

The science of supportive care:

A research framework for
psychosocial
oncology and palliative care

Gary Rodin MD
University of Toronto/University Health Network
Chair in Psychosocial Oncology and Palliative Care

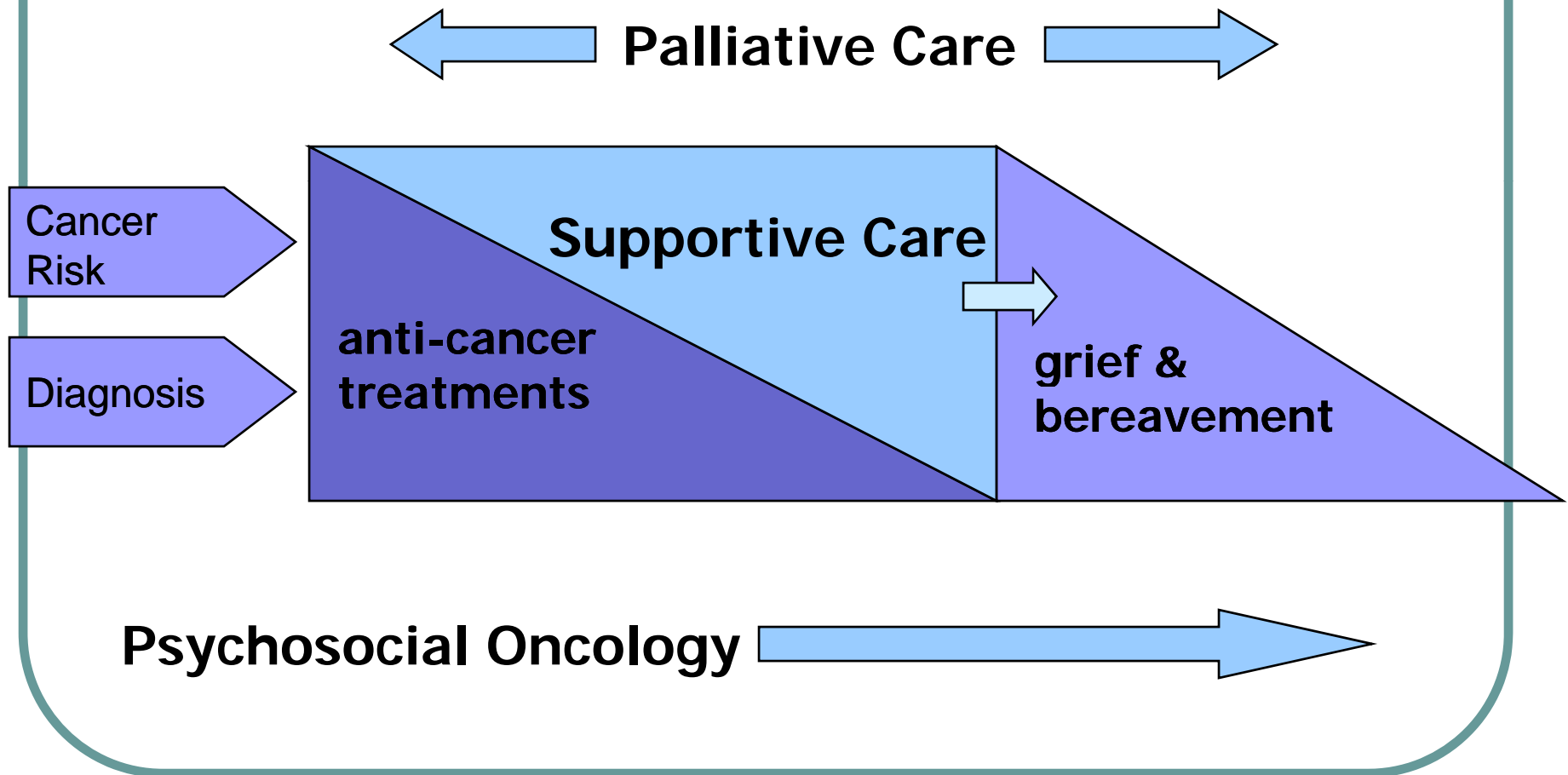
The Short (and long) history of Palliative Care

