube for his feedings. Chemotherapy and radiation took their turns in causing more difficulties with nausea and some painful radiation effects.

Eventually the cancer recurred. More chemotherapy did not affect the tumor, and radiation was given with palliative intent. He began to have more pain, and at that point, one of his oncologists sat down with him and his wife and told them that he likely had little time to live, that his tumor was most likely going to progress quickly, and that his last days would become much more difficult, with increasing pain. The oncologist suggested that he might consider Medical Assistance in Dying (MAiD), to avoid what was sure to be a time of significant suffering.

Bert and his wife were a religious couple who had relied on prayer and the community around them to get them through over the years. They could not agree to MAiD. It was just not on their list of potential options. When he met with the palliative care consultant, he was having increasing pain, which was felt to have a large neuropathic component. A mix of gabapentin and small doses of methadone helped to reduce his pain to a very manageable level. The addition of immunotherapy by another oncologist resulted in a surprisingly good outcome, and now six months later, although still depending on gastrostomy feedings, he is frequently out in the garden, watering and weeding, and hoping to take part in harvest. He recently indicated his quality of life was excellent (C. Woelk, pers. comm.).

The Golden Rule—*do unto others as you would have them do unto you*—conveys deep wisdom, which can be found in some form in many religious and ethical traditions. In medicine this means treating patients and families the way we would want to be treated or would want our loved ones to be treated in similar circumstances. The Golden Rule is based on the idea of reciprocity and being able to see ourselves in others. *If I were that patient, how would I want to be treated? What if this was my spouse, my child, my parent or sibling,*

---

[1] Department of Psychiatry, University of Manitoba, Winnipeg, Manitoba, Canada.
[2] CancerCare Manitoba Research Institute, Winnipeg, Manitoba, Canada.

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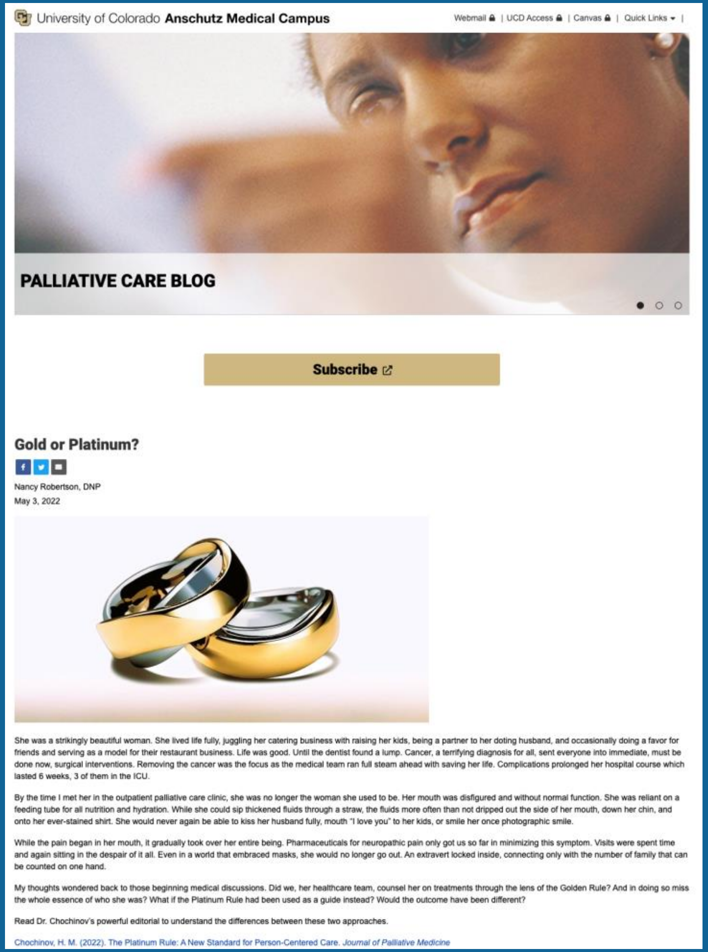
Pallium Canada



Gold or Platinum?

Nancy Robertson, DNP
May 3, 2022

She was a strikingly beautiful woman. She lived life fully, juggling her catering business with raising her kids, being a partner to her doting husband, and occasionally doing a favor for friends and serving as a model for their restaurant business. Life was good. Until the dentist found a lump. Cancer, a terrifying diagnosis for all, sent everyone into immediate, must be done now, surgical interventions. Removing the cancer was the focus as the medical team ran full steam ahead with saving her life. Complications prolonged her hospital course which lasted 6 weeks, 3 of them in the ICU.

By the time I met her in the outpatient palliative care clinic, she was no longer the woman she used to be. Her mouth was disfigured and without normal function. She was reliant on a feeding tube for all nutrition and hydration. While she could sip thickened fluids through a straw, the fluids more often than not dripped out the side of her mouth, down her chin, and onto her ever-stained shirt. She would never again be able to kiss her husband fully, mouth "I love you" to her kids, or smile her once photographic smile.

While the pain began in her mouth, it gradually took over her entire being. Pharmaceuticals for neuropathic pain only got us so far in minimizing this symptom. Visits were spent time and again sitting in the despair of it all. Even in a world that embraced masks, she would no longer go out. An extravert locked inside, connecting only with the number of family that can be counted on one hand.

