HOPE & VULNERABILITY

The ethical challenges of end-of-life care planning in chronic illness

Work in Progress – NELS-ICE

April 15, 2009

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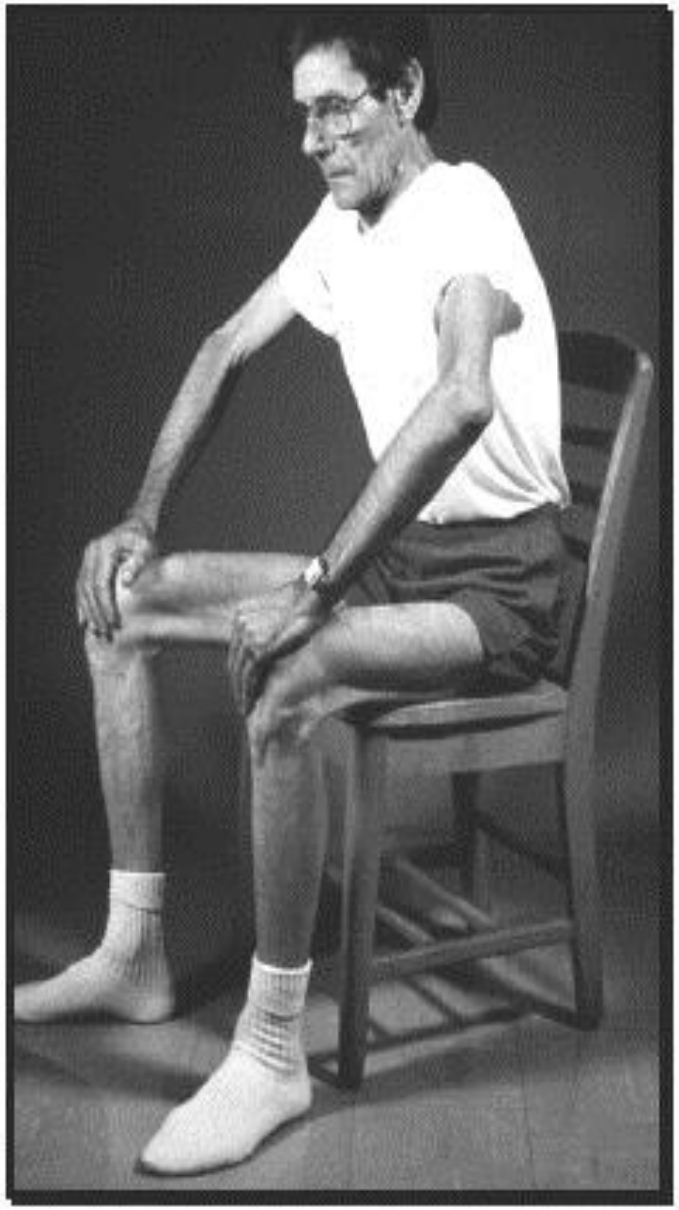
Outline

- Introduction
- COPD – exemplar of chronic illness
- Thesis
- IMPACT Study
- Caregiver Experience Studies
  - EMP study
  - NS Legacy Grant
- Opioids Studies
- Where to from here?
- Conclusion

Introduction

- Experience: “either/or” – silo thinking
- Goal: to work towards a “both/and” model of care to better issues (injustices) in this context (COPD)
- Thesis:

Negotiating Hope in a Context of Uncertainty: ethics & end-of-Life care planning in advanced COPD