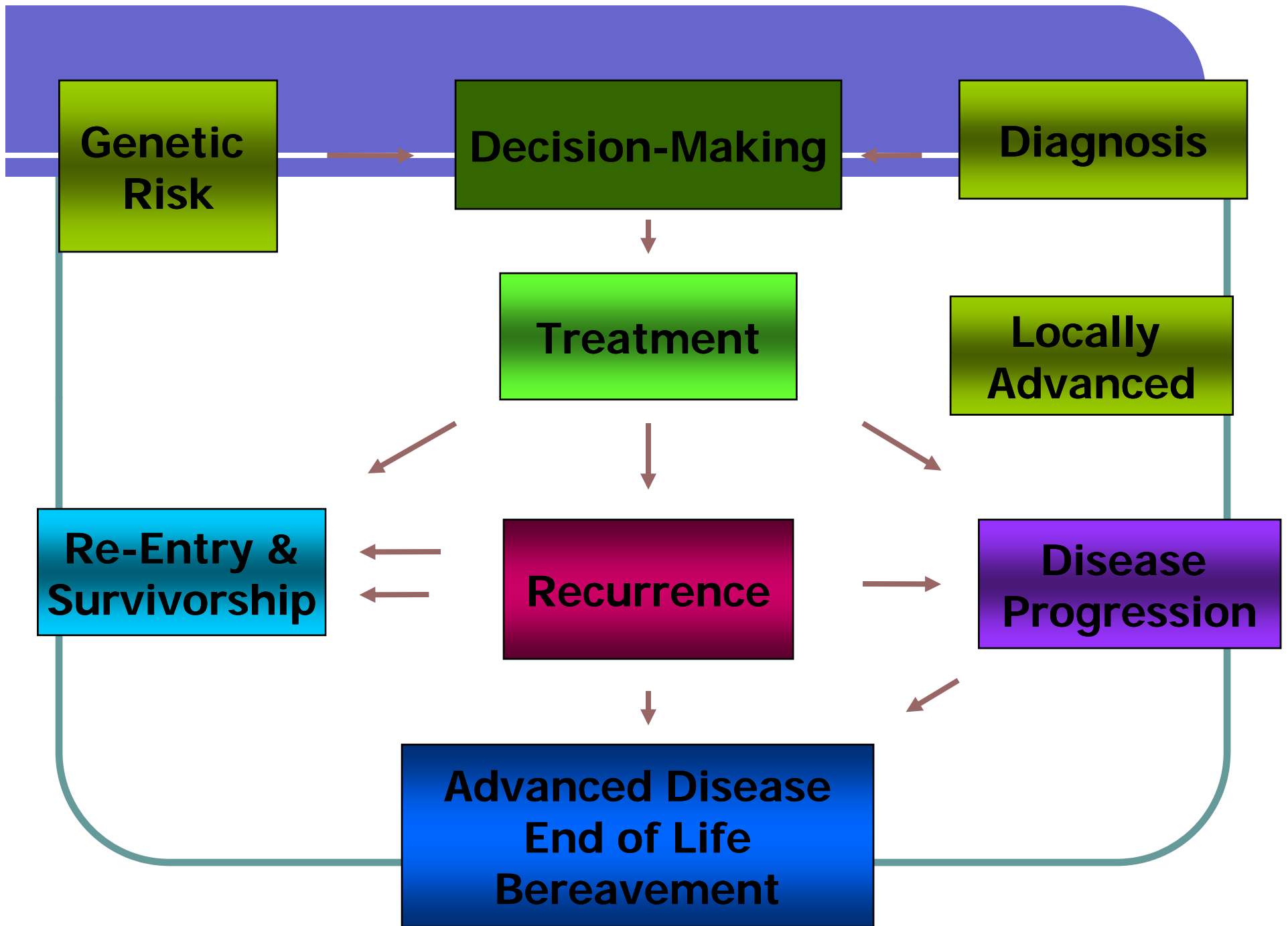


Matron Helen Willans brings a bed to the door to welcome a new patient.

