



Tra realismo e speranza
il valore della comunicazione in Oncologia

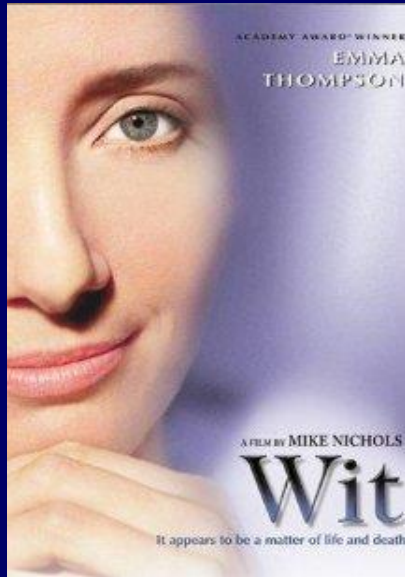
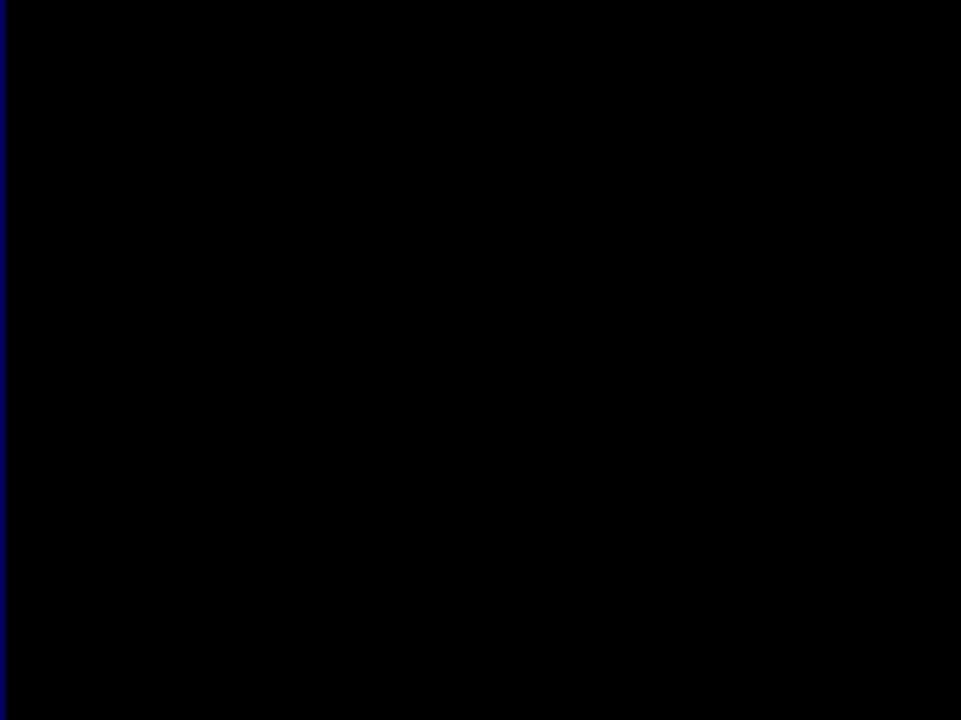
Roberto Magarotto

Unita' di Cure continuative in Oncologia

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Prognosi

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Patients' Expectations about Effects of Chemotherapy for Advanced Cancer

Jane C. Weeks, M.D., Paul J. Catalano, Sc.D., Angel Cronin, M.S.,
Matthew D. Finkelman, Ph.D., Jennifer W. Mack, M.D., M.P.H.,
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Prognosi

METHODS

We studied 1193 patients participating in the Cancer Care Outcomes Research and Surveillance (CanCORS) study (a national, prospective, observational cohort study) who were alive 4 months after diagnosis and received chemotherapy for newly diagnosed metastatic (stage IV) lung or colorectal cancer. We sought to characterize the prevalence of the expectation that chemotherapy might be curative and to identify the clinical, sociodemographic, and health-system factors associated with this expectation. Data were obtained from a patient survey by professional interviewers in addition to a comprehensive review of medical records.