COPD

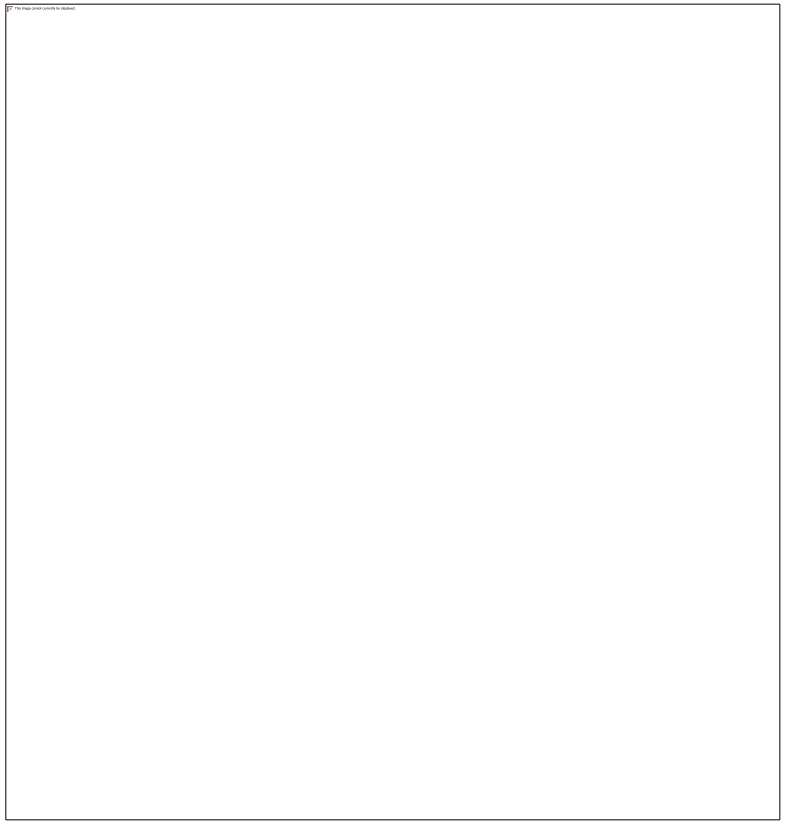
Patients with advanced Chronic Obstructive Pulmonary Disease (COPD) live with a progressive and irreversible respiratory illness.

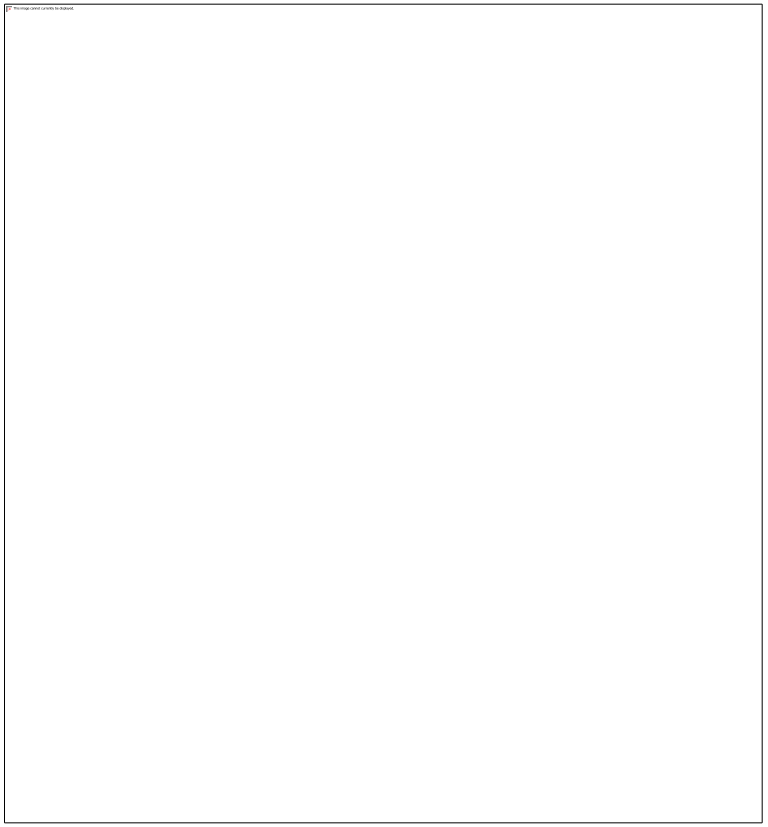
In later stages:

Symptom burden is similar to or worse than that experienced in advanced lung cancer.

