The Relief of Pain and Suffering in Advanced Disease:







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The Good Death

Common Denominators Across Cultures

- Relief from physical suffering
- Psychological/spiritual well-being
- Social connection
- Appropriate health care
- Life closure and death preparation
- The desired circumstances and location of death Hales, Zimmermann and Rodin 2008

World Health Organization Definition of Palliative Care



- An approach that improves the quality of life of patients and their families facing lifethreatening illness by providing:
 - Relief from pain and other distressing symptoms
 - Attention to the psychological and spiritual aspects of patient care;
 - A support system to help patients live as actively as possible until death and to help families cope during the patients illness and in their own bereavement;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life

Painful Inequities* The Cultural Divide

- Education
- Income
- Health policy
- Health care delivery
- Palliative care training and resources
- Religious and cultural attitudes
- Circumstances of living

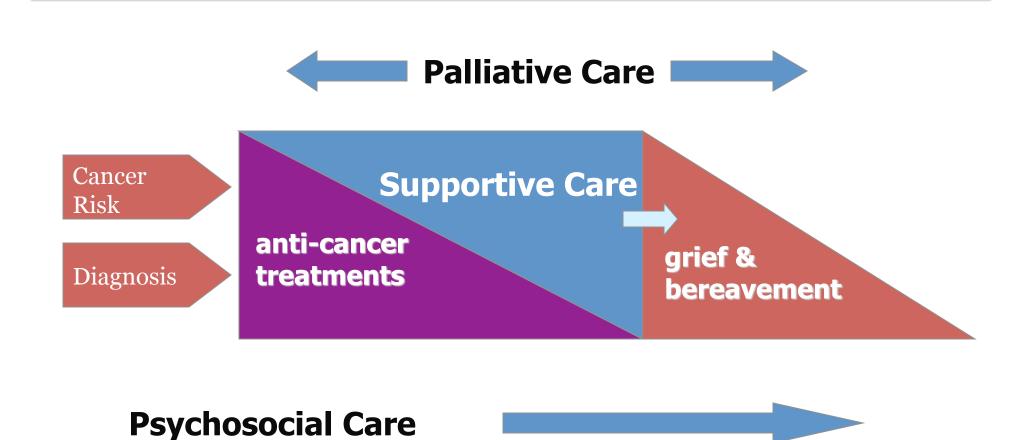


Lamas and Rosenbaum NEJM 2012



- Urging governments to relieve suffering and recognize palliative care as a human right
 - health policies that address the needs of patients with life-limiting or terminal illnesses.
 - Access to essential medicines, including controlled medications, to all who need them.
 - adequate training of health care workers on palliative care and pain management at undergraduate and subsequent levels.
 - integration of palliative care into healthcare systems at all levels.

The Widened Trajectory



The Trauma of Diagnosis The impact of medical communication

"..I was completely shattered...like everything fell beneath me...I'll never forget the doctor's words when he said it...I went to see him as one person, and I left completely devastated."



Will to Live study participant

The Will to Live Study

- A longitudinal study examining the predictors of depression, hopelessness and the desire for hastened death
- Examined depression as a final common pathway in response to multiple interacting risk factors



Will to Live Study

Recruitment Flowchart

Screened for Eligibility N=2237

Ineligible N=412 (349 LB; 31 CD; 32 other)