RESULTS

Overall, 69% of patients with lung cancer and 81% of those with colorectal cancer did not report understanding that chemotherapy was not at all likely to cure their cancer. In multivariable logistic regression, the risk of reporting inaccurate beliefs about chemotherapy was higher among patients with colorectal cancer, as compared with those with lung cancer (odds ratio, 1.75; 95% confidence interval [CI],



Realism and hope

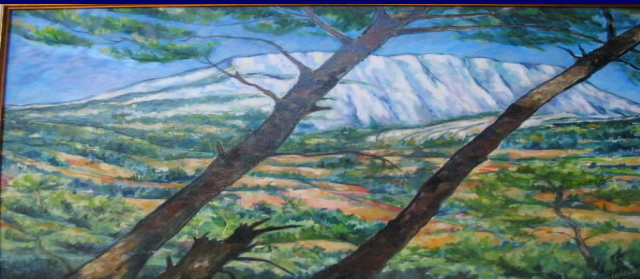
VOLUME 23 - NUMBER 6 - FEBRUARY 20 2005

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Communicating With **Realism and Hope**: Incurable Cancer Patients' Views on the Disclosure of Prognosis

*Rebecca G. Hagerty, Phyllis N. Butow, Peter M. Ellis, Elizabeth A. Lobb, Susan C. Pendlebury,
Natasha Leighl, Craig MacLeod, and Martin H.N. Tattersall*



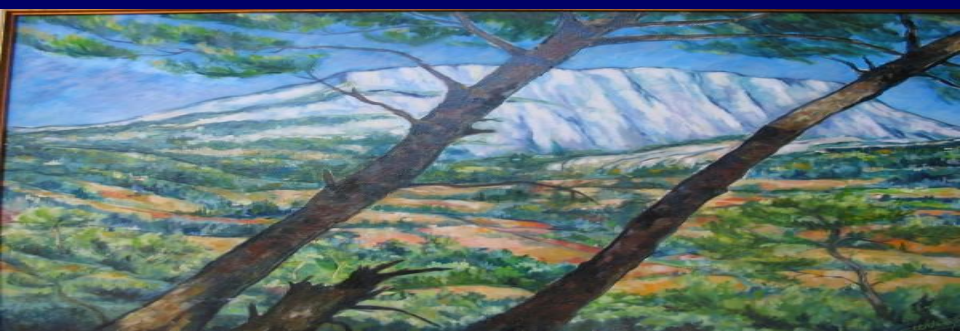
Realism and hope

Results

Ninety-eight percent of patients wanted their doctor to be realistic, provide an opportunity to ask questions, and acknowledge them as an individual when discussing prognosis. Doctor behaviors rated the most hope giving included offering the most up to date treatment (90%), appearing to know all there is to know about the patient's cancer (87%), and saying that pain will be controlled (87%). The majority of patients indicated that the doctor appearing to be nervous or uncomfortable (91%), **giving the prognosis to the family first (87%)**, or using euphemisms (82%) would not facilitate hope. Factor analysis revealed six general styles and three hope factors; the most strongly endorsed styles were realism and individualized care and the expert/positive/collaborative approach. A range of demographic, psychological, and disease factors were associated with preferred general and hope-giving styles, including anxiety, information-seeking behavior, expected survival, and age.

Conclusion

The majority of patients preferred a realistic and individualized approach from the cancer specialist and detailed information when discussing prognosis.



Hope

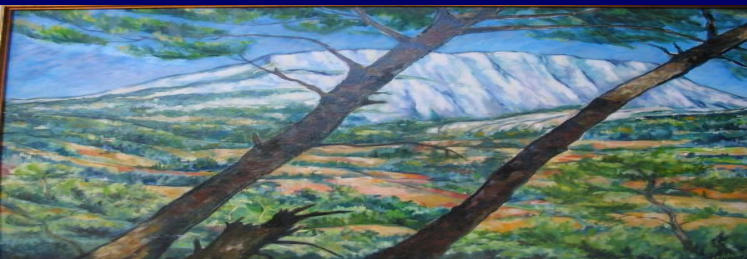
VOLUME 26 - NUMBER 36 - DECEMBER 20 2008

JOURNAL OF CLINICAL ONCOLOGY

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

Surprised by Hope

Prudence A. Francis



Surprised by hope

When this patient presented me with a specific request, in the presence of her spouse, regarding prognostic communication, it seemed that my optimism was a necessary component in the support of her psyche and maintenance of hope. She wished to maintain hope for an unlikely outcome, and it seemed a reasonable decision to support her in this. Just as medical oncologists make differing therapeutic decisions on an individual patient and tumor basis, so it may also be appropriate to respond differently to individualized patient existential needs. Ironically, the approach of supporting this patient's view of her prognosis saw the realization of many of her hopes as the years unfolded. This approach may be criticized, nevertheless, on the grounds that patients who overestimate their survival probabilities may be more likely to choose to undergo aggressive treatment, without experiencing better survival.²



Ragioni per non parlare di prognosi?

