McGill Palliative Care
National Grand Rounds
2025 Series

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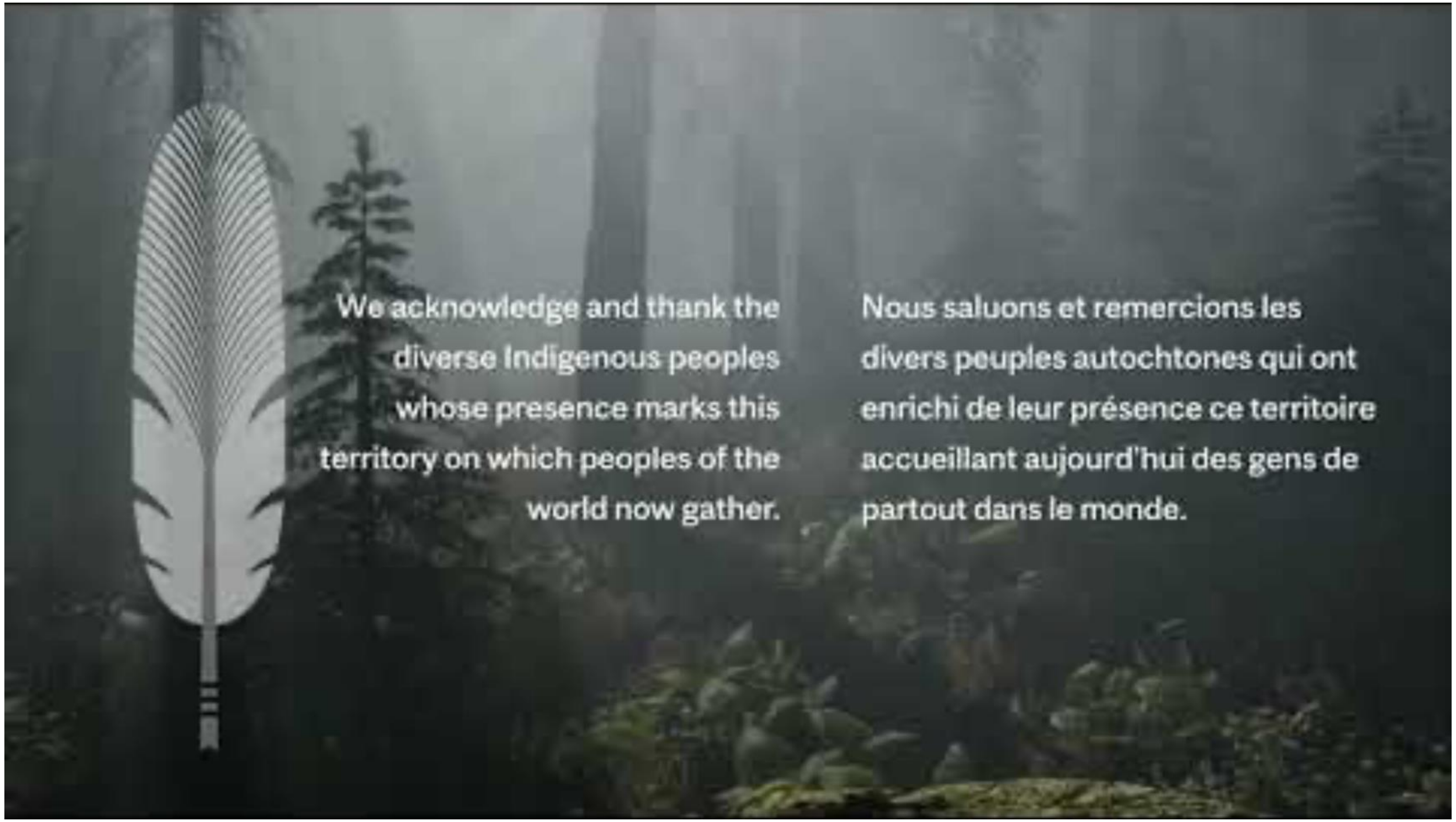

We acknowledge and thank the diverse Indigenous peoples whose presence marks this territory on which peoples of the world now gather.

Nous saluons et remercions les divers peuples autochtones qui ont enrichi de leur présence ce territoire accueillant aujourd'hui des gens de partout dans le monde.

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- *Cedars Cancer Foundation*
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- *MUHC Foundation*
- *Pallium Canada*
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Strategies discussed by the Scientific Planning Committee (SPC) to manage or mitigate the identified potential sources of bias prior to or during the CPD (Continuous Professional Development) activity.

- Potential conflicts of interest for every member of the SPC is listed in writing at the start of the presentation.
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Overall Program Learning Objectives

- Review innovative approaches for the implementation of palliative care in different settings
- Assess strategies to address the most important challenges in palliative care today
- Appraise the latest research in the field of palliative care

McGill Palliative Care
National Grand Rounds
2025 Series

Dr. Jane Poulson Lecture
of the Montreal General Hospital Foundation

Harvey Max Chochinov, OC OM MD PhD FRCPC FRSC

September 17, 2025

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Conflict of Interest Declaration

Harvey Max Chochinov, OC OM MD PhD FRCPC FRSC

I have no conflicts of interest to declare

The CanMED competencies that will be identified during this presentation:

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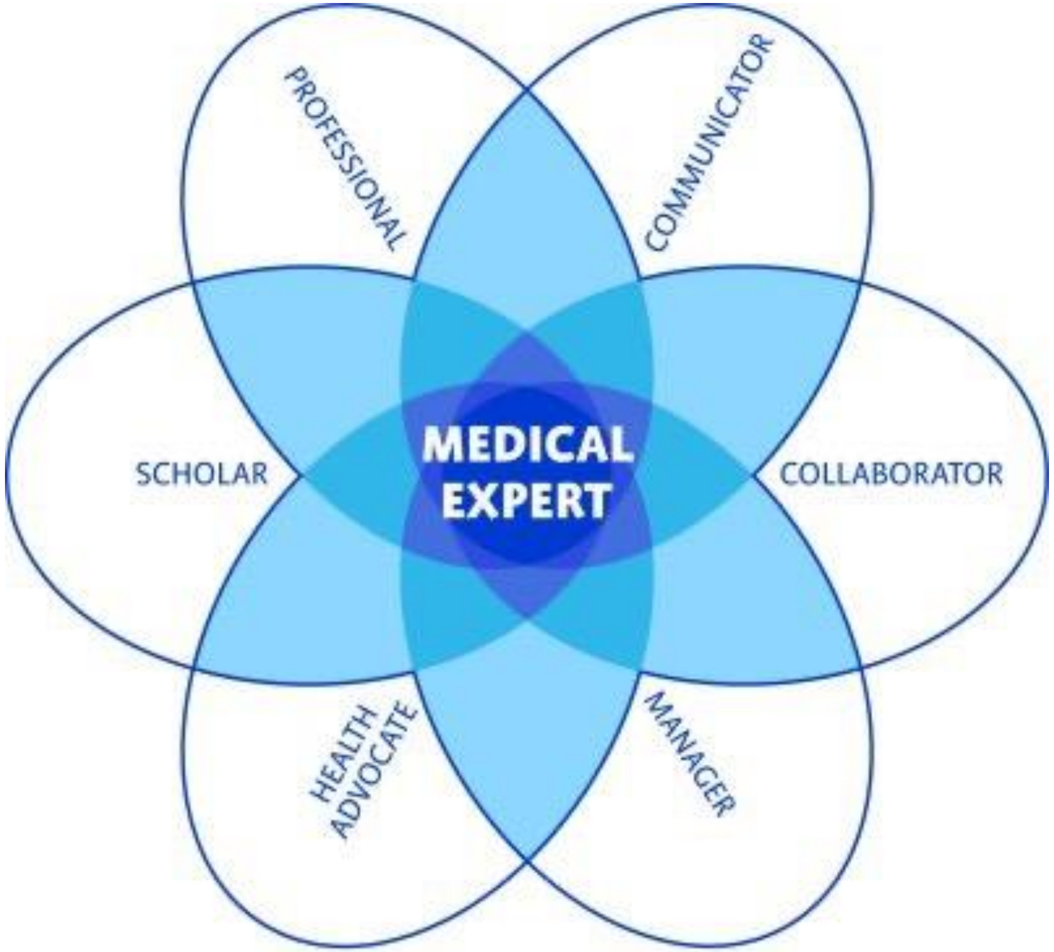
- Health Advocate
- Scholar and Professional.



Learning Objectives

- Attendees will be introduced to a body of empirical research detailing the experimental landscape of palliative/end-of-life care.
- Attendees will understand how to apply considerations of human dignity in clinical care.
- Attendees will be given an overview of the core tenets of intensive caring and applications to addressing patients’ suffering.

Dignity, Personhood and Intensive Caring:

Addressing Patient Suffering in Palliative Care

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

Reasons, According to Dutch Physicians, Why Patients Requested Euthanasia/PAS

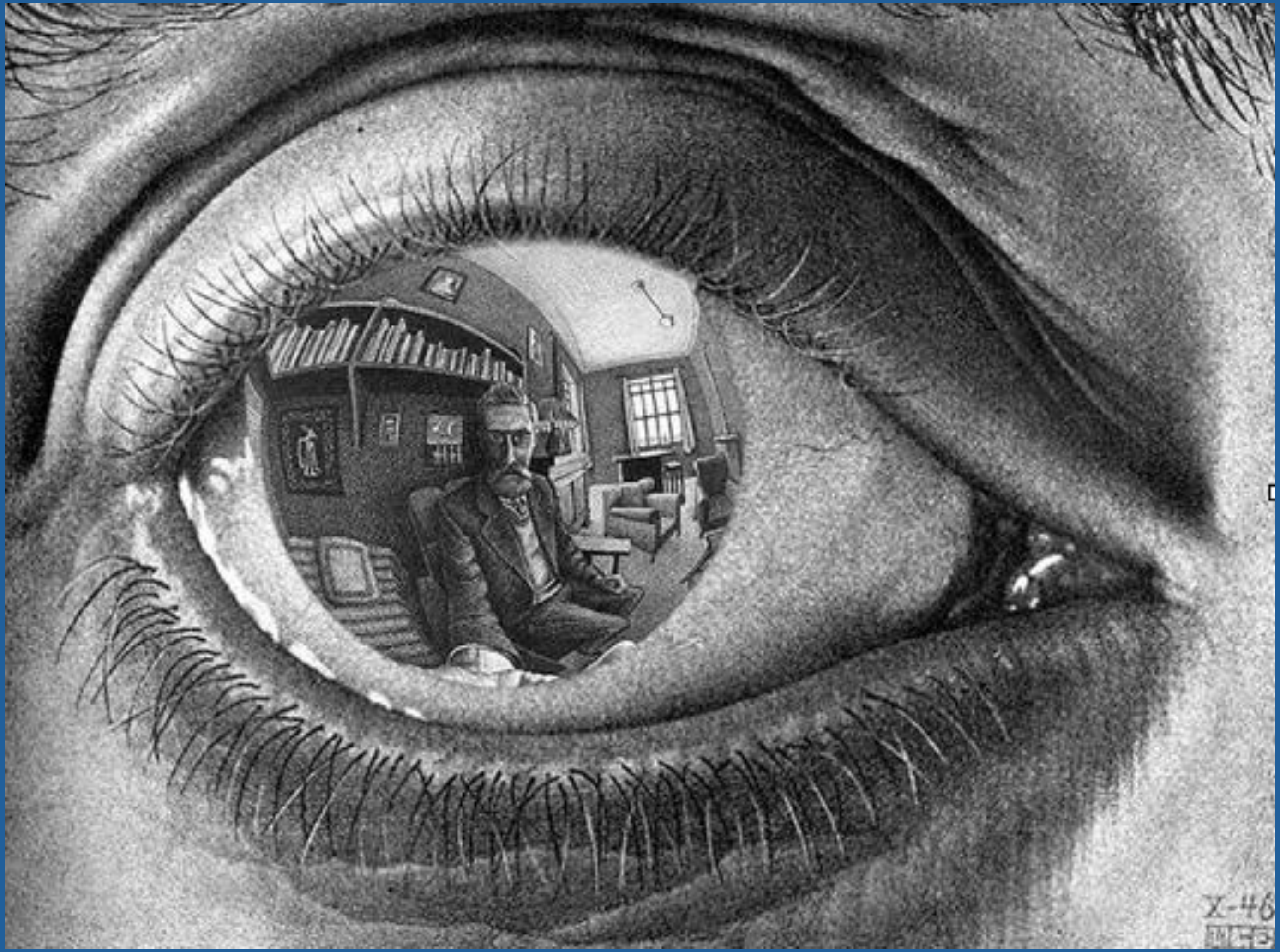
- **Loss of Dignity: 57%**
- Pain: 49%
- Unworthy Dying: 49%
- Being Dependent: 33%
- Tiredness of Life: 23%
- Pain Alone: 5%