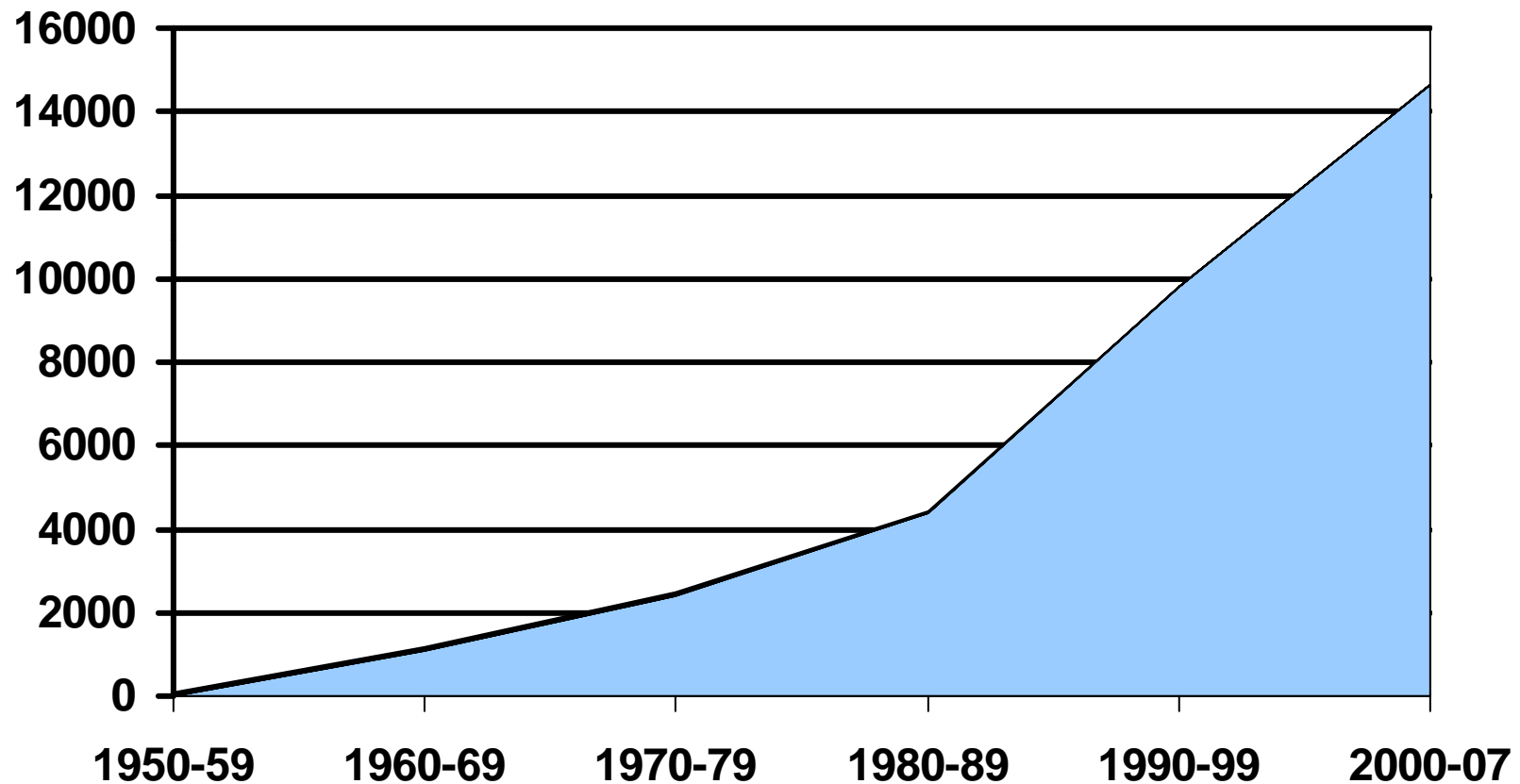


Longitudinal & Integrated Cancer Care





The Rise of Research in Palliative Care



Unproven Beliefs in Palliative and Supportive Care

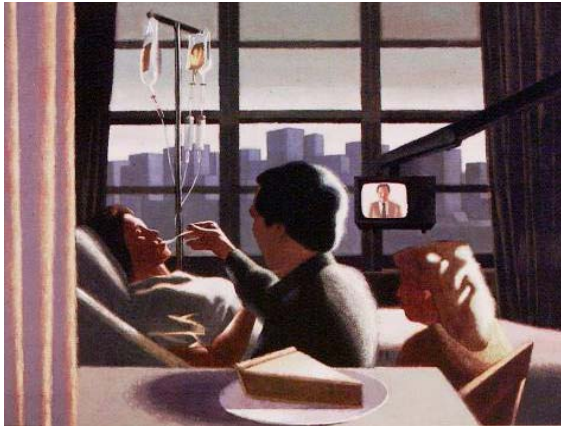
- Psychosocial and symptomatic outcomes improved by:
 - Routine distress screening
 - Early palliative care
 - Routine bereavement counseling
- Psychosocial interventions prolong survival
- Psychostimulants are effective for the treatment of depression



Has the Revolution of Palliative & Supportive Care Changed Medical Practice?

- Pain
 - 50% of patients who died in hospital report moderate to severe pain
 - SUPPORT
- Depression
 - only 1/3 of patients with MDD attending a UK cancer center received any potentially effective RX
 - *Sharpe et al, 2004*
- End of Life
 - 18.5% of cancer patients receive chemotherapy in the last two weeks of life
 - Earle et al 2004
 - <30% referred to palliative care
 - SUPPORT
- Communication
 - Severe communication problems reported by up to 40% of patients at the EOL in UK, Ireland and Italy
 - Higginson et al, 2002

The Domains of Research



- Distress
- Needs
- Meaning
- Communication
- Planning the end
- The “good death”
- Bereavement