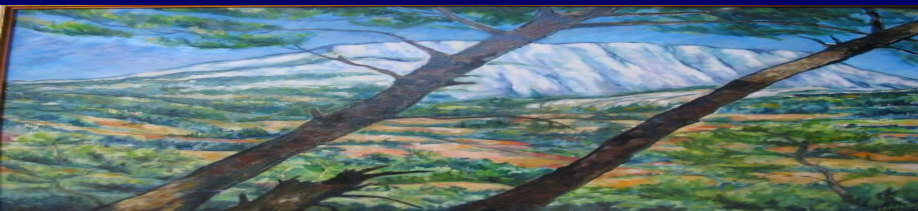
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JOURNAL OF CLINICAL ONCOLOGY

COMMENTS AND CONTROVERSIES

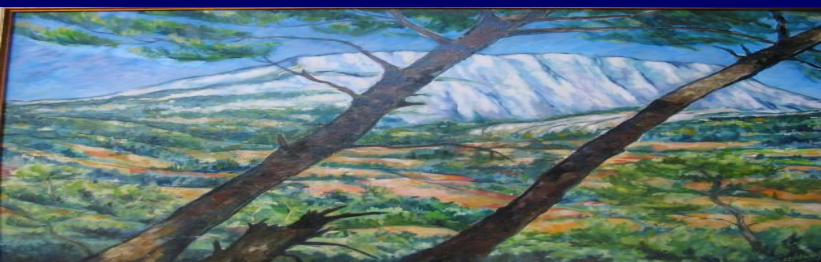
Reasons Why Physicians Do Not Have Discussions About Poor Prognosis, Why It Matters, and What Can Be Improved

Jennifer W. Mack, *Dana-Farber Cancer Institute and Children's Hospital, Boston, MA*
Thomas J. Smith, *Johns Hopkins Medical Institutions, Baltimore, MD*



6 ragioni per non parlare di prognosi

- 1) deprime i pazienti **falso (vero se non accompagnato da un percorso di sostegno)**
- 2) toglie la speranza **falso (idem)**
- 3) affidare all'hospice o alle cure palliative riduce la sopravvivenza **falso**
- 4) non si e' mai sicuri della prognosi **vero , con precisazioni**
- 5) non è culturalmente appropriato **falso**
- 6) e' difficile e stressante parlarne **vero**



Prognosi

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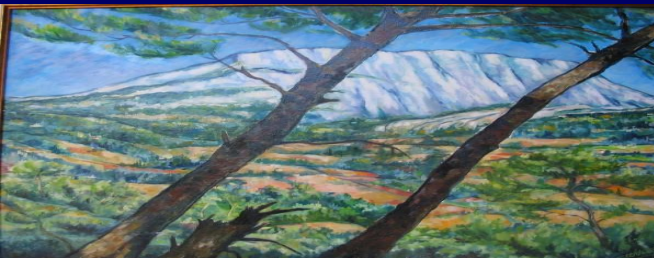
original article

Annals of Oncology 00: 1–7, 2012
doi:10.1093/annonc/mds341

Prognosticating in patients with advanced cancer – observational study comparing the accuracy of clinicians' and patients' estimates of survival

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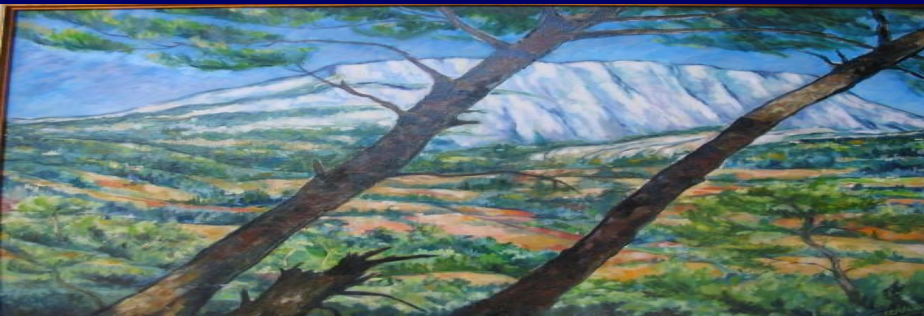
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Background: Clinicians' prognoses in patients with advanced cancer are imprecise. The aim of this study was to compare doctors', nurses' and patients' survival predictions and to identify factors which influence accuracy.