My thoughts wondered back to those beginning medical discussions. Did we, her healthcare team, counsel her on treatments through the lens of the Golden Rule? And in doing so miss the whole essence of who she was? What if the Platinum Rule had been used as a guide instead? Would the outcome have been different?

Read Dr. Chochinov's powerful editorial to understand the differences between these two approaches.

Chochinov, H. M. (2022). The Platinum Rule: A New Standard for Person-Centered Care. *Journal of Palliative Medicine*

Caregivers should overcome unconscious bias

Published on: April 11, 2022

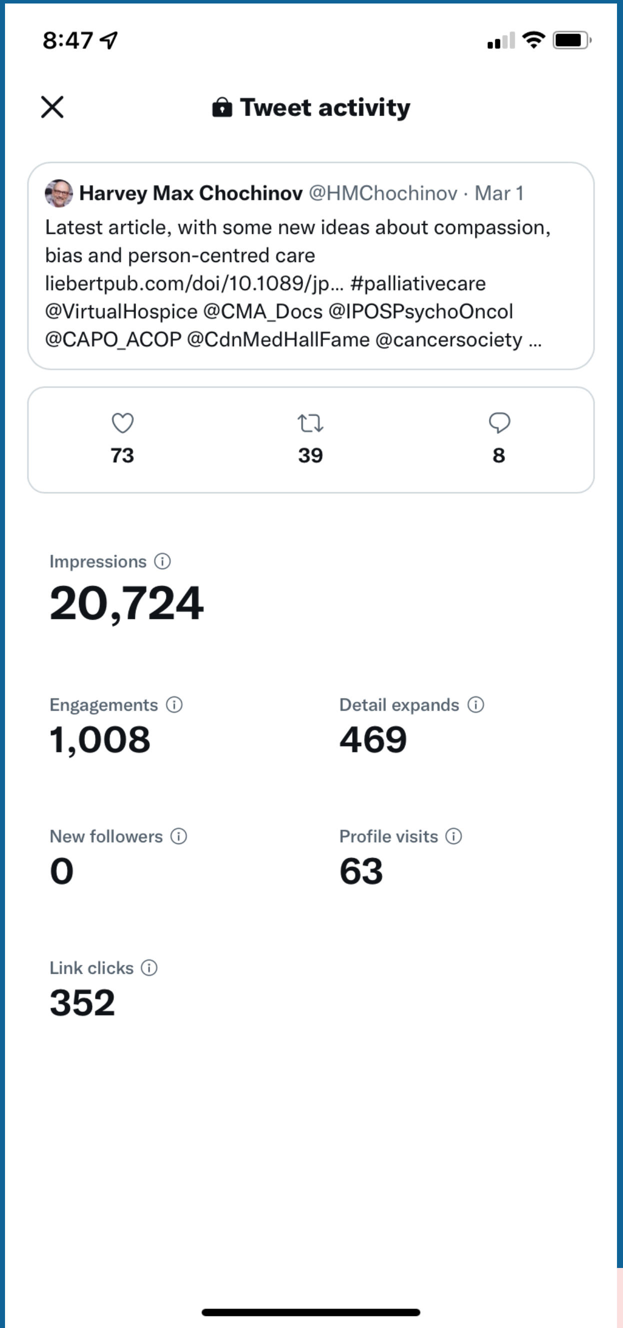
How decisions are made and patients cared for are often guided by the Golden Rule: *Treat patients as we would want to be treated in similar circumstances.* But when patients' lived experiences and outlooks deviate substantively from our own, we stop being a reliable barometer of their needs, values, and goals, writes Dr Harvey Max Chochinov, in the *Journal of Palliative Medicine*.

In his guest editorial titled 'The Platinum Rule: A New Standard for Person-Centred Care' Dr Chochinov writes, "So long as the patient's values and priorities align with our own, we can infer their needs based on how we would want to be treated in their situation, not so when our worldview and lived experience deviates from theirs."

Unconscious bias can influence the way we process patient information, affecting our behaviour, interactions, and decision making. Rather than feeling that they have been heard, distorted compassion can result in patients feeling devalued, misunderstood, and further demoralised at the very hands of those who are meant to help.

Dr Chochinov adds that not all patient preferences can or should be accommodated, especially when they are driven by nihilistic self-loathing (I don't want anything), or motivated by expectations that exceed any objective reality (I want everything). Even then, it is important to understand their wishes, and what approaches might provide them with optimal comfort and reassurance.

