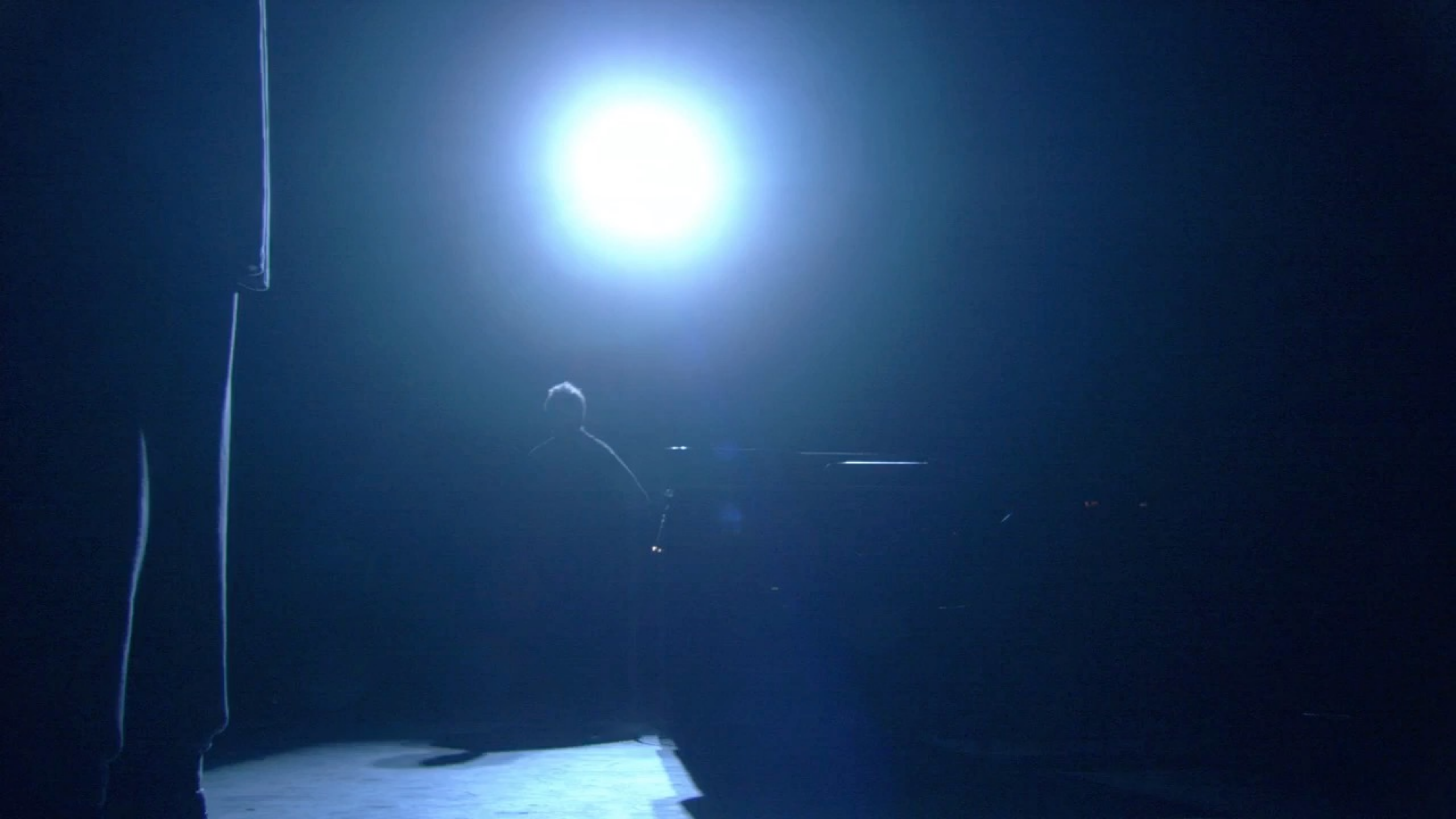
Dignity in Care: A Virtual Workshop Sept 14, 21, 28, 2023

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

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




Special
BLEND

Is It Normal for Terminally Ill Patients to Desire Death?

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

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

(Am J Psychiatry 143:208–211, 1986)

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

Because the number of suicides increases as a result of publicity and imitative behavior (1–3), the publicity currently attracted by voluntary euthanasia may add to the number of suicides, but it is not clear whether any of the additional suicides will be rational. Some studies (4–7) have provided indirect evidence that suicide is highly dependent on mental disorder, and four retrospective studies (8–11) have provided direct evidence that almost all people who complete suicide have a mental disorder at the time; a prospective study (12) has suggested that few individuals with no identifiable mental illness commit suicide. Depression, however, is underdiagnosed and often inadequately treated (13), and although most individuals who complete suicide are under medical care at the time of death, the doctors of many have failed to recognize the symptoms of depressive illness or have given inadequate treatment (11, 14).

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

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

METHODOLOGIC PROBLEMS

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

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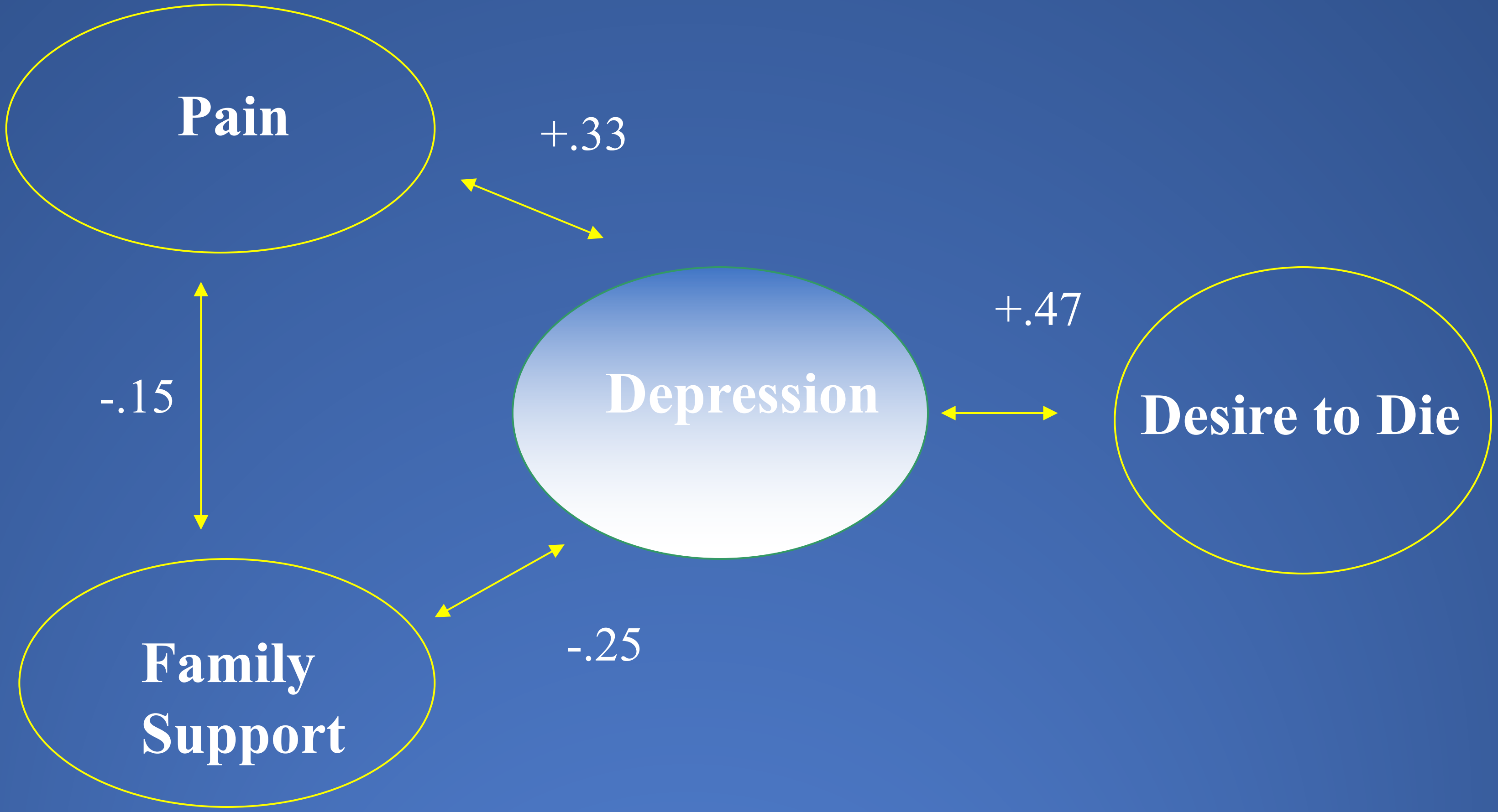
Received Jan. 25, 1985; revised June 27, 1985; accepted Oct. 1, 1985. From the Departments of Psychiatry and Social and Preventative Medicine, Faculty of Medicine, University of Manitoba. Address reprint requests to Dr. Brown, Department of Psychiatry, 770 Bannatyne Ave., Winnipeg, Man. R3E 0W3, Canada.

The authors thank Dr. J. Varsamis, who had previously devised the checklist for *DSM-III* depression for use by psychiatric nurses.

Distribution of Desire for Death Responses

Responses	**Prevalence (%)**
0 No information	1 (0.5%)
1 No desire for early death	110 (55%)
2 Slight; has had occasional or fleeting thoughts	60 (30%)
3 Mild; has had a desire for early death, but not always	12 (6.0%)
4 Moderate; has a genuine and consistent desire for early death	15 (7.5%)
5 Severe; has had difficulty diverting thoughts from desire to die; prays for death	1 (0.5%)
6 Extreme; obsessed with desire to die; talks of little else; asks for euthanasia; prays for death almost constantly	1 (0.5%)

Chochinov HM, Wilson KG, et al. Am J Psychiatry. 1995;152:1185-91.



