

# Cancer Self-Management for Patients with Limited English Proficiency

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# Cancer self-Management

- ▶ Self-management: more than adherence and self-care ability; a self-determination involved in health promoting and disease management behaviors (Glasgow, 2008)
- ▶ Why this is important for cancer patients? **Empowerment**
- ▶ It involves **collaborative** partnership with the health care providers (McCorkle et al., 2011)

# Evidence of Effectiveness

Selected types of programs (Gao, et al, 2011; NHS et al., 2010)

Program	Focus
Taking CHARGE (Chung et al., 2009)	<ul style="list-style-type: none"> <li>• Physical, psychological, social, and functional well-being</li> <li>• Group-based and individual telephone assistance</li> </ul>
PRO-SELF (Dodd et al., 2000)	<ul style="list-style-type: none"> <li>• Symptom Management</li> <li>• Consultation Seminars</li> </ul>
Living with Cancer Education Program (Todd et al., 2002)	<ul style="list-style-type: none"> <li>• Coping and Education</li> <li>• Facilitator-assisted course</li> </ul>
FOCUS program (Northouse et al., 2002)	<ul style="list-style-type: none"> <li>• Coping and Symptom Management</li> <li>• Family-Based counseling program</li> </ul>
ENRICH program (James et al., 2011)	<ul style="list-style-type: none"> <li>• Diet and physical Activity</li> <li>• Diet education and home-based walking and resistance</li> </ul>

# Evidence of Effectiveness

## Trend in Recent Evidence (2013-2014)

- ▶ Transcultural studies (*Zhao et al., 2013; Watson et al., 2014; Lou et al., 2013; Loh et al., 2010*)
- ▶ Expanded to other cancer
  - Prostate (*Watson et al., 2014; McCaughan et al., 2013*)
  - Head & Neck (*Turner et al., 2014;*
  - Colon (*Tofthagen et al., 2014;*
  - Ovarian (*Schulman-Green et al., 2012*)
- ▶ Expanded to younger group
  - Adolescents (*Rogers et al., 2013*)
- ▶ Technology (*Van De Berg et al., 2012; Moody et al., 2014*)

## Develop Cancer Self-Management Intervention for Patients with Limited-English-Proficiency

- Cancer demographics in the United States have changed as the country has become more culturally diverse with growing numbers of new immigrants from various cultural backgrounds.
- Some patients, particularly those from non-mainstream backgrounds, experience delays in seeking health care and lack appropriate health seeking behaviors.
- Studies have suggested that Limited-English-Proficiency (LEP) seems to be associated with symptom distress and reduced breast cancer screening.
- Health care providers also expressed difficulty in communication to these patients.

## PURPOSE/AIM

- ▶ A pilot study to develop a self-management intervention handbook for Chinese American cancer patients with LEP.

# METHOD

- A prototype of cancer self-management intervention handbook is developed based on the conceptual and research literature.
- The handbook includes 3 sections:
  - 1. Symptom Management Strategies,
  - 2. Physical Activity,
  - 3. Communication with the Health Care Providers.
- Forward and backward translation; Both English and Chinese versions are available; about 35 pages

## METHOD (Cont.)

**Content experts from health care providers are invited to review the intervention handbook prototype to establish the content validity and feasibility.**

**complete a web-based survey for feedback**

**Chinese version developed**

**Monolingual/bilingual Chinese American cancer survivors were invited to provide feedback of the handbook.**



# FINDING

- 7 Health care providers agreed to be the content reviewers.
  
- The content reviewers are oncology practitioners from 4 different medical centers, including:
  - 2 Physicians
  - 1 Physician Assistant
  - 1 Physical Therapist
  - 2 Oncology Clinical Nurse Specialists
  - 1 Oncology Nurse Educator.

# FINDING

	Comments from the Content Reviewers
<b>Usefulness</b>	Helpful major med side effects & suggestions for caregiver; Can be more concise; Helpful for symptom self-care and applicable for outpatient care; Can be translated into other languages; Need to pay attention to Culturally-appropriate self-care to minority patients
<b>Feasibility</b>	The handbook can be used in the community and translated into other languages; Can be used as a reference for patient self-care; Suggest to pay attention to literacy and reading level.
<b>Types of Cancer Information the provider consider are needed for the Patients with LEP</b>	Medication management and side effect management ; Chemo/ hormonal/ targeted therapy; End of Life needs; Staging and Prognosis; Follow-up; When to contact health care providers.
<b>Barriers and Challenges faced by health care providers when giving care to patients with LEP</b>	Choosing regimen; managing side effects; Prefer patient to be the decision maker rather than family member; Different cultural health beliefs; Cannot speak to patient in their primary language; Patients do not engage in discussion about care but defer to medical providers.

# Overall Experience with the LEP patients reported by HCP

- Different beliefs about illness, poor understanding about cancer and related treatments.
- Disconnect in goals and patients' understanding of it, even with translation
- Less likely to speak about emotion and social challenges about illness and treatment
- Children make decisions and parents are passive participants.
- Unclear about how much they understand or want to understand about their health, esp. about prognosis
- Patients have mystical/cultural beliefs about Rx that is not necessarily "Chinese"

# Overall Experience Reported from the Cancer Survivors

16 cancer survivors participated; community recruitment

- The Chinese version handbook is useful and feasible tool.
- The common reported barriers and experiences during their treatment included:
  - limited understanding about
  - treatment/medication and side effects;
  - unable to communicate in order to make decision;
  - language barriers;
  - unable to understand information related to resources and do not know what to ask.

# Discussion

- ▶ The finding provides preliminary data of the feasibility and need of cancer self-management for culturally-diverse LEP cancer patients.
- ▶ Further research includes testing and applying the intervention.

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