Van der Maas Lancet 1991

Distribution of Sense of Dignity

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



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

Dignity and the Eye of the Beholder

Harvey Max Chochinov

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

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

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DOI: 10.1200/JCO.2004.12.095

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

Desire for Death in the Terminally Ill

Harvey Max Chochinov, M.D., Keith G. Wilson, Ph.D., Murray Enns, M.D.,
Neil Mowchun, M.D., Sheila Lander, R.N., Martin Levitt, M.D., and Jennifer J. Clinch, M.A.

Objective: *Euthanasia and physician-assisted suicide have become prominent medical and social issues. This study investigated the prevalence of the desire for death in terminally ill patients, the stability of this desire over time, and its association with psychiatric disorders.* *Method:* *Two hundred terminally ill inpatients were given semistructured interviews that assessed their desire for death and evaluated them for major and minor depressive episodes according to the Research Diagnostic Criteria. Each patient also completed a short form of the Beck Depression Inventory and provided ratings of pain and social support. When possible, patients who expressed a desire for death received a follow-up interview after a 2-week interval.* *Results:* *Although occasional wishes that death would come soon were common (reported by 44.5% of the patients), only 17 (8.5%) of these individuals acknowledged a serious and pervasive desire to die. The desire for death was correlated with ratings of pain and low family support but most significantly with measures of depression. The prevalence of diagnosed depressive syndromes was 58.8% among patients with a desire to die and 7.7% among patients without such a desire. Follow-up interviews were conducted with six patients; in four cases, the desire to die had decreased during the 2-week interval.* *Conclusions:* *The desire for death in terminally ill patients is closely associated with clinical depression—a potentially treatable condition—and can also decrease over time. Informed debate about euthanasia should recognize the importance of psychiatric considerations, as well as the inherent transience of many patients' expressed desire to die.*

(Am J Psychiatry 1995; 152:1185–1191)

Few problems in contemporary medicine have generated as much controversy as the issues of euthanasia and physician-assisted suicide. Among the general public, support for the "right to die" has grown steadily since the 1950s, with over 60% of the population now favoring the legalization of voluntary euthanasia for patients with terminal illness (1, 2). Within the medical community, concern has been raised in response to several highly publicized case reports in which physicians have complied with patients' requests for assisted death (3, 4). These cases have promoted a spirited debate (5–11), including the publication of proposed clinical criteria and procedural safeguards for euthanasia and physician-assisted suicide (12, 13). Recent surveys suggest that 35%–60% of responding physicians believe that laws prohibiting these practices should be changed (14–16); 28%–40% of physicians have reported that if euthanasia were legally condoned, they would be willing to perform it in some circumstances (14–17). In the Netherlands, where euthanasia has been decriminalized, 54% of physicians have acknowledged assisting in at least one death at the patient's request (18).

Although it is clear that euthanasia has a strong base of support, there remain a number of central issues that are still poorly understood. First, little is known about how common it is for terminally ill patients to desire death in order to relieve their suffering. In North America, overt requests for assisted death are apparently rare (15–17), but they might become more frequent with changes in social, medical, and legal policies. In the Netherlands, voluntary euthanasia and assisted suicide account for an estimated 2.1% of all deaths (18). Patients with advanced cancer constitute the majority of these cases; in this population, 6%–7% of patients eventually choose to die with physician assistance (18).

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

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Received Nov. 2, 1994; revisions received Feb. 14 and March 21, 1995; accepted April 6, 1995. From the Departments of Psychiatry and Medicine, University of Manitoba; the Manitoba Cancer Treatment and Research Foundation, Winnipeg; the Department of Medicine and School of Psychology, University of Ottawa; the Rehabilitation Centre, Ottawa; and the World Health Organization Collaborating Centre for Quality of Life in Cancer Care, Winnipeg. Address reprint requests to Dr. Chochinov, Department of Psychiatry, University of Manitoba, 771 Bannatyne Ave., Winnipeg, Man. R3E 3N4, Canada.

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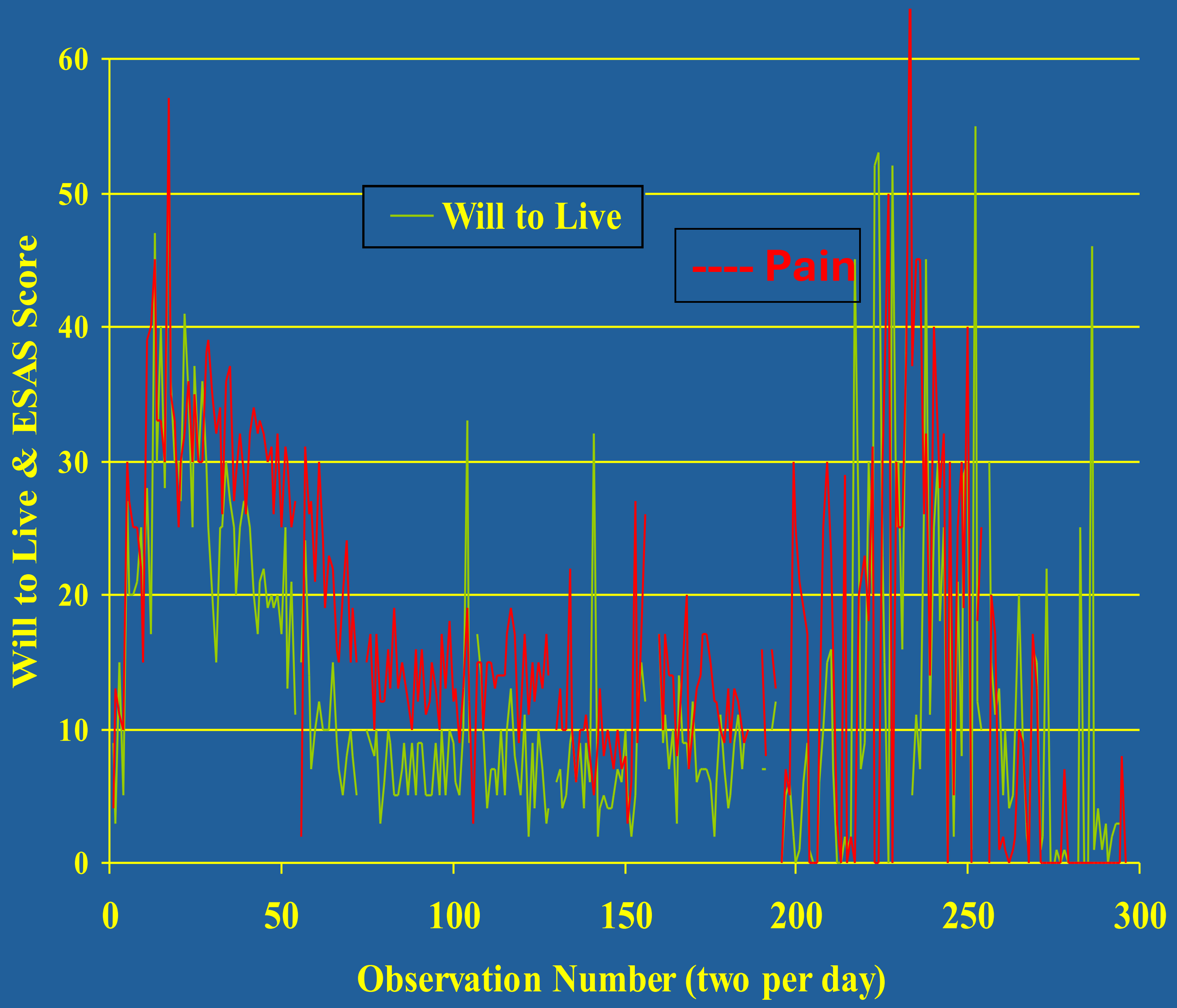
Stability of WLT with Pain in an 80 Year-old with Colorectal Cancer



Will to live in the terminally ill

Harvey Max Chochinov, Douglas Tataryn, Jennifer J Clinch, Deborah Dudgeon

Summary

Background Complex biomedical and psychosocial considerations figure prominently in the debate about euthanasia and assisted suicide. No study to date, however, has examined the extent to which a dying patient's will to live fluctuates as death approaches.

Methods This study examined patients with cancer in palliative care. Will to live was measured twice daily throughout the hospital stay on a self-report 100 mm visual analogue scale. This scale was incorporated into the Edmonton symptom assessment system, a series of visual analogue scales measuring pain, nausea, shortness of breath, appetite, drowsiness, depression, sense of well-being, anxiety, and activity. Maximum and median fluctuations in will-to-live ratings, separated by 12 h, 24 h, 7 days, and 30 days, were calculated for each patient.

Findings Of 585 patients admitted to palliative care during the study period (November, 1993, to May, 1995), 168 (29%; aged 31–89 years) met criteria of cognitive and physical fitness and agreed to take part. The pattern of median changes in will-to-live score suggested that will to live was stable (median changes <10 mm on 100 mm scale for all time intervals). By contrast, the average maximum changes in will-to-live score were substantial (12 h 33·1 mm, 24 h 35·8 mm, 7 days 48·8 mm, 30 days 68·0 mm). In a series of stepwise regression models carried out at 12 h, 24 h, and 1–4 weeks after admission, the four main predictor variables of will to live were depression, anxiety, shortness of breath, and sense of well-being, with the prominence of these variables changing over time.

Interpretation Among dying patients, will to live shows substantial fluctuation, with the explanation for these changes shifting as death approaches.

Lancet 1999; **354:** 816–19

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Introduction

A patient's state of mind is the single most important factor in understanding of a request for physician-hastened death. Euthanasia and physician-assisted suicide raise critical issues about the psychological underpinnings of death-hastening requests. This study is part of a programme of research that has addressed various psychiatric dimensions of palliative care.[1–4] The defining characteristic of this research has been that dying patients have served as the key informants. These studies have helped establish the prevalence of clinical depression among the terminally ill[1] and the extent to which dying patients may endorse a desire for death.[2] A limitation of the latter study was its largely cross-sectional design, with very little information on whether there are fluctuations in patients' will to live over the course of a terminal disease. Thus, although we now know that occasional or fleeting thoughts of a desire for death are common among the terminally ill and that some of these patients express a genuine desire for death, little is known about how these thoughts may change over the course of time.[2] Although the stability and determinants of will to live in a palliative-care setting are fundamental issues, they have received surprisingly little critical attention.