Pain

+.33

-.15

Depression

+.47

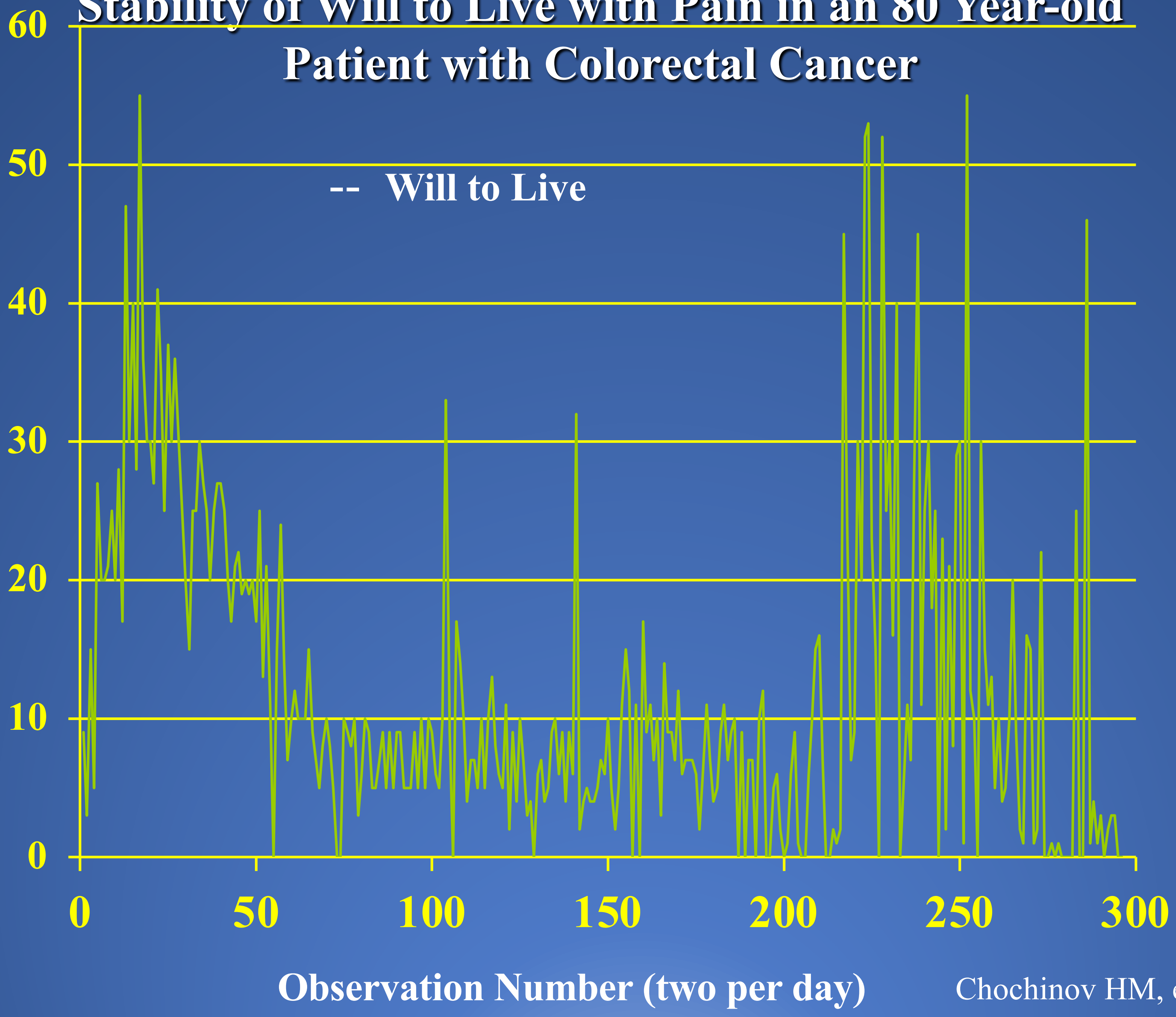
Desire to Die

Family Support

-.25

Chochinov, Wilson. Canadian Journal of Psychiatry 1995

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



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

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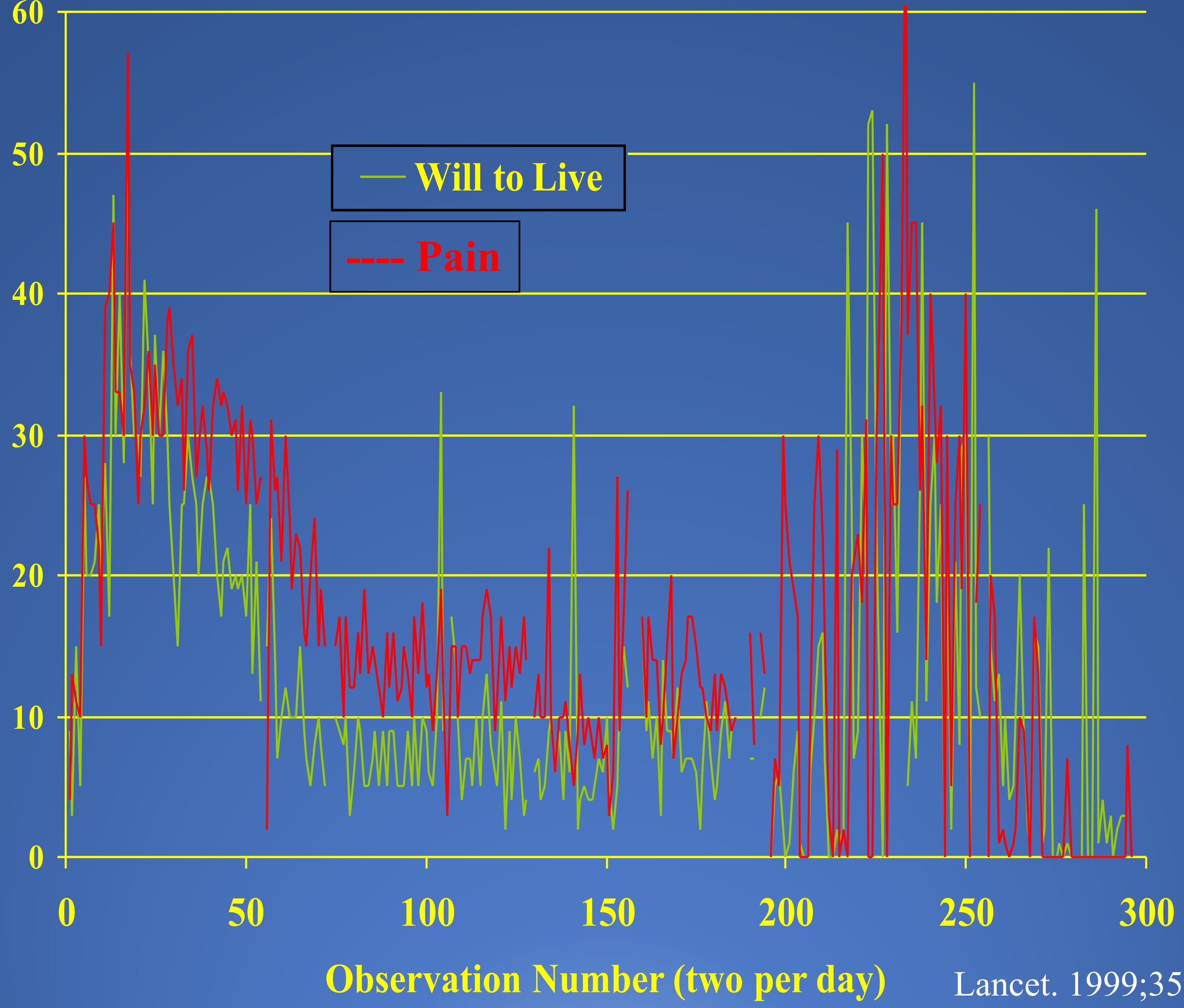


Lancet. 1999;354:816-9.

The Father of the Anti-Vaxxers

Newsweek

02.20.2015

DEATH
BECOMES
THEM

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

Reasons, According to 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

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

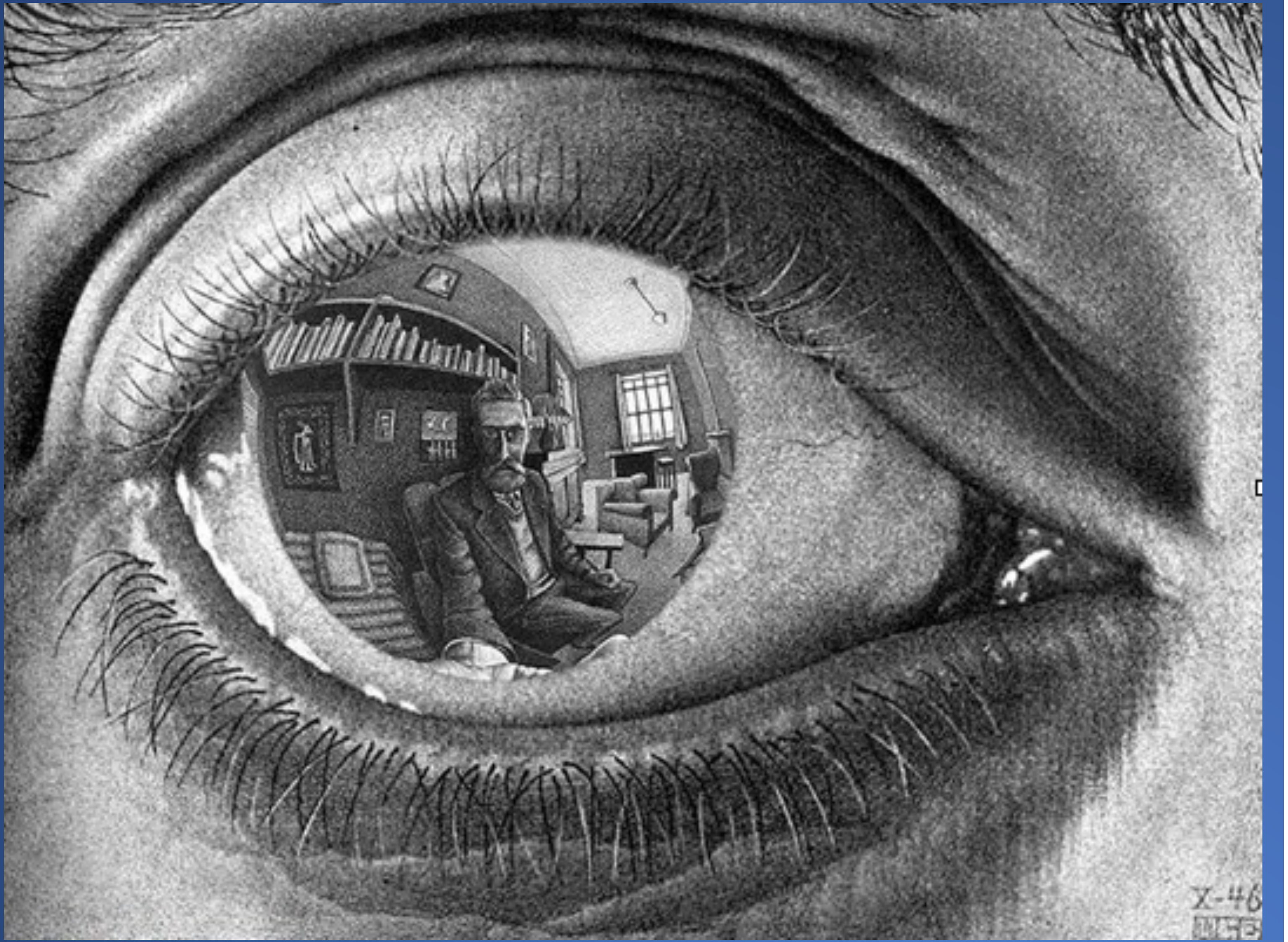
- Pain ($p < 0.048$)
- Difficulty with bowel functioning ($p < 0.026$)
- Physical appearance ($p < 0.002$)