Gore et al., Thorax 2000

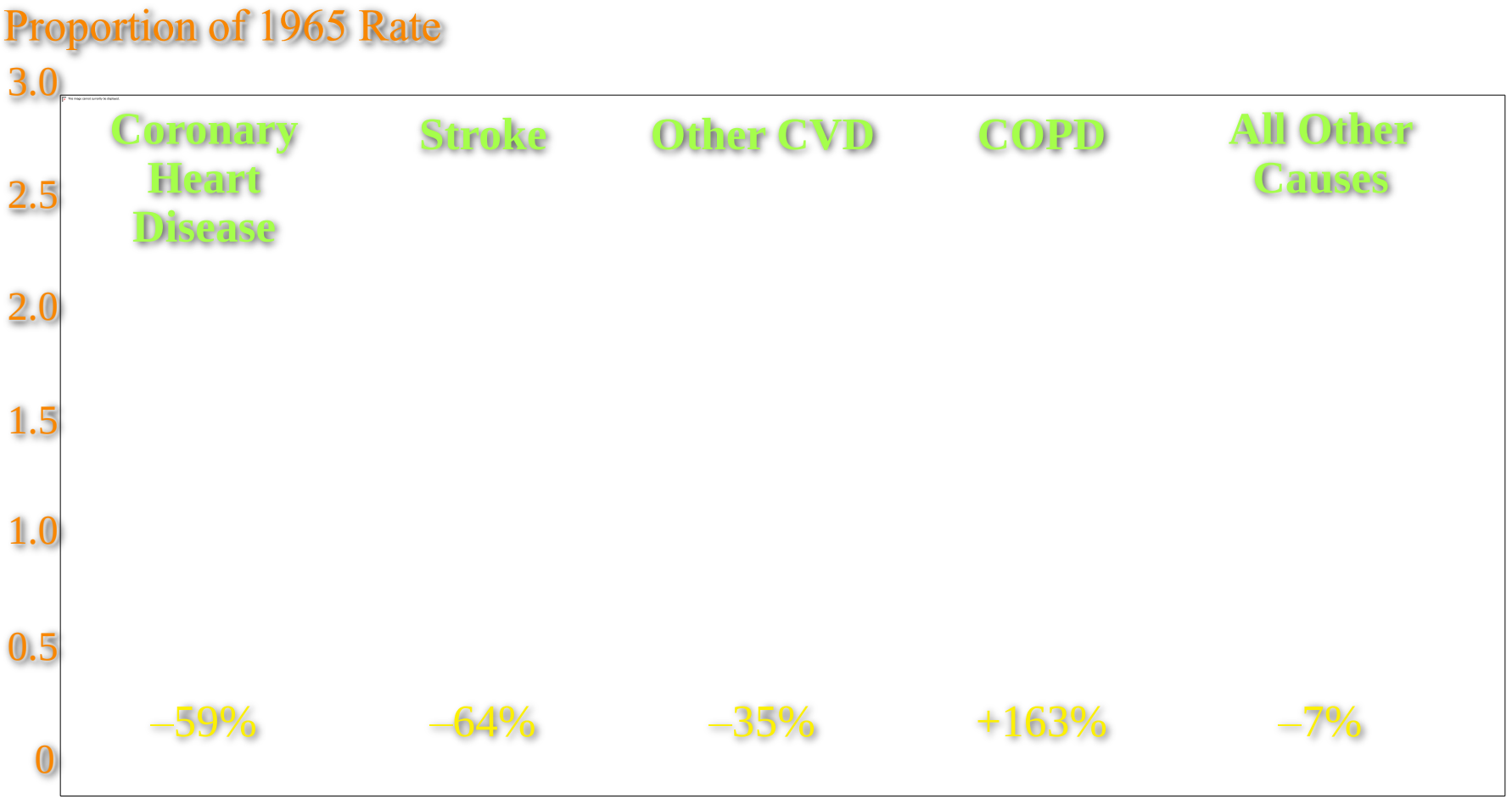
Natural History of COPD





- Characterized by frequent near death experiences
- Unpredictability, so poor prognostication
- Uncertain trajectory, but trend is downward spiral

