

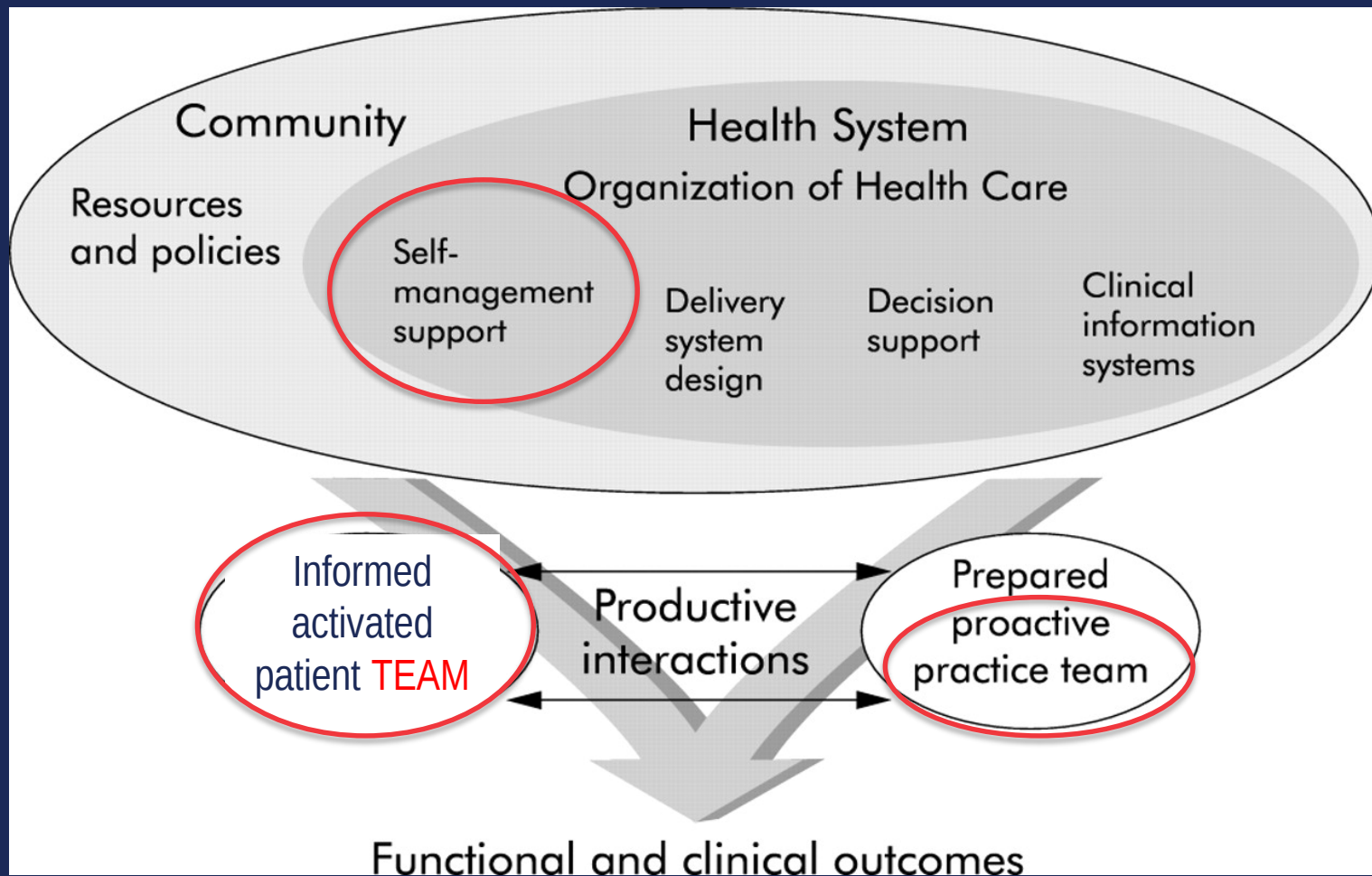
Clinic-Based Programs to Improve Symptom Management and Patient-Clinician Communication

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Team-based approaches to support the work of self- management in oncology





