La dignité, l'empathie et la culture de la médecine

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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, 1996), 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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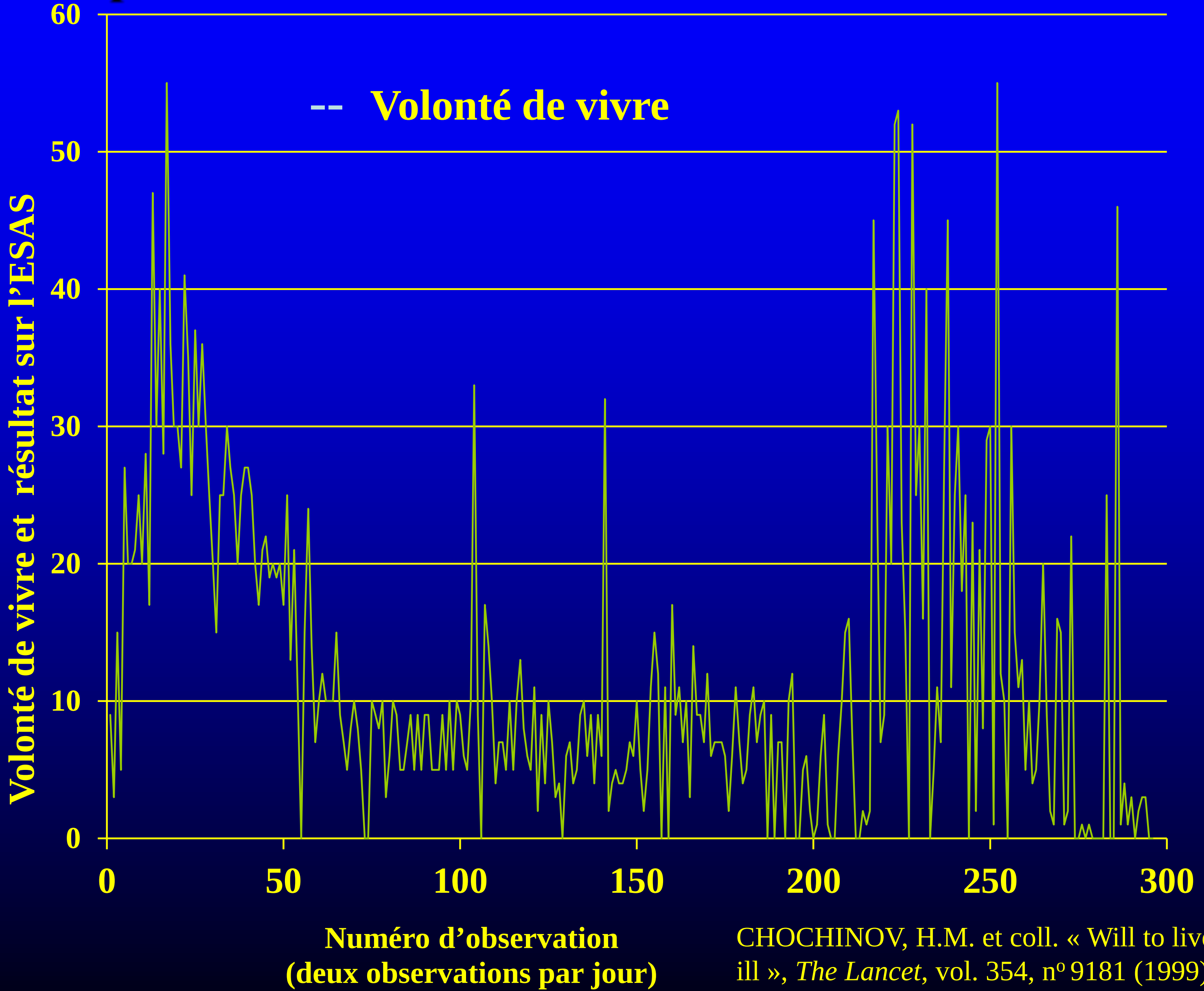
Introduction

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,[2,4,5,7,8] pain,[2,5,7,9–11] and other distressing symptoms.[7,9–12] 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

Évolution de la volonté de vivre dans la douleur chez un patient de 80 ans atteint du cancer colorectal