Eligible Patients Approached N=1435

Not Approached N=390

Consented N=1060

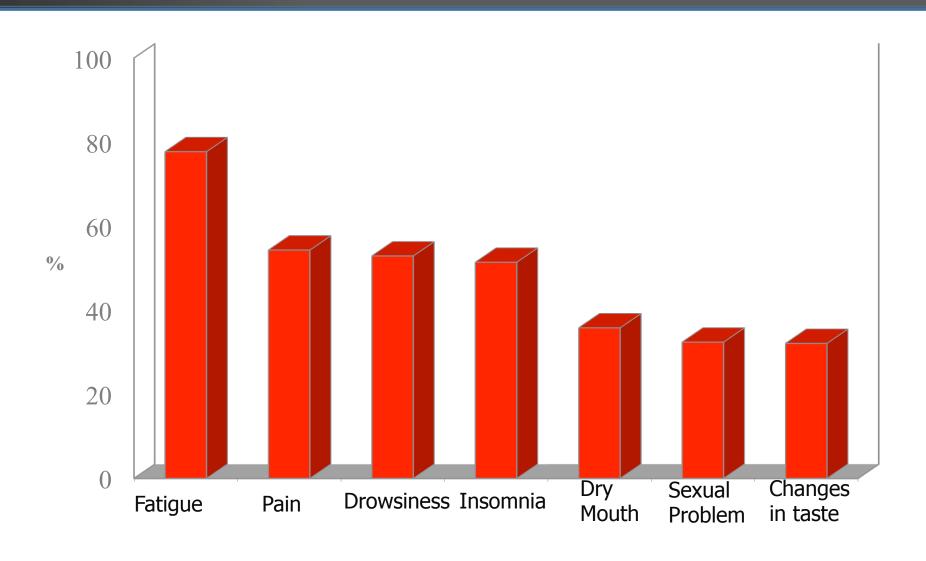
Refused N=375

Completed Baseline N=747

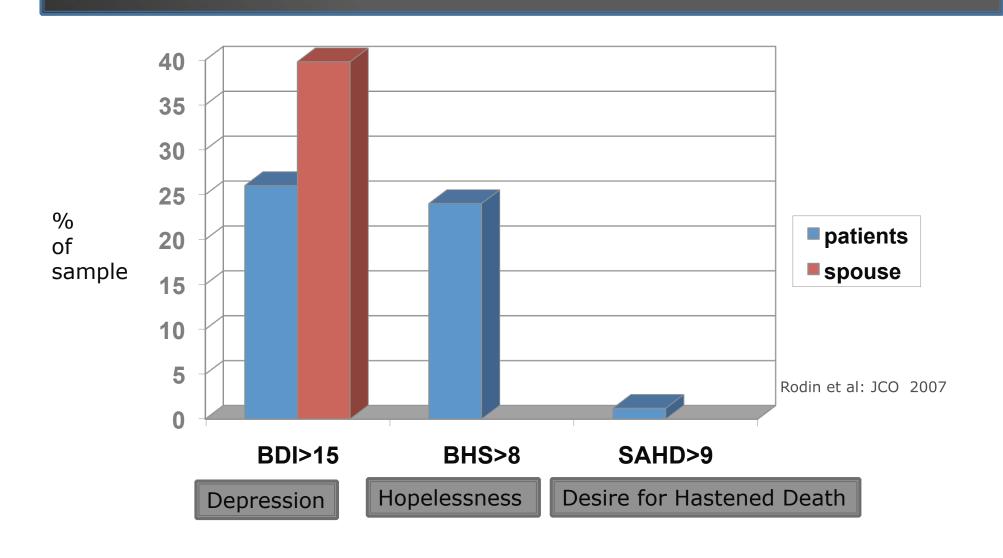
(412 longitudinal + 335 cross-sectional only)

Baseline Not
Completed
N=313
(232 WD; 72 died; 9 other)