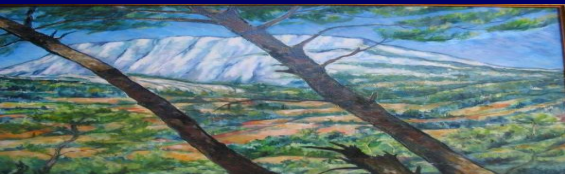
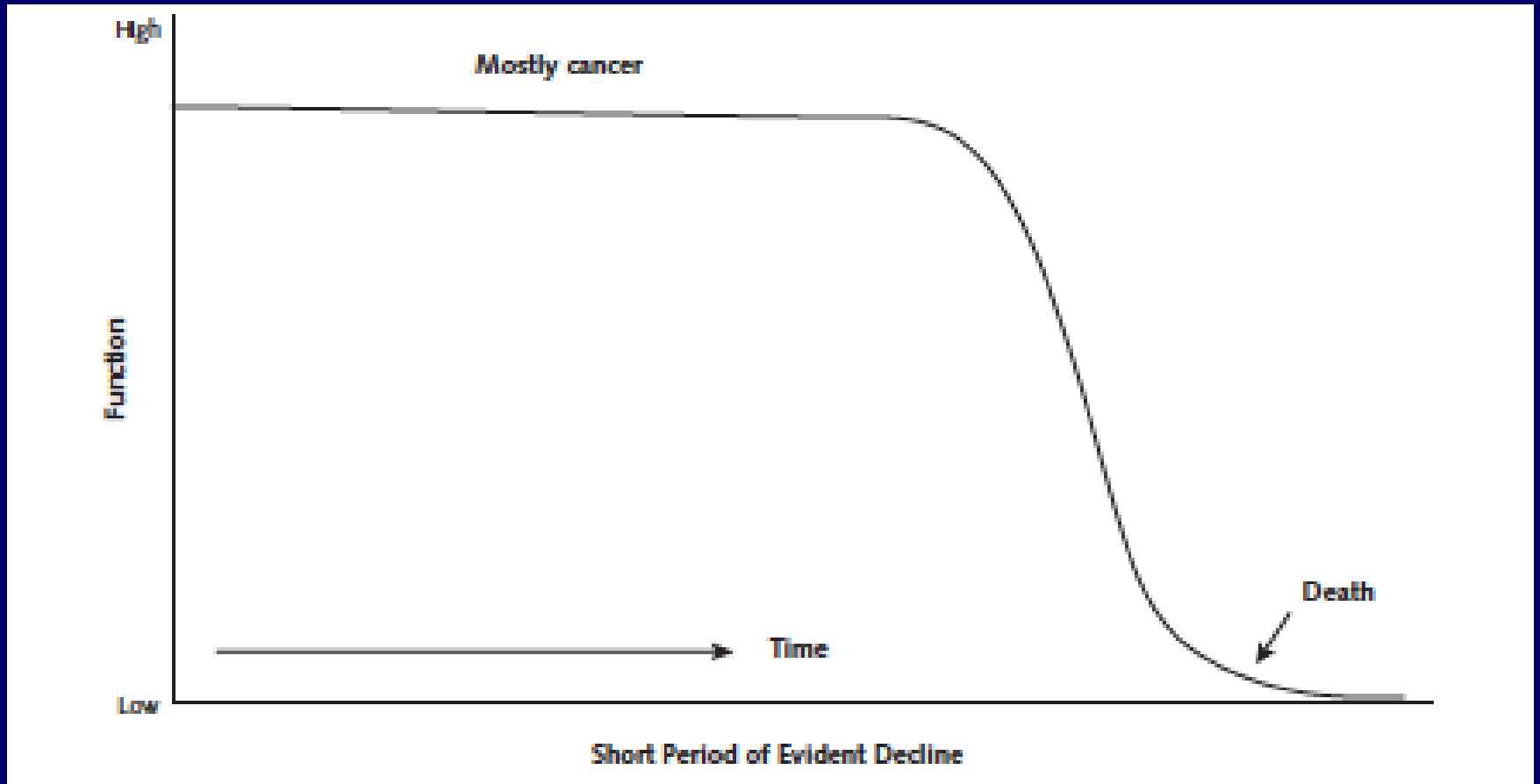
Patients and methods: Some 1018 patients with advanced cancer were recruited. Survival estimates were obtained from the attending doctor, nurse, multidisciplinary team (MDT) and patient ($n = 829, 954, 987$ and 290 estimates, respectively) and were compared with actual survival. Clinician and patient characteristics were recorded.