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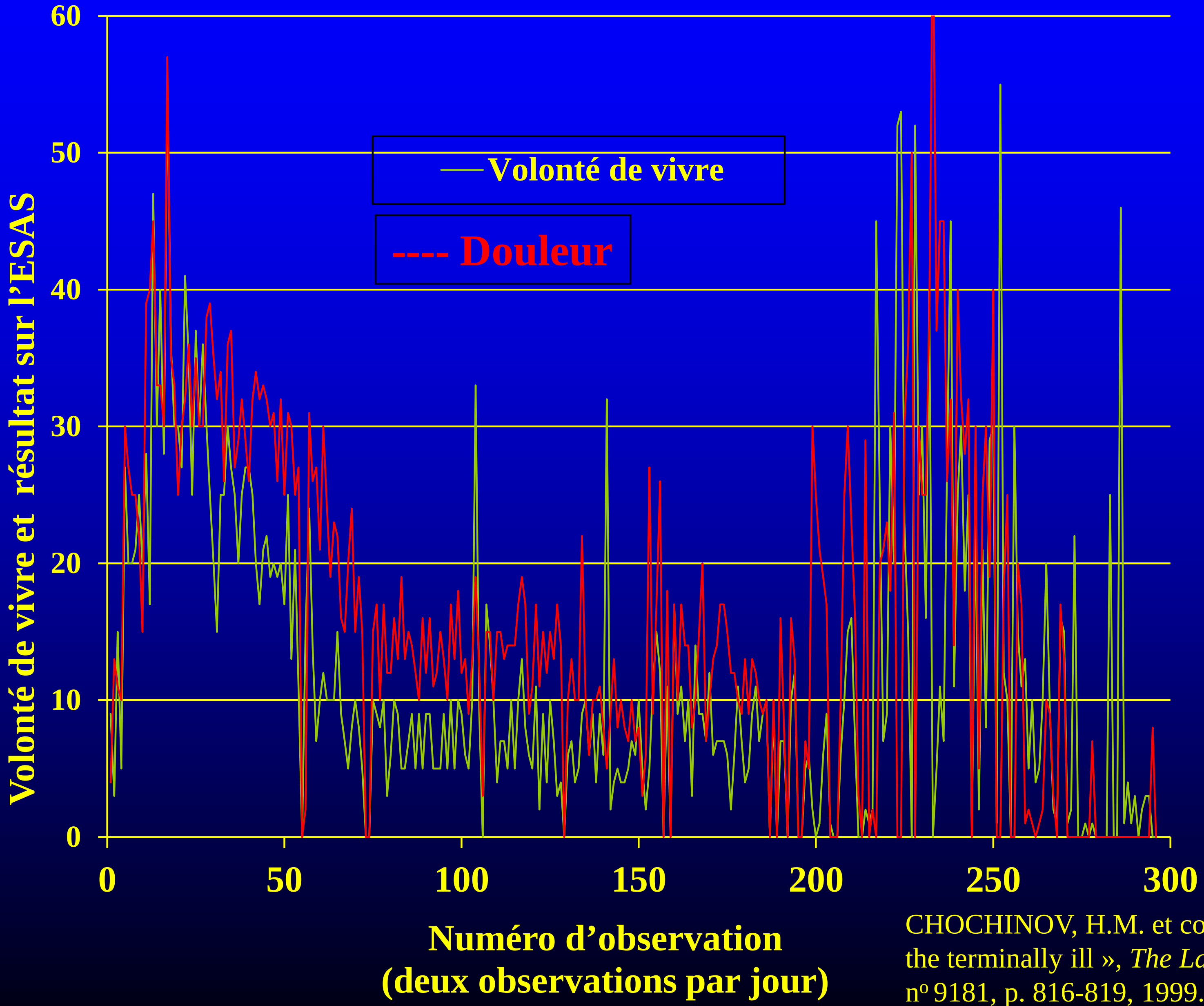