Chochinov et al. Lancet. 1999;354:8169

Intact versus Fracture Sense of Dignity

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

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

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

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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

ANALYSIS

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

PLAINPICTURE/OPIZ

Dignity Model Questions

N=211

#	Variable	% Agree or strongly agree
1	thinking how life might end	41.7%
2	distressing symptoms	53.1%
3	uncertainly regarding illness	59.2%
4	feeling depressed or anxious	59.7%
5	feeling your privacy has been reduced	65.9%
6	changes in physical appearance	66.4%
7	not being able to accept things the way they are	71.6%

DIGNITY
CONSERVING CARE

QUESTIONS

HOW WOULD I BE FEELING?

WHAT IS MAKING ME DRAW these CONCLUSIONS?

ARE my ASSUMPTIONS ACCURATE?

HOW is my ATTITUDE AFFECTING the PATIENT?

COULD my attitude be BASED on MY OWN EXPERIENCES, ANXIETIES and FEARS?

DOES MY ATTITUDE as a HEALTH PROFESSIONAL HELP or HINDER me to DEVELOP OPEN EMPATHIC PROFESSIONAL RELATIONSHIPS?

ACTIONS

REFLECT on these questions for EACH PATIENT.

DISCUSS attitudes & assumptions at CASE REVIEWS & CLINICAL MEETINGS.

For PROFESSIONAL DEVELOPMENT, CHALLENGE your own ATTITUDES & ASSUMPTIONS.

CREATE a CULTURE where DISCUSSION of these ISSUES is STANDARD care provision.

DIGNITY. ALWAYS DIGNITY

Chochinov HM, Krisjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Dignity in the terminally ill: revisited. J Palliat Med. 2006;9:666-72.

Dignity Model Questions

8	not having a meaning spiritual life	73.7%
9	no longer feeling who you were	74.4%
10	not being able to mentally fight	74.5%
11	not being able to continue with usual routines	74.9%
12	feeling life no longer has meaning or purpose	75.1%
13	not being able to think clearly	77.3%
14	not being able to carry out important roles	78.5%
15	tasks of daily living	79.6%

DIGNITY

n. the state or quality of being worthy of respect or honour.

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Dignity Model Questions

17	not feeling worthwhile or valued	81.4%
18	bodily functions	82.9%
19	not feeling you made a meaning or lasting contribution	83.3%
20	feeling you don't have control over your life	83.7%
21	feeling a burden to others	87.1%
22	not being treated with respect or understanding	87.1%

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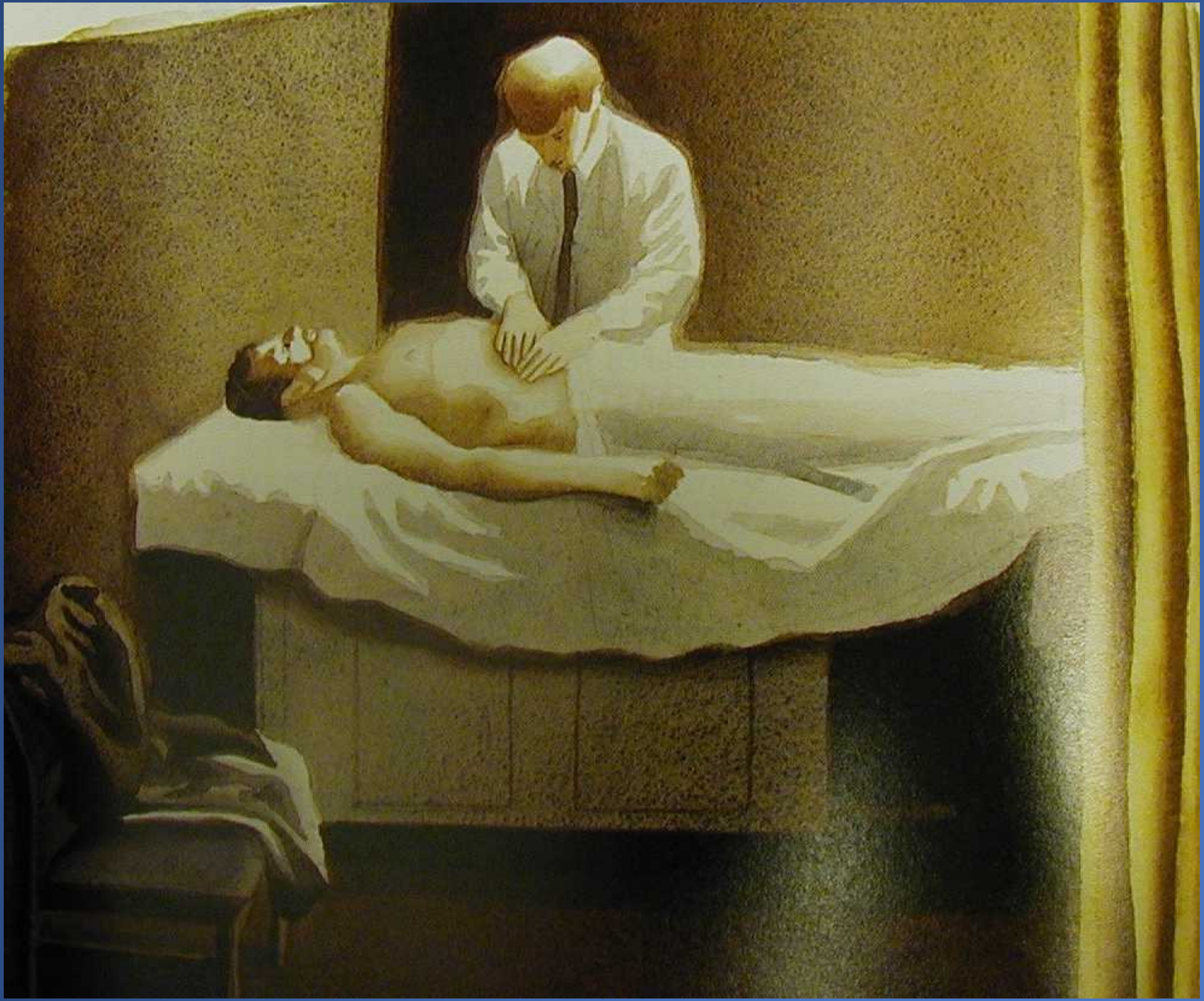

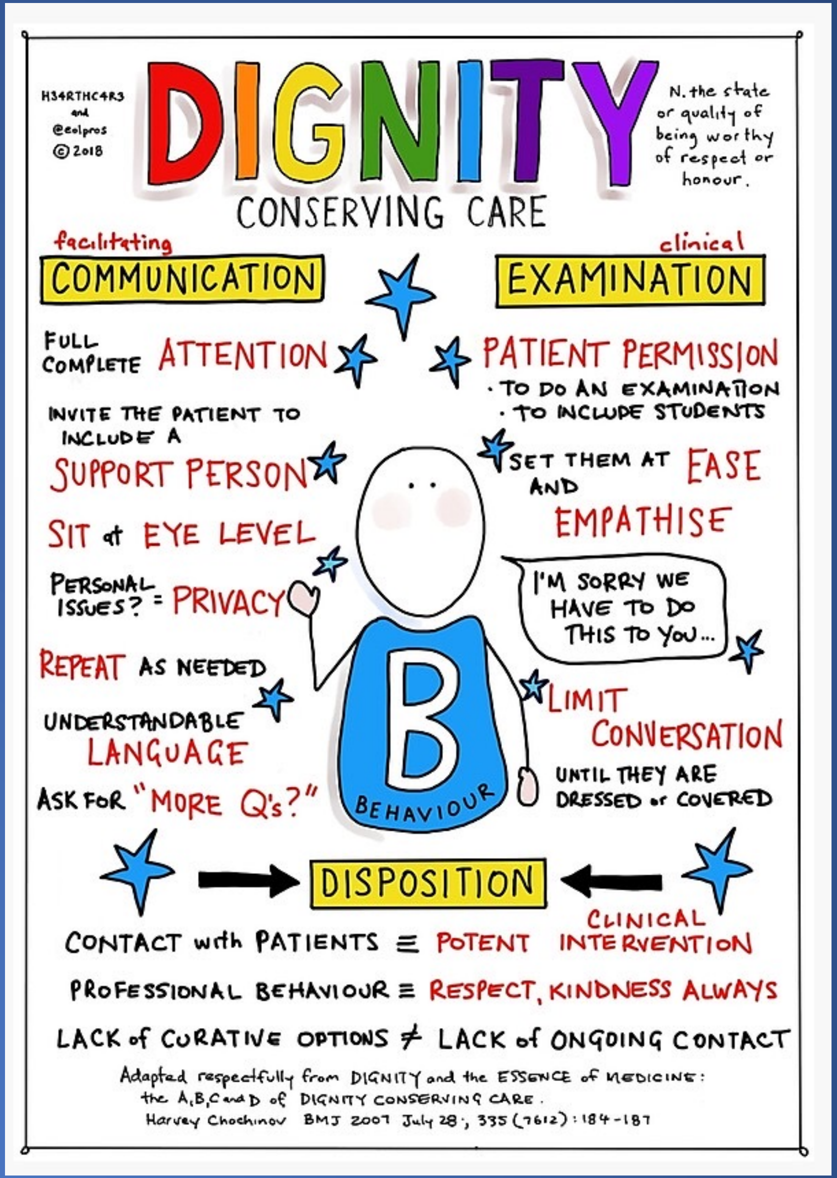

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DIGNITY

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CONSERVING CARE

facilitating
COMMUNICATION

FULL COMPLETE ATTENTION

INVITE THE PATIENT TO INCLUDE A SUPPORT PERSON

SIT at EYE LEVEL

PERSONAL ISSUES? = PRIVACY

REPEAT AS NEEDED

UNDERSTANDABLE LANGUAGE

ASK FOR "MORE Q's?"