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

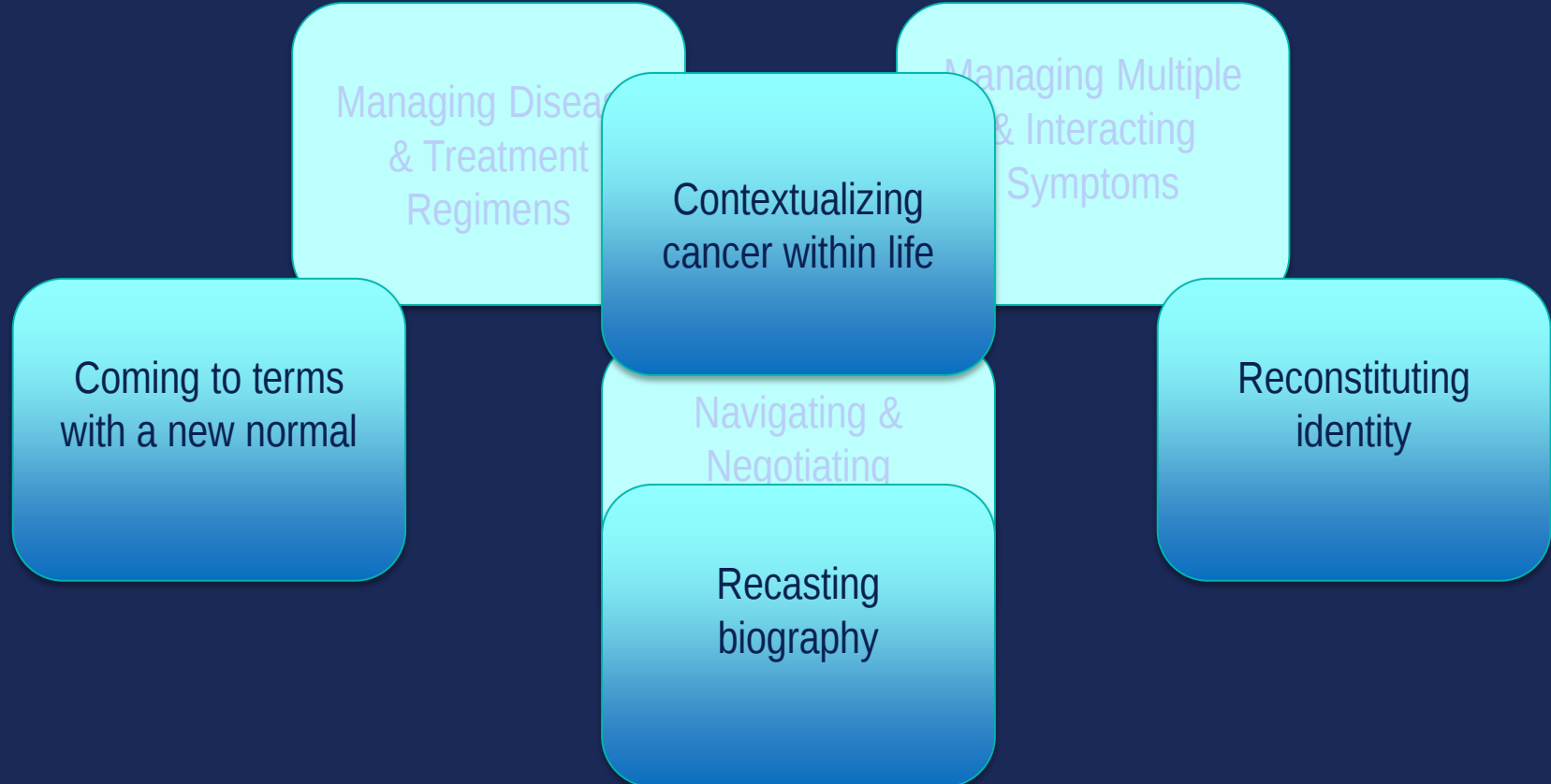
Illness-Related Work

Managing Disease
& Treatment
Regimens

Managing Multiple
& Interacting
Symptoms

Navigating &
Negotiating
Transitions

Illness-Related Work + Biographical Work



Illness-Related + Biographical + Everyday Work

Relationship Work

Managing Disease
& Treatment
Regimens

Contextualizing
cancer within life

Managing Multiple
& Interacting
Symptoms

Occupational Work

Coming to terms
with a new normal

Navigating
Negotiating
Transition

Health
Maintenance Work

Reconstituting
identity

Emotional and
Psychological Work

biography

Housekeeping
Work

Illness-Related + Biographical + Everyday Work

Relationship Work

Managing Disease
& Treatment
Regimens

Contextualizing

Occupational 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

Coming to terms
with a new normal

Emotional and
Psychological Work

Reconstituting
identity

Housekeeping
Work

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

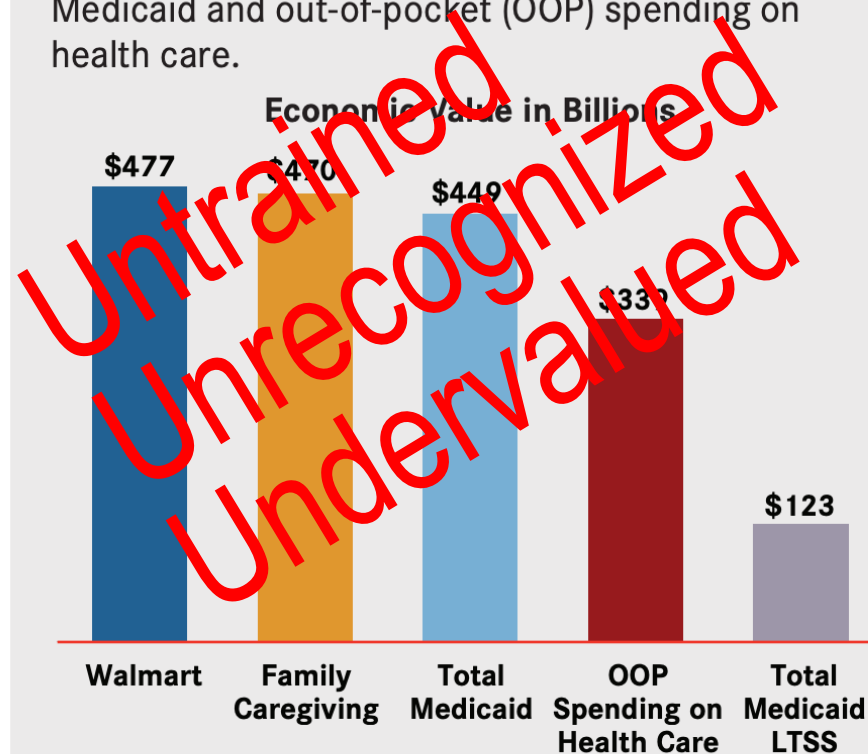
Value the Invaluable

~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)

EXHIBIT 1

How Much Is \$470 Billion?

The economic value of family caregiving is as big as the world's largest company, and bigger than Medicaid and out-of-pocket (OOP) spending on health care.



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

Current Efforts at Magee-Womens of UPMC



GynOnc Family CARE Center

Cancer Reaches Beyond the Patient; So Should Cancer Care

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): _____



GynOnc Family CARE Center

Cancer Reaches Beyond the Patient; So Should Cancer Care

Instructions: Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress

No distress

Check any of the following issues that are contributing to your overall distress:

- ☐ Need for information on the cancer
- ☐ Need for information about cancer treatment
- ☐ Managing patient symptoms
- ☐ Managing patient medications
- ☐ Maintaining your emotional health
- ☐ Maintaining your own physical health
- ☐ Finding time for yourself
- ☐ Spiritual Concerns
- ☐ Finances
- ☐ Legal Issues
- ☐ Transportation/Parking
- ☐ Work/Employment issues
- ☐ Self-Confidence as a caregiver
- ☐ Communicating with providers
- ☐ Talking with others about cancer
- ☐ Relationship with patient
- ☐ Family Dynamics

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



Pitt