No previous studies have specifically examined the issue of will to live per se, but a few have addressed constructs that may serve as its proxy. Some studies, using responses to hypothetical scenarios before and after treatment, have documented the extent to which treatment of depression can favourably influence a patient's endorsment of life-sustaining therapy.[5,6] Other studies have shown a strong association between interest in physician-assisted suicide and depression,[2,4,7,8] pain,[2,7,9–11] and other distressing symptoms.[7,9–13] To date, only one small study reported that a desire for death may fluctuate over a brief period in a palliative-care setting.[2] Our study prospectively addressed the temporal stability of will to

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Guest Editorial

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Fractured Personhood, Suicide, and Lessons from Those Nearing Death

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

Abstract

Sometimes dying patients teach us things that apply across the entirety of the life cycle. There is a significant literature indicating that some patients toward end of life covet an earlier, or hastened, death. Many of the things that move patients toward a wish to die can be subsumed under the rubric of *fractured personhood*. This idea describes a state of *brokenness*, causing people to feel they are no longer the person they once were, and that the person they have become is no longer worthy of living. This article explores the idea of fractioned personhood, and how this concept might inform our understanding of self-harm and suicide within the general population.

Keywords: depression; dignity; loss of autonomy; personhood; suicide; terminal illness

Introduction

CONDUCTING RESEARCH IN PALLIATIVE CARE has taught me that dying patients often reveal insights that apply across the entirety of human experience.[1] For those nearing death, meaning, purpose, feeling affirmed for who they are, and connections with others are paramount.[2] Dying, however, does not have a monopoly on those issues, which are vital throughout life although perhaps more pressing or amplified as time is running out. This leads one to speculate whether the dynamic moving terminally ill patients toward a wish to die might provide insights regarding suicide and self-harm across the entire life cycle.

Our studies of the terminally ill demonstrate strong associations between depression, hopelessness, and a desire for death.[3] Similarly associations between depression, hopeless, and suicide throughout life are well documented.[4] A deeper dive into the psychological, existential, and spiritual antecedents of a wish to die reveals dying patients disclose struggles that cut to the core of who they are as persons. For those coveting hastened death, the inability to carry out meaningful activities, loss of autonomy, diminished agency, and loss of dignity figure prominently.[5]

Each describe influences that can cause people to feel they are no longer the person they once were. In other words, wanting to die emerges within a state of *fractured personhood*, marked by dissatisfaction, contempt, and rejection of who they are, relative to who they were or want to be, ultimately making life intolerable.

Looking Toward Suicide

How might those insights regarding the fragility of personhood apply to self-harm and suicide beyond the confines of terminal illness? While facing death is the penultimate existential trauma, trauma in all its various forms heightens the risk of suicide. Sexual and other interpersonal traumas (such as rape, sexual assault, intimate partner violence, spousal abuse, and child abuse) are all significantly associated with suicide attempts in both men and women, even when controlling for sociodemographic characteristics and mental disorders.[6] There is also strong evidence that the number of traumatic events experienced is positively associated with increased risk of suicide attempts, indicating a dose–response effect of exposure to trauma.

Even witnessing traumatic events, such as bad injury, rape, physical attack, and physical abuse, appears to heighten the risk of suicide.[7] Like at end of life, perhaps patients exposed to trauma experience an assault on integrity of personhood, causing them to feel they are no longer the

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Self-Reported Dignity among People Admitted to Psychiatric Wards and Its Association with Suicidal Behaviour

Perte de dignité auto-évaluée chez les personnes admises dans des services psychiatriques et son association avec les comportements suicidaires

Matthew Buchok, MD[1], Harvey M. Chochinov, MD, PhD[1,2], Sarah Kowall, BA[1], Shay-Lee Bolton, PhD[1,3], Renée El-Gabalawy, PhD[1,4,5,6], Jennifer M. Hensel, MD, MSc[1] and James M. Bolton, MD[1]

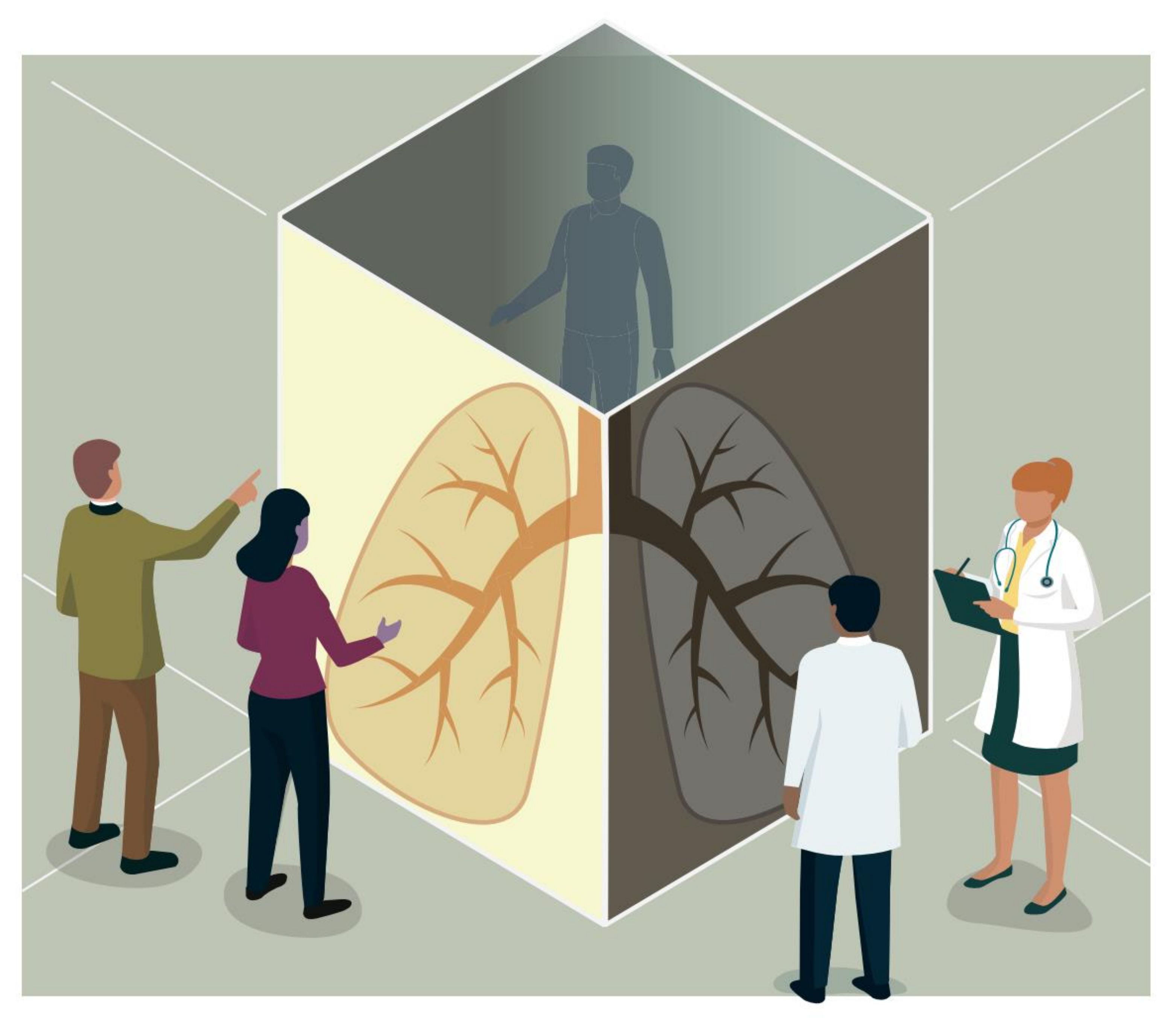
Abstract

Objective: Dignity is an important construct in vulnerable persons; however, there is limited research examining dignity in patients with mental illness. Our study aims to examine self-reported dignity-related distress among psychiatric inpatients using the patient dignity inventory (PDI) and investigate the relationship between this distress and demographic and clinical variables, including suicidality.

Methods: Between June 2021 and July 2022, 97 participants were recruited from two hospitals in Winnipeg, Canada. Participants were patients admitted to acute psychiatric wards, 18 years or older, and provided informed consent. Participants completed a series of standardized self-report measures including the PDI and validated measures of depression, alcohol use, and suicidal behaviour. Demographic and clinical information was also obtained from patient charts. General linear models were used to investigate the relationship between dignity-related distress and demographic and clinical variables.

Results: The majority of the study sample had moderate to high depression symptomatology (57.7%), previous psychiatric hospitalizations (67.4%), and previous suicide attempts (52.6%). Dignity-related distress was not associated with gender, sexual orientation, age, marital status, or education. Higher levels of dignity-related distress were associated with mental disorder comorbidities ($P < 0.01$), greater depressive symptoms ($P < 0.001$), and higher risk alcohol use behaviours ($P < 0.001$). Increasing levels of dignity-related distress were associated with greater intensity of suicidal ideation ($P < 0.001$) having at least one previous suicide attempt ($P < 0.001$), and having a high desire to die during that attempt ($P < 0.001$).

Conclusion: Among psychiatric inpatients, impairment in their sense of dignity was associated with greater clinical severity including both a history of suicide attempt and current suicidal ideation. Further investigation may lead to targeted interventions to mitigate dignity-related distress and improve patient outcomes.



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

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

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

Broyard's words underscore the costs and hazards of becoming a patient. The word "patient" comes from the Latin patiens, meaning to endure, bear, or suffer, and refers to an acquired vulnerability and dependency imposed by changing health circumstances. Relinquishing autonomy is no small matter and can exact considerable costs.[2] These costs are sometimes relatively minor—for example, accepting clinic schedules or hospital routines. At other times, the costs seem incompatible with life itself. When patients experience a radical unsettling of their conventional sense of 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

