

Supporting the Caregiver of the Older Adult with Cancer: Lessons Learned

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Objectives

1. Define who family caregivers are and estimated impact for the future.
2. Identify family caregiver responsibilities and information needed to minimize their burdens.
3. Describe interventions that can impact outcomes.

Defining Caregiving

- The act of assisting someone who is chronically ill, or has a chronic problem and is unable to independently care for themselves
- One who provides care, and health related assistance to a family member during illness or chronic conditions.

Why we expect caregiving needs to increase

- Estimated new cases for the 4 major cancers-Colon, Lung, Breast and Prostate in 65 and older for 2015: 370,130/848,200.
- Probability of developing invasive cancer during selected age intervals-2009-2011

– All sites Male-Female

| | 50 -59 | 60 – 69 | 70 and Older |
|--------|---------------|---------------|---------------|
| Male | 6.7 (1 in 15) | 15.1 (1 in 7) | 36.0 (1 in 3) |
| Female | 6.0 (1 in 17) | 10.0(1 in10) | 26.4 (1 in 4) |

- Selected numbers of new cases by state-all sites
 - CA- 172,090, FL- 114,040, TX-113,630, NY- 107,840

Consider Age Related Changes: Just to Name a Few

- Decreased vision and hearing
- Decreased taste and smell
- Decreased GI function
- Loss of bone mass
- Reduced mental capacity
- Loss of muscle control, strength and endurance
- Decreased liver and kidney function
- Decreased heart and lung fitness

Who are the Caregivers?

- 4.6 million Americans are caring for loved ones with cancer.
- 14.7 million Americans over the age of 65 require a family caregiver (National Health and Aging Trends Study)
- Consider how caregiving needs change throughout the cancer treatment trajectory

Caregiver Responsibilities

- Family Caregivers
 - Caring for pts. with metastatic disease, multiple comorbidities, active treatments
 - Assisting with daily living needs, cancer-specific care, managing side effects, medication administration, problem solving (when to call the doctor), managing dressing changes and what medications to give.
 - Errands/bill paying
 - Coordinating medical care, physical, psychosocial and spiritual support
 - Communicating with healthcare providers and others

Objective burden, resources and other stressors among informal cancer caregivers (2015) N=677

- 50% of caregivers feel they were not trained to provide necessary care.
- 49% work for pay in other jobs
- 21% report poor to fair health for themselves
- One in four report low confidence in the quality of the care they provided.
- 50% have problems communicating with the providers

Caregivers Make a Difference

- An effective family caregiver influences:
 - adherence to medication regimens
 - Exercise protocols
 - Dietary recommendations
 - Seeking early medical interventions
 - Reducing frequency & length of hospitalizations

What Do Caregivers Need to Know?

- Planning and coordinating activities
- Monitoring symptoms and clinical needs
- Problem solving
- Decision making (interpreting information)
- How to access resources
- Communication
- Providing direct patient care

Caregiving Across the Cancer Care Trajectory

- Family members provide 75-80% or more of care
 - Diagnosis
 - Treatment
 - Maintenance
 - Recurrent or progression of disease
 - Survivorship with late effects, and residual effects
 - Palliative care
 - End-of-life care
 - Equivalent to 3.0 FTE from diagnosis to death

Family Concerns

- Care activities that are not accompanied by training or instruction
- Concern about “quality” of available help
- Lack of access due to financial and “eligibility” barriers
- Lack of quality information from providers or internet access
- “Price” they pay for decision to provide care (trapped in responsibilities)

Predictors of Risks to Caregivers

- Caregivers age
- Sex (younger female caregivers)
- Relationship to patient
- Length of time as a caregiver
- Patient's cancer type
- Caregivers own comorbidities
- Transitions over time
- Limited personal resources
- Disruptive behavior

Negative Impact on Caregivers

- Family caregivers experience

- Depression (39%)

- Anxiety (40%)