Results: MDTs', doctors' and nurses' predictions were accurate 57.5%, 56.3% and 55.5% of occasions, respectively. Nurses were less accurate than the MDT ($P = 0.007$) but were no worse than doctors ($P = 0.284$). Estimates of clinicians and patients were more optimistic (doctors: 31%; nurses: 34%; MDT: 31.1%; patients: 45.1%) than pessimistic (12.7%, 11%, 11.4% and 2.7%). Nurses' accuracy increased if they had reviewed the patient within 24 h. Most patients (61.4%) wanted to know their prognosis. Only 37.1% were willing to offer an estimate regarding their own survival. Patients' prognostic estimates were less accurate than health care professionals' ($P < 0.001$).

Conclusions: MDTs were better at predicting survival than doctors' or nurses' alone. Patients were substantially worse. Among nurses, recency of review was related to improved prognostic accuracy.



Traiettoria



Sintomi

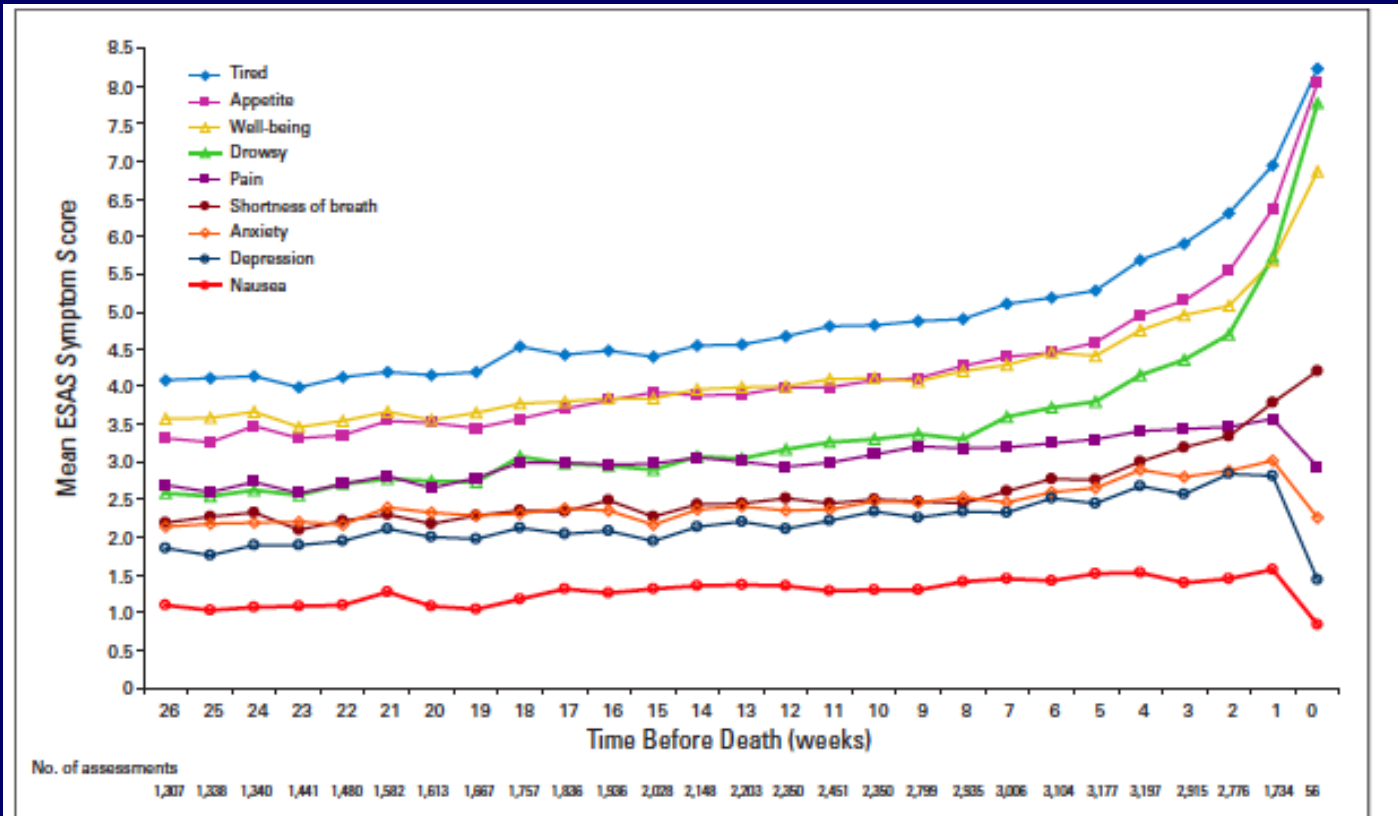


Fig 2 Mean Edmonton Symptom Assessment System (ESAS) symptom scores over time. Number of assessments is maximum number available among all nine symptoms. Missing ESAS values for a given symptom were not included when calculating the mean.



Symptoms tell it all



Critical Reviews in Oncology/Hematology 84 (2012) 130–148

CRITICAL REVIEWS IN
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Symptoms tell it all: A systematic review of the value of symptom assessment to predict survival in advanced cancer patients

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Caregivers

Research

Open Access

Caregiver assessment of patients with advanced cancer: concordance with patients, effect of burden and positivity

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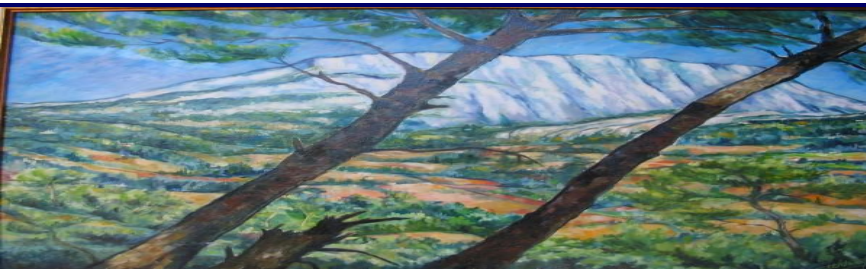
* Corresponding author

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Caregivers