EDITORIAL, p 167

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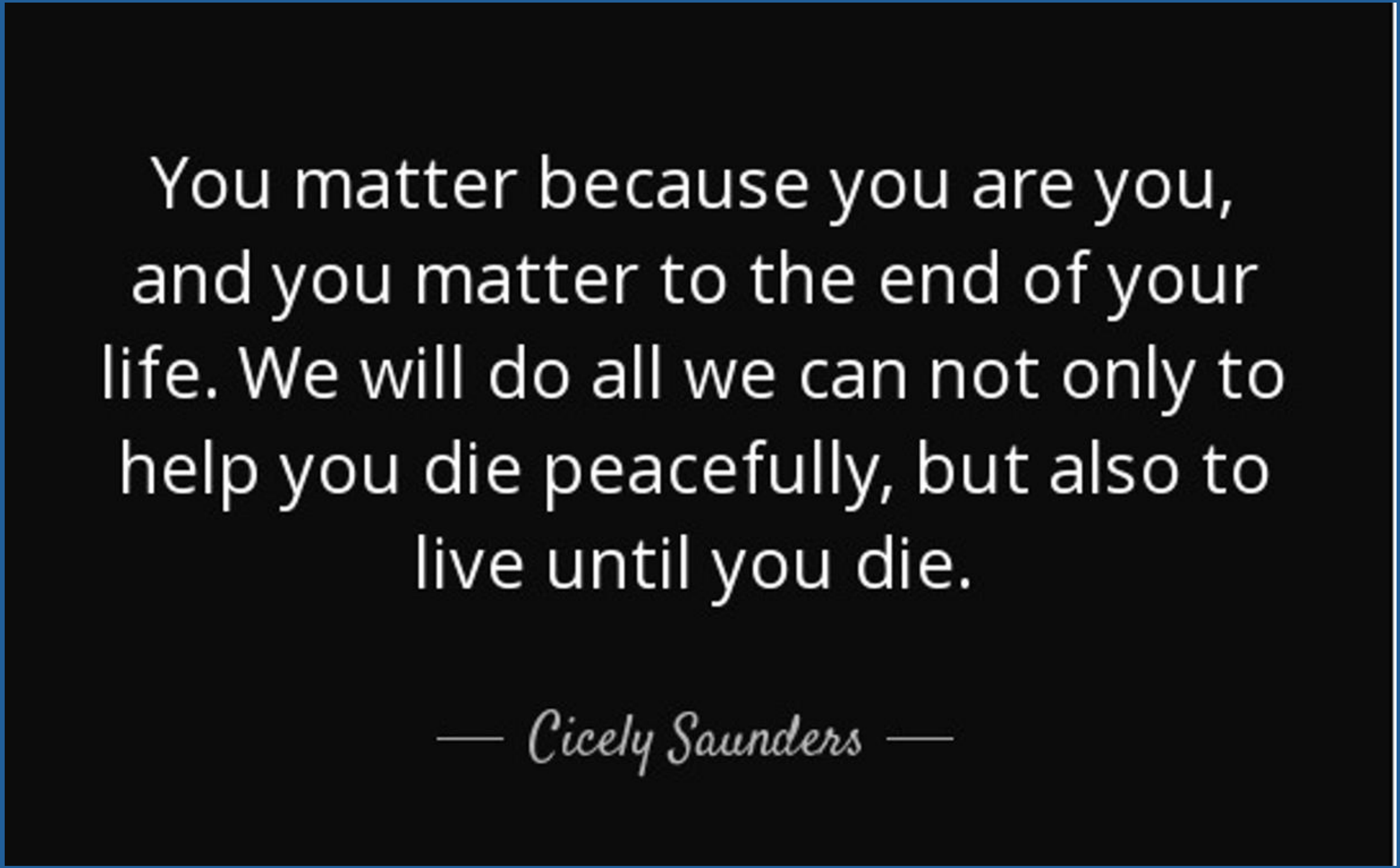
PLAINPICTURE/OPITZ



You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.

— Cicely Saunders —

Intensive Caring: Reminding Patients They Matter

Harvey Max Chochinov, MD, PhD[1]

Introduction

Dame Cicely Saunders, the founder of the modern hospice movement and palliative care, famously said, *You matter because you are you, and you matter to the last moment of your life.*[1] This quote has become the central philosophical tenet of palliative care. It implores us to remind patients, who may be feeling helpless, hopeless, or worthless, that *they matter*. Even when they feel life is no longer worth living, we, their health care professionals, must affirm their intrinsic worth, for all that they are, all that they were, and all that they will become in the collective memories of those they will eventually leave behind. While Dame Cicely gave us this inspiring direction, missing is a well-articulated approach centered on affirming patients matter. This approach, which I will coin *Intensive Caring*, incorporates various empirically derived components that collectively describe a way of being with patients who have lost hope, who have lost any sense of meaning or purpose, and who ultimately feel they *no longer matter*.

Why It Matters to Matter

There is abundant evidence that patients approaching death are susceptible to feeling they *no longer matter*. Our own research demonstrates that patients approaching death may feel a burden to others[2]; that life is futile, and an affliction to those they feel encumbered by having to look after them. Self-perceived burden is contagious and self-perpetuating; patients who experience it may cause family members to feel helpless and exhausted, tacitly affirming that they are indeed a burden.[3] Feeling a burden has consistently been reported as a driver of desire for death, loss of will to live, and interest in physician-hastened death.[3] From the patient's perspective, death offers a way to relieve the burden they sense they have become, while ending a life they feel *no longer matters*.

I recall one such patient early in my career, who struggled with feelings of futility and hopelessness in the face of end-stage brain cancer. He'd been admitted to an inpatient neuro-oncology ward, where he felt a burden to his health care team and wanted me to help him die. He saw little point in continuing his life, which had been marked by bipolar disorder, polysubstance abuse, and family estrangement; he emphatically felt he no longer mattered. I told him that I could not and would not hasten his death, but was prepared to support him in any way that I could until the very end. We began to meet weekly, occasionally twice a week, while I delved into learning more about who he was, including the origins of his chronic self-loathing. He would often complain about things such as hospital routines, the medical staff—and one day began to berate me and the futility of my efforts to help him. Being young and naïve, I suggested that if our meetings were not helpful, neither of us was under any obligation to continue. He responded as if I had gone mad. "Are you crazy?" he said. "These appointments are the only thing that keep me going!"

Elements of Intensive Caring

Intensive Caring requires finding ways to remind patients that they still matter (Table 1). A foundational element of this approach is **nonabandonment**, which demands committed, ongoing care, and caring, even when patients no longer care about themselves. Dame Cicely wrote "suffering is only intolerable when nobody cares."[1] Absent someone who cares, suffering, like cancer, can grow, spread, and even kill. Studies have shown that when patients feel abandoned and bereft of care, they are more likely to contemplate or to die by suicide.[4] Other studies have reported that a sustained, quality connection between patients and their oncologist provides better protection against suicidal ideation than mental health interventions, including psychotropic medications.[5] Our studies on desire for death in the terminally ill found those who desire death report lower family support relative to those who don't.[6] Hence, the assurance of continued caring and support is a vital component of helping patients feel *they matter*.

Another component of *Intensive Caring* **is taking a keen interest in who the patient is as a person**. Our studies of the Patient Dignity Question (PDQ), which asks "what do I need to know about you as a person to give you the best care possible," helps patients feel they are seen as whole persons, rather than the embodiment of their disease or disability.[7] A recent study of more than 2,000 inpatients and outpatients being seen at a quaternary care cancer center in the

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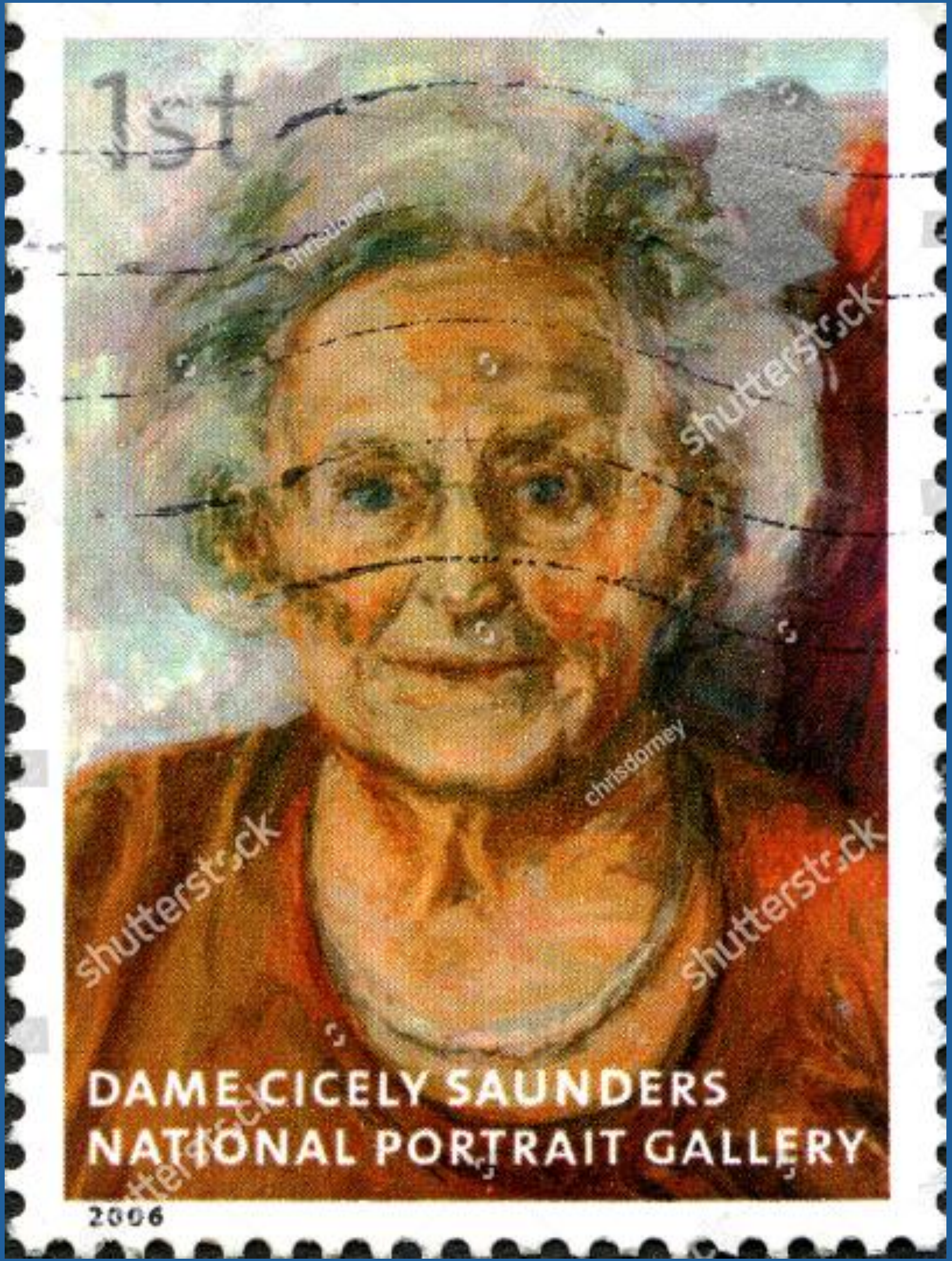
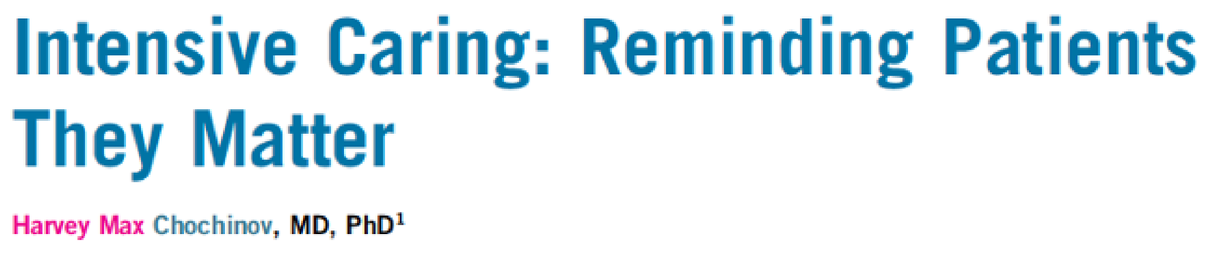
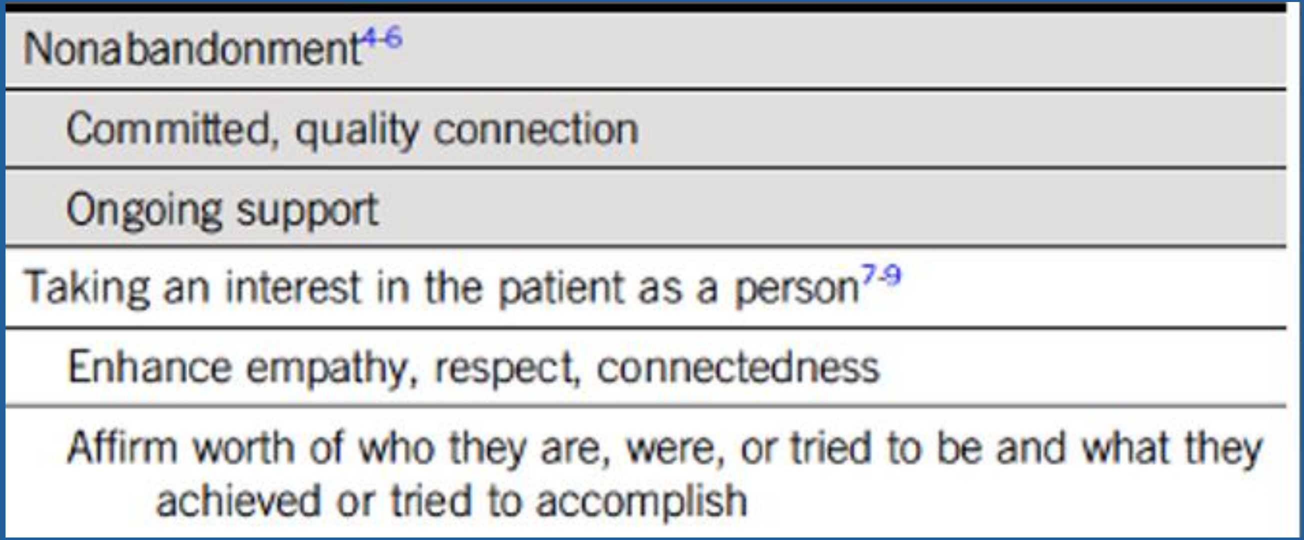