Read the Editorial by Dr Harvey Chochinov, published in Journal of Palliative Medicine: 'The Platinum Rule: A New Standard for Person-Centred Care'



Harvey Max Chochinov @HMChochinov · Mar 1

Latest article, with some new ideas about compassion, bias and person-centred care
liebertpub.com/doi/10.1089/jp... #palliativecare
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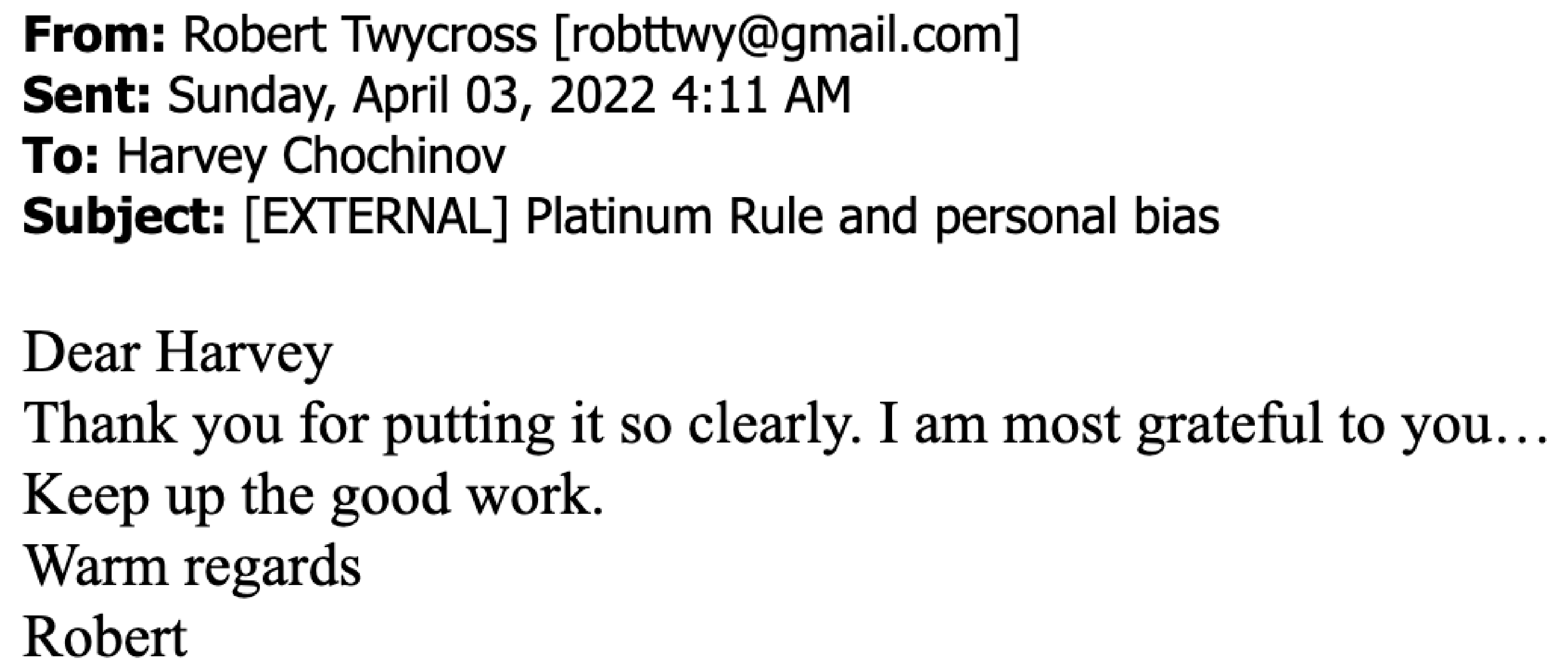
@CAPO_ACOP @CdnMedHallFame @cancersociety ...

Likes	Retweets	Replies
73	39	8

Impressions
20,724

Engagements	Detail expands
1,008	469
New followers	Profile visits
0	63

Link clicks
352



From: Robert Twycross [robttwy@gmail.com]
Sent: Sunday, April 03, 2022 4:11 AM
To: Harvey Chochinov
Subject: [EXTERNAL] Platinum Rule and personal bias

Dear Harvey
Thank you for putting it so clearly. I am most grateful to you…
Keep up the good work.
Warm regards
Robert

PLOS ONE

RESEARCH ARTICLE

Athletic trainers' viewpoints of patient-centered care: Preliminary findings

Carly J. Wilson[1☯], Lindsey E. Eberman[2☯], Ansley S. Redinger[3☯], Elizabeth R. Neil[4☯], Zachary K. Winkelmann[1☯*]

1 Department of Exercise Science, University of South Carolina, Columbia, South Carolina, United States of America, 2 Department of Applied Medicine and Rehabilitation, Indiana State University, Terre Haute, Indiana, United States of America, 3 St. Luke's Health System, Boise, Idaho, United States of America, 4 College of Public Health, Temple University, Philadelphia, Pennsylvania, United States of America

☯ These authors contributed equally to this work.
* winkelz@mailbox.sc.edu

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Data Availability Statement: The data cannot be shared publicly because the data contain confidential information which could be potentially identifying. The data is also embedded into the Q Method software which requires a subscription. Data requests can be sent to the senior investigator, Dr. Zachary Winkelmann at winkelz@mailbox.sc.edu or to the IRB Manager, Lisa Johnson at lisaj@mailbox.sc.edu.