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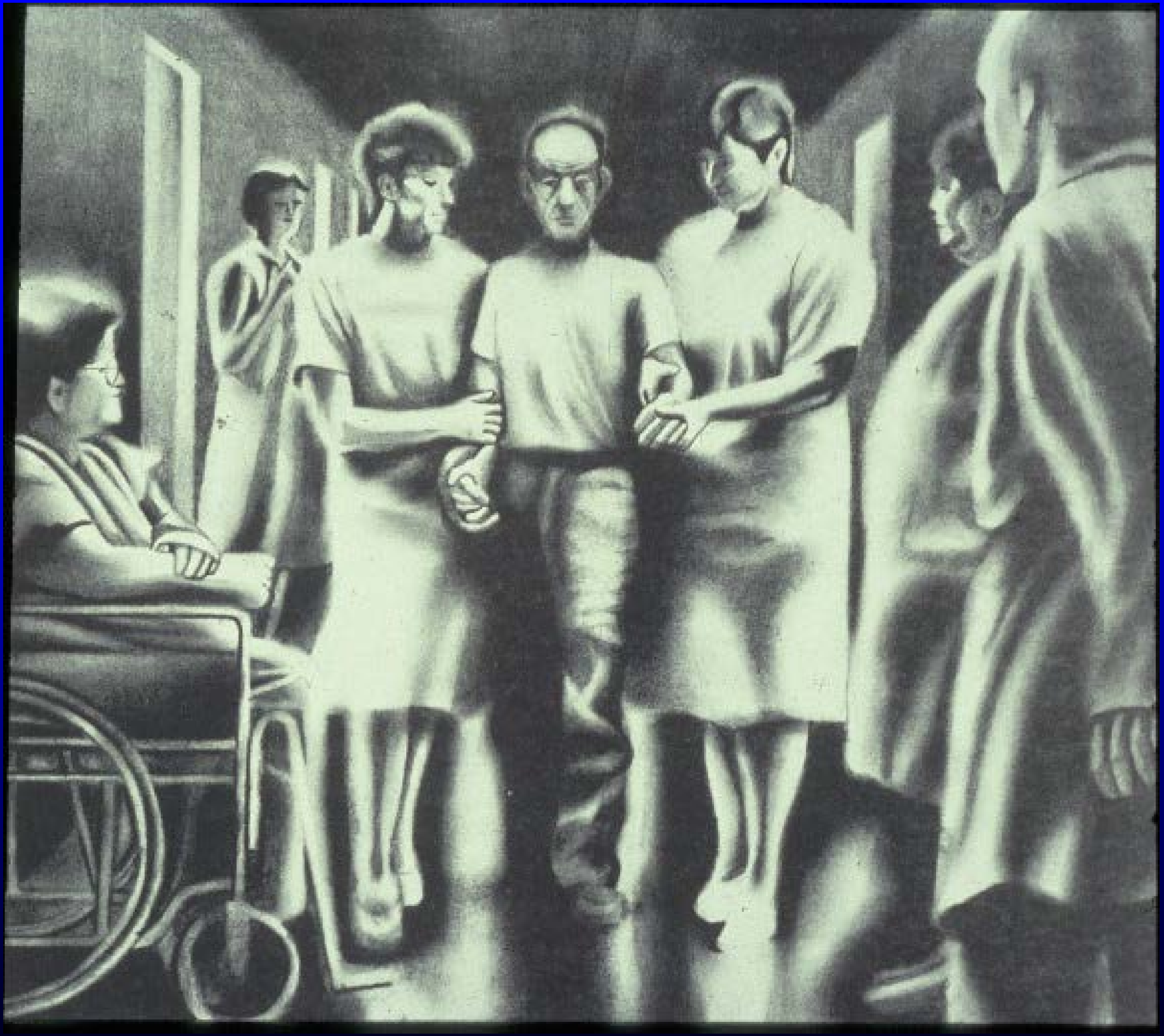


- Désir de mourir ($p < 0,0014$)
- Perte de volonté de vivre ($p < 0,013$)
- Dépression ($p < 0,0084$)
- Désespoir ($p < 0,020$)
- Anxiété ($p < 0,003$)