Intensive Caring: Reminding Patients They Matter

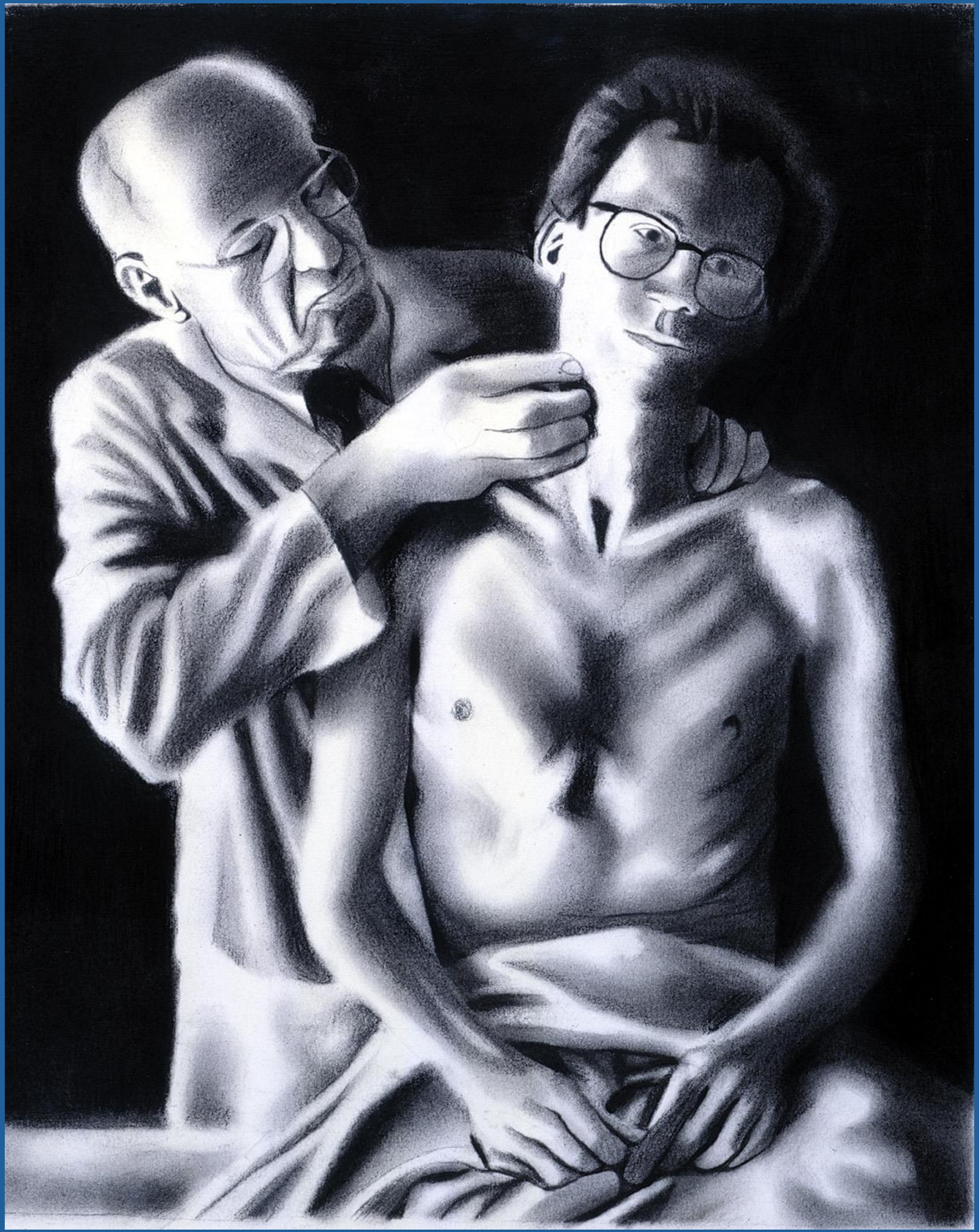
Harvey Max Chochinov, MD, PhD[1]

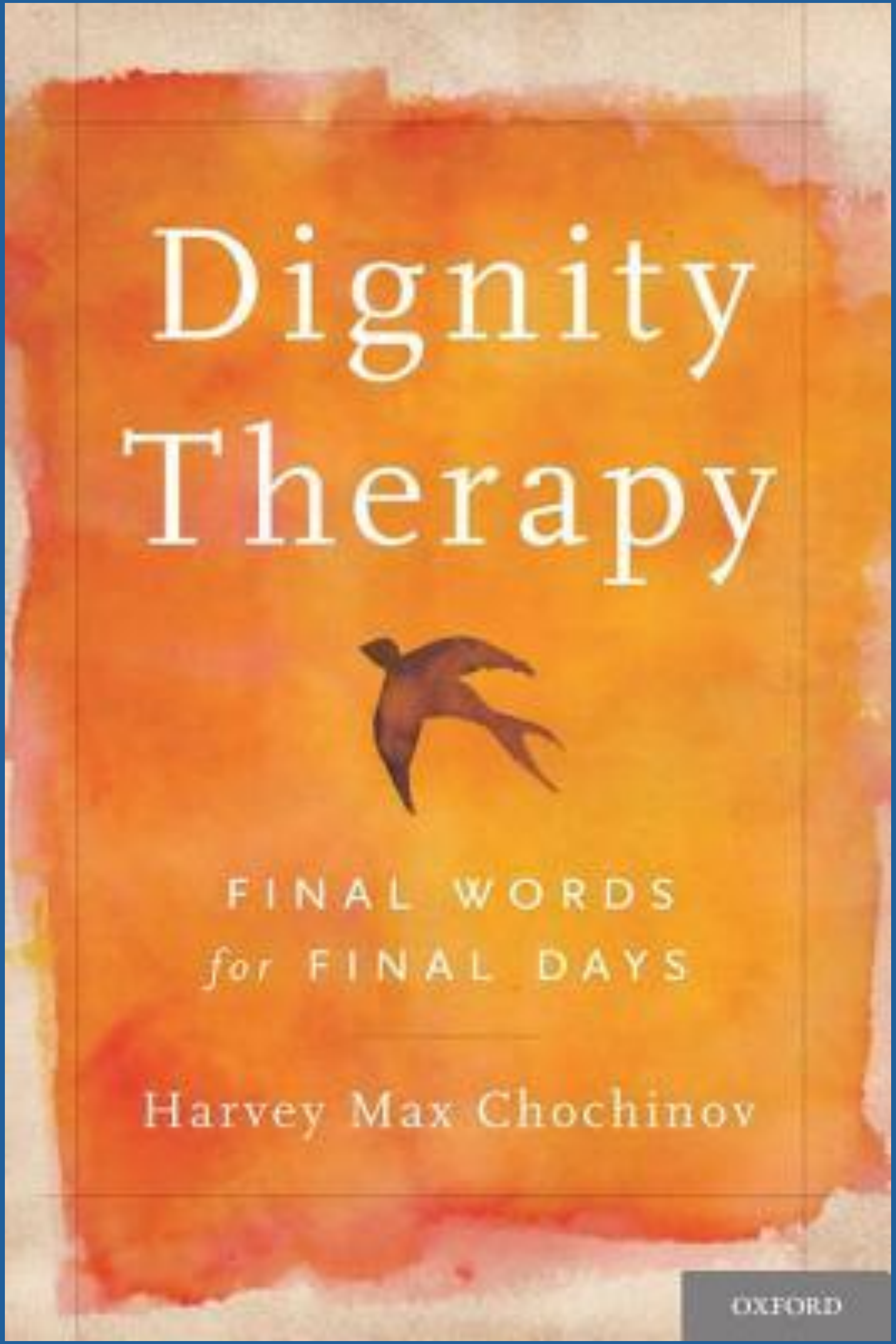


- Nonabandonment[4-6]
  - Committed, quality connection
  - Ongoing support
- Taking an interest in the patient as a person[7-9]
  - Enhance empathy, respect, connectedness
  - Affirm worth of who they are, were, or tried to be and what they achieved or tried to accomplish

> Suffering is only intolerable when nobody Cares
>
> – Dame Cicely Sanders

Broyard … abandon to my illness



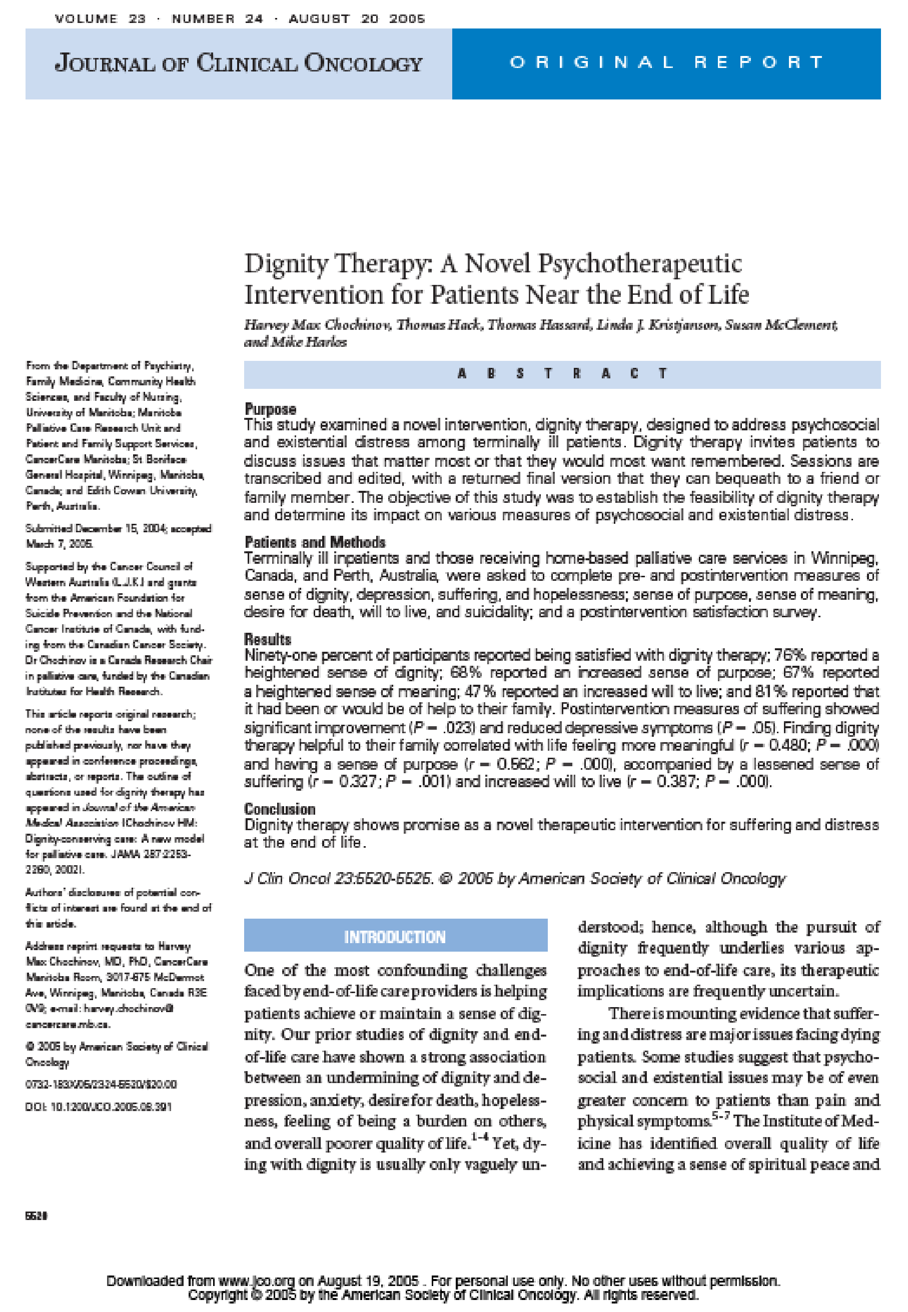


Dignity Therapy

FINAL WORDS for FINAL DAYS

Harvey Max Chochinov

OXFORD



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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.