Abstract

Background: Clinicians and researchers often have to rely on information from caregivers to assess patients with advanced cancer. This study aims to assess the validity (using patients' assessment as the gold standard) of caregiver reports of patient concerns and the roles of caregiver burden and positivity.

Methods: A total of 64 advanced cancer patient and informal caregiver dyads were recruited from regional palliative care services and interviewed. Patients' outcomes were assessed with both the patient and the caregiver version of the Palliative Outcome Scale (POS); caregiver burden and positivity were collected with the Zarit Burden interview (ZBI) and three questions on achievements and relationships. The agreement between patient- and caregiver-rated POS was measured with weighted kappa statistics. The roles of caregiver burden and positivity in POS agreement were studied with logistic regression controlling for potential confounders; adjusted odds ratios were estimated from the models.

Results: Agreement was substantial for pain, moderate for four items, fair for three items and slight for two items. Compared with patients self-ratings, caregivers described more problems with information given and sharing feelings and were less likely to assess the patient felt their life was worthwhile or felt good about themselves. Disagreement for three POS item ratings was significantly associated with higher caregiver burden: "feeling anxious" (OR: 4.5; 95%CI: 1.3 to 15.6), "life worthwhile" (OR: 12.4; 95%CI: 2.9 to 54.3) and "felt good" (OR: 7.7; 95%CI: 2.0 to 29.6). Caregivers with higher positivity scores were more likely to agree patients' rating of "felt good" (OR: 0.3; 95%CI: 0.1–0.9) but at increased risk of disagreeing about patient's "practical problems" (OR: 4.2; 95%CI: 1.1 to 16.6).