clinical
EXAMINATION

PATIENT PERMISSION
- TO DO AN EXAMINATION
- TO INCLUDE STUDENTS

SET THEM AT EASE AND EMPATHISE

LIMIT CONVERSATION UNTIL THEY ARE DRESSED or COVERED

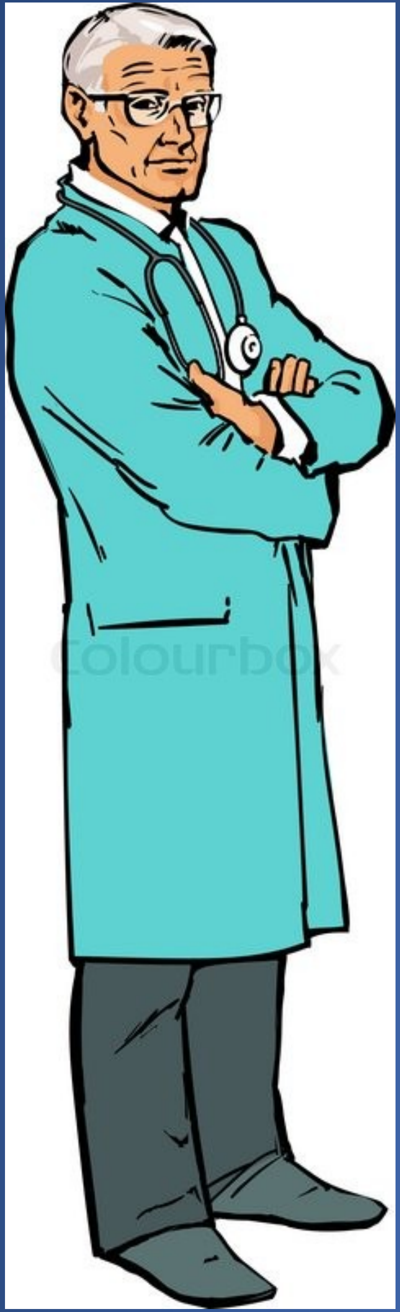
DISPOSITION

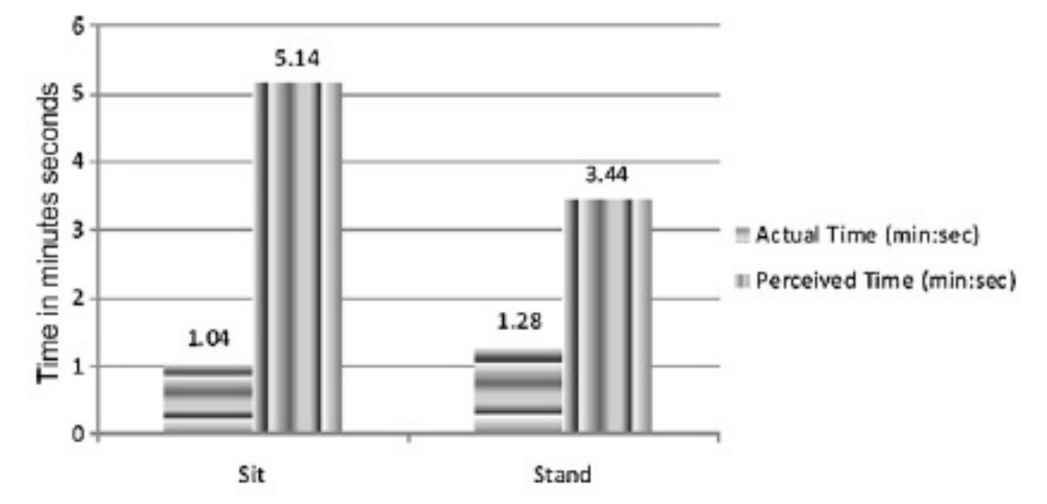
CONTACT with PATIENTS ≡ POTENT CLINICAL INTERVENTION

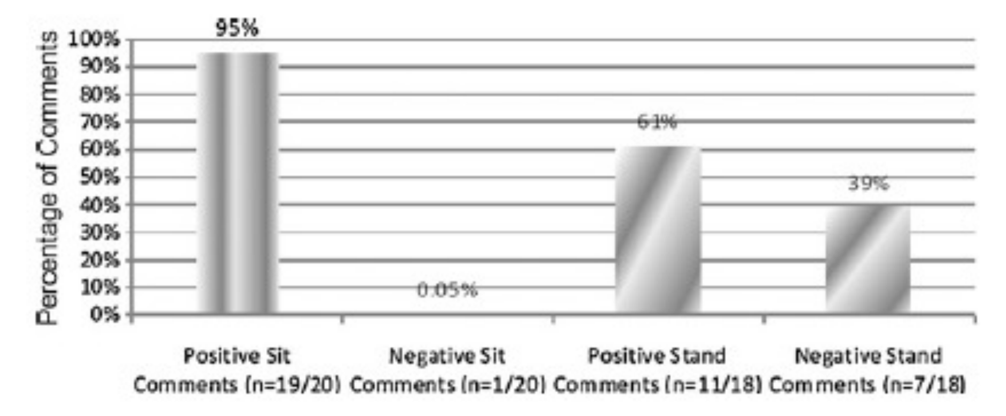
PROFESSIONAL BEHAVIOUR ≡ RESPECT, KINDNESS ALWAYS

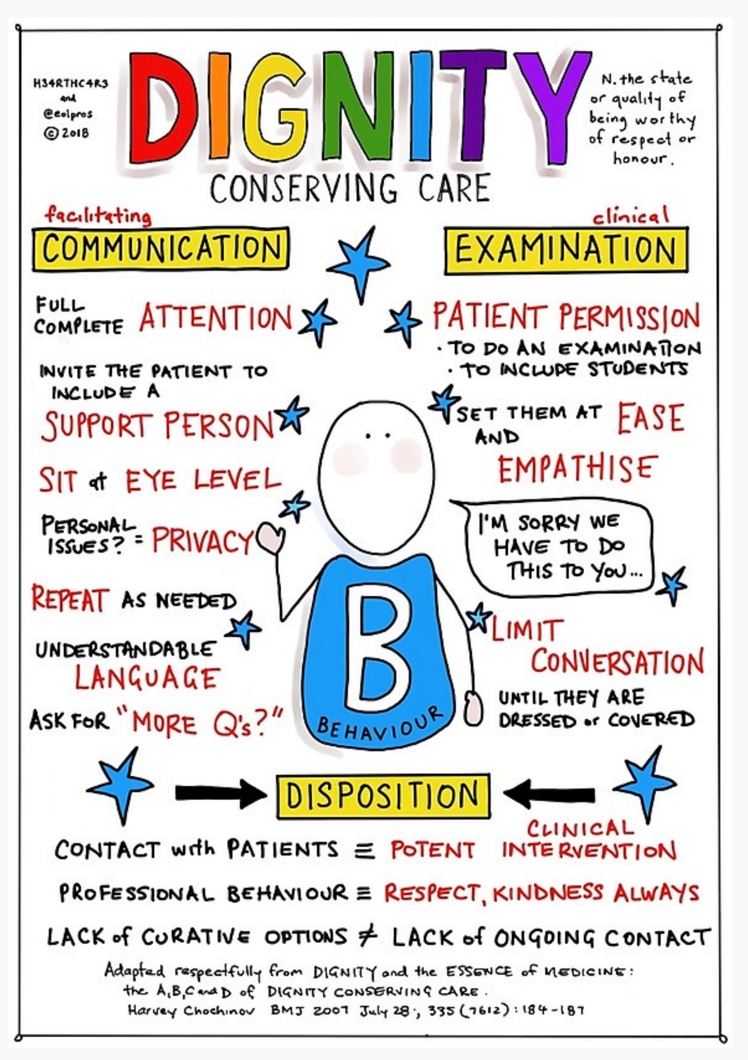
LACK of CURATIVE OPTIONS ≠ LACK of ONGOING CONTACT

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









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B
BEHAVIOUR

DISPOSITION

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Harvey Chochinov BMJ 2007 July 28; 335 (7612): 184-187

Swayden KJ et al. Effect of sitting vs. standing on perception of provider time at bedside: A pilot study Patient Education and Counseling 2012:86:166–171

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DIGNITY

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CONSERVING CARE

GET IN **TOUCH** & **SHOW** IT!

- READ STORIES and NOVELS
- WATCH FILMS, THEATRE, ARTS
- DISCUSS NARRATIVES, PAINTINGS and INFLUENTIAL ROLE MODELS
- CONSIDER PERSONAL STORIES of ILLNESS