Percent Change in Age-Adjusted Death Rates, U.S., 1965-1998



COPD Only major disease increasing in prevalence

Buist. Lancet 2007;370:741 Mannino. Lancet 2007;370:765

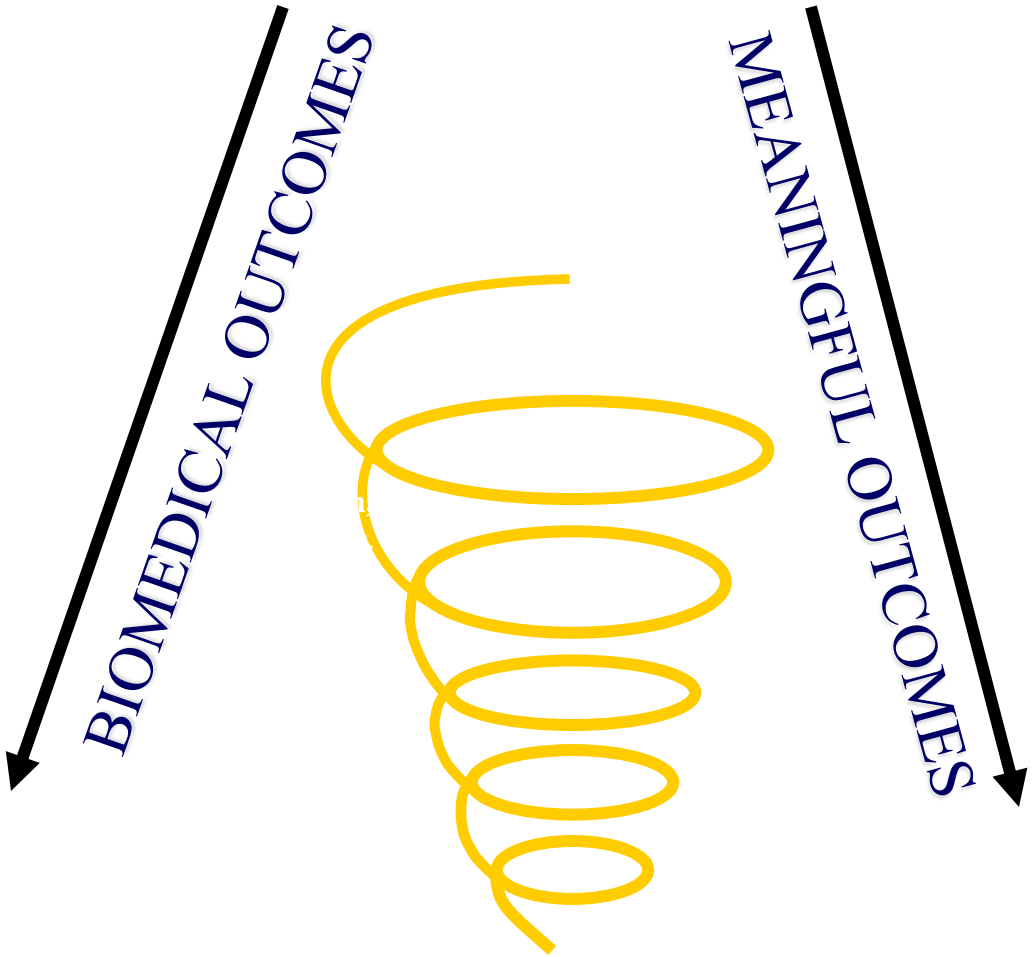
Downward Spiral of COPD

(pts, carers & HCPs)

BIOMEDICAL

DYSPNEA, universal, sometimes incapacitating

Depression
Panic disorders
Sleep disturbances
Fatigue
Anxiety-dyspnea-anxiety cycle
Muscle wasting
Weight loss
Cachexia



PSYCHOSOCIAL & SPIRITUAL

Feeling of being burden
Family strain
Social isolation
Lack of support
Vulnerability
Feeling helpless
Loss of freedom
Frustration
Financial hardships
Guilt (stigma)
Self-blame
Loss of faith and hope
Changes in self-identity
Fear

MISMATCH IN GOALS OF CARE

COPD Summarized

- prevalent, costly, incurable chronic illness ($3M/yr)
- incidence rising (3rd major cause of death globally by 2020; 4th in Canada now; 2nd cause of HC admissions in NS)
  - NS: **2004 – 447**; by **2020 – 770** (NELS ICE Surveillance Report)
- characterized by **uncertainty, unpredictability** & episodic care (disease v. illness) – ***mismatched goals of care***
- essentially unrecognized role of informal caregivers
- vulnerable population – pts & caregivers (low SES, age, co-morbidities, orphan disease, Rx limited) - *HOPE*

Key Elements…

COPD – uncertainty**

- exemplar of chronic terminal illness

Ethics – care-related decision-making

- relational dynamic
- informed choice

Communication – medium for care planning

- central to ethics, therapeutic relationship & care
- care planning/decision making
  - advance care planning - EOL

Hope – factor in all 3

- HCPs/pts/family

Mismatched goals of care

Ethics informally…

- *how we do, and should treat each other; a systematic analysis of the values and decisions underlying these actions (**Jiwani, 2003**)*
- embedded in 4 goals of medicine
- articulated in codes of ethics
- moral importance of attending to emotions…major component of COPD

To cure sometimes, to relieve often, to comfort always…

Ethics formally…

CMA Code of Ethics

#1. Consider first the *well-being* of the patient.

#3. Provide for *appropriate care* for your patient, even when cure is no longer possible, including physical comfort and *spiritual and psychosocial support*.