Un aiuto per chi aiuta

The image shows the cover of a book titled "Support for Cancer Caregivers: Caring for the Caregiver". The cover features a photograph of two hands clasped together, one resting on the other, symbolizing support and care. The text is arranged as follows:

- On the left side, oriented vertically: National Cancer Institute
- At the top right: Support for Cancer Caregivers
- In the center: Caring for the Caregiver
- At the bottom left: U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES National Institutes of Health



Quando le parole feriscono come coltelli (E.Jannelli)



- Evitare di banalizzare (“forza e coraggio” ... “con le cure che ci sono oggi”)
- Evitare il pietismo (“ Devi stare proprio male...”)
- Evitare l’esaltazione (“non sembri neanche malato” ... “il tuo e’ quasi un miracolo” ...)
- La spontaneità e la disponibilità all’ascolto sono le chiavi per entrare nel cuore della persona malata di tumore



Day hospital (V.Evangelisti)



- 2009 :diagnosi di linfoma HG; 6 cicli di R-CHOP con Remissione Completa (tutt'ora)
- fin dal primo ciclo formicolii agli arti inferiori ; dopo la chemioterapia esito in neuropatia periferica (compresa la neuropatia autonoma) : effetto collaterale duraturo conseguente alle infusioni di vincristina



Day hospital (V.Evangelisti)

- “Trovo paradossale la mia situazione : ho avuto salva la vita , per ora, ma non la qualita' della vita . Perche' non sono stato messo in guardia?
- Una volta dimessomi dal DH gli onco-ematologi ritengono esaurito il loro compito; la palla passa ad altri colleghi : dovranno essere loro a riparare le conseguenze delle cure originarie
- Sono un po' zoppo eppure vivo : cos'altro dovrei esigere ? Ad essere onesti mi manca la possibilita' di viaggiare in liberta', se non con la fantasia ; quella , il linfoma non l'ha nemmeno sfiorata”



C.HITCHENS -Mortalità

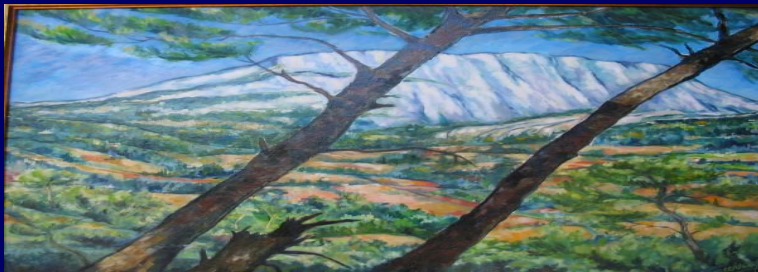


- La gente non ha il cancro : si dice che lotta contro il cancro : non c'è amico o parente che si astenga da questa immagine bellicosa : “puoi sconfiggerlo !” “ se c'è qualcuno che puo' cavarsela quello sei tu “ “Il cancro non ha alcuna possibilita' contro un tipo come te...”
- Se crepo , avro' deluso tutti...
- Benvenuti a Tumortown , dove a volte hai l'impressione di morire di consigli, molti dei quali gratuiti e non richiesti
- Quando mi chiedono “ Come stai?” rispondo “ un po' presto per dirlo “



C.HITCHENS –Mortalità

- Gli abitanti di Tumortown sono continuamente assillati da cure e voci di possibili cure
- Dovrei girare con un grosso distintivo sul bavero che avverte : ditemi del cancro all'esofago al quarto stadio con metastasi e solo di quello
- Se non avete notizie da darmi su quello e soltanto di quello , e su cio' che succede quando sono coinvolti i linfonodi e i polmoni , non ho un grande interesse a sentirvi



C.HITCHENS-Mortalita'

- Anche l'approccio pianificato e coordinato apre la strada agli eufemismi “ Le piacerebbe conoscere il nostro psicologo? “ Ha già incontrato la nostra equipe di terapia del dolore?”
- A questo punto tento ancora di tenere viva una **fiammella di curiosità e di sfida**: intendo giocarmela fino alla fine e vorrei che non mi fosse risparmiato nulla di ciò che appartiene all'esistenza

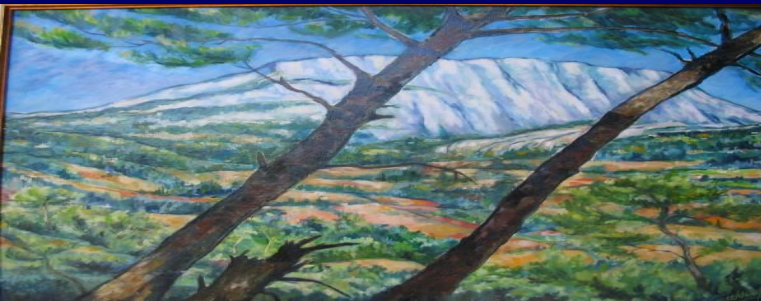


Quattro modelli

Special Communication

Four Models of the Physician-Patient Relationship

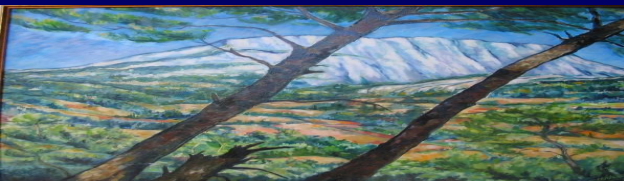
Ezekiel J. Emanuel, MD, PhD, Linda L. Emanuel, MD, PhD