Abstract

The core competency of patient-centered care (PCC) states that for positive patient outcomes, the provider must respect the patient's views and recognize their experiences. The Athletic Training Strategic Alliance Research Agenda Task Force identified a profession-wide belief that examining the extent to which athletic trainers (ATs) provide PCC in their clinical practice would benefit the profession. To first address this line of inquiry, we must study the subjectivity of how ATs view PCC. This study used Q methodology which is a research design that collects data from participants from a quantitative and qualitative perspective. A total of 115 (males = 62, females = 53, age = 37±10 y, experience = 13±10 y) ATs dispersed between 11 job settings volunteered for this study. Participants were asked to pre-sort (agree, disagree, neutral) 36 validated statements representing the 8 dimensions of PCC, then completed a Q-sort where they dragged-and-dropped the pre-sorted statements based on perceived importance in providing PCC. The Q-sorts were analyzed using QMethod software. A principal component analysis was used to identify statement rankings and factors. Factors were determined by an Eigenvalue > 1 and analyzed using a scree plot. The 6 highest selected statements per factor were assessed to create the distinguishing viewpoints. Two distinguishing viewpoints emerged from the factor analysis of the Q-sorts: 1) the interpersonal connection that valued teamwork, open communication, and respectful care with varied populations; 2) the holistic gatekeeper that valued personal promotion for activities of daily living, self-care, and quality of life. Overall, ATs value patient's preferences and respect. However, a lack of importance was identified for incorporating the disablement model which is a core competency and adopted framework by the athletic training profession.

Introduction

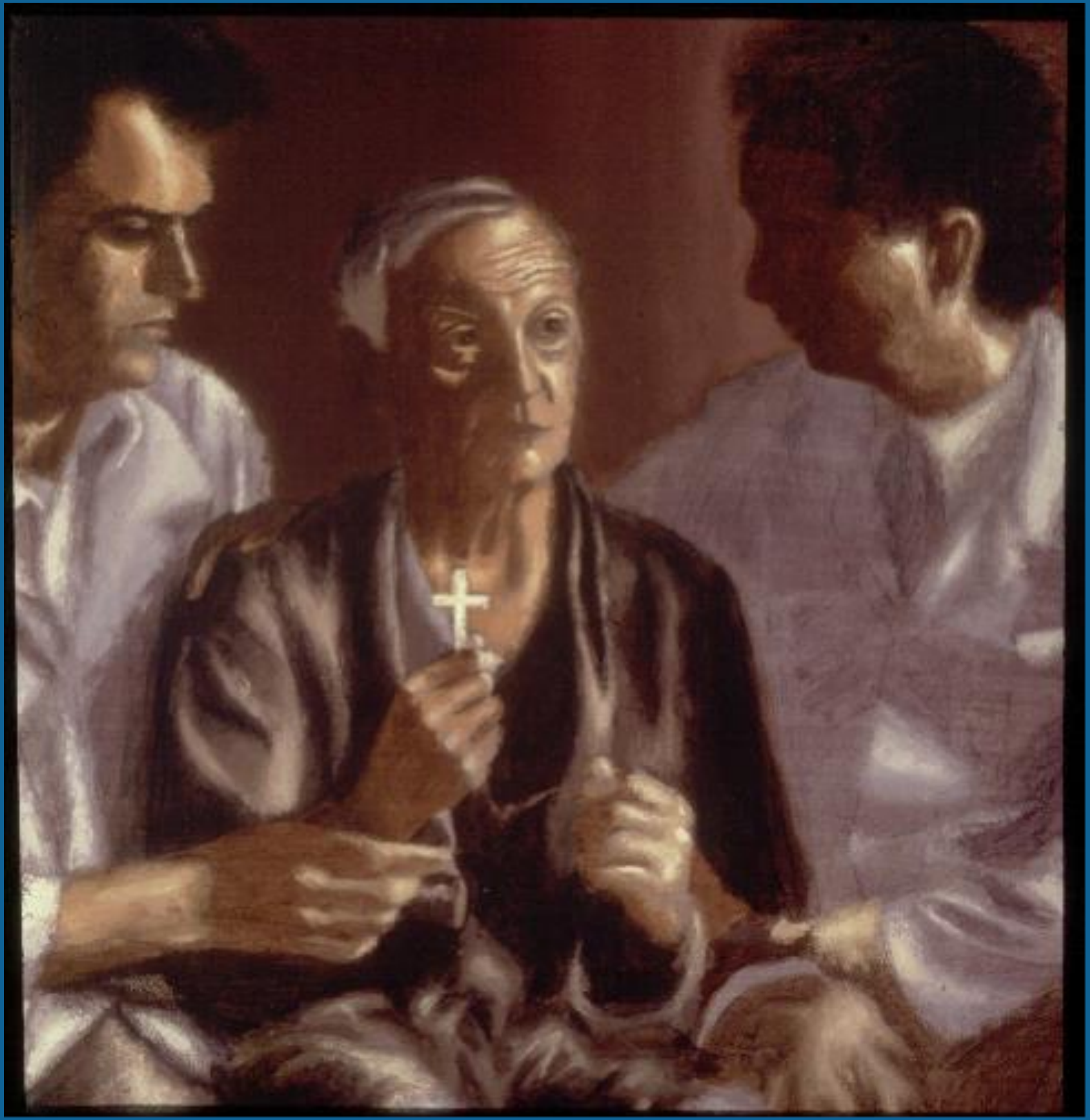
The Institute for Healthcare Improvement created the Triple Aim for Healthcare which is a set of linked missions with the intent to raise the standards of the United States healthcare system.