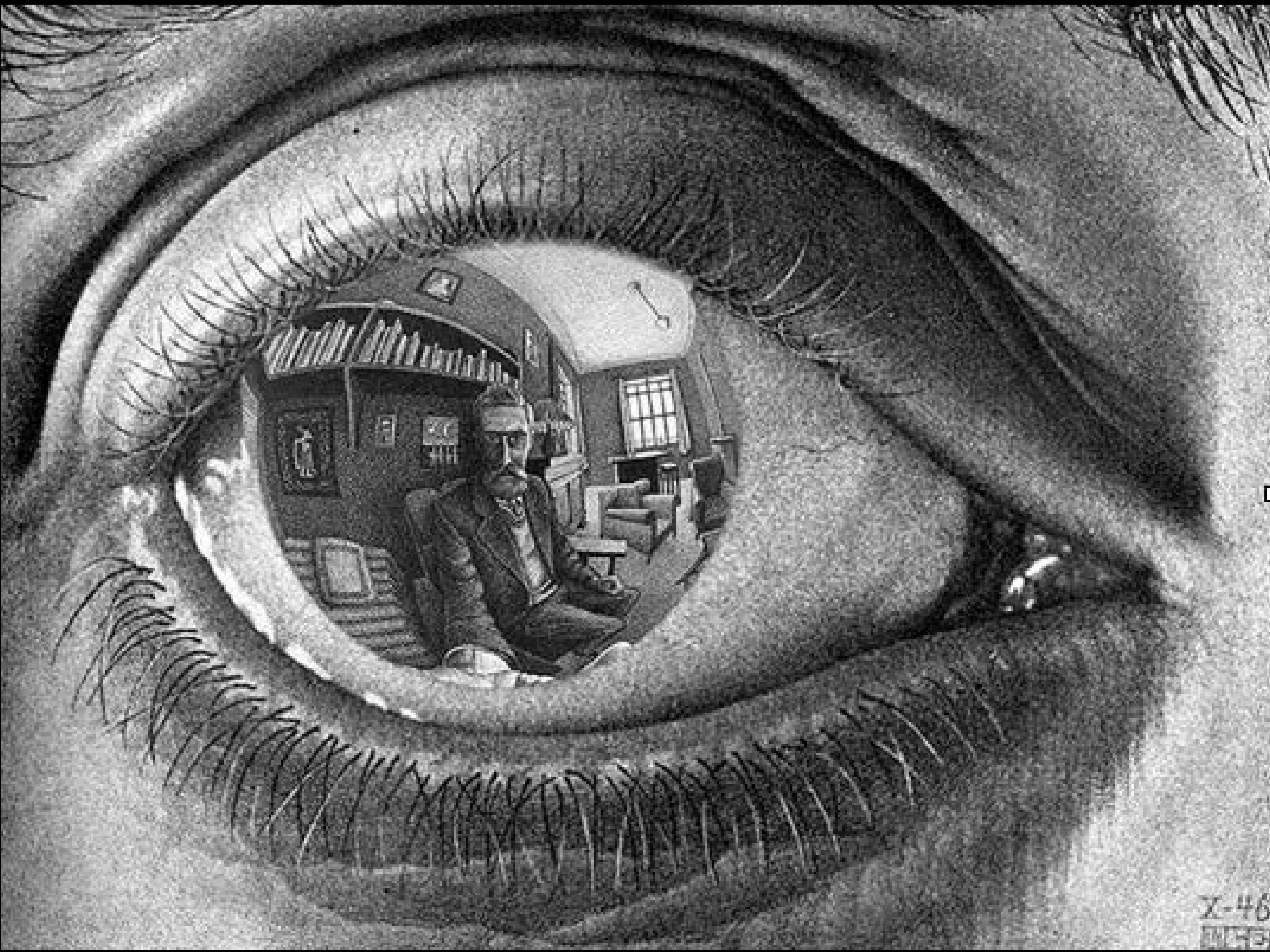
CHOCHINOV, H.M. et coll. « Will to live in the terminally ill », *The Lancet*, vol. 354, nº 9181 (1999), p. 816-819.

- Douleur ($p < 0{,}048$)
- Difficultés de transit intestinal ($p < 0{,}026$)
- Apparence physique ($p < 0{,}002$)

CHOCHINOV, H.M. et coll. « Will to live in the terminally ill », *The Lancet*, vol. 354, n° 9181 (1999), p. 816-819, 1999.

- Se laver (OR = 8,45 [1,50 à 47,70]; $p < 0,016$)
- S’habiller (OR = 2,79 [0,95 à 8,15]; $p < 0.061$)
- Incontinence (OR = 3,47 [1,27 à 9,51]; $p < 0,016$)

CHOCHINOV, H.M. et coll. « Will to live in the terminally ill », *The Lancet*, vol. 354, n° 9181 (1999), p. 816-819.



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PERSPECTIVES ON CARE
AT THE CLOSE OF LIFE

Dignity-Conserving Care— A New Model for Palliative Care

Helping the Patient Feel Valued

Harvey Max Chochinov, MD, PhD, FRCPC

THE PATIENT'S STORY

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

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

PERSPECTIVES

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

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

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

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

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

Why Is the Notion of Dignity Important?