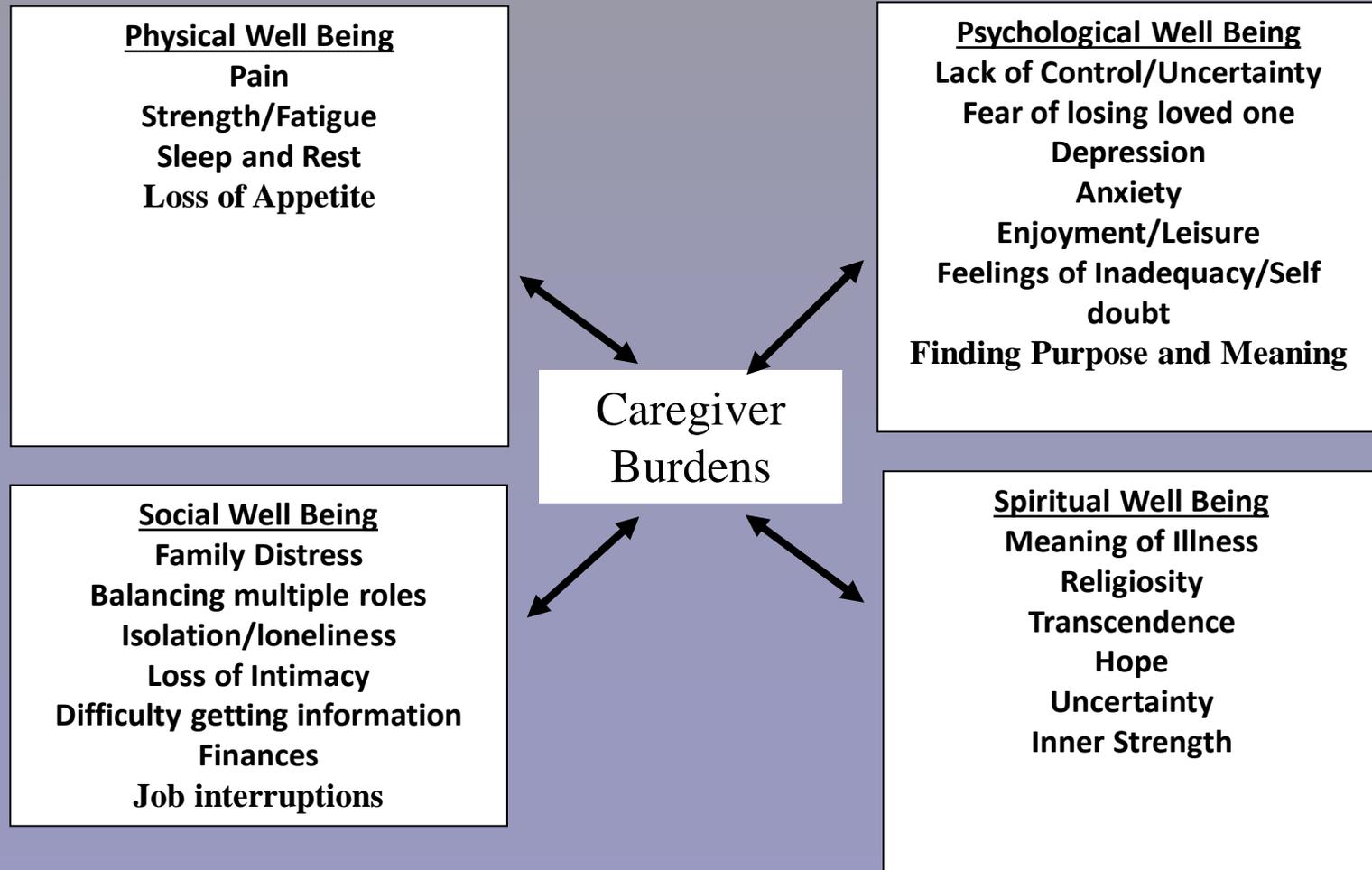
- Sleep disturbance (95%)

- Pain

- Fatigue (53%)

↑ Increased symptoms associated with ↑ burden

Caregiver Burdens Related to Domains of Quality of Life



Adapted from Ferrell, Dow
(1997), Fletcher et al.,
2008, Stenberg, 2010

Modifiable risk factors for caregiver depression

- Sleep deprivation
- Personal health decline
- Perceived burden of caregiving
- Caregivers' roles and responsibilities
- Leisure activities
- Lifestyle interferences
- Social isolation

Caregivers Burden Risk of Morbidity

- “At 4 yr. follow-up high caregiving burden in spouses was an independent risk factor for coronary heart disease”
- “Caregiver Health Effects Study-spousal caregivers who reported caregiver strain had a 63% greater risk of death 4 yrs later compared to non caregivers matched for demographics and physical health status”

Burden versus Positive Aspects of Caregiving

- Perception of caregiver burden associated with perceived positive aspects of the role and greater appreciation of their family.
- Caregiver's feel more burdened when they feel less self-efficacy, lack skills to perform needed tasks and disruptions in their lifestyles
- Restrictions to social activities leads to social isolation

Financial Impact

- Estimated average hours per day that family caregivers spend caring for cancer patients is 8.3 hours for 13.7 months.
- Estimated cost over the course of disease
 - Initial phase-\$7,028
 - Continuing phase (1 yr-6 mo before death)
\$19,701
 - Terminal phase-\$14,234(accumulated value of caregiver's time providing care, value of lost employment, out-of-pocket costs)

Interventions to Meet Caregivers Needs

- Psycho-educational
 - Emotional aspects of care
 - Information about managing patients' symptoms
 - Physical aspects of caring for patient
- Skills Training
 - Development of caregiver's coping, communication and problem solving skills
- Therapeutic counseling
 - Strengthening patient-caregiver relationships, managing conflict and dealing with loss

How do Interventions Impact Outcomes

- Interventions targeted at caregivers alone or to caregivers and patients had positive effects.
- Compared to controls-caregivers reported significantly less burden, less depression and less distress
- Improved knowledge, coping skills
- Reported greater mental well-being and better quality of life.

Barriers to Implementing Caregiver Interventions

- Research-tested interventions in real practice settings
- Lack of awareness of caregivers' needs
- Lack of professional training on how to intervene
- Greater focus on medical care needs
- Lack of professional time allowed to train caregivers
- Low organizational support for caregiver interventions (\$\$)

What More!



Legislative Reform

- Systematic assessment of caregivers' ability to provide care-resources, training to support role.
- Family Leave Act (1993) provided short term relief for families but not enough
- Affordable Care Act (2010) –need to integrate caregiving role needs throughout the trajectory of illness

What's the Benefit?

- Improves patient recovery and clinical outcomes leading to reduced complications and early identification of problems, better control of adverse effects and increased adherence to oral medications all ...

Reducing health care use and costs

What Can be Done?

- Seattle based Group Health Cooperative-use of Medical Home to coordinate needs of primary care clients-comprehensively-patient caregiver dyads.
- International Classification of Diseases (ICD) code for caregiver burden should be established. Effects morbidity and mortality statistics for insurance payment and would allow reimbursement for primary care providers who evaluate and treat the caregiver.

Prepare clinicians to work with caregivers

- Assess their needs
- Recognize the overall responsibilities they will need to care for their loved one
- Learn strategies to improve caregivers lifestyle and health behaviors, coping skills and how and where to access resources