#27. *Ascertain* whenever possible and *recognize* your patient's wishes about initiation, continuation, or cessation of life-sustaining treatment.

Ethics in COPD Context (chronic illness)

Mismatched goals represent breaches in:

- bioethics principles - respect for autonomy, beneficence, non-maleficence, justice
  - **power differential**
  - treatment by default *(Kinlaw, 2005; Lynn & Goldstein, 2003; Nicolasora, 2006)*
  - ICU & hospital admissions (O'Donnell et al, 2004)
  - disclosure - truth-telling
  - confidentiality/privacy
  - understanding, voluntariness, authorization
- 'ethic of care' – attentiveness, responsibility, competence, responsiveness

Another factor related to gaps in care…

Gaps in Care in Chronic Illness

- Continuity - episodic, fragmented
- Comprehensiveness - narrow focus
- Relevance - ***mismatched goals***

Why?

  - Trajectory - uncertainty, hope, unpredictability
  - Optic - biomedical paradigm, silos
  - System constraints – time, space
  - HCP constraints - training, "*hope*"

Communication

Pts want to know “truth”…

- EOL an emotional topic
- hype v. hope
- “how” matters as much as “what”

Barriers

- Uncertainty, ambiguity - PIT
- Time/timing
- Lack of training
- Potential to erode **hope**

Communication & EOL

Advance Care Planning (ACP) = process

- 3 elements: communication, values, decision guide (AD discussed, written &/or proxy named)

- Related to ethics:
  - informed choice
  - disclosure & truth-telling
  - content and process
  - relational dynamics (power, trust)

- Involves emotion – values, goals**, hope(s)**, coping

Accountability: whose responsibility is it… (should it be)?

A factor in mismatched goals & gaps in care

Nature of Hope

Definition: an emotional attitude that involves

- wants/desires
- *values, goals & identity*
- imagined potentially realizable outcomes
- action (agency)
  - Snyder – agency & pathways

Key features:

- context- and person-relative
- presence/absence felt most at times of uncertainty/change
- relational aspect
- multilevel, paradoxical, specific & general

Role of Hope in Care Planning

- Hope is a personal & relational source of:
  - coping/agency/resilience
  - vulnerability (imaginal, relational)
  - meaning-making, *well-being*, identity – spiritual strength
  - guidance in care planning

- Hope is also a consideration in ethics of care planning
  - moral importance of attending to emotional dimensions of illness
  - disclosure, truth-telling – content & process, i.e., **communication**
  - therapeutic relationship – power, trust, compliance issues

Hope & vulnerability…

- Goal: *shared decision-making*
  - *timely consultation* re: preferences related to *care planning & care*
  - attentiveness to *communication* processes & relationship
  - consideration of *hope dimensions* as inherent & significant part of process (also spirit)

…exploring patients' hope(s) appears to be a logical path toward facilitating more ethically responsible and meaningful [EOL] care planning & delivery

NEGOTIATING HOPE IN A CONTEXT OF UNCERTAINTY: EOL care planning in advanced COPD

Purpose

- To explore patients' & carers' experience of a two-part hope/uncertainty focused EOL care planning conversation in the context of advanced COPD

- To refine this communication process based on these findings as a potential model for patient-centred EOL care planning appropriate to the context of advanced COPD, and perhaps other chronic terminal conditions

Methodology & Method

- Participants:
  - Purposive sampling; pts & carers
  - 8-10 family units (16-20 participants)
  - Inclusion criteria:
    - Dx COPD, advanced stage (CTS mod or severe – MRC 3, 4, 5)

- Data collection:
  - Format: 2 stages, 3 sessions:
    - Intervention – 2 sessions (Seidman, 2006)
      - » study motivation, illness experience, QoL, changes, coping, AECOPD
      - » hope, uncertainty, fear(s), dying/death, ACP materials
    - Evaluation – 1 interview – experience of discussion; suggestions

Timeline

- REB approval Nov 2008
- Recruiting: April 2009
  - First meeting – informed choice
- First 5 family units, visit 1- Apr‘09
- Visit #2: 7 - 14 days later
- Final interview – 7 -10 days later
- Analysis, write-up – May/09 - Aug/09
- Defense – Nov 2009