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

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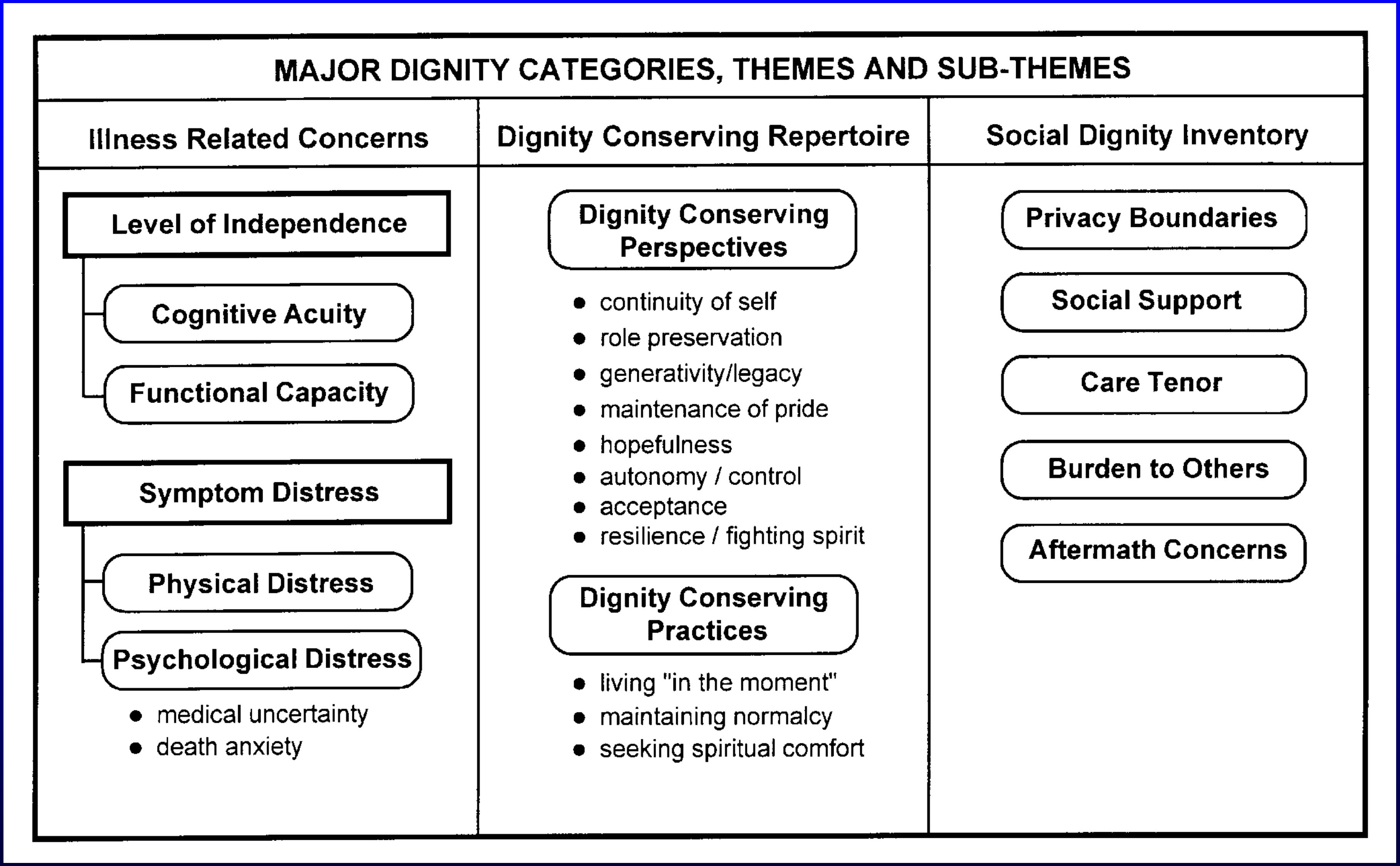


MAJOR DIGNITY CATEGORIES, THEMES AND SUB-THEMES

Illness Related Concerns

Level of Independence

- **Cognitive Acuity**
- **Functional Capacity**

Symptom Distress

- **Physical Distress**
- **Psychological Distress**
  - medical uncertainty
  - death anxiety

Dignity Conserving Repertoire

Dignity Conserving Perspectives

- continuity of self
- role preservation
- generativity/legacy
- maintenance of pride
- hopefulness
- autonomy / control
- acceptance
- resilience / fighting spirit