C
COMPASSION

- AN UNDERSTANDING LOOK
- A GENTLE TOUCH ON SHOULDER, ARM, HAND
- SPOKEN AND UNSPOKEN ACKNOWLEDGEMENT

"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

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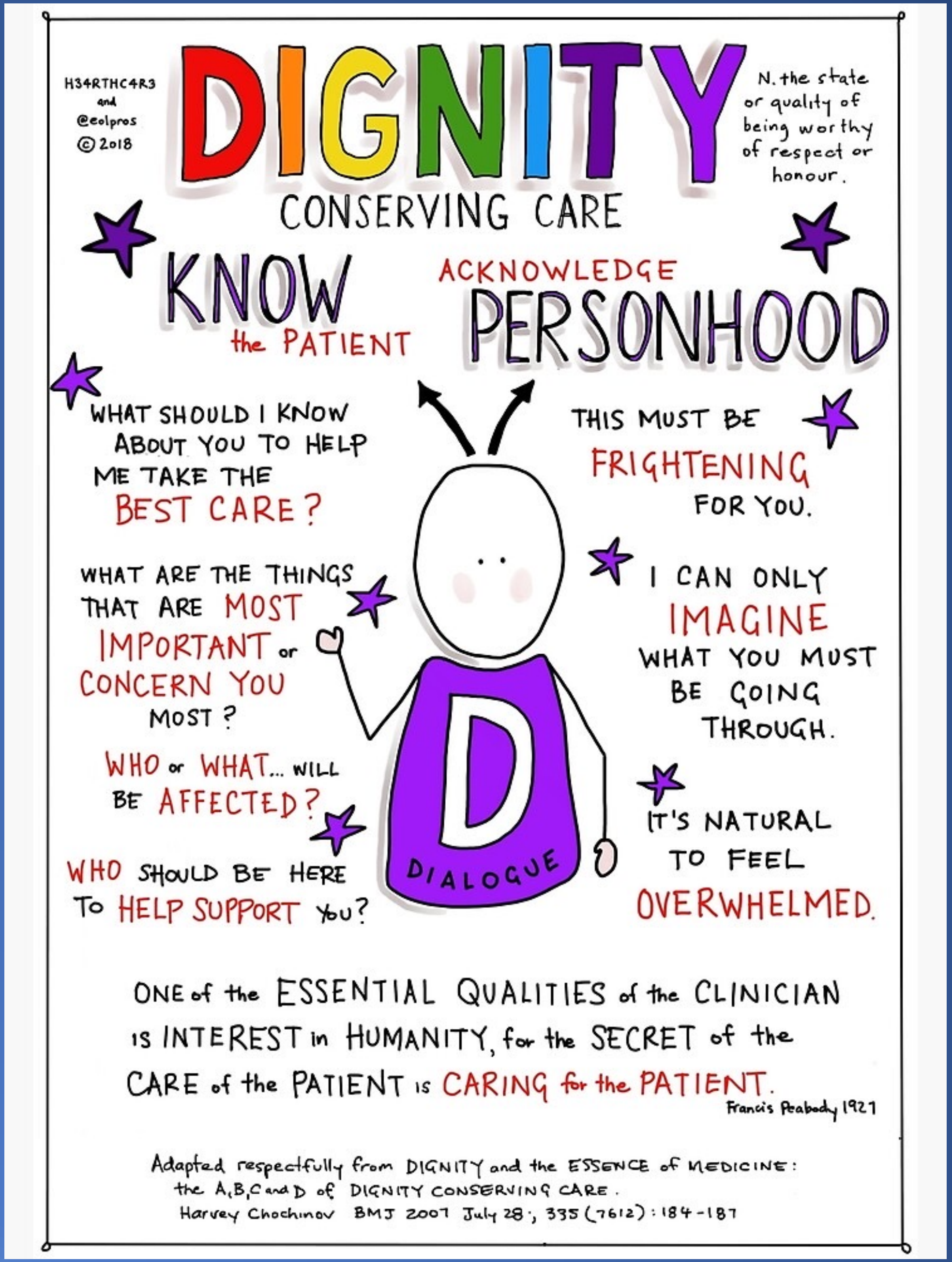

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CONSERVING CARE

KNOW the PATIENT

ACKNOWLEDGE PERSONHOOD

WHAT SHOULD I KNOW ABOUT YOU TO HELP ME TAKE THE BEST CARE?

WHAT ARE THE THINGS THAT ARE MOST IMPORTANT or CONCERN YOU MOST?

WHO or WHAT... WILL BE AFFECTED?

WHO SHOULD BE HERE TO HELP SUPPORT YOU?

THIS MUST BE FRIGHTENING FOR YOU.

I CAN ONLY IMAGINE WHAT YOU MUST BE GOING THROUGH.

IT'S NATURAL TO FEEL OVERWHELMED.

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

Adapted respectfully from DIGNITY and the ESSENCE of MEDICINE:
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The Patient Dignity Inventory (PDI)

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

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

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

Original Article

The Landscape of Distress in the Terminally Ill

Harvey Max Chochinov, MD, PhD, Thomas Hassard, PhD, Susan McClement, PhD, Thomas Hack, PhD, CPsych, Linda J. Kristjanson, PhD, Mike Harlos, MD, Shane Sinclair, BA, MDiv, PhD (C), and Alison Murray, MD, CCFP, MPH

Abstract

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Original Article

The Landscape of Distress in the Terminally Ill

Harvey Max Chochinov, MD, PhD, Thomas Hassard, PhD, Susan McClement, PhD,
Thomas Hack, PhD, CPsych, Linda J. Kristjanson, PhD, Mike Harlos, MD,
Shane Sinclair, BA, MDiv, PhD (C), and Alison Murray, MD, CCFP, MPH
Manitoba Palliative Care Research Unit (H.M.C.), Community Health Sciences (H.M.C., T.Has.), and Faculty of Nursing (S.M., T.Hac.), University of Manitoba, Winnipeg; Manitoba Palliative Care Research Unit (H.M.C., S.M.), and Patient and Family Support Services (H.M.C., T.Hac.) CancerCare Manitoba, Winnipeg, Manitoba, Canada; Western Australian Centre for Cancer & Palliative Care (H.M.C., L.J.K.), Curtin University of Technology, Perth, Australia; St. Boniface General Hospital (M.H.), Winnipeg, Manitoba; Tom Baker Cancer Centre (S.S.), Calgary; Department of Oncology (S.S.), Faculty of Medicine, University of Calgary, Calgary; and Calgary Health Region (A.M.), Calgary, Alberta, Canada

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Abstract

Understanding the complexities of distress and knowing who is most vulnerable is foundational to the provision of quality, palliative end-of-life care. Although prior studies have examined the prevalence of symptom distress among patients nearing death, these studies have tended to largely focus on physical and to a lesser extent, psychological challenges. The aim of this study was to use the Patient Dignity Inventory (PDI), a novel, reliable, and validated measure of end-of-life distress, to describe a broad landscape of distress in patients who are terminally ill. The PDI, a 25-item self-report, was administered to 253 patients receiving palliative care. Each PDI item is rated by patients to indicate the degree to which they experience various kinds of end-of-life distress. Palliative care patients reported an average of 5.74 problems (standard deviation, 5.49; range, 0–24), including physical, psychological, existential, and spiritual challenges. Being an inpatient, being educated, and having a partner were associated with certain kinds of end-of-life problems, particularly existential distress. Spirituality, especially its existential or "sense of meaning and purpose" dimension was associated with less distress for terminally ill patients. A better appreciation for the nature of distress is a critical step toward a fuller understanding of the challenges facing the terminally ill. A clear articulation of the landscape of distress, including insight regarding those who are most at risk, should pave the way toward more effective, dignity-conserving end-of-life care. J Pain Symptom Manage 2009;■:■–■. *© 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

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Address correspondence to: Harvey Max Chochinov, MD, PhD, Manitoba Palliative Care Research Unit, University of Manitoba, CancerCare Manitoba, Rm. 3021, 675 McDermot Avenue, Winnipeg, Manitoba R3E 0V9, Canada. E-mail: harvey.chochinov@cancercare.mb.ca

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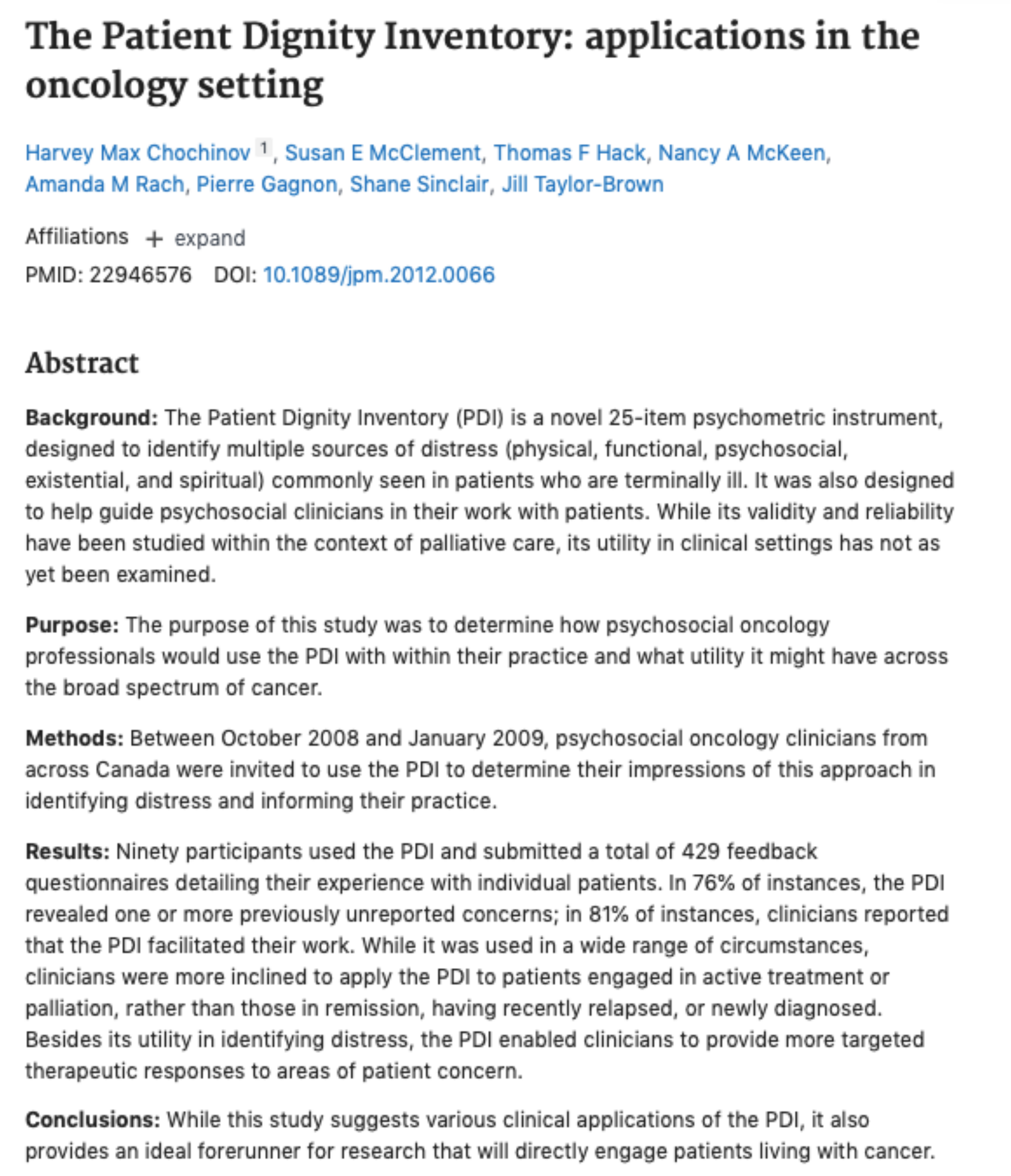
Prevalence of Distress in the Terminally Ill