Thesis: Summary

- COPD a significant disease/illness
  - prevalent, costly (personal, HC, society)
  - uncertainty/hope characteristic
- Gaps in care – communication related
  - continuous, comprehensive, relevant
  - barriers: time, skill, “hope”
- Ethical integrity – respect for autonomy, benevolence, non-maleficence, justice; ethic of care
  - informed choice, “good” death
  - role of hope/uncertainty
- Hope
  - common thread through all
  - potentially valuable indicator, seen as a “virtual” barrier to ethical care planning inclusive of EOL implications

Hope & resilience…

2. IMPACT Study

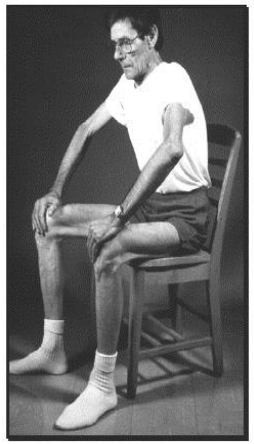
Purpose:

- To determine the feasibility of enrolling patients in, and implementing, an educational and integrated home-based PC program designed to improve patient symptoms and caregiver burden for patients with advanced COPD.

Method:

- mixed
  - quantitative – questionnaires (demographics, health status, CCI, CRQ, CRA, ESAS, CANHELP (pt & carer forms))
  - qualitative (caregiver experience)
  - 30-40 participants (+ carers)
  - initial visit; add education modules & PC home care support; 3 more visits

Experience of caregiving in advanced COPD



Booth et al (2003):

Caregivers expressed stress secondary to feeling restricted, anxious, and profoundly helpless in the face of episodic or worsening dyspnea

A sense of preoccupation with the patient, debilitating hyper-vigilance.

Women caring for their male spouses identified: inadequate recreation opportunities and inconsistent family, social, and healthcare support as their primary stressors

3. Caregiver Experience - NB

- **<u>EMP Study, Region 2, NB</u>**

  Objectives:

  - To increase our understanding of the experience of informal caregivers of caring for patients living with advanced COPD (as per CTS guidelines) in a rural setting
  - To identify potential interventions to enhance the experience of those providing informal care to patients living with advanced COPD

4. Caregiver Experience NS

NS Legacy Grant

- Obj 1: To increase our understanding of the experience of informal caregiver of caring for patients living with advanced COPD
- Obj 2: to identify potential interventions to enhance the experience of those providing informal care to pts living with advanced COPD
- Obj 3: to understand whether the components of the Caregiver Reaction Assessment (CRA) survey reflect domains important to informal caregivers of pts living with advanced COPD

5. Opioid studies

Pts & loved ones desire control of symptoms, e.g., dyspnea, an often refractory symptom in advanced COPD.

"There's nothing more I can do for you…"

HCP Attitudes to using opioids

- Risk of respiratory depression remains a fear for many physicians.
- Most were comfortable and/or found them effective in terminal stages
- More than 40% of respondents were comfortable or neutral concerning use of opioids for long term use in advanced COPD

Palliation of Dyspnea in Advanced COPD:

Understanding patient and caregiver experiences with opioid therapy

Primary Research Question

- What is the experience of patients living with advanced COPD and their caregivers when low dose morphine is added to manage dyspnea?