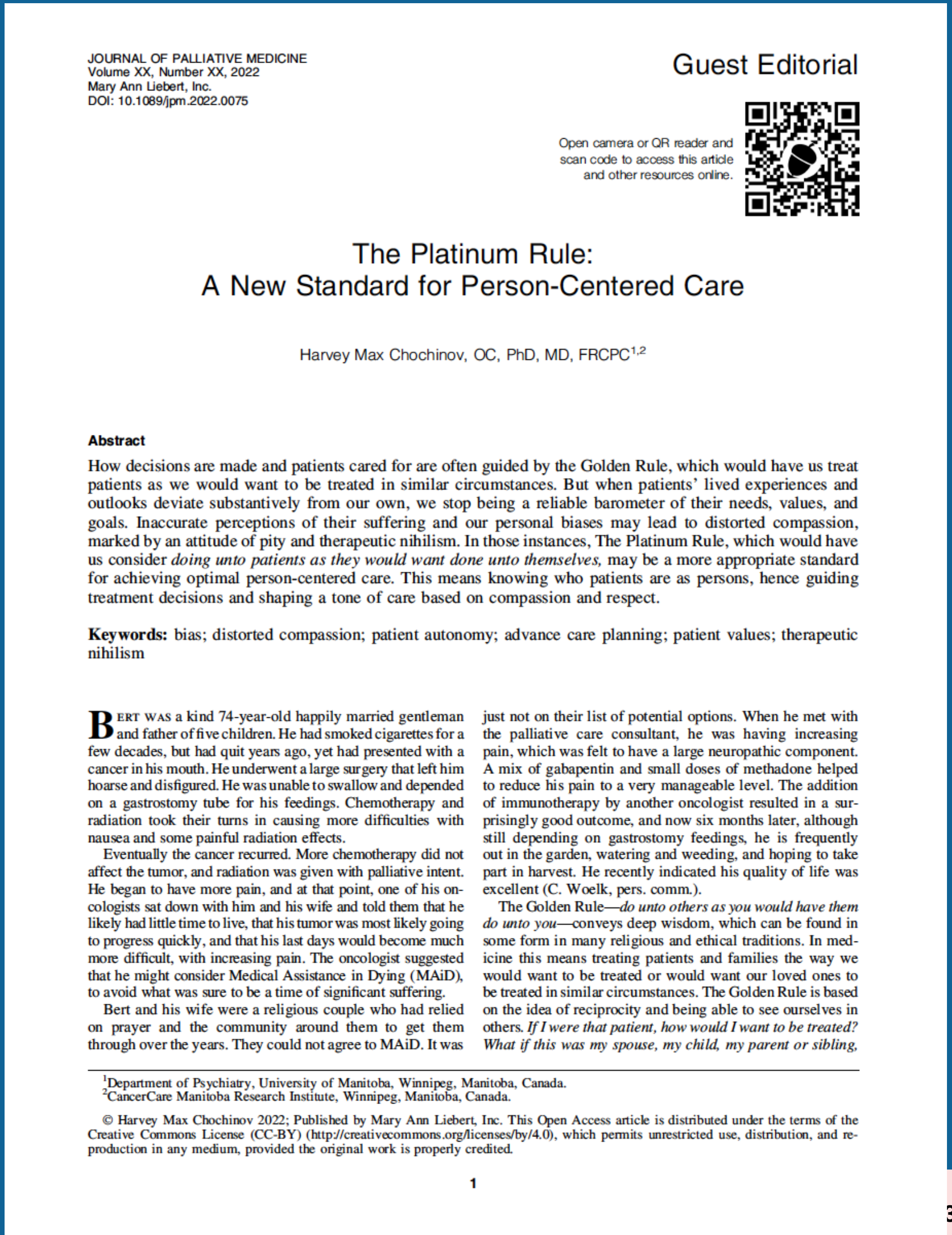
"Just as medicine has evolved, the Golden Rule of "do unto others as you would have them do unto you" has slowly been phased out and been replaced by the newer "Platinum Rule," which states "treat people the way they want to be treated, rather than how you would want to be treated". As a much needed upgrade of an outdated cultural principle, the Platinum Rule fits the definition of PCC seamlessly and directly incorporates the dimension of patient preferences into patient-provider interactions. The findings from our study and recent literature on the Platinum Rule suggest a positive alternative in PCC that needs further exploration in different healthcare settings."

Wilson CJ, Eberman LE, Redinger AS, et al. (2022) Athletic trainers' viewpoints of patient-centered care: Preliminary findings. PLoS ONE 17(9): e0274577.

The Platinum Rule

Do unto patients as they would want done unto themselves





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Guest Editorial

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The Platinum Rule: A New Standard for Person-Centered Care

Harvey Max Chochinov, OC, PhD, MD, FRCPC[1,2]

Abstract

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Merits of The Platinum Rule

- Always considers patient perspective
- Helps us recognized and confront personal biases
- Important standard for substitute decision maker
- Raises the bar of Person-Centered Care

ON THE BRAIN

Seeing Ellen and the Platinum Rule

Harvey Max Chochinov, OC, OM, MD, PhD
Department of Psychiatry, University of Manitoba, Winnipeg, Manitoba, Canada; and CancerCare Manitoba Research Institute, University of Manitoba, Winnipeg, Manitoba, Canada.