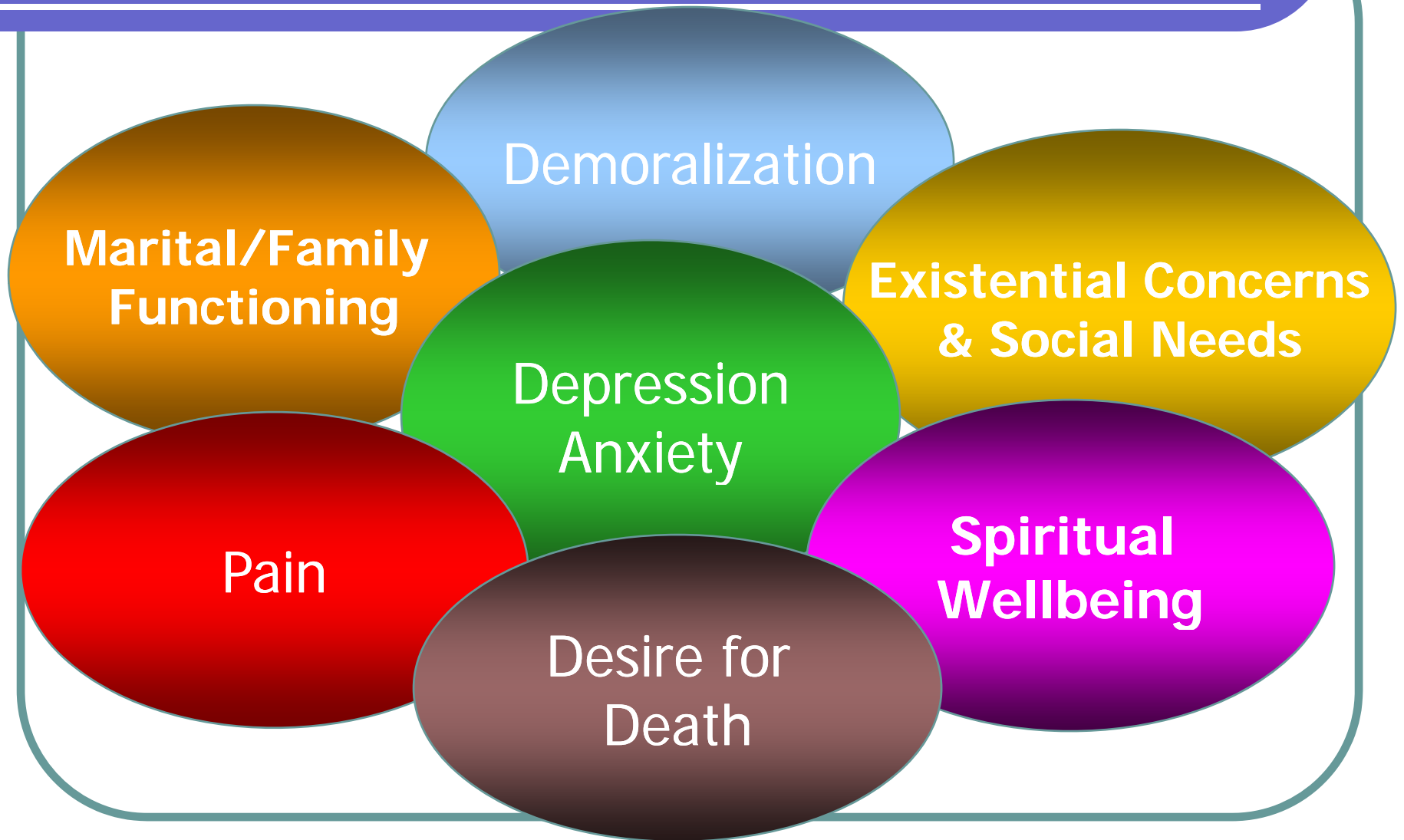
Why Has Competence and Research in Palliative Care Been Slow to Develop

- Curative model of medicine
- Teaching and research in acute care settings
- Professional incentives for active treatment
- Medical education
- Nonacademic tradition of palliative care
- Interdisciplinary requirements
- The complexity of the problems addressed