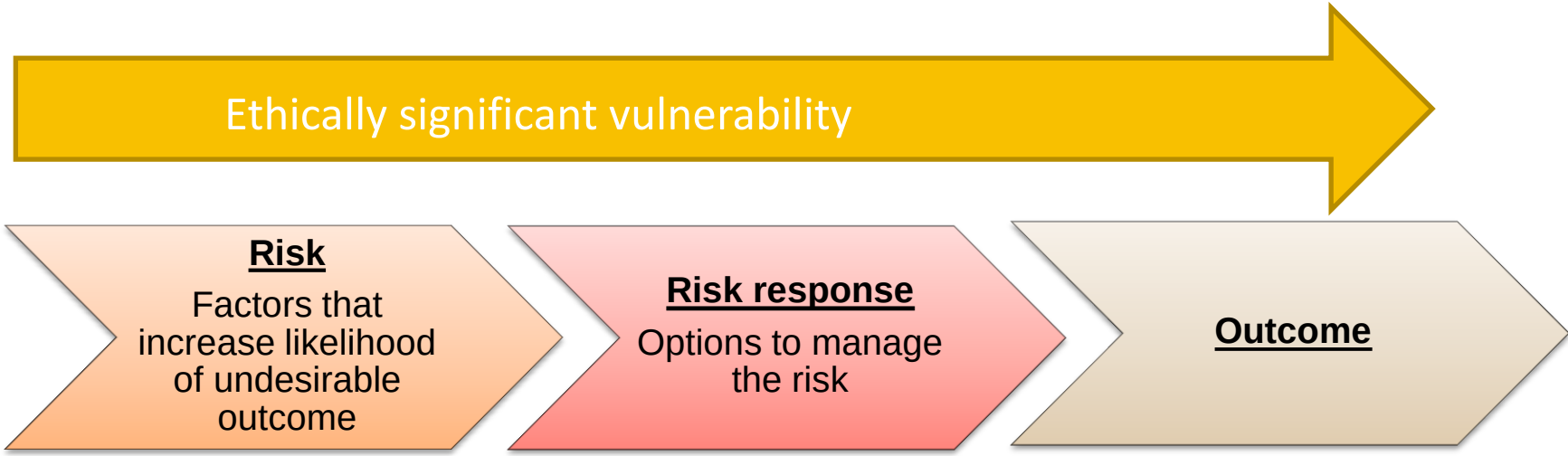
Study Design

- an exploratory study in which we begin a process of understanding patients' experiences of opioids that ultimately will inform design of an RCT

6. Where to from here…?

- CANHELP themes
  - communication, relational issues, spirituality
- Concepts of vulnerability and inequity (emic v. etic views)
  - How do individuals living with advanced COPD understand and/or experience illness-related vulnerability &/or inequity?
  - Integrating emic & etic views?
  - Implications for care (models, policy)?
- Spiritual/existential distress
  - potential but unexplored dimension of advanced chronic illness (COPD) – access to information, support, or relevant care? Urban versus rural differences?

Inequity & Vulnerable Populations

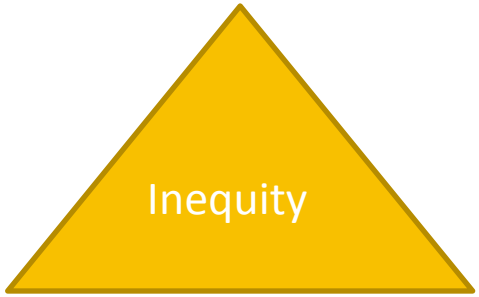


SES, age, co-morbidity, isolation, stigma

Shared decision-making

Quality EOL care

From **Yukiko Asada**
Inequity and Vulnerability in end of life care: Ethical Analysis
Full audio/PPT presentation is available at: **www.nels.dal.ca**



6. An Integrated Care Model

As an ethical response to gaps [*inequity, vulnerability*] in current care planning & delivery:

- "…pts with other [non-cancer] life-threatening conditions, not the least the elderly, would benefit from PC, and it is a question of ethics and justice to develop PC adapted to their needs" (Elofsson & Ohlen, 2004)
- "The ethical imperative to create a more inclusive paradigm of EOL care, to manage people dying of chronic illnesses other than cancer, and focusing on needs, rather than diagnosis, will intensify as demographics shift in the future" (Goodridge, 2006)

- **Integrating the silos…**

“Palliative” Care:

- an interdisciplinary therapeutic model appropriate for all types of patients with serious or life-threatening illness…model is appropriate throughout the course of illness and is guided by core concepts, including a focus on patient and family; support for patient autonomy and respect for culture and individual differences; *shared decision-making based on empathic communication about goals of care*; coordination in care planning; and expertise in the management of suffering related to biomedical, psycho-social, and spiritual factors.