Dignity Conserving Practices

- living "in the moment"
- maintaining normalcy
- seeking spiritual comfort

Social Dignity Inventory

Privacy Boundaries

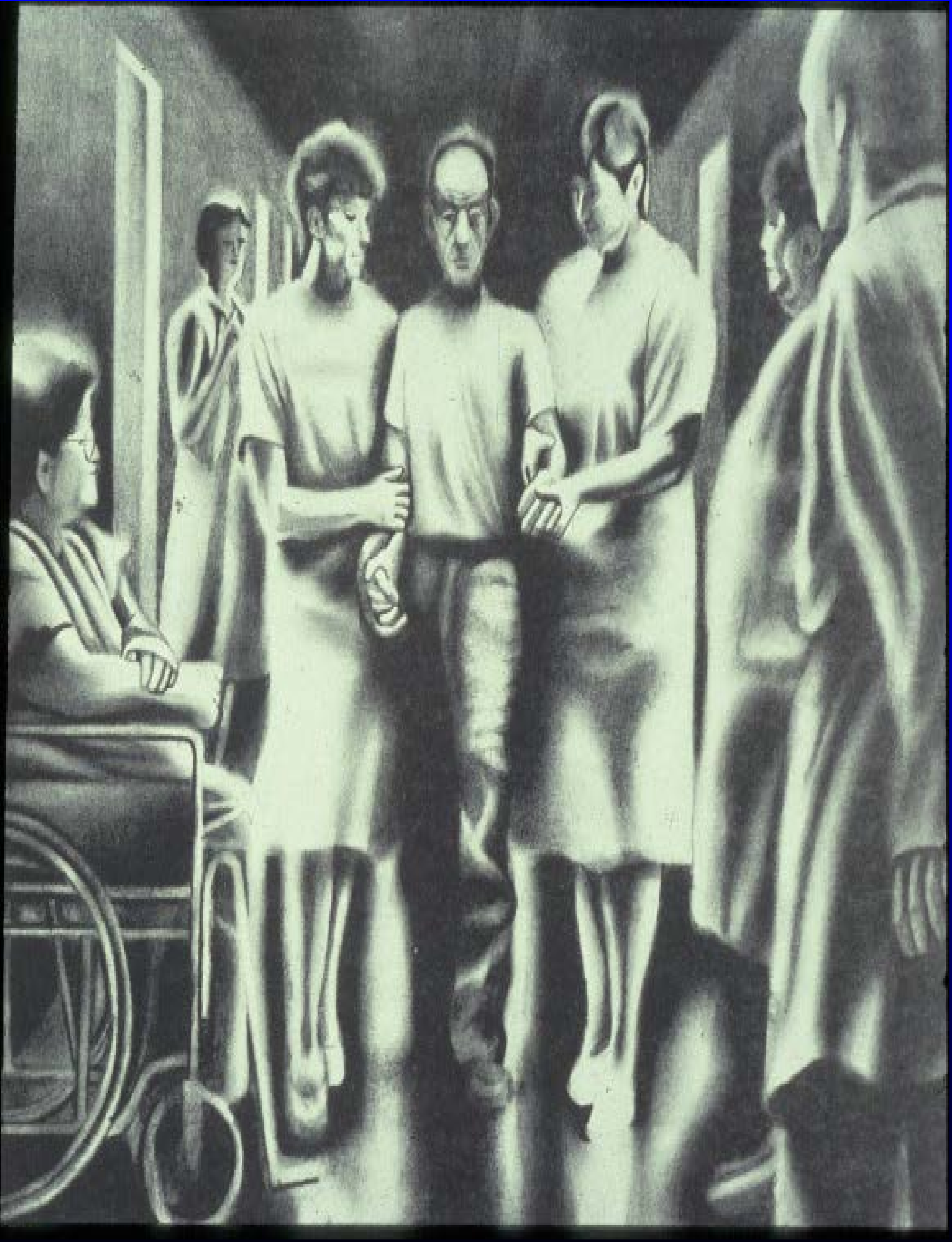
Social Support

Care Tenor

Burden to Others

Aftermath Concerns

CHOCHINOV, H.M. et coll. « Dignity in the terminally ill: a developing empirical model », *Social Science and Medicine*, vol. 54, nº 3 (2002), p. 433-443.



Soins

- Fondés sur les aptitudes cognitives et la connaissance
- Approche technique et procédurale

Empathie

- Satisfaction du patient et de la famille
- Épuisement professionnel
- Passerelle vers la divulgation
- Plaintes et conflits

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

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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/SPITZ

A : Attitude

Prestation de soins qui préservent la dignité

A Prestation de soins qui préservent la dignité : Attitude

L’attitude du prestataire de soins influence grandement la dignité des patients

Déterminants de la dignité

N=211

Nº	Variable	% de répondants en accord ou fortement en accord
1	Réflexions sur la fin de la vie	41,7 %
2	Symptômes angoissants	53,1 %
3	Incertitude face à la maladie	59,2 %
4	Déprime ou anxiété	59,7 %
5	Sentiment de perte d'intimité	65,9 %
6	Changements d'apparence physique	66,4 %
7	Incapacité d'accepter son sort	71,6 %

CHOCHINOV, H.M. et coll. « Dignity in the terminally ill: revisited », *Journal of Palliative Medicine*, vol. 9, nº 3 (2006), p. 666-672.