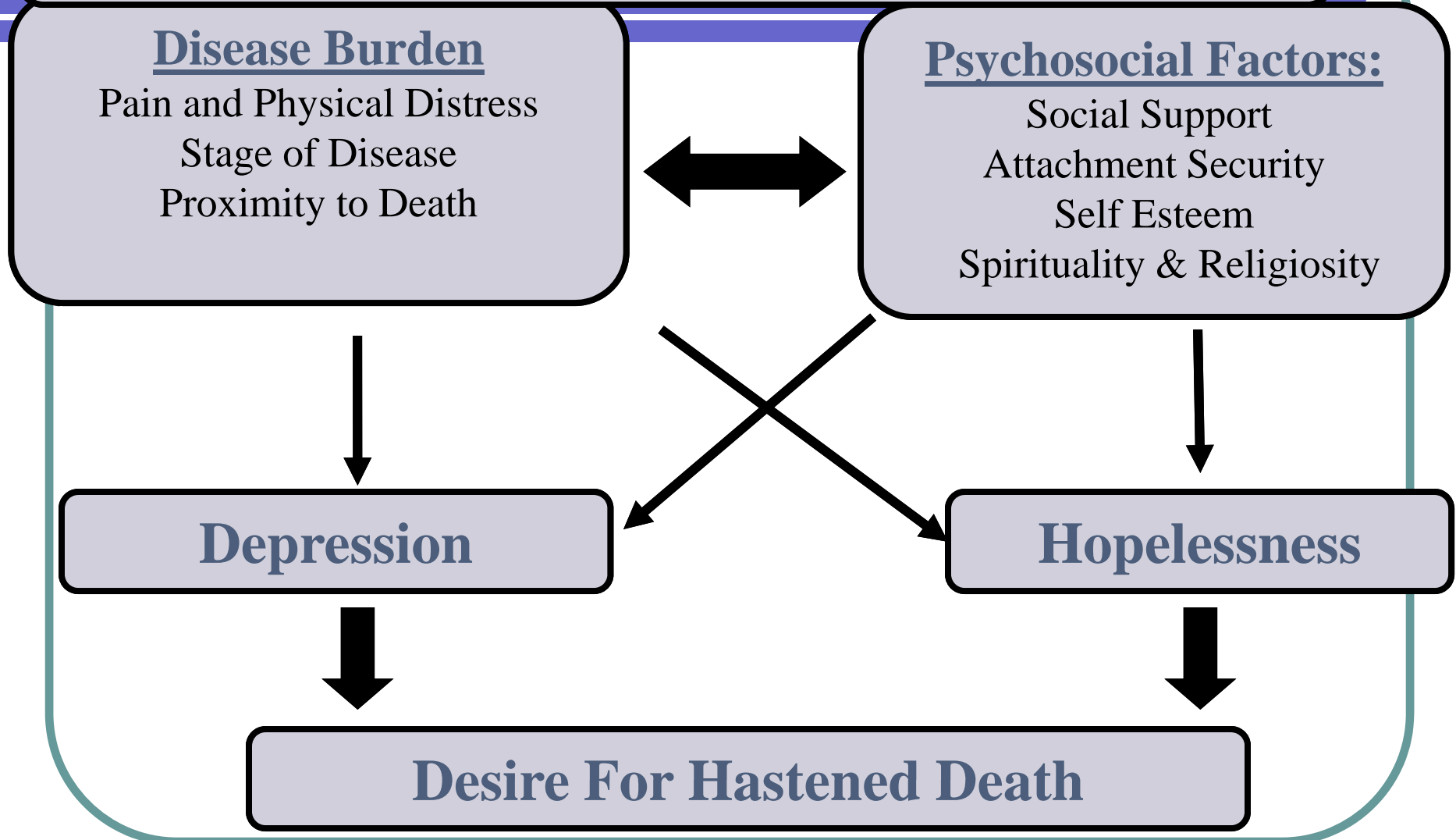
Methodological and Practical Challenges of Research in Palliative and Supportive Care

- Recruitment & informed consent in vulnerable populations
- Valid and reliable measures
- Proxy measures
- Retrospective reports
- Fragmentation of health care
- Lack of system-wide database
- Predictably deteriorating course
- Multiple interacting risk factors
- Complexity of the problems