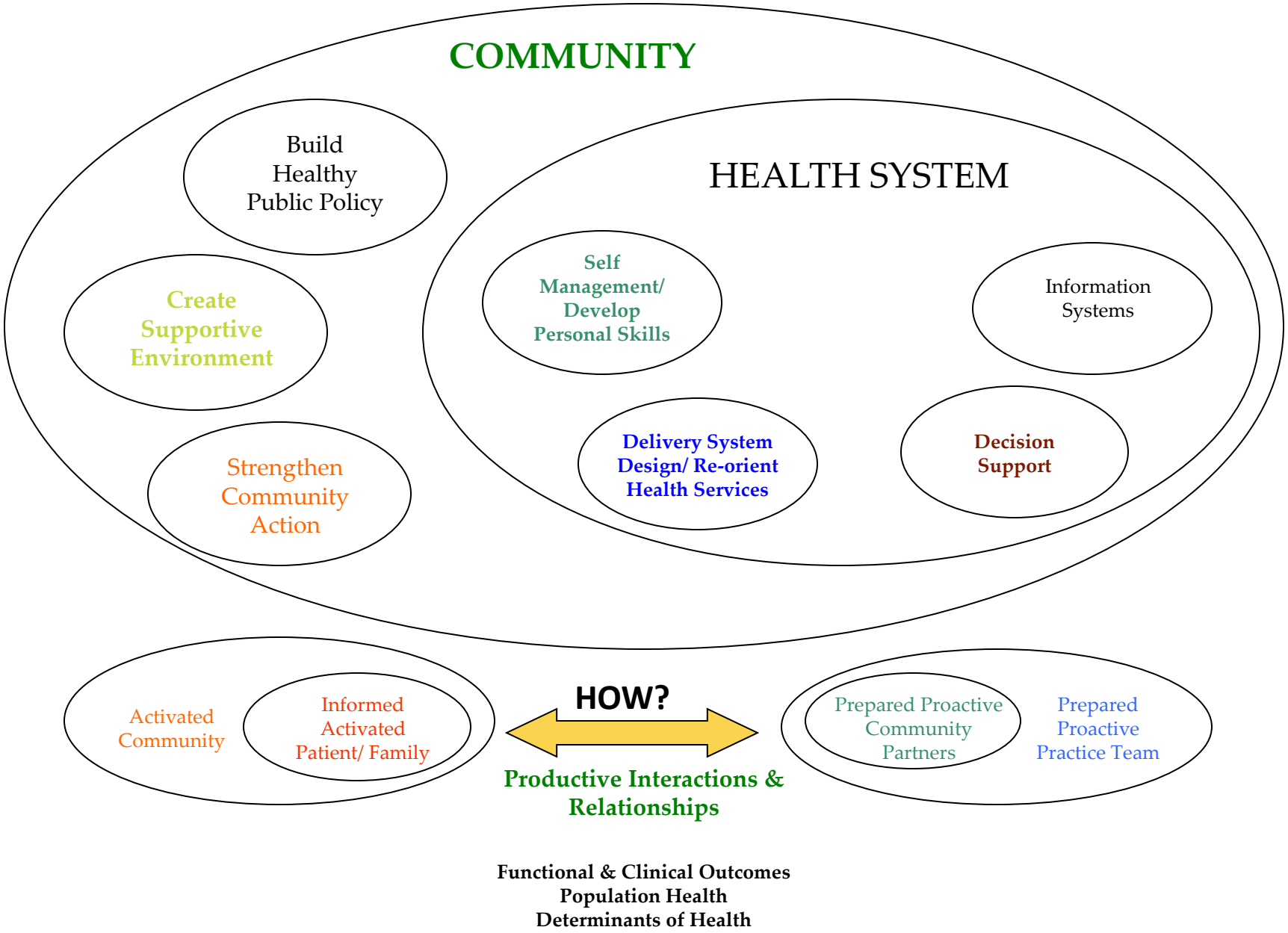
  (Portenoy, JPM 11(8), 2008)

Integrated care…

The suffering human being needs a place where he/she can rest, a place which breathes genuine hospitality, where fear and hope are permitted to exist side by side…a place where the naked face appeals for compassion and finds response. *(Eriksson & Lindstrom, 2003)*

———————

Undoubtedly, such issues as happiness and life satisfaction factor heavily into an individual's judgment of his or her quality of life. Yet, these issues are so distal to the goals and objectives of health care that it would seem inappropriate to apply them as criteria against which to judge the efficacy of medical interventions.
(quoted by I. Byock, 2004)


COMMUNITY
Build Healthy Public Policy
HEALTH SYSTEM
Self Management/ Develop Personal Skills
Information Systems
Create Supportive Environment
Delivery System Design/ Re-orient Health Services
Decision Support
Strengthen Community Action
Activated Community
Informed Activated Patient/ Family
HOW?
Prepared Proactive Community Partners
Prepared Proactive Practice Team
Productive Interactions & Relationships
Functional & Clinical Outcomes
Population Health
Determinants of Health

Ultimately…

Being a part of this research focus & team approach - a way to begin to respond to the "how" questions:

"How do 'necessary evils' become seen as remediable, thus shrinking the bounds of necessity and enlarging the bounds of responsibility?"

…in the context of an increasingly important healthcare context--chronic illness.

An interdisciplinary pathway to integrative care …