Déterminants de la dignité

8	Absence d’épanouissement spirituel	73,7 %
9	Dépersonnalisation	74,4 %
10	Incapacité de combattre mentalement	74,5 %
11	Incapacité de poursuivre ses activités habituelles	74,9 %
12	Impression que la vie n’a plus de but, ni de sens,	75,1 %
13	Difficulté à penser clairement	77,3 %
14	Incapacité d’exercer des fonctions importantes	78,5 %
15	Tâches de la vie quotidienne	79,6 %

Déterminants de la dignité

17	Sentiment d’inutilité et de dévalorisation	81,4 %
18	Fonctions de l’organisme	82,9 %
19	Impression de ne pas avoir contribué de façon significative ou durable à la société	83,3 %
20	Impression de ne pas être maître de sa vie	83,7 %
21	Impression d’être un fardeau pour les autres	87,1 %
22	Manque de respect ou de compréhension dans la prestation des soins	87,1 %

Attitude…

- Que ressentirais-je dans la situation du patient?
- Qu’est-ce qui m’amène à ces conclusions?
- Ai-je vérifié l’exactitude de mes hypothèses?
- Suis-je conscient de l’incidence de mon attitude sur mes patients?
- Et si c’était moi plutôt que le patient qui dictais mon attitude à son égard?
- Est-ce que mon attitude favorise ou gêne mes capacités à tisser des relations franches et empathiques avec mes patients?