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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.

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INTRODUCTION

One of the most confounding challenges faced by end-of-life care providers is helping patients achieve or maintain a sense of dignity. Our prior studies of dignity and end-of-life care have shown a strong association between an undermining of dignity and depression, anxiety, desire for death, hopelessness, feeling of being a burden on others, and overall poorer quality of life.[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

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?

DEFINING DIGNITY AT END OF LIFE: ONE QUESTION TO ASK HOSPICE PATIENTS

by Lizzy Miles

"happy-go-lucky"

PALLIMED

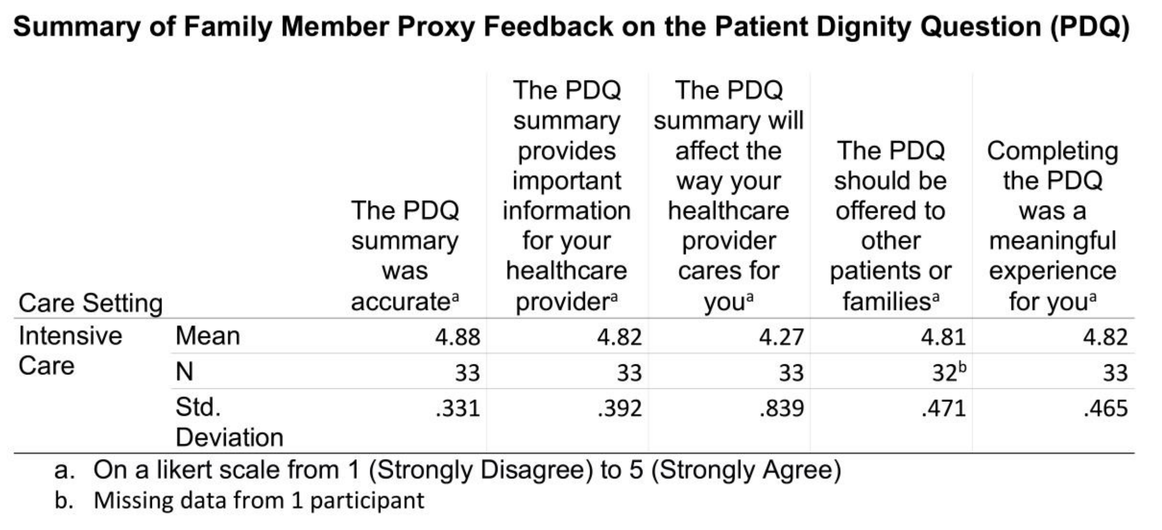
A Hospice & Palliative Medicine Blog

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%)



Summary of Family Member Proxy Feedback on the Patient Dignity Question (PDQ)

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	4.88	4.82	4.27	4.81	4.82
	N	33	33	33	32[b]	33
	Std. Deviation	.331	.392	.839	.471	.465

a. On a likert scale from 1 (Strongly Disagree) to 5 (Strongly Agree)
b. Missing data from 1 participant

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.”

• Dignity • Respect • Honour • Esteem • Importance • Worth • Kindness • You Matter •

Patient
DIGNITY QUESTION

People around the world want to be seen and respected for who they are. The Patient Dignity Question offers a simple way of initiating a brief conversation, focused on who the patient is as a person. It can be easily introduced by saying, "I know a lot about you medically, but much less about who you are as a person. So, tell me, *what do I need to know about you as a person to give you the best care possible?"* If required, prompts may include inquiry about values and beliefs, worries and concerns, roles and responsibilities, relationships, qualities, history and stories. Responses are summarized into two or three paragraphs, which are then read to the patient, edited based on their feedback; and with the patient's permission, placed on their medical chart.

What do I need to know about you as a person to give you the best care possible?
ENGLISH

Que dois-je savoir à ton égard pour t'offrir les soins les plus appropriés pour toi?
FRENCH

¿ Qué debería saber de usted, como persona, para ofrecerle el mejor cuidado posible ?
SPANISH

Cosa potrebbe dirmi di lei come persona in modo da poterla assistere e curare al meglio?
ITALIAN

O que precisamos saber sobre si enquanto pessoa para podermos dar-lhe o melhor cuidado possível?
PORTUGUESE

מה אני צריך לדעת עליך כאדם על מנת להעניק לך את הטיפול המיטבי האפשרי?
HEBREW

Що мені потрібно знати про вас як про людину, щоб забезпечити вам найкращий догляд та лікування?
UKRAINIAN

आपको सर्वोत्तम संभव देखभाल देने के लिए एक व्यक्ति के रूप में मुझे आपके बारे में क्या जानने की आवश्यकता?
HINDI

Was sollte ich über Sie als Person wissen, um Sie bestmöglich versorgen zu können?
GERMAN

Was muess ich über Sie als Person wüsse, um Sie beschtmöglichscht versorge zchönne?
SWISS-GERMAN

ما هو الشيء الذي احتاج اني اعرفه عنك كشخص لاجل اقدر اقدم لك أفضل مساعدة و خدمة ممكنه؟
ARABIC

Что мне нужно знать о вас как о человеке, чтобы обеспечить вам наилучший уход и лечение?
RUSSIAN

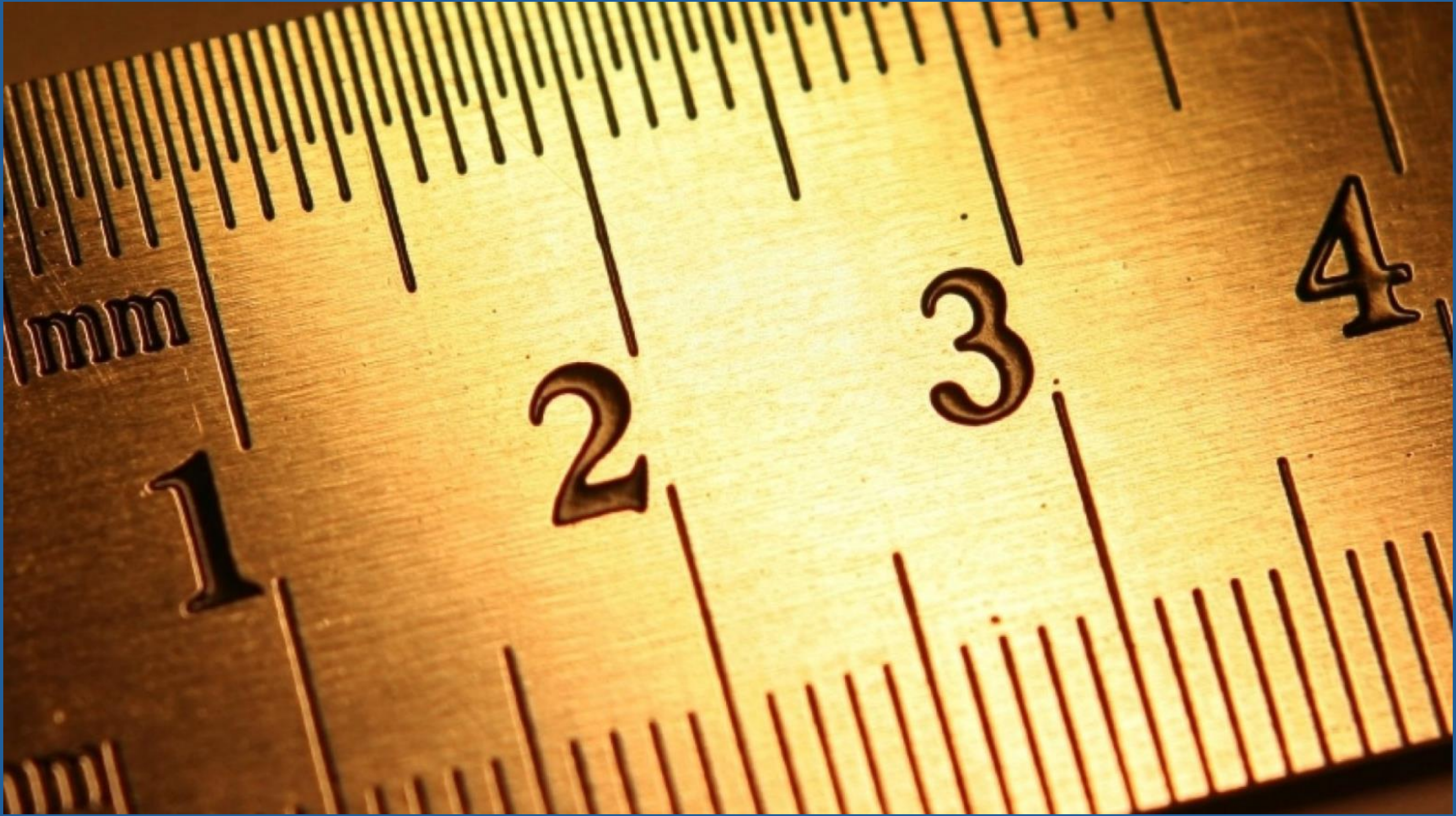
为了给您提供最佳的照护，我们需要了解您的什么信息?
MANDARIN

對您個人來講，我需要了解您的咩信息，才能為您提供最好的護理呢?
CANTONESE

가능한 한 최선의 치료를 해드리기 위해 귀하를 한 사람으로써 저희가 무엇을 알아두어야 할까요?
KOREAN

できる限り最善のケアをするために, あなたという一人の人間について, 私はどんなことを知っておくとよいでしょうか？
JAPANESE

Dignity IN CARE dignityincare.ca


mm
1
2
3
4

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

The Platinum Rule

Do unto patients as they would want done unto themselves

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."

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Additional Contributions: I thank my parents and Ellen's nieces and nephews for granting permission to publish this information.