PDI Item	% with problem
Not able to continue usual routines	51.4
Physically distressing symptoms	47.8
Not able to carry out important roles	37.5
Feeling no longer who I was	36.4
Not able to perform tasks of daily living	30.4
Feeling of not having control	29.2
Feeling uncertain	26.9
Not able to attend to bodily functions	26.5
Feeling anxious	24.5
Feeling of reduced privacy	24.5
Feeling a burden to others	24.1
Feeling how you look has changed	22.5

Prevalence of Distress in the Terminally Ill

Feeling depressed	22.5
Worried about future	20.9
Not being able to think clearly	20.2
Feeling of unfinished business	19.4
Feeling life no longer has meaning or purpose	17.4
Not feeling worthwhile of valued	17.0
Feeling have not made meaningful contribution	11.9
Not feeling able to mentally fight illness	11.9
Not being able to accept things as they are	11.5
Concerns regarding spiritual life	6.3
Not being treated with respect	2.8
Not feeling supported by health care providers	2.0
Not feeling supported by friends or family	1.6



The Patient Dignity Inventory: applications in the oncology setting

Harvey Max Chochinov [1], Susan E McClement, Thomas F Hack, Nancy A McKeen, Amanda M Rach, Pierre Gagnon, Shane Sinclair, Jill Taylor-Brown

Affiliations + expand

PMID: 22946576 DOI: 10.1089/jpm.2012.0066

Abstract

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

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

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

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

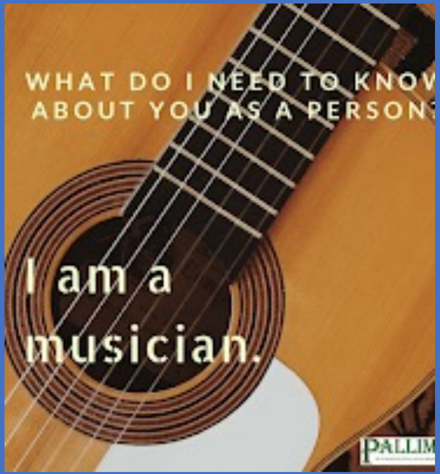
Conclusions: While this study suggests various clinical applications of the PDI, it also provides an ideal forerunner for research that will directly engage patients living with cancer.

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?

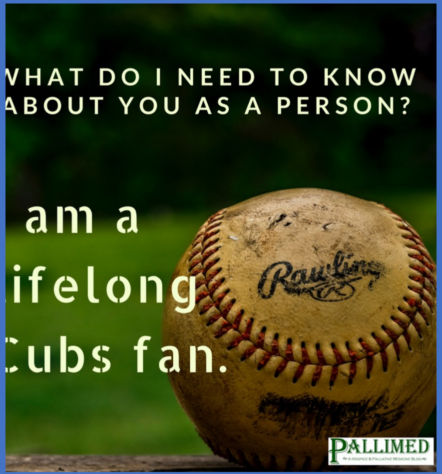
WHAT DO I NEED TO KNOW ABOUT YOU AS A PERSON?

I am precise in my care of things.



WHAT DO I NEED TO KNOV
ABOUT YOU AS A PERSON

I am a musician.



VHAT DO I NEED TO KNOW
ABOUT YOU AS A PERSON?

am a
ifelong
Cubs fan.

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

by Lizzy Miles
"happy-go-lucky"

Patient: 82 women with colorectal cancer

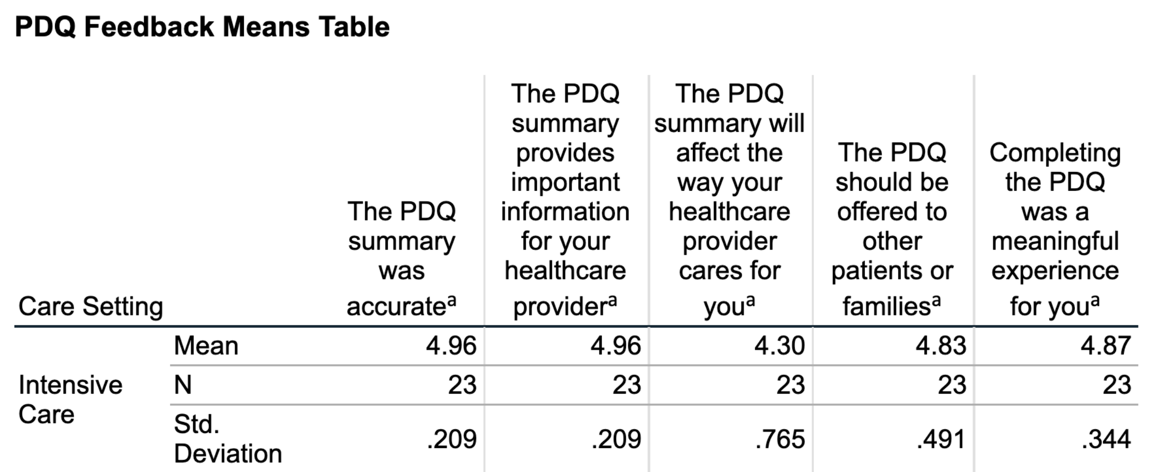
Mrs. F. says that because of the residential school, she always had a hard time trusting people. She in fact moved 82 times so as not to let anyone get too close to her. While this has gotten better over time, she still struggles with being able to trust people. She wants to, but it is hard for her. She sometimes worries that she won't be told the whole truth, or that people will see her as not being deserving of the whole truth. She appreciates people being friendly towards her, but is frightened of authority figures. 'Authority scares me, but I'm not as bad as I used to be'.

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”.

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

by Lizzy Miles
"happy-go-lucky"

PALLIMED
A HOSPICE & PALLIATIVE MEDICINE BLOG

External Panel on Options for a Legislative Response to Carter v. Canada
Comité externe sur les options de réponse législative à Carter c. Canada

Consultations on Physician-Assisted Dying

Summary of Results and Key Findings

FINAL REPORT

15 December 2015

Canada

Model of

Therapeutic Effectiveness

OPTIMAL THERAPEUTIC POTENTIAL

By skillfully combining elements contained within each of the domains, clinicians are able to achieve optimal therapeutic effectiveness.

THERAPEUTIC APPROACHES

- Clarify & name sources of distress
- Problem-solve
- Educate, inform client
- Debunk myths
- Reinforce client strengths & positive ways of coping
- Provide techniques (e.g., mindfulness, Therapeutic Touch)
- Advocate for client with the care team
- Foster positive relationships between client & family
- Elicit client needs
- Probe for feelings underlying events & circumstances
- Help client identify what they can & can't control
- Help client understand by mirroring & reflection
- Use silence to encourage client expression
- Explore image & metaphor
- Offer comfort through touch
- Acknowledge spiritual distress

CREATION OF A SAFE SPACE

- Provide privacy
- Provide calming environment
- Assure confidentiality

PERSONAL GROWTH & SELF-CARE

- Maintain a balanced life
- Work at self-awareness
- Acknowledge / work through our own fears
- Acknowledge your own feelings of vulnerability or helplessness
- Debrief with colleagues
- Value professional development

THERAPEUTIC PACING

- Listen attentively
- Hold or ground client
- Keep client in the here & now
- Maintain slow pace - don't rush therapy
- Encourage client to talk about fear & distress
- Normalize & validate client experience & distress
- Use skillful tentativeness, i.e., 'purposefully hesitant' so as to be non-threatening

THERAPEUTIC PRESENCE

- Being compassionate & empathetic
- Being respectful & non-judgmental
- Being genuine & authentic
- Being trustworthy
- Being fully present
- Valuing intrinsic worth of client
- Being mindful of boundaries
- Being emotionally resilient

THERAPEUTIC HUMILITY

- Do not avoid emotion
- Tolerate clinical ambiguity
- Be able to explore difficult topics
- Accept and honour client as expert
- Be a catalyst for therapeutic change
- Trust in the process
- 'Sit with' client emotional distress
- Avoid urge to have to fix
- Model healthy processing of emotion

Chochinov et al. (2013), Health care provider communication: An empirical model of therapeutic effectiveness. Cancer. doi: 10.1002/cncr.27949

Participant Characteristics

Profession	N	Percent
Social Work	50	64
Medicine	8	11
Psychology	6	8
Spiritual Care	5	6
Nursing	5	6
Other healthcare	4	5

Experience	Mean	SD
Years in Profession	17.5	(10.3)
Years in Oncology	8.5	(8.0)

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Results

- 49 primary codes/themes
- 8 validation workshops held across Canada
- 83% said it would enhance their ability to understand patient psychosocial distress (PSD)
- 95% said it would enhance their ability to teach how to address PSD

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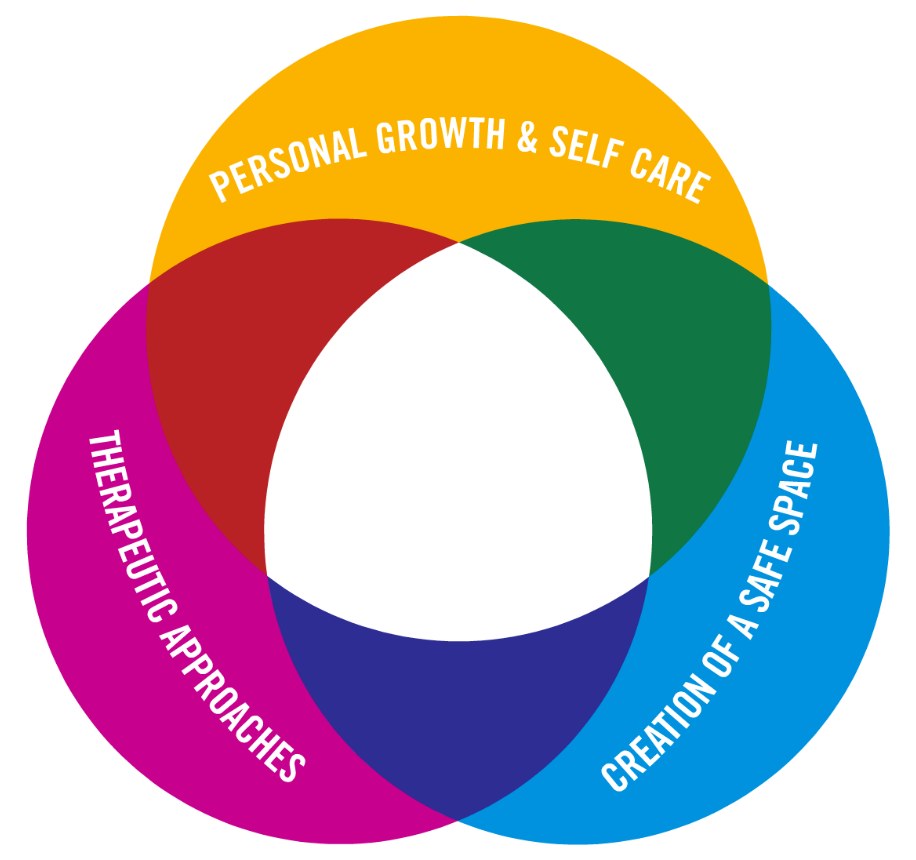