Several years before her death at the age of 55 years due to complications of cerebral palsy, my sister Ellen was again in hospital, this time in intensive care and on the brink of respiratory collapse and the possible need for intubation. To say cerebral palsy had shaped her life is an understatement, in that it molded nearly every facet of her being, from the contours of her body to the way she saw and experienced the world. And based on this, while one might assume that her life was defined by suffering, the only ones who suffered were those whose toes she managed to crush under the mighty weight of her electric wheelchair when she was on the dance floor.

With the passage of time, her body became increasingly contorted, affecting her ability to take a deep breath or fight off upper respiratory tract infections. So long as I can remember, blowing out birthday candles was impossible without the assistance of her nieces, nephews, friends, or extended family. Time at the family cottage in Winnipeg Beach, ice cream on a summer's day, chocolate milk, or meals prepared by my parents were among her greatest pleasures. But health challenges often interfered with her various plans and wishful thinking that one day she might actually get to see the world.

While being in hospital with Ellen was not an unfamiliar experience, this time felt different, with life and death hanging perilously in the balance. The attending physician, whom I knew from occasional work-related encounters, was diligently reviewing her medical record, scanning her monitors, and calculating if her deteriorating condition would soon require inserting a breathing tube. At one point her physician turned to me, asking "Does she read magazines?" While this was a seemingly innocent question, it was the only question I was asked about her personal life. The subtext was chilling, as this was not an attempt to get to know Ellen as a person or how she spent her days, but rather a cryptic way of deciding if hers was a life worth saving. While it was never said, I could intuit the rational and detached mental calculus. *Her body looks like a train wreck. Who would want to live this way? Perhaps we'd all be better off by letting nature take its course.*

To be clear, this physician was not a bad person and was regarded as a highly skilled clinician. But the lens through which my sister was being viewed was one that had been shaped in ways her physician was entirely unaware of. From the time we are young, there are images and values that are elevated above all others, including youth, beauty, wealth, and power. We learn to worship at the altar of this ephemeral perfection, with all else deemed of lesser value, lesser utility, and lesser consequence. The results are insidious, from the way we perceive bodies—our own and those of others—to the social policies we do and do not support. It is no coincidence that older individuals, for instance, have been disproportionately affected by the COVID-19 pandemic, given our chronic failure to invest in the supports needed to safeguard their well-being and vitality. You bankroll what you value, and some lives are simply valued more than others.

But something else was happening that day at my sister's bedside that threatened to undermine the care she desperately wanted and needed. Treatment decisions are often based on considerations of reciprocity and The Golden Rule. *If I were that patient, what would I want for myself?*—doing unto others as we would want done unto ourselves. This means using our own values, wants, and needs as an indicator of those we assume are held by the patient. But what happens when these don't align? It is hard to imagine a wider chasm between my sister's lived experience and outlook, and that of her intensivist. When this degree of misalignment occurs, it is easy to anticipate health care recommendations based on the conviction that *I wouldn't want to live that way? I wouldn't want to be that disabled, dependent, disfigured, or disenfranchised. Why offer opportunities to sustain an existence that I would personally find unimaginable and intolerable?*

This is where a new standard of person-centered care—The Platinum Rule[1]—comes into play: do unto others as they would want done unto themselves. This means not presuming that we know what is in the patient's best interest based on what we would want in their circumstances and taking the time to consider what they would want, hope, or wish for. While not every patient request can be accommodated, The Platinum Rule provides insights that strip away biases and assumptions, helping us see who patients are as people and raising the bar on person-centered care. Not being seen erodes human dignity and undermines personhood, experiences that are at the core of human suffering.[2]

So when Ellen's physician asked me if she read magazines, I scrambled to come up with a response that would have this physician see beyond her distorted body and failing lungs. There wasn't enough time to talk about jiving on the dance floor or Winnipeg Beach or birthday celebrations. I wanted Ellen to be seen as not just the patient, but the well-loved sister, daughter, aunt, niece, cousin, disability rights activist, and friend. I wanted everyone to understand that she had a rich emotional life, and an imagination that could take her to places that, as fate would have it, she would never get to see. And so, after a few seconds I responded, "Yes, she reads magazines. But only when she's in between novels."

Corresponding Author: Harvey Max Chochinov, OC, OM, MD, PhD, University of Manitoba, CancerCare Manitoba Research Institute,
675 McDermot Ave, Winnipeg, MB R3E 0V9, Canada (harvey.chochinov@cancercare.mb.ca).

