Patient-family reported outcomes in cancer: Symptom experience

Princess Margaret Hospital
University Health Network

Dr. Doris Howell RN, PhD
RBC Chair, Oncology Nursing Research, UHN &
Scientist, Psychosocial Oncology and Palliative Care & Adjunct Scientist, Cancer Care Ontario.
Focus for the Paper

- Define patient-reported outcomes and importance for quality cancer care.
- Disseminate information about a CIHR patient-reported outcome study in progress.
- Highlight what we have learned about symptom experience so far.
Patient-Reported Outcome (PRO): A Definition

- A PRO is a measurement of any aspect of a patient’s health status that comes directly from the patient, whether collected in the clinic, in a diary, or by other means, including single-item outcome measures, event logs, symptom reports, formal instruments to measure HRQoL, health status, adherence, and satisfaction with treatment (Wilke et al., 2004) without interpretation of patient’s responses by physicians or anyone else (Reeve B, Donaldson MS, Clauser SB. National Cancer Institute, PROMIS, 2006).
Why does it matter?

QUALITY GRAND ROUNDS
Series Editors: Robert M. Wachter, MD; Kaveh G. Shojania, MD; Sanjay Saint, MD, MPH; Amy J. Markowitz, JD; and Mark Smith, MD, MBA

A Hospitalization from Hell: A Patient’s Perspective on Quality

Paul D. Cleary, PhD*

Patients usually cannot assess the technical quality of their care; however, examining a hospitalization through the patients’ eyes can reveal important information about the quality of care. Patients are the best source of information about a hospital system’s communication, education, and pain-management processes, and they are the only source of information about whether they were treated with dignity and respect. Their experiences often reveal how well a hospital system is operating and can stimulate important insights into the kinds of changes that are needed to close the chasm between the care provided and the care that should be provided.

This article examines the case of a patient admitted for ankle arthrodesis due to severe hemophilia-related arthritis. The surgery was successful, but the hospital stay was marked by inefficiency and inconveniences, as well as events that reveal fundamental problems with the hospital’s organization and teamwork. These problems could seriously compromise the quality of clinical care. Unfortunately, most of these events occur regularly in U.S. hospitals. Relatively easy and inexpensive ways to avoid many of these problems are discussed, such as reducing variability in non-urgent procedures and routinely asking patients about their experiences and suggestions for improvement.

For author affiliation, see end of text.
Report on Quality: Cancer Care Ontario

Patient Satisfaction

Emotional Support

Cancer Centres


Notes:
* Data not available for all years, as there are new cancer centres
** Surveys are still in the field for these programs so data may not be complete
*** Surveys have just gone out for these centres so there is no data
Value of PRO in clinical care

- "You cannot manage what you cannot measure".
  - Comprehensive description of health status to detect treatable problems.
  - Detecting unresolved levels of physical, emotional, and social distress or unmet needs.
  - Guiding selection of or changes in the therapeutic plan and team communication.
  - Empower the patient to be actively involved in treatment and well-being collaboration.
  - Monitoring quality care and stimulating improvement.
  - Routine assessment makes a difference but use of data alone is problematic.

Patient-Family Centered Outcomes Scoping Review (CIHR 2008-2009)

- **Purpose:** To identify a core set of patient-reported outcomes and candidate measures that are relevant, meaningful, and feasible to monitor patient experience and clinical care quality.
  - cancer phases (treatment through to follow-up care and including palliative)
  - sentinel cancers (generic vs disease-specific)
  - consensus of health care decision-makers, practitioners, and survivors

Howell D, Doran D, Fitch M, Green E, Bakker D, Sussman J.

Princess Margaret Hospital
Patient-Reported Outcomes: Symptom Experience

• What have we learned so far…….
Theoretical Underpinnings

- Multiple Theoretical Understandings and Propositions
  - (1) UCSF School of Nursing Centre Model for Symptom Management (Dodd et al. 2001).
  - (2) Theory of Unpleasant Symptoms (Lenz et al., 1995)
  - (3) Symptom Interpretation Model (Teel et al., 1997)
  - (4) Hybrid Model (Wells & Ridner, 2008, Research in Nursing and Health, 31, 52-62)
Theory of Unpleasant Symptoms

Symptom Interpretation Model (SIM)

ROLE OF ILLNESS PERCEPTION ON SYMPTOM EXPERIENCE AND DISTRESS IN WOMEN RECEIVING TREATMENT FOR BREAST CANCER

Symptom Stimuli (occurrence & severity)

Cognitive Representation of Illness:
- a) Cure/control
- b) Cause
- c) Consequences
- d) Identity
- e) Timeline

Demographics Disease and Treatment

Symptom Distress

Emotional Representation of Illness

Overall Psychological Distress

Figure 1: Hypothesized relationship between illness representations, symptom experience, symptom distress and overall psychological distress
Emerging consensus....

• Symptoms are multidimensional and have multi-causal etiology.
• Symptoms are subjective and self-report is gold standard.
• Symptoms cluster together and have a multiplicative effect but...
• Cognitive perception and affective states (anxiety and depression) play a role but...
• Symptom experience has 3 distinct dimensions (frequency, intensity and distress) but....
Continuing Debate …. 

• Intensity distinct from symptom distress?
  – Different schools of thought
    • Patients unable to distinguish/high correlation (Turk, 1992).
    • Patients can separate these concepts (measurement dependent)
      – Symptoms with high intensity are not always the most distressing (Larsen 2003; Tishelman et al., 2000; Boehmke et al., 2004)
      – Interventions studies show distress can be reduced but not always intensity (Howell; Rainville et al., 1999)

• Symptom distress distinct from psychological distress
  • Pain related distress decreased but psychological distress showed no change (Wells et al, 2004, AJHPM, 21, 373-380)
Debate Reflected in Measures…

• Review of 21 symptom measures (Kirkova et al., 2006): no ideal measure found
  – Limited coverage of symptom experience dimensions
  – Gold standard measure (side by side differentiation?; global score severity and distress summed).
  – Assumption that total symptom score = burden of symptoms (additive vs multiplicative effect).
  – Different terms for symptom distress (bother).
  – Timeframe (now to 3 days to past week).
  – 9 rigorously validated (moderate to good)
  – Symptom assessment measures as outcome measures?

Moving Forward

• Reducing the burden and suffering of cancer is a daunting challenge.

• Patient-centered outcome assessment combined with traditional survival and mortality outcomes will enable us to monitor technical quality and improve patient experience.

• Symptom understanding highlights the challenges in selection and measurement of candidate indicators for a patient-reported outcome measurement information system.