Quattro modelli

Comparing the Four Models

	Informative	Interpretive
Patient values	Defined, fixed, and known to the patient	Inchoate and conflicting, requiring elucidation
Physician's obligation	Providing relevant factual information and implementing patient's selected intervention	Elucidating and interpreting relevant patient values as well as informing the patient and implementing the patient's selected intervention
Conception of patient's autonomy	Choice of, and control over, medical care	Self-understanding relevant to medical care
Conception of physician's role	Competent technical expert	Counselor or adviser



Quattro modelli

Deliberative	Paternalistic
Open to development and revision through moral discussion	Objective and shared by physician and patient
Articulating and persuading the patient of the most admirable values as well as informing the patient and implementing the patient's selected intervention	Promoting the patient's well-being independent of the patient's current preferences
Moral self-development relevant to medical care	Assenting to objective values
Friend or teacher	Guardian



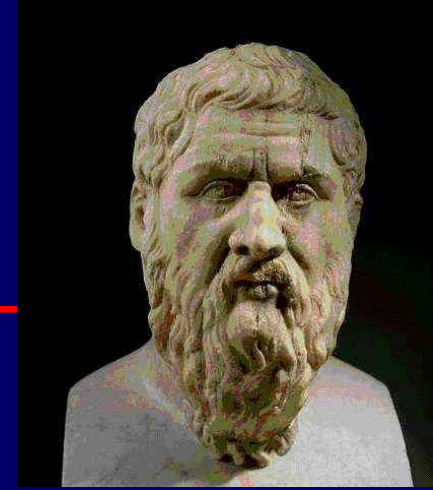
Quattro modelli

CONCLUSION

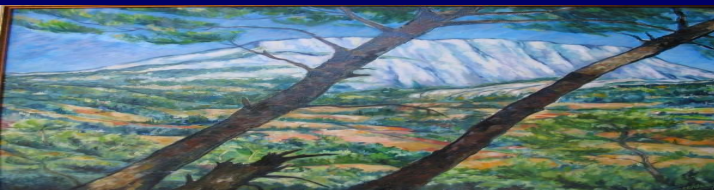
Over the last few decades, the discourse regarding the physician-patient relationship has focused on two extremes: autonomy and paternalism. Many have attacked physicians as paternalistic, urging the empowerment of patients to control their own care. This view, the informative model, has become dominant in bioethics and legal standards. This model embodies a defective conception of patient autonomy, and it reduces the physician's role to that of a technologist. The essence of doctoring is a fabric of knowledge, understanding, teaching, and action, in which the caring physician integrates the patient's medical condition and health-related values, makes a recommendation on the appropriate course of action, and tries to persuade the patient of the worthiness of this approach and the values it realizes. The physician with a caring attitude is the ideal embodied in the deliberative model, the ideal that should inform laws and policies that regulate the physician-patient interaction.



Platone- Le leggi



- il medico libero invece cura e studia
nella maggior parte dei casi le malattie dei liberi esaminandole
sin dal principio e secondo la loro natura
- **e rende partecipe l'ammalato stesso e i suoi amici della sua indagine
e lui stesso apprende qualcosa dai malati**
- **e nello stesso tempo per quanto gli è possibile insegna al malato; e non
prescrive nulla prima di averlo convinto e allora rendendo docile e
preparando il paziente mediante la persuasione tenta di riportarlo alla
salute .**



Giovani dottori crescono.

- Ricerca dell'Università degli Studi di Padova pubblicata quest'anno su North American Journal of Medical Science
- 423 studenti di medicina
- Graduatoria su 13 valori professionali
- 1° rispetto del paziente
- 2° affidabilità (attitudine ad assumersi le proprie responsabilità)
- 3° competenze professionali



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GRAZIE PER L'ATTENZIONE!