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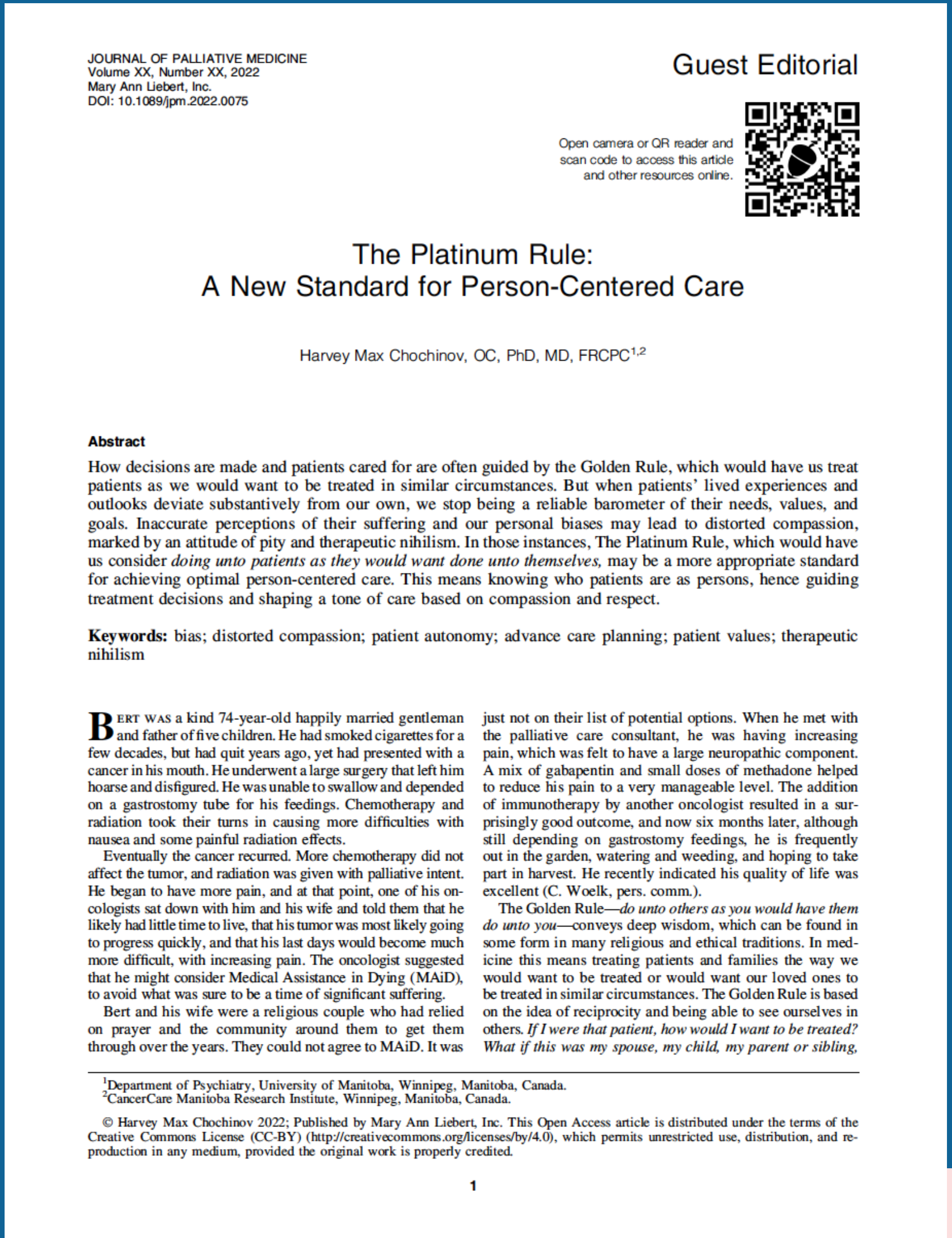

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Guest Editorial

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The Platinum Rule:
A New Standard for Person-Centered Care

Harvey Max Chochinov, OC, PhD, MD, FRCPC[1,2]

Abstract

How decisions are made and patients cared for are often guided by the Golden Rule, which would have us treat patients as we would want to be treated in similar circumstances. But when patients' lived experiences and outlooks deviate substantively from our own, we stop being a reliable barometer of their needs, values, and goals. Inaccurate perceptions of their suffering and our personal biases may lead to distorted compassion, marked by an attitude of pity and therapeutic nihilism. In those instances, The Platinum Rule, which would have us consider *doing unto patients as they would want done unto themselves,* may be a more appropriate standard for achieving optimal person-centered care. This means knowing who patients are as persons, hence guiding treatment decisions and shaping a tone of care based on compassion and respect.

Keywords: bias; distorted compassion; patient autonomy; advance care planning; patient values; therapeutic nihilism

BERT WAS a kind 74-year-old happily married gentleman and father of five children. He had smoked cigarettes for a few decades, but had quit years ago, yet had presented with a cancer in his mouth. He underwent a large surgery that left him hoarse and disfigured. He was unable to swallow and depended on a gastrostomy tube for his feedings. Chemotherapy and radiation took their turns in causing more difficulties with nausea and some painful radiation effects.

Eventually the cancer recurred. More chemotherapy did not affect the tumor, and radiation was given with palliative intent. He began to have more pain, and at that point, one of his oncologists sat down with him and his wife and told them that he likely had little time to live, that his tumor was most likely going to progress quickly, and that his last days would become much more difficult, with increasing pain. The oncologist suggested that he might consider Medical Assistance in Dying (MAiD), to avoid what was sure to be a time of significant suffering.