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1. Chochinov HM. The platinum rule: a new standard for person-centered care. *J Palliat Med*. 2022;25(6):854-856. doi:10.1089/jpm.2022.0075

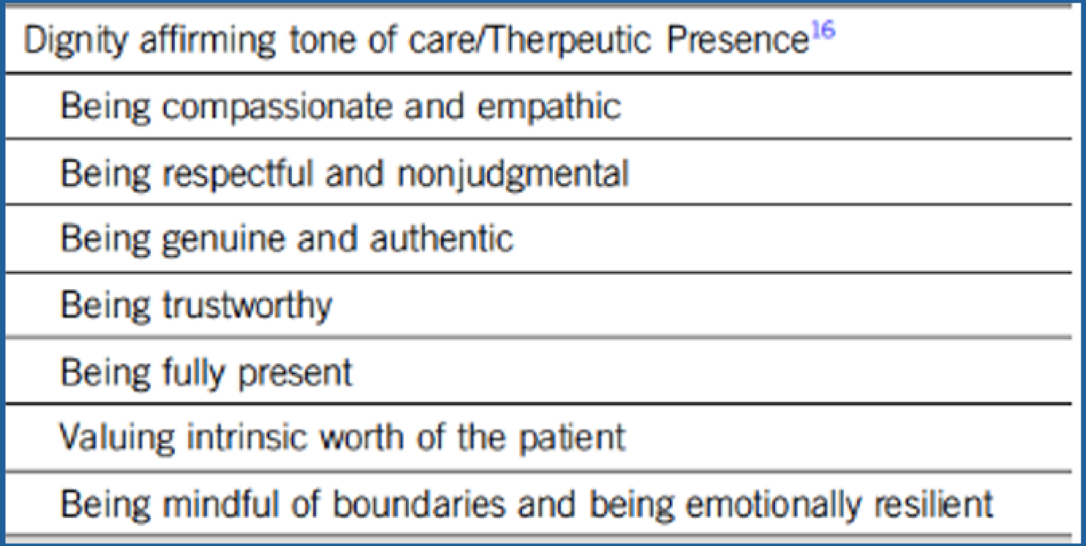
2. Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med*. 1982;306(11):639-645. doi:10.1056/NEJM198203183061104

Merits of the Platinum Rule

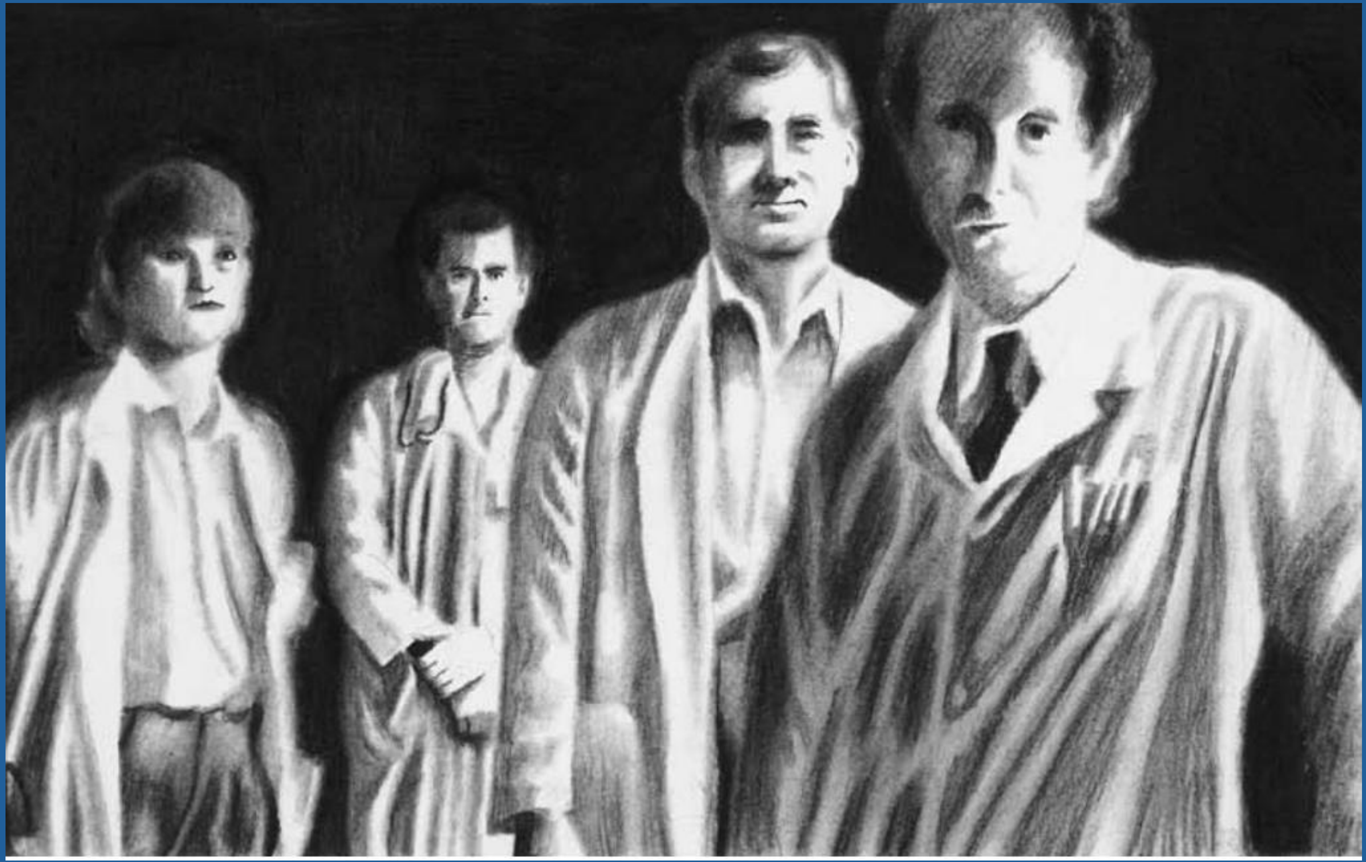
- Always considers patient perspective
- Helps us recognized and confront personal biases
- Important standard for substitute decision maker
- Raises the bar of Person-Centered Care

Intensive Caring: Reminding Patients They Matter

Harvey Max Chochinov, MD, PhD[1]



Dignity affirming tone of care/Therpeutic Presence[16]
Being compassionate and empathic
Being respectful and nonjudgmental
Being genuine and authentic
Being trustworthy
Being fully present
Valuing intrinsic worth of the patient
Being mindful of boundaries and being emotionally resilient



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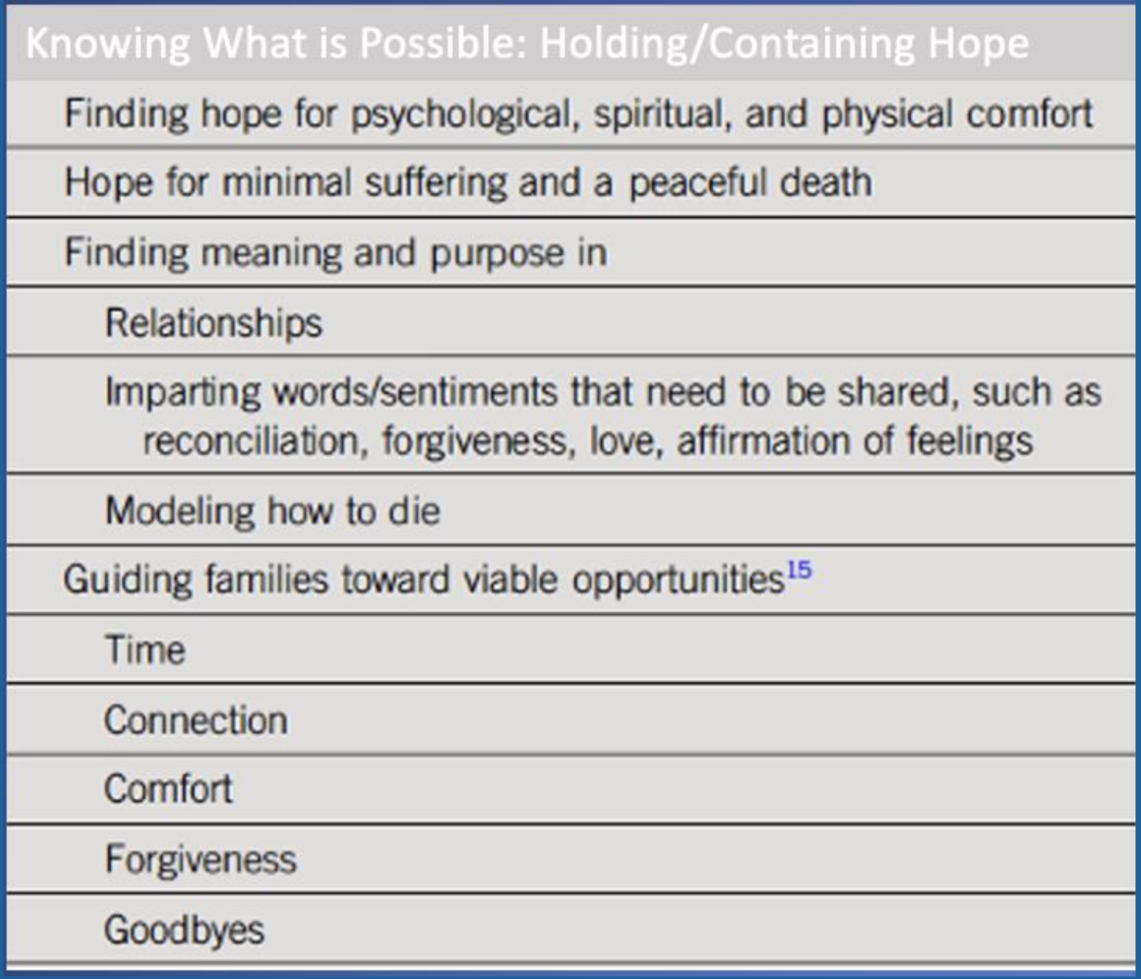

Knowing What is Possible: Holding/Containing Hope
Finding hope for psychological, spiritual, and physical comfort
Hope for minimal suffering and a peaceful death
Finding meaning and purpose in
Relationships
Imparting words/sentiments that need to be shared, such as reconciliation, forgiveness, love, affirmation of feelings
Modeling how to die
Guiding families toward viable opportunities[15]
Time
Connection
Comfort
Forgiveness
Goodbyes

comments and controversies

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Introduction

Dame Cicely Saunders, the founder of the modern hospice movement and palliative care, famously said, *You matter because you are you, and you matter to the last moment of your life.*[1] This quote has become the central philosophical tenet of palliative care. It implores us to remind patients, who may be feeling helpless, hopeless, or worthless, that *they matter*. Even when they feel life is no longer worth living, we, their health care professionals, must affirm their intrinsic worth, for all that they are, all that they were, and all that they will become in the collective memories of those they will eventually leave behind. While Dame Cicely gave us this inspiring direction, missing is a well-articulated approach centered on affirming patients matter. This approach, which I will coin *Intensive Caring*, incorporates various empirically derived components that collectively describe a way of being with patients who have lost hope, who have lost any sense of meaning or purpose, and who ultimately feel they *no longer matter*.

Why It Matters to Matter

There is abundant evidence that patients approaching death are susceptible to feeling they *no longer matter*. Our own research demonstrates that patients approaching death may feel a burden to others[2]; that life is futile, and an affliction to those they feel encumbered by having to look after them. Self-perceived burden is contagious and self-perpetuating; patients who experience it may cause family members to feel helpless and exhausted, tacitly affirming that they are indeed a burden.[3] Feeling a burden has consistently been reported as a driver of desire for death, loss of will to live, and interest in physician-hastened death.[3] From the patient's perspective, death offers a way to relieve the burden they sense they have become, while ending a life they feel *no longer matters*.

