Health Literacy &
Cancer Self-Management

Janet Papadakos, MEd, PhD (c)
Manager, Patient & Survivorship Education
Princess Margaret Cancer Centre
October 24, 2014

Conflict of interest disclosure: I, or an immediate family member, including spouse or partner, I have no financial relationship(s) relevant to the content of this CME activity.
Agenda

• Introduction
• Importance of health literacy
• Role of self-management in cancer
• Evidence for the influence of health literacy on cancer self-management behaviors
• Recommendation for focal areas in future research

Introduction

• Unsustainable demands on healthcare system
• Much of the demand from patients with chronic disease
• Patients with chronic disease consume large fraction of resources
• Often due to inability to self-manage their disease

• Health literacy is an important predictor of successful self-management in chronic disease

Health Literacy

The ability of individuals to obtain, process, and understand the basic health information and services they need to make appropriate health decisions.


Low Health Literacy is Common

60% of Canadians have difficulty getting, understanding and acting on health information and services

88% of Seniors

Canadian Council on Learning, 2007
Effects of Low Health Literacy

Low health literacy associated with:
• decreased patient engagement
• worse self-management
• poor health outcomes
• avoidable health service utilization

Health literacy predicts health status.

Importance of Health Literacy in Cancer Self-Management

Cancer continuum:
1. Prevention
2. Screening
3. Diagnosis
4. Treatment
5. Survivorship
6. End of Life Care

• Each phase puts demands on healthcare system
• Models of care moving to shared models
• More responsibility placed on the patient
## Cancer Self-Management Behaviours

1. **Prevention**
   - Smoking cessation
   - Health eating
   - Physical exercise
   - Sun safety

2. **Screening**
   - Regular Pap tests
   - Mammography
   - FOBT, Colonoscopy

3. **Diagnosis**
   - Cope with psychological impacts of diagnosis
   - Manage leave from work
   - Manage Child/elderly care
   - Manage finances

4. **Treatment**
   - Identify and respond to complications arising from treatment
   - Manage the expected side effects of treatment
   - Cope with the psychological impacts of diagnosis
Cancer Self-Management Behaviours

5. Survivorship
- Manage side effects
- Monitor for late and long-term effects
- Communicate with healthcare professionals

6. End of Life Care
- Understand legal processes (power of attorney, advanced care directives)
- Select place of death (home, hospital, hospice)
- Make decisions about pain management

Self-Management of Symptoms

In both acute and chronic phases of disease
- Unrelieved Symptoms:
  - interfere with quality of life
  - ability to perform life roles
  - interrupt treatment
  - negatively effect effectiveness of treatment
Self-Management of Symptoms and Health Literacy

Optimal management of symptoms requires collaboration between clinicians and patients

- Clinicians teach patients requisite knowledge and skills to self-manage
- Patients develop ability to judge how and when to use them
- To be effective, patients need health literacy skills


Health Literacy in Cancer and Other Chronic Diseases

- Minimal research examines role of health literacy on cancer self-management behaviours
- Minimal activity within healthcare system to support individuals affected by cancer with self-management strategies
- In diabetes and other chronic disease, self-management strategies developed to mitigate the effects of low health literacy
Scoping Review

Research Question:
- What is known in the literature about the impact of health literacy in cancer patients on self-management behaviours, outcomes, and health services utilization?

Methods: Scoping Review
- Comprehensive search of databases with health librarian completed (OVID, EMBASE, CINAHL, PsycINFO, ERIC).
- Data abstraction and appraisal performed independently by 2 reviewers.
- Results summarized qualitatively with narrative summary reported.

Arksey H, 2011.
Results

• Search yield 1604 articles
• Reduced to 212 articles by title scan
• Abstract review reduced further to 53 articles
• Review of full manuscripts reduced to 11 articles

Results

• 9 Preventative care behaviors and knowledge
• 1 Health-related quality of life (prostate cancer)
• 1 Self-care behaviors – radiation therapy
• 4/11 high quality studies*
Low Health Literacy in Cancer

• Gap in empirical literature - influence of health literacy during and after cancer treatment
• Gap may be due to emerging classification of cancer as a chronic disease
• Small number of cancer studies have examined the relationship between health literacy and uptake of preventative cancer behaviours.

The case for further study

In other chronic diseases health literacy is:
• A predictor of increased health service use.
• Linked to effective self-management:
  – Interpretation of medication and nutrition labels
  – Adherence to and management of medications
  – Self-Efficacy
  – Patient Activation

My study

• The Influence of health literacy, self-efficacy and patient activation on chemotherapy self-management behaviors and health service utilization.

Acknowledgements

Secondary Reviewer:
Tina Papadakos, MA (Ed)

Supervisor:
Doris Howell, RN, PhD

Committee:
Whitney Berta, MBA, PhD
Jan Barnsley, PhD
Questions?

Janet Papadakos, MEd, PhD (c)
Manager, Patient & Survivorship Education
Princess Margaret Cancer Centre
Janet.Papadakos@rmpuhn.on.ca