Bert and his wife were a religious couple who had relied on prayer and the community around them to get them through over the years. They could not agree to MAiD. It was just not on their list of potential options. When he met with the palliative care consultant, he was having increasing pain, which was felt to have a large neuropathic component. A mix of gabapentin and small doses of methadone helped to reduce his pain to a very manageable level. The addition of immunotherapy by another oncologist resulted in a surprisingly good outcome, and now six months later, although still depending on gastrostomy feedings, he is frequently out in the garden, watering and weeding, and hoping to take part in harvest. He recently indicated his quality of life was excellent (C. Woelk, pers. comm.).

The Golden Rule—*do unto others as you would have them do unto you*—conveys deep wisdom, which can be found in some form in many religious and ethical traditions. In medicine this means treating patients and families the way we would want to be treated or would want our loved ones to be treated in similar circumstances. The Golden Rule is based on the idea of reciprocity and being able to see ourselves in others. *If I were that patient, how would I want to be treated? What if this was my spouse, my child, my parent or sibling,*

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[1] Department of Psychiatry, University of Manitoba, Winnipeg, Manitoba, Canada.
[2] CancerCare Manitoba Research Institute, Winnipeg, Manitoba, Canada.

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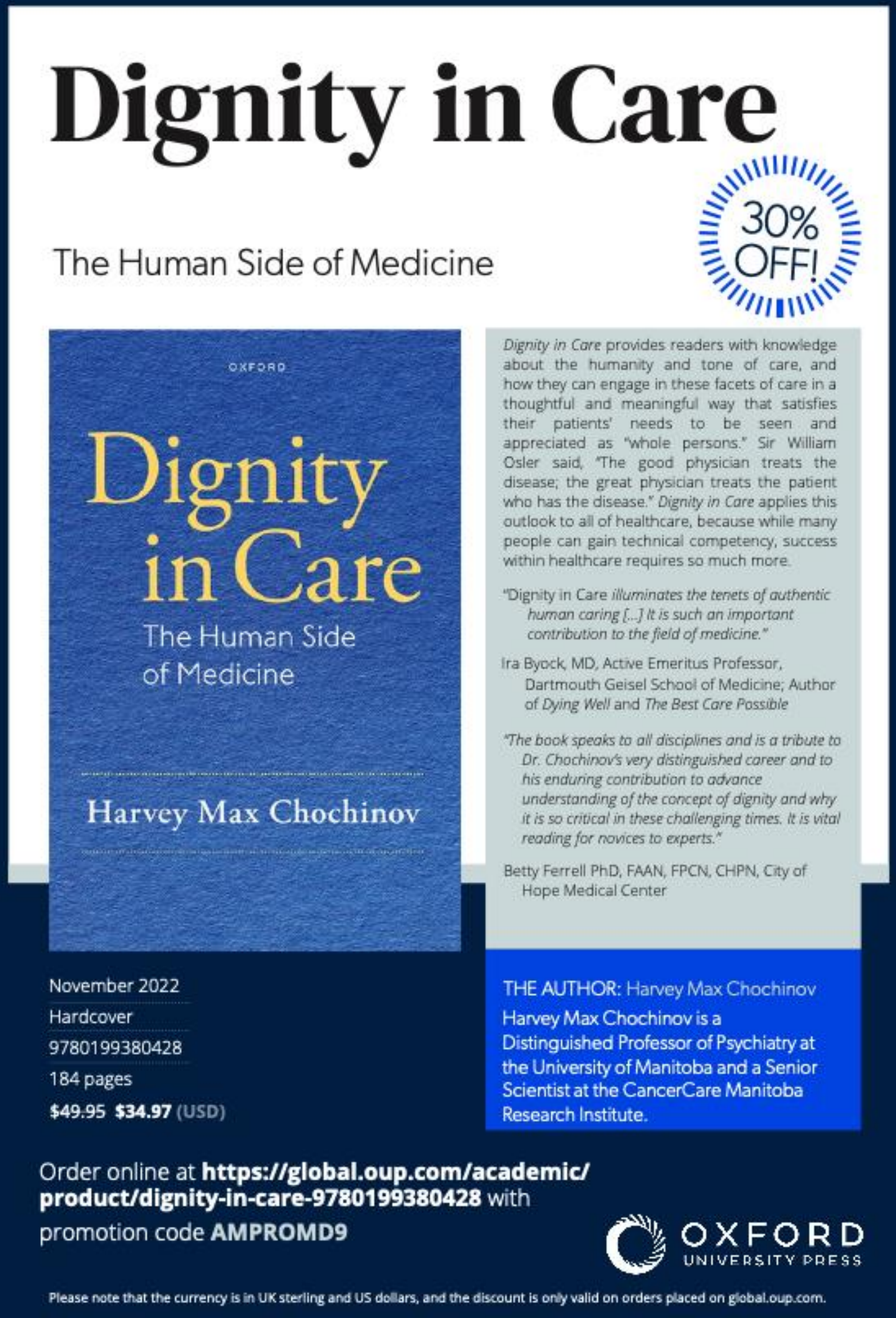

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THE AUTHOR: Harvey Max Chochinov

Harvey Max Chochinov is a Distinguished Professor of Psychiatry at the University of Manitoba and a Senior Scientist at the CancerCare Manitoba Research Institute.

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Q & A

Session Wrap Up

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