PERSONAL GROWTH & SELF CARE

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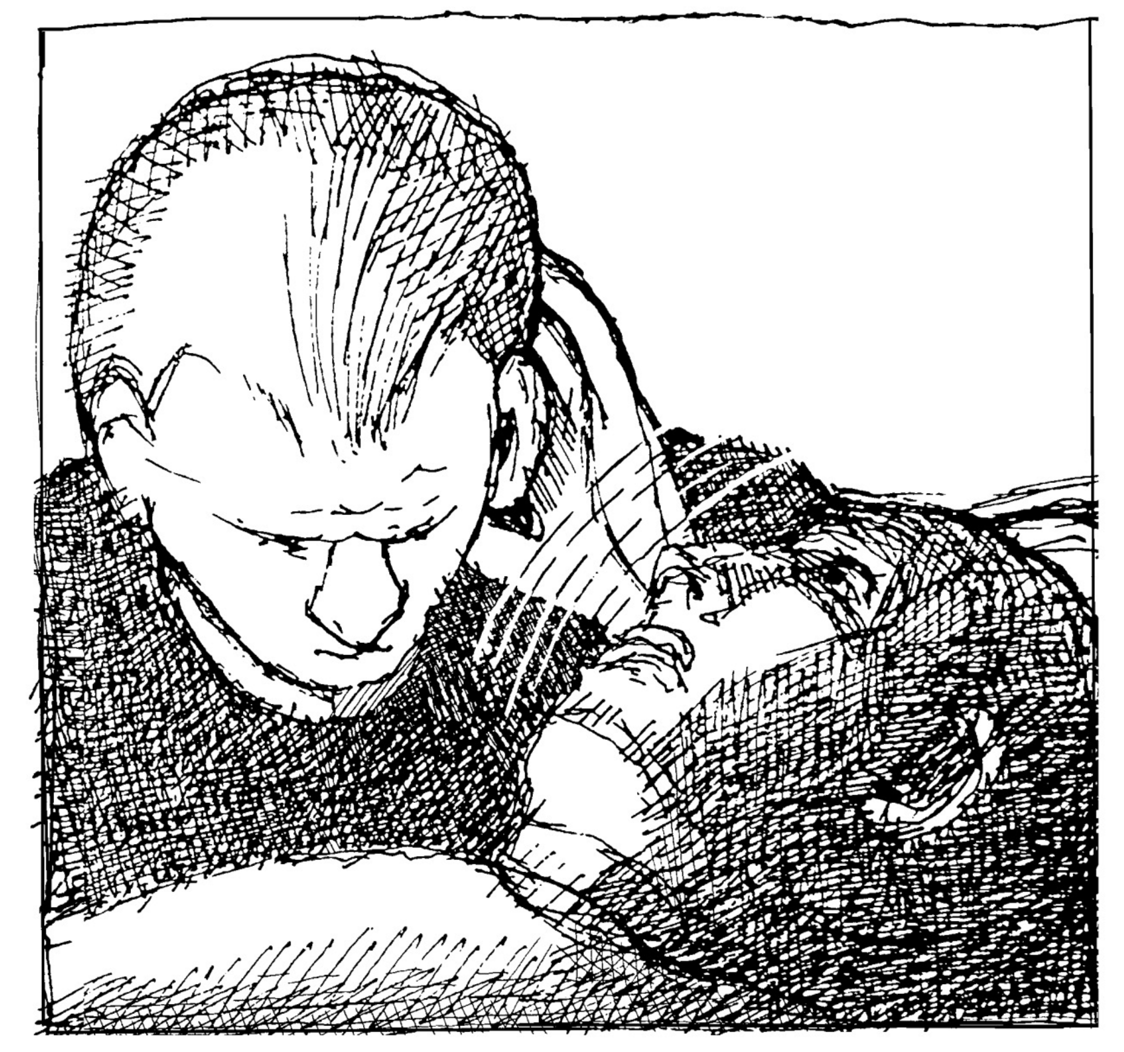

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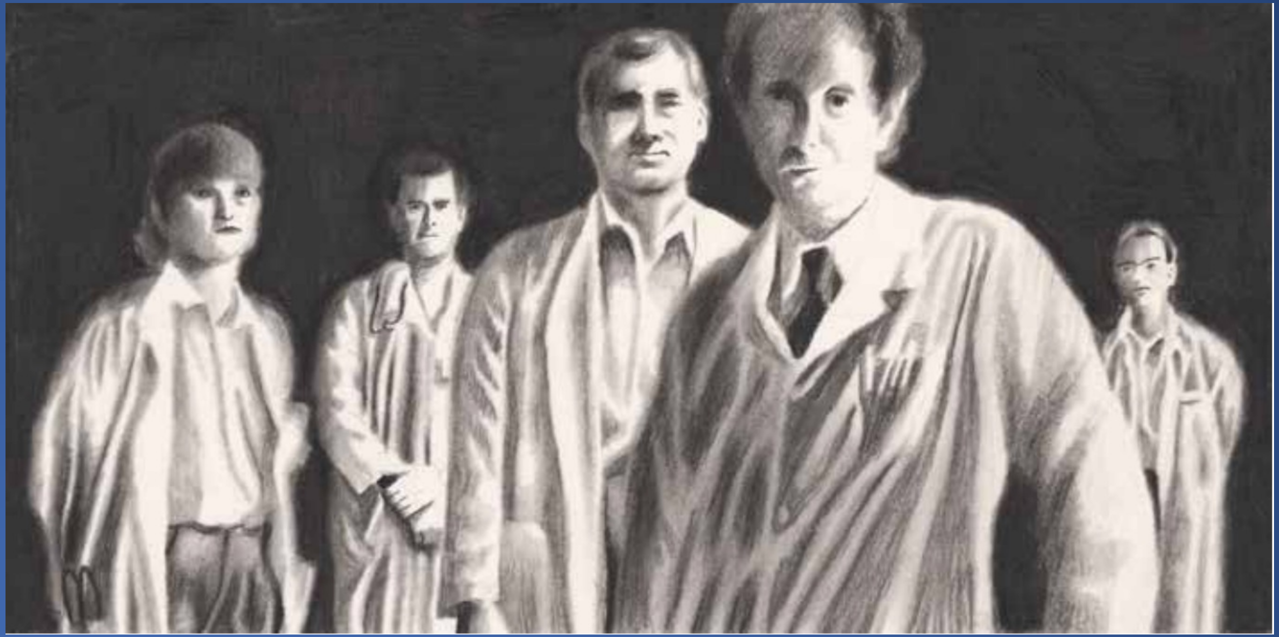

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Mary Ann Liebert, Inc.
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Guest Editorial

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

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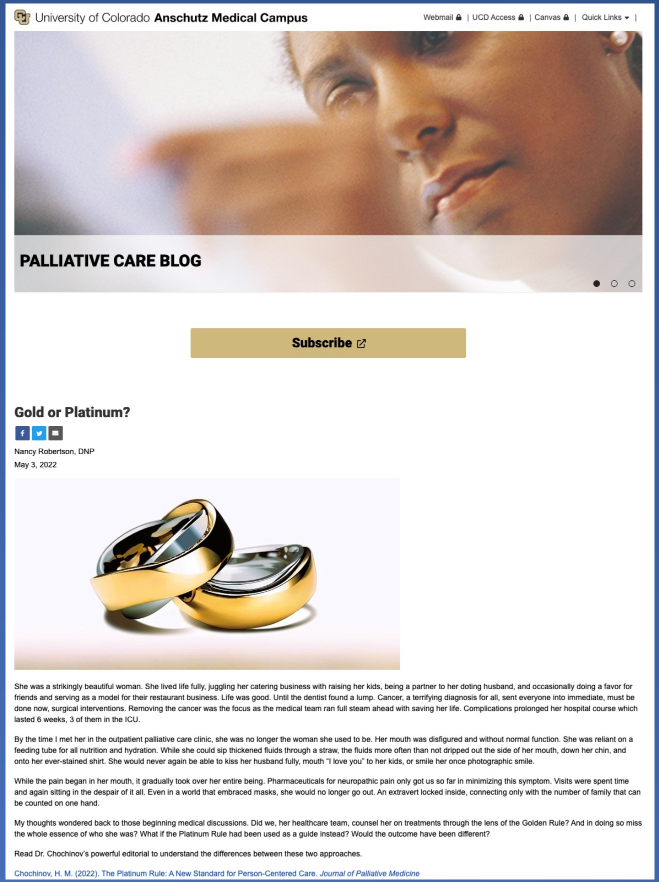
[1] Department of Psychiatry, University of Manitoba, Winnipeg, Manitoba, Canada.
[2] CancerCare Manitoba Research Institute, Winnipeg, Manitoba, Canada.



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.