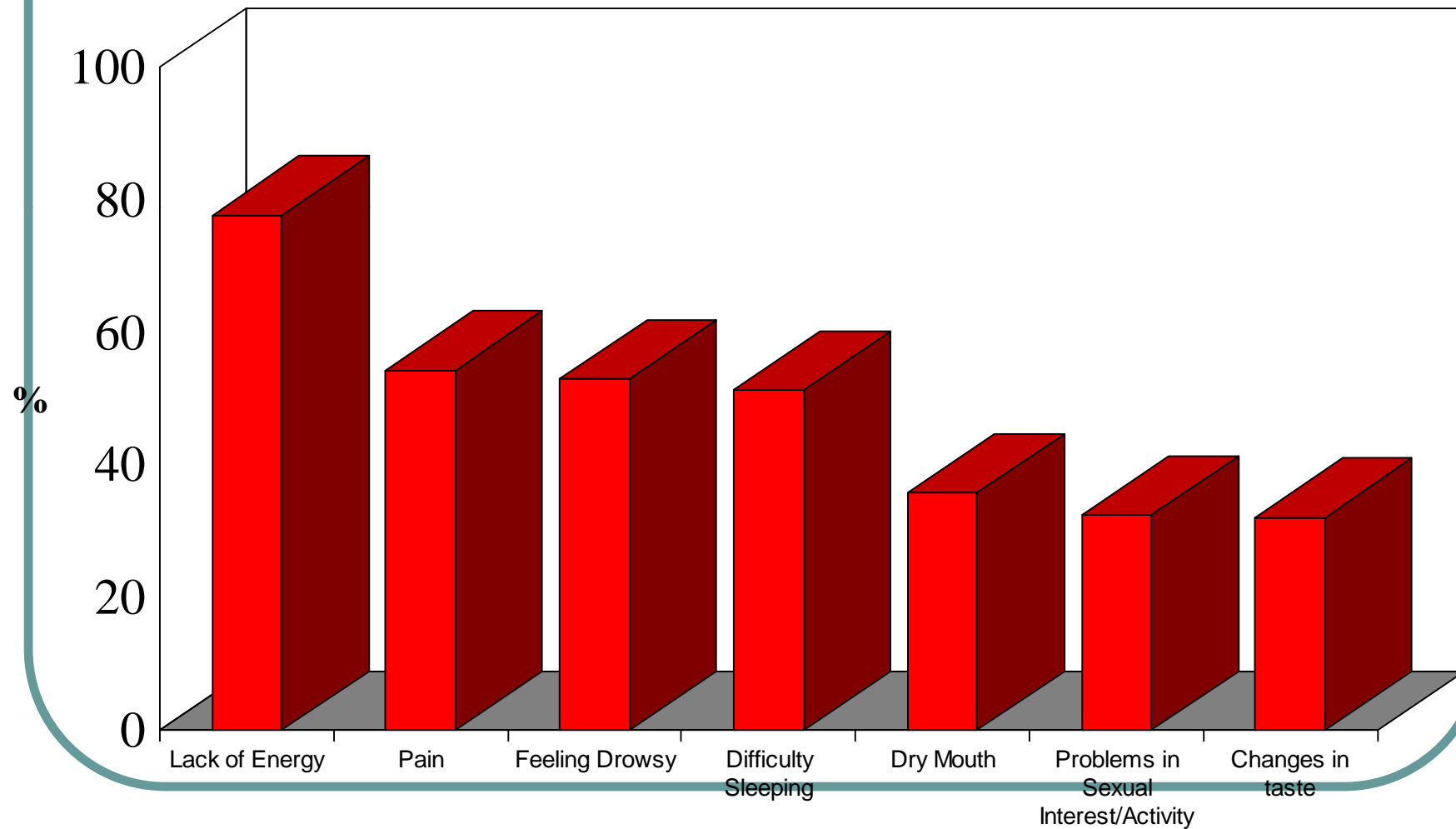
The Problem of Measurement



The Cascade Effect of Multiple Risk & Protective Factors

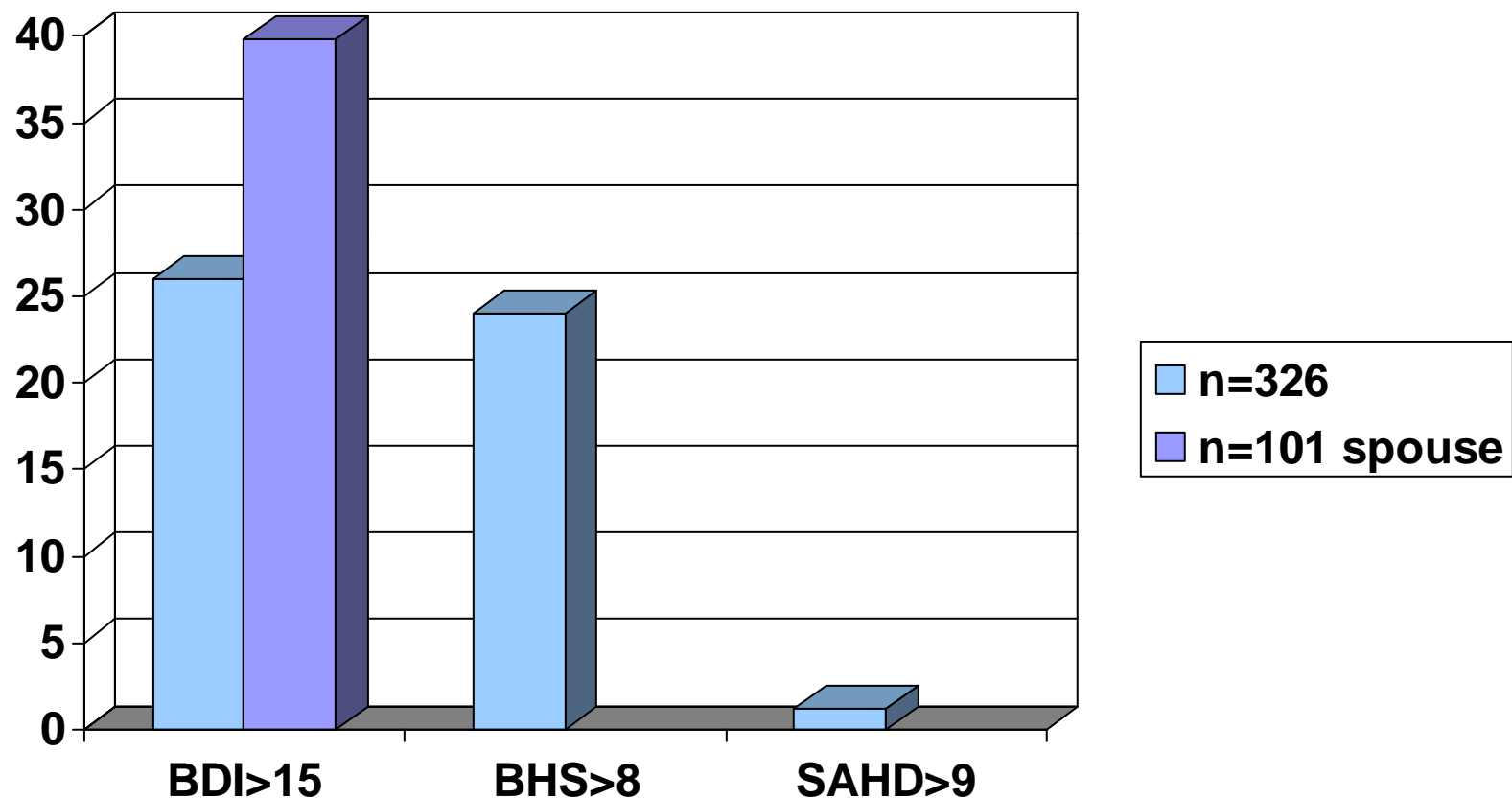


Frequency of Specific Physical Symptoms in Patients with Metastatic GI and Lung Cancer