I recall one such patient early in my career, who struggled with feelings of futility and hopelessness in the face of end-stage brain cancer. He'd been admitted to an inpatient neuro-oncology ward, where he felt a burden to his health care team and wanted me to help him die. He saw little point in continuing his life, which had been marked by bipolar disorder, polysubstance abuse, and family estrangement; he emphatically felt he no longer mattered. I told him that I could not and would not hasten his death, but was prepared to support him in any way that I could until the very end. We began to meet weekly, occasionally twice a week, while I delved into learning more about who he was, including the origins of his chronic self-loathing. He would often complain about things such as hospital routines, the medical staff—and one day began to berate me and the futility of my efforts to help him. Being young and naïve, I suggested that if our meetings were not helpful, neither of us was under any obligation to continue. He responded as if I had gone mad. "Are you crazy?" he said. "These appointments are the only thing that keep me going!"

Elements of Intensive Caring

Intensive Caring requires finding ways to remind patients that they still matter (Table 1). A foundational element of this approach is **nonabandonment**, which demands committed, ongoing care, and caring, even when patients no longer care about themselves. Dame Cicely wrote "suffering is only intolerable when nobody cares."[1] Absent someone who cares, suffering, like cancer, can grow, spread, and even kill. Studies have shown that when patients feel abandoned and bereft of care, they are more likely to contemplate or to die by suicide.[4] Other studies have reported that a sustained, quality connection between patients and their oncologist provides better protection against suicidal ideation than mental health interventions, including psychotropic medications.[5] Our studies on desire for death in the terminally ill found those who desire death report lower family support relative to those who don't.[6] Hence, the assurance of continued caring and support is a vital component of helping patients feel *they matter*.

Another component of *Intensive Caring* **is taking a keen interest in who the patient is as a person**. Our studies of the Patient Dignity Question (PDQ), which asks "what do I need to know about you as a person to give you the best care possible," helps patients feel they are seen as whole persons, rather than the embodiment of their disease or disability.[7] A recent study of more than 2,000 inpatients and outpatients being seen at a quaternary care cancer center in the

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ASCO

Journal of Clinical Oncology

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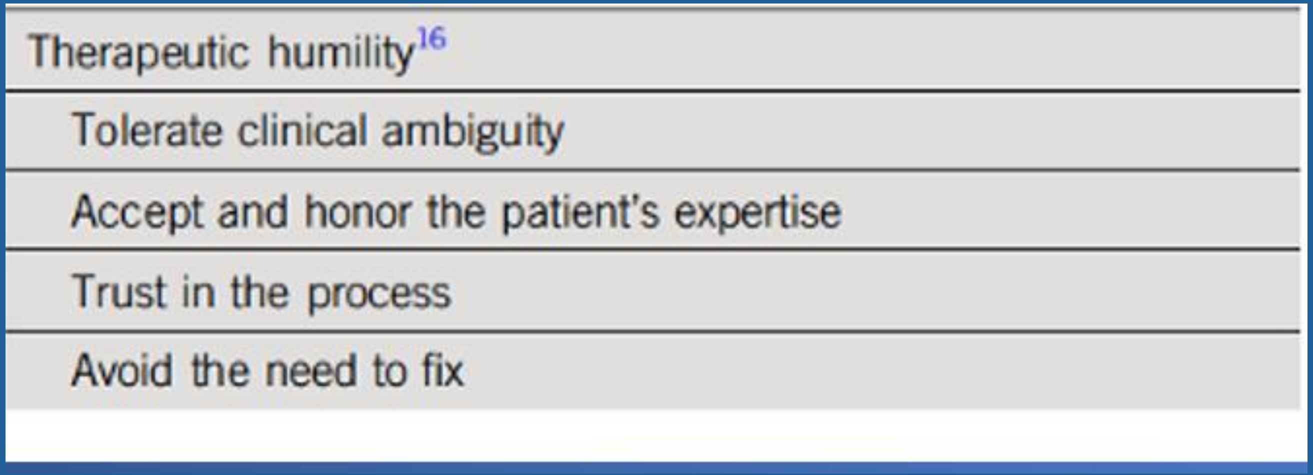

Therapeutic humility[16]
Tolerate clinical ambiguity
Accept and honor the patient's expertise
Trust in the process
Avoid the need to fix

Therapeutic humility sees notions of fixing yield to commitment to understand the nature of the patient's suffering, while creating a safe space to bear witness, to validate, and to comfort always.

comments and controversies

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There is abundant evidence that patients approaching death are susceptible to feeling they *no longer matter*. Our own research demonstrates that patients approaching death may feel a burden to others[2]; that life is futile, and an affliction to those they feel encumbered by having to look after them. Self-perceived burden is contagious and self-perpetuating; patients who experience it may cause family members to feel helpless and exhausted, tacitly affirming that they are indeed a burden.[3] Feeling a burden has consistently been reported as a driver of desire for death, loss of will to live, and interest in physician-hastened death.[3] From the patient's perspective, death offers a way to relieve the burden they sense they have become, while ending a life they feel *no longer matters*.

I recall one such patient early in my career, who struggled with feelings of futility and hopelessness in the face of end-stage brain cancer. He'd been admitted to an inpatient neuro-oncology ward, where he felt a burden to his health care team and wanted me to help him die. He saw little point in continuing his life, which had been marked by bipolar disorder, polysubstance abuse, and family estrangement; he emphatically felt he no longer mattered. I told him that I could not and would not hasten his death, but was prepared to support him in any way that I could until the very end. We began to meet weekly, occasionally twice a week, while I delved into learning more about who he was, including the origins of his chronic self-loathing. He would often complain about things such as hospital routines, the medical staff—and one day began to berate me and the futility of my efforts to help him. Being young and naïve, I suggested that if our meetings were not helpful, neither of us was under any obligation to continue. He responded as if I had gone mad. "Are you crazy?" he said. "These appointments are the only thing that keep me going!"

Elements of Intensive Caring

Intensive Caring requires finding ways to remind patients that they still matter (Table 1). A foundational element of this approach is **nonabandonment**, which demands committed, ongoing care, and caring, even when patients no longer care about themselves. Dame Cicely wrote "suffering is only intolerable when nobody cares."[1] Absent someone who cares, suffering, like cancer, can grow, spread, and even kill. Studies have shown that when patients feel abandoned and bereft of care, they are more likely to contemplate or to die by suicide.[4] Other studies have reported that a sustained, quality connection between patients and their oncologist provides better protection against suicidal ideation than mental health interventions, including psychotropic medications.[5] Our studies on desire for death in the terminally ill found those who desire death report lower family support relative to those who don't.[6] Hence, the assurance of continued caring and support is a vital component of helping patients feel *they matter*.

Another component of *Intensive Caring* **is taking a keen interest in who the patient is as a person**. Our studies of the Patient Dignity Question (PDQ), which asks "what do I need to know about you as a person to give you the best care possible," helps patients feel they are seen as whole persons, rather than the embodiment of their disease or disability.[7] A recent study of more than 2,000 inpatients and outpatients being seen at a quaternary care cancer center in the

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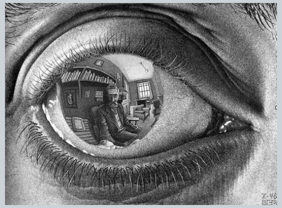
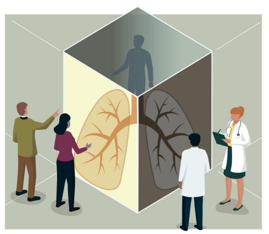
Traditional Medical Paradigm		*Intensive Caring*
Examine		Who is this person?
Diagnose		Understanding suffering
Fix		Comfort/Being With

comments and controversies

Intensive Caring: Reminding Patients They Matter

Harvey Max Chochinov, MD, PhD[1]

Introduction

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It has been more than 50 years since Dame Cicely shared the wisdom informing this clinical approach. Decades later, when medicine's reach to fix exceeds its grasp, the time to consider the role of Intensive Caring
is now


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CA/HEALTHSCIENCES
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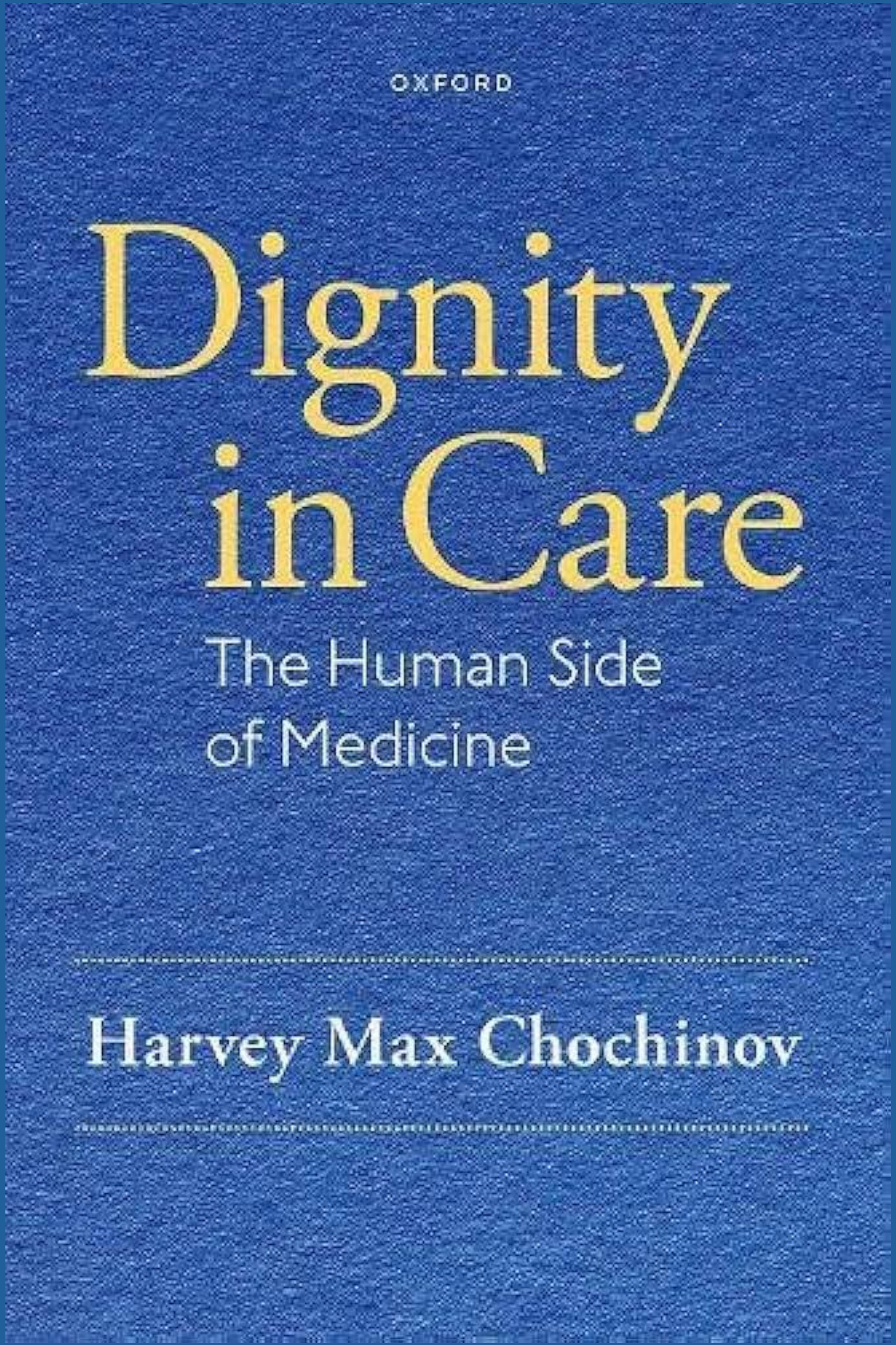

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Dignity in Care

The Human Side of Medicine

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