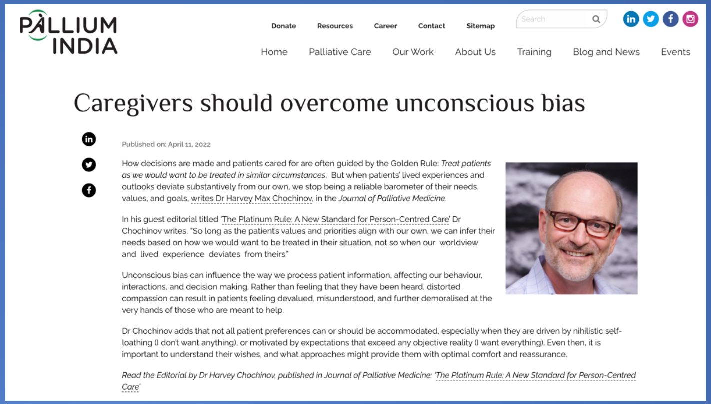
By the time I met her in the outpatient palliative care clinic, she was no longer the woman she used to be. Her mouth was disfigured and without normal function. She was reliant on a feeding tube for all nutrition and hydration. While she could sip thickened fluids through a straw, the fluids more often 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

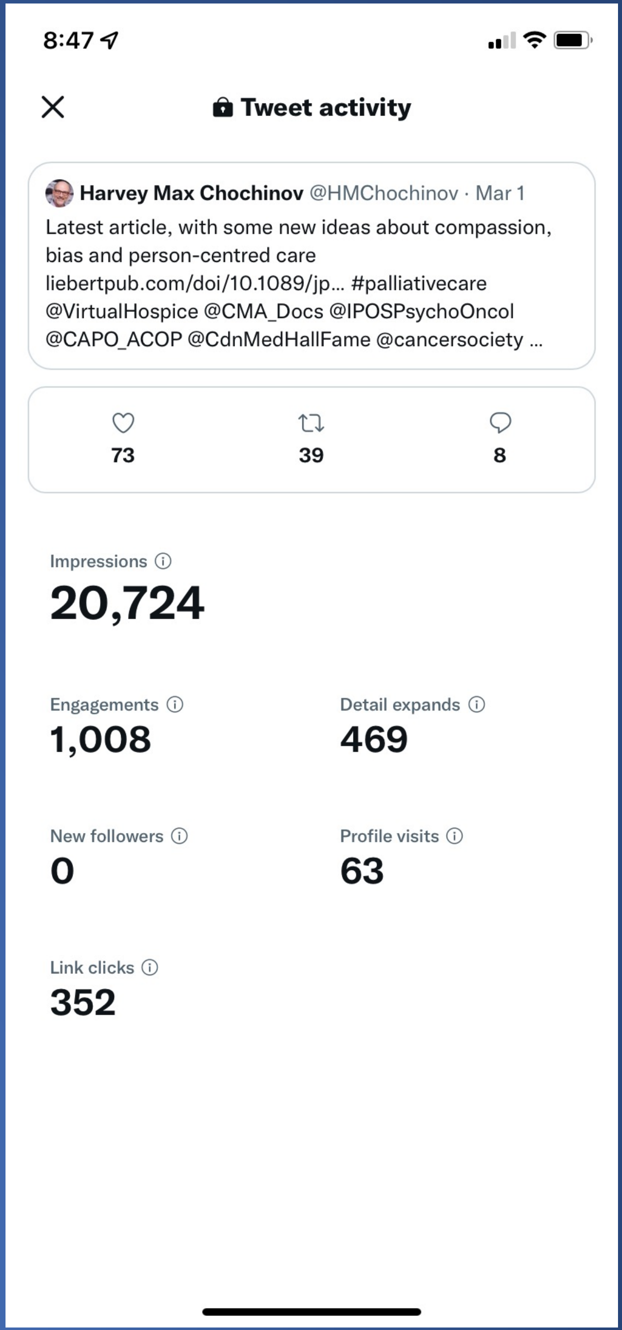
How decisions are made and patients cared for are often guided by the Golden Rule: *Treat patients as we would want to be treated in similar circumstances.* But when patients' lived experiences and outlooks deviate substantively from our own, we stop being a reliable barometer of their needs, values,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



Tweet activity

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 @VirtualHospice @CMA_Docs @IPOSPsychoOncol @CAPO_ACOP @CdnMedHallFame @cancersociety ...

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1,008

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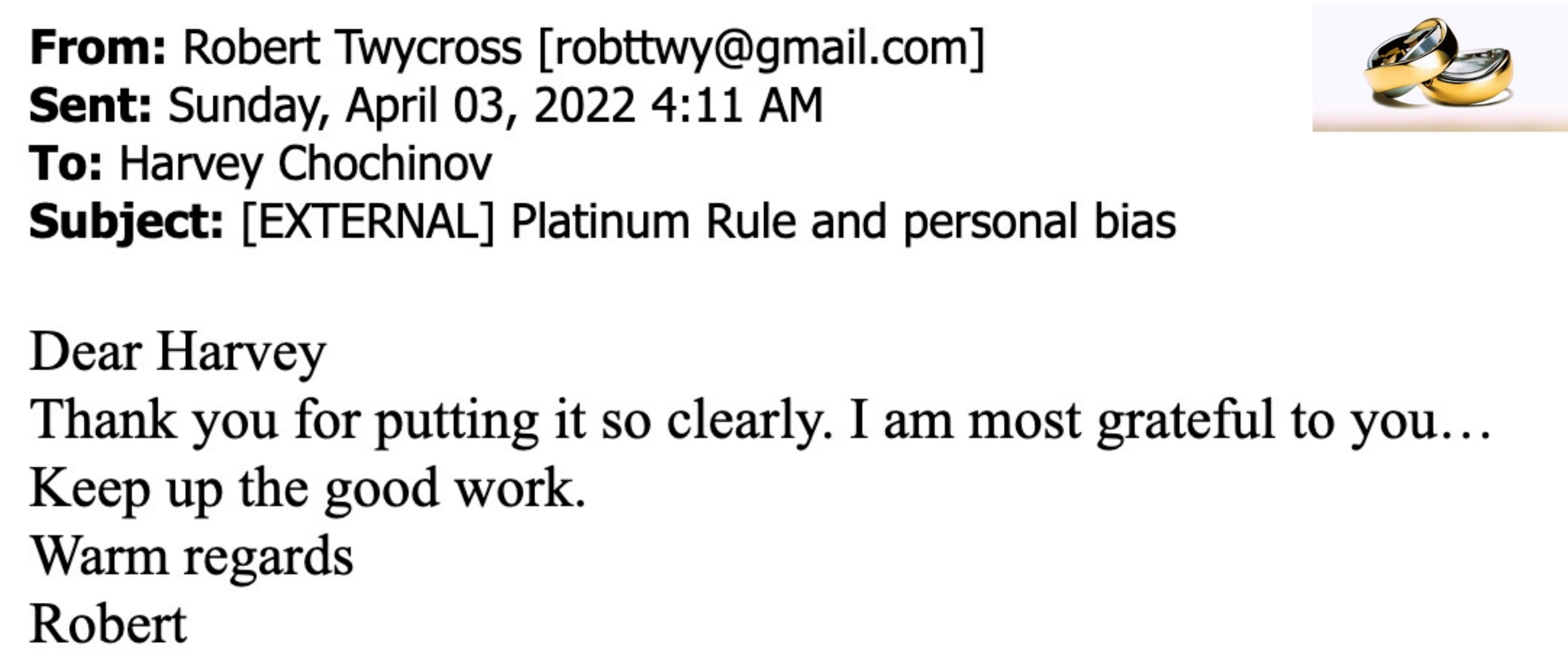
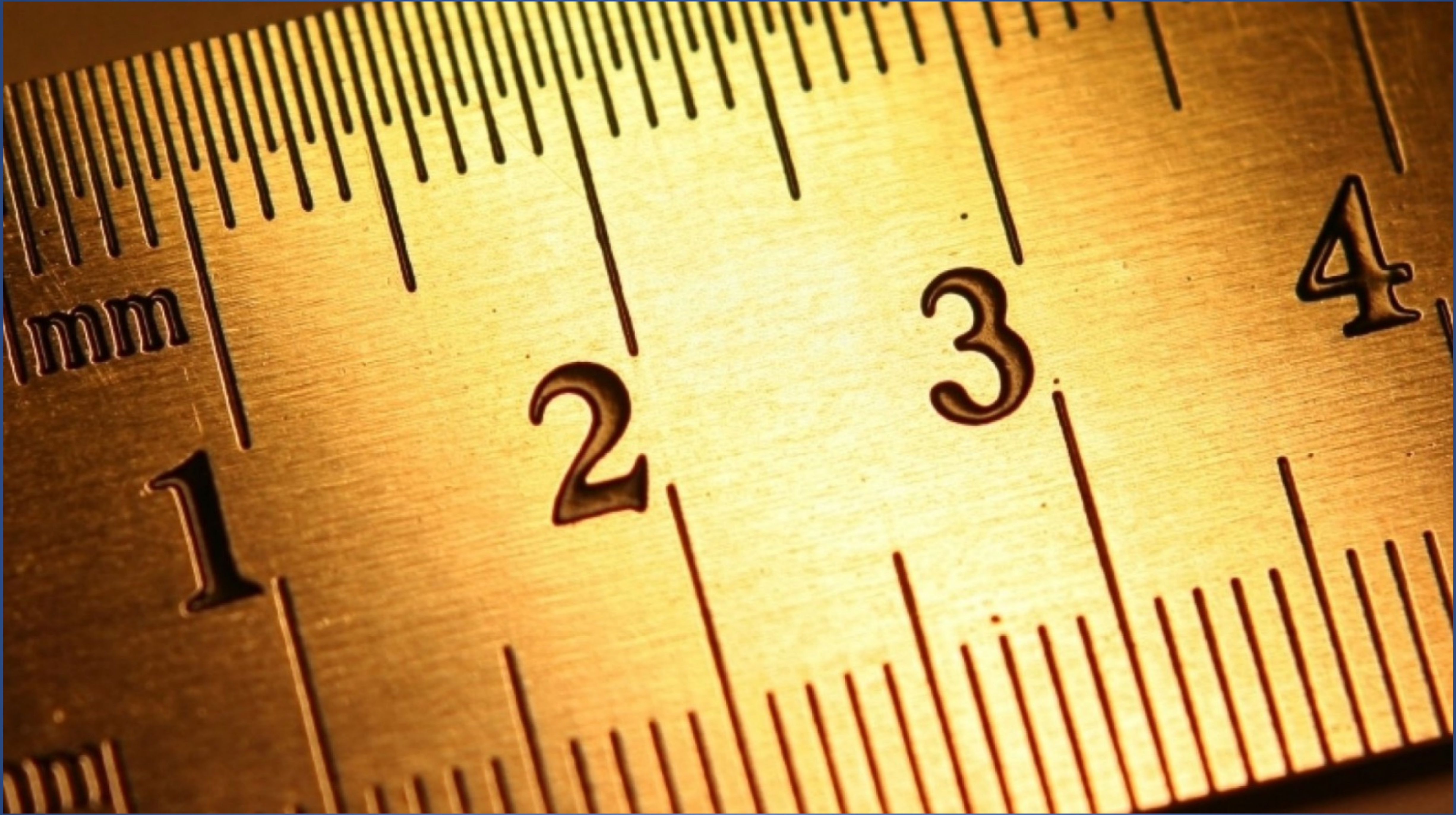
352



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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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

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

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Harvey.chochinov@cancercare.mb.ca

#dignityincare22

Twitter: @HMChochinov

LinkedIn: Harvey Max Chochinov

DignityinCare.ca

VirtualHospice.ca