WTL Study

Prevalence of Depression, Hopelessness and the Desire for Hastened Death



J Pain & Symptom Mgmt, 2007

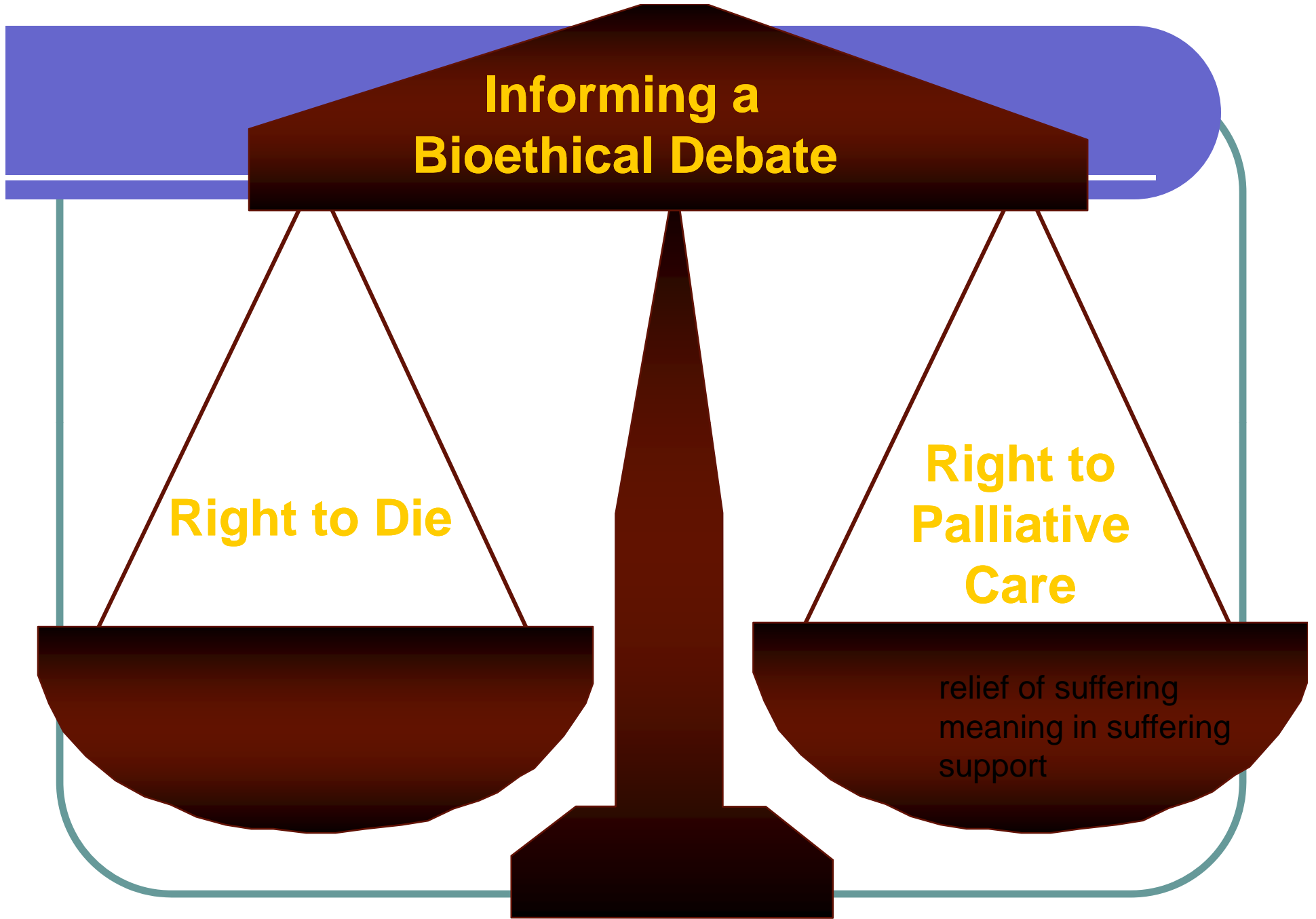
Journal of Clinical Oncology, 2007

Informing a Bioethical Debate

Right to Die

**Right to
Palliative
Care**

relief of suffering
meaning in suffering
support

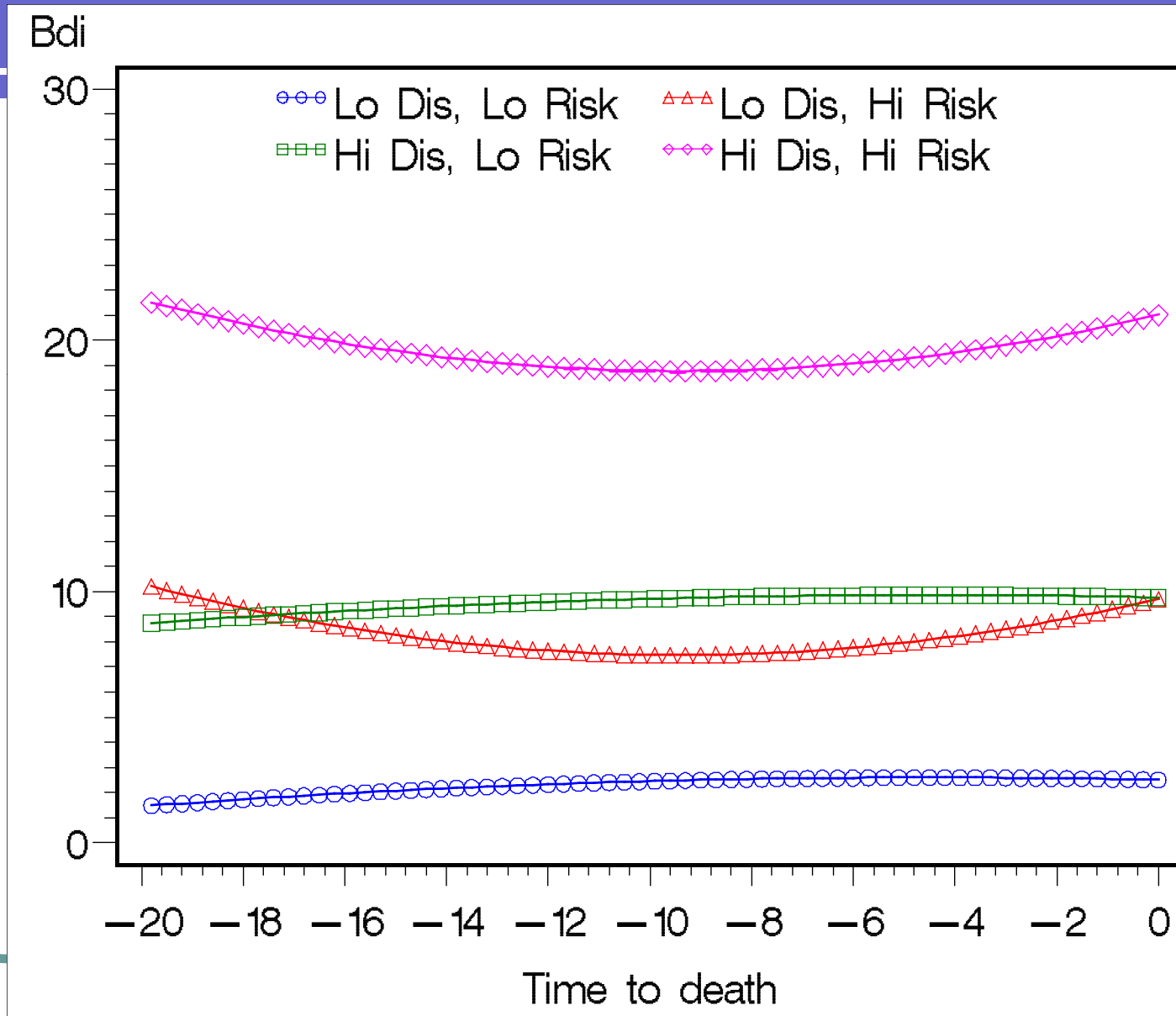


Significant Predictors of Depression

- Proximity to death
- Performance status
- Severity and number of physical symptoms
- Self esteem
- Attachment anxiety
- Spiritual well-being
- Hopelessness
 - Rodin et al Soc Sci & Med, in press



Disease burden, psychosocial risk & time



The Future of Research in Palliative and Supportive Care