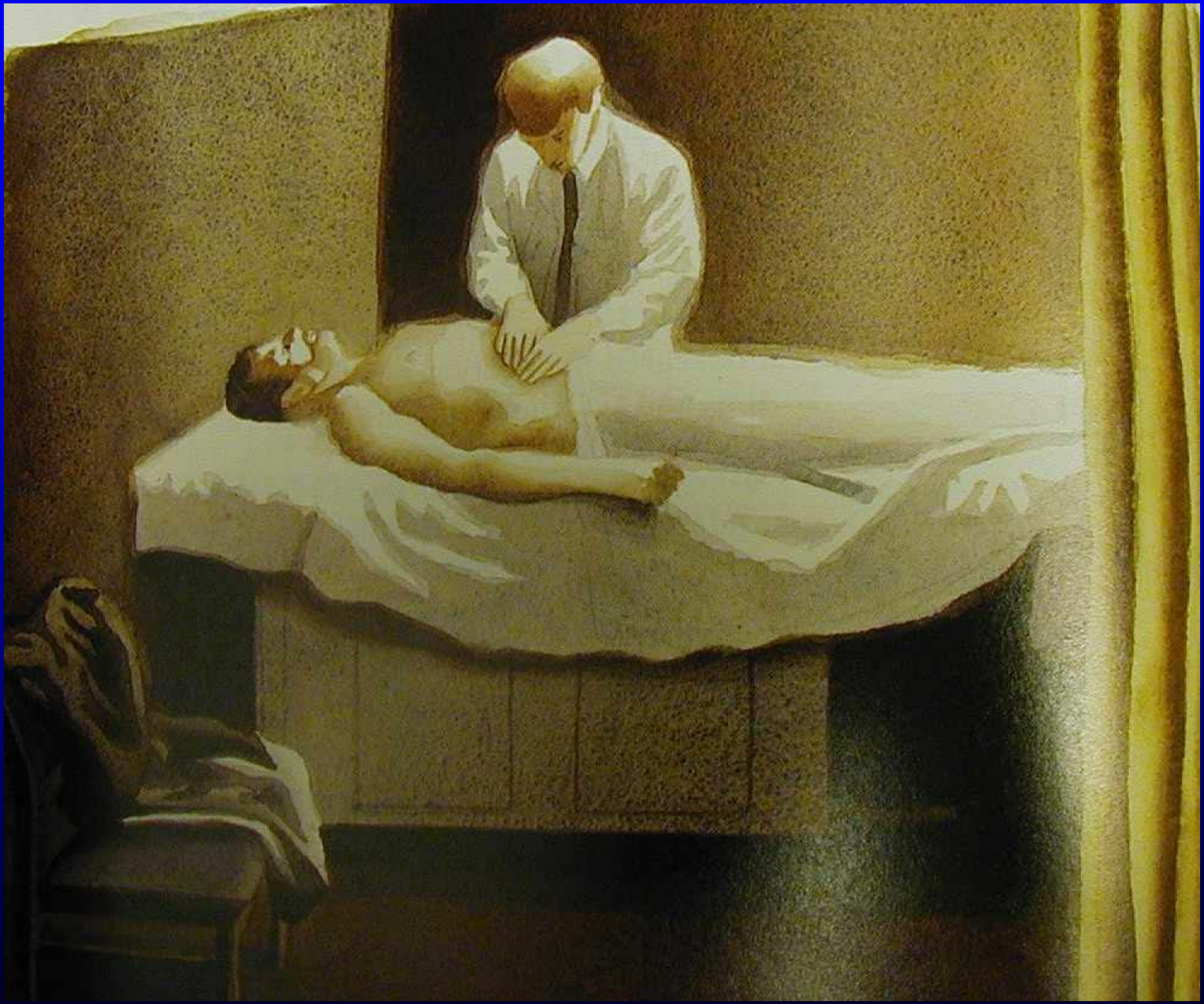
Règle d’or

Ne pas faire aux autres ce qu’on ne voudrait pas qu’ils nous fassent

Règle de platine

Faire aux autres ce qu’ils voudraient qu’on leur fasse

B : Bonne conduite
Prestation de soins qui préservent la dignité



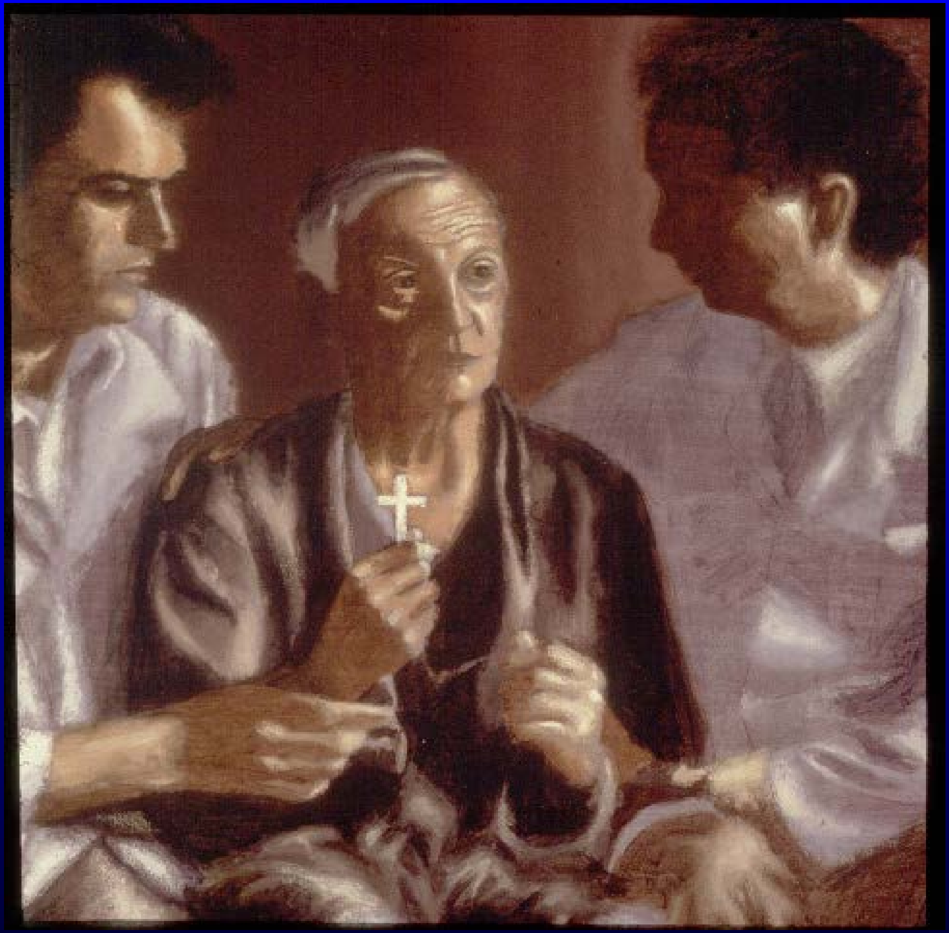
C : Compassion
Prestation de soins qui préservent la dignité

Compassion…

« […] profonde sensibilité à la souffrance d’autrui combinée à la volonté de la soulager. »

Voies vers la compassion

- Sciences humaines
  - Littérature
  - Philosophie
  - Éthique
  - Histoire
  - Théologie
- Sciences sociales
  - Anthropologie
  - Études culturelles
  - Psychologie
  - Sociologie
- Arts
  - Littérature
  - Théâtre
  - Cinéma
  - Arts visuels



Vues de loin, les choses peuvent nous sembler identiques et impossibles à distinguer. Ce n’est que lorsqu’on s’en approche qu’elles se révèlent uniques et inoubliables.

D : Dialogue
Prestation de soins qui préservent la dignité

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Original Article

The Landscape of Distress in the Terminally Ill

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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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Intégrer l'identité individuelle à la pratique médicale

« Qu'est-ce que je dois savoir sur vous en tant que personne pour vous prodiguer les meilleurs soins possible? »