Clinic-Based Programs to Improve Symptom Management and Patient-Clinician Communication

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Team-based approaches to support the work of self-management in oncology
Informed activated patient TEAM

Community
- Resources and policies
  - Self-management support

Health System
- Organization of Health Care
  - Delivery system design
  - Decision support
  - Clinical information systems

Informed activated patient TEAM

Functional and clinical outcomes

Prepared proactive practice team

Productive interactions
Provider Team
Patient Team
Valuing the Invaluable

• 15.6 million cancer survivors
• 4.6 million family caregivers (conservative estimate!)
• Asked to provide higher and higher levels of care at home
Self-Management

The tasks of illness-related work for patients and families with cancer.
Self-management in cancer is the “awareness and active participation by the person [and their family] in their recovery, recuperation, and rehabilitation, to minimize the consequences of treatment, promote survival, health and well being.

- Barlow et al. Patient Educ Couns 2002
Self-management is hard work and has to be understood in the context (culture, setting, resources) of everyday life

- Corbin & Strauss (1985): Domains of Illness-Related Work
  - Illness-Related Work
  - Biographical Work
  - Everyday Life Work
Symptom self-management is a key feature of illness-related work in oncology

Nine Domains and Tasks of Illness Related Work in Oncology

- Howell, 2018; Supp Care Cancer
- Klimmek, 2012; Onc Nurs Forum
Illness-Related Work

- Managing Disease & Treatment Regimens
- Managing Multiple & Interacting Symptoms
- Navigating & Negotiating Transitions
Illness-Related Work + Biographical Work

- Managing Disease & Treatment Regimens
- Managing Multiple & Interacting Symptoms
- Contextualizing cancer within life
- Navigating & Negotiating
- Recasting biography
- Coming to terms with a new normal
- Reconstituting identity

Managing Multiple & Interacting Symptoms

Navigating & Negotiating

Recasting biography

Coming to terms with a new normal

Reconstituting identity

Contextualizing cancer within life

Managing Disease & Treatment Regimens
Illness-Related + Biographical + Everyday Work

- Relationship Work
  - Coming to terms with a new normal
- Occupational Work
  - Reconstituting identity
- Emotional and Psychological Work
- Health Maintenance Work
- Contextualizing cancer within life
- Navigating & Negotiating Transitions
  - Managing Disease & Treatment Regimens
  - Managing Multiple & Interacting Symptoms
  - Recasting biography
- Housekeeping Work
Supporting patients and families in the very complex tasks of monitoring, communicating, and managing disease- and treatment-related symptoms in this complex system is ESSENTIAL for quality cancer care.
Self-Management...

is **NOT** a knowledge-based skill; self-management is a behavior requiring **ongoing** behavior change support from a proactive interdisciplinary healthcare team supported by systems, resources and policies that value and reward this challenging work.
Core Elements of (symptom) Self-Management Support in Cancer

- Tailored to individual, illness & tx
- Coaching in behaviors/skills by a trained educator
- Increase confidence to manage symptoms, illness and care
- Teach/support self-monitoring of symptoms to adapt behaviors
- Support development of skills for communicating with care team
- Support development of problem solving skills and daily decision making
- Facilitate knowledge and uptake of health behaviors through goal setting and action plans
- Foster collaborative partnership with health care team and use of available support and resources
Recommendations
Value the Invaluable

~40 million family caregivers in the US provide an estimated 37 billion hours of care/year. The estimated economic value of their unpaid care is ~$470 billion/year (2013)

Reinhard et al., 2015, AARP Policy Institute
Recommendations

• The Oncology Community should actively participate in policy initiatives to support families facing cancer (see AARP; NASEM Report on Families Caring for an Aging America; Administration for Community Living; Bell et al., JAGS, 2019)

• Assure caregiver preparation and support across the serious illness care trajectory.
  – Identify, assess, and support family caregivers across the cancer trajectory
  – Explicitly invite caregivers to serve as members of the care team
Dear Family Support Person,

Facing cancer and cancer treatment can be a stressful experience for the whole family. In addition to the worry you may have about your loved one, you may also feel like you need new information and skills to help her. The Family CARE Center, located in the outpatient gynecologic oncology clinic at Magee, is here to support you. Please fill out this card (front and back) so that we can reach out to you about any of your questions or concerns. Also feel free to stop by, call, or email with any questions.

P: 412-641-5605; email: CARECenter@upmc.edu

Date:

Caregiver (CG) Name:_________________________ Age_____ Gender_______

My phone:____________________ My email:__________________________

I am supporting my (mother, sister, wife, partner, daughter, friend, other) ____________________________ who has cancer.

Do you live with your family member/friend with cancer? _____Yes _____No

Do you have children living in the home with you? _____Yes _____No

Name of patient with cancer:_________________________________

Patient's Birthdate (MM/DD/YEAR):__________________________
Recommendations

• The Oncology Community should advocate for policies and systems that promote multi-disciplinary care teams with each member working at the full capacity of their training and licensure. [e.g. NASM/RWJF Future of Nursing]

• Identify and implement models of care and reimbursement that enable the health care team to provide self-management support across key transitions in the illness trajectory. [Shift from an acute care model to a chronic disease model]
  – e.g. Diabetes Education and Management; Cardiac Rehabilitation
“Ultimately, it is patients (and their families) who shoulder responsibility for adopting the necessary self-management behaviours to reduce the acute and chronic physical and psychological effects of cancer while dealing with multiple transitions and navigating an increasingly complex health and cancer care system”.

– Doris Howell

• And the work of everyday life doesn’t stop with cancer