The Physical Burden of Disease

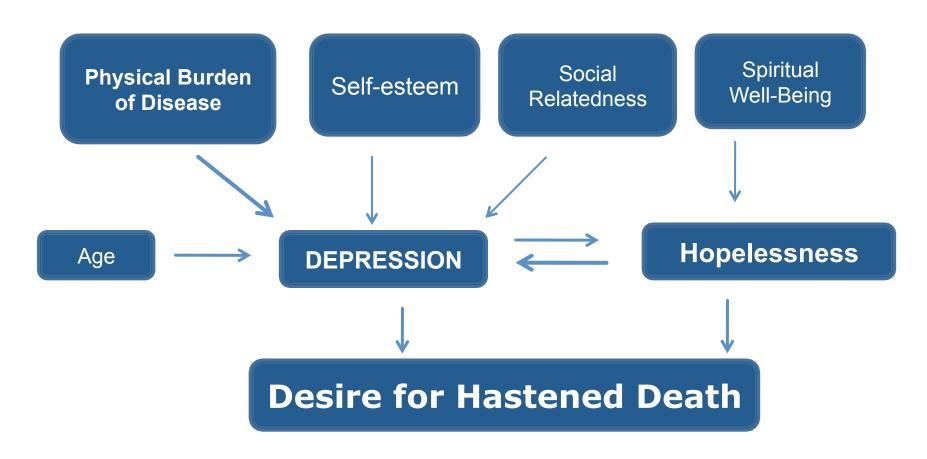


The Proportion with Elevated Symptoms of Depression, Hopelessness and DHD



Pathways to Distress

Cross-Sectional and Longitudinal Test of The Model



Rodin et al Soc Med, 2009 Lo .. Rodin Journal of Clinical Oncology 2010

Early and Longitudinal Palliative Care in Comprehensive Cancer Care Center

- Outpatient consultation and Treatment services
 - 3272 consultations/year
 - Psychosocial Oncology
 - Palliative care
- Inpatient Services
 - Acute Palliative Care Unit
 - 12 beds
 - Average LOS of stay 11 days
 - Residential Hospice
 - 10 beds
 - Average LOS two week
 - Median LOS
- Partnership with home palliative care network









Managing Cancer and Living Meaningfully (CALM)

A Brief Psychotherapeutic Intervention

Symptom management & communication with healthcare providers

Changes in self & relations with close others

Spirituality & sense of meaning/purpose

Thinking of the future, hope, and mortality

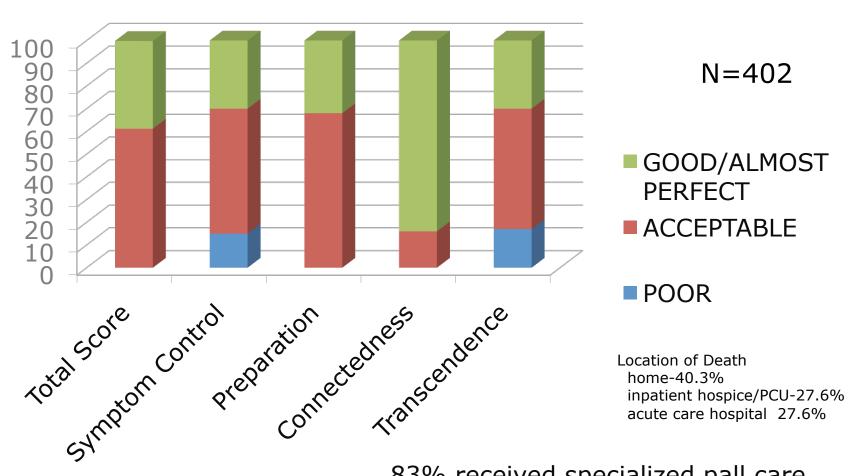


Quality of Dying and Death An Assessment tool

- The Quality of Death and Dying Questionnaire*
 - An interview with bereaved caregivers to assess 31 items related to satisfaction with:
 - Symptom control
 - Preparation for death
 - Connectedness
 - time with family & whole person concerns
 - Transcendence
 - Vs Distress and fear of dying



The Quality of Dying and Death of Cancer Patients in a Large Urban Center



83% received specialized pall care Better ratings for home death

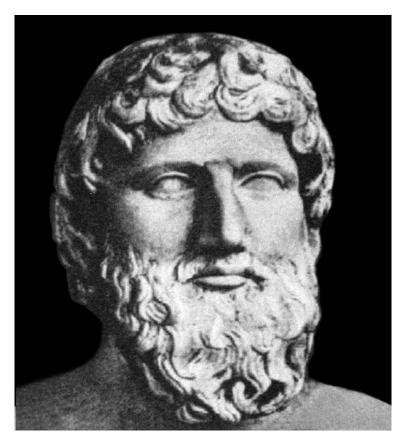
The Human Impact of Palliative Care

 This has been the only opportunity for us to be looked at as people by the medical system. I think that is really important, because you are more than the sum of your parts...it makes me feel like I will be able to handle death in a peaceful way

Nissim.. Rodin Palliative Medicine 2011

The Whole Person Project of Palliative Care

`The greatest mistake in the treatment of diseases is that there are physicians for the body and physicians for the soul, although the two cannot be separated".



Plato 429-347 BC