Stress of Family Caregiving During Chronic Illness

Chapter 1: Introduction

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Objectives

1) Understand the negative and positive effects of caring for a loved one with a chronic illness.

2) Develop competence in assessing components of caregiver burden.

3) Become familiar with approaches to mitigating the negative effects and maximizing the benefits of caregiving and how these might be applied in clinical practice.

4) Prioritize future research needs in family caregiving for persons with chronic illness.
Scope of the Issue (US data)

- 7 of 10 deaths occur at end of chronic illness
- ~1/4 of people with chronic illness need assistance with $\geq 1$ daily activity
- ~29.2 million informal family caregivers for adults with chronic illness
Scope of the Issue (US data) (cont’d)

- Number is expected to increase to 37 million by 2050
- Caregivers disproportionately female
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Chapter 2: Family Caregivers Stress

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Caregiver Stressors

Caregivers as “hidden patients”
  • Often suffer from stress-induced problems

Stressors
  • Managing physical and emotional needs of loved one
  • Communicating with health care providers and family
  • Finances
Caregiver Stressors (cont’d)

Stressors

• Maintaining ongoing work
• Maintaining household
• Self-care responsibilities
Caregiving Experience

The idealized caregiving experience....

What happens too often.......
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Chapter 3: Emotional & Physical Burden

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Emotional and Physical Burden of Family Caregivers

Psychosocial Distress

- 40-70% with depressive symptoms;
- ~50% meet criteria for major depression
Emotional and Physical Burden of Family Caregivers (cont’d)

Maladaptive Behaviors

- ↓ self-care ⇒ poor health status
  - Less physical activity
  - ↓ attention to diet and nutrition
  - ↑ alcohol, tobacco, other drugs

- Inattention to own medical needs
Caregiver stress exacerbated by uncertain trajectory of chronic progressive illness
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Chapter 4: Communication & Caregiving Experience

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Communication and the Caregiving Experience

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Chapter 5: Coping Strategies

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Caregiver Adaptive Coping Strategies

- Social support
- Decision making
- Positive reframing
- Venting
- Self-efficacy
- Positive benefit-finding
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Chapter 6: Caregiver Needs

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Caregiver Needs

- Psychological and emotional support
- Information
- Help with personal, nursing and medical care of the patient
Caregiver Needs (cont’d)

- Assistance at night
- Respite care
- Financial assistance
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Chapter 7: Assessment & Provider Role

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Assessing Family Caregivers

Assessment = Prevention
Provider Role in Caregiver Communication

Providers who can recognize, acknowledge and engage families with varying responses to serious illness can ease patients’ suffering and help families manage the often unknown terrain.
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Chapter 8: Caregiver Assessment Instruments

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Caregiver Assessment Instruments

Most developed for research, rather than clinical use

• Clinicians: discern the purpose for which the instrument was developed and used
Caregiver Assessment Instruments (cont’d)

Use existing instruments – *don’t reinvent the wheel*

- Satisfaction with service delivery
- Caregiver burden
- Caregiver quality of life
- Caregiver needs
- Bereavement
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Chapter 9: Evidence-Based Strategies

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Evidence-Based Strategies to Respond to Family Caregiver Needs

- Limited number of longitudinal studies
- Support often provided *ad hoc*
CaLL Conceptual Model

Patient & Caregiver Characteristics
- Sociodemographics
- Caregiving experience
- Caregiver comorbidity
- Diagnosis/symptoms of pt
- Relationship of CG to pt.

Caregiver Stressors
- Emotional
- Physical
- Social
- Functional/Practical

Adaptive Resources
- Coping
- Self-efficacy
- Social support
- Positive Benefit Finding

Caregiver Burden
- Psychosocial Distress
  - Depressive symptoms
  - Perceived Stress
  - Mood States

Self-care Behaviors
- Sleep behavior
- Adherence to medical advice
- Change in diet and exercise

Caregiver Outcomes
- Quality of Life
  - Life satisfaction
  - Health Status

CaLL Intervention

Patient Resource Utilization
- Urgent calls to the clinic
- Unexpected medical visits
- ER visits/Hospitalizations

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Chapter 10: Goals & Challenges of Future Research

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Goals and Challenges for Future Research

- Explore caregiver characteristics that are likely to impact the caregiving experience
- Recruit caregivers earlier, conduct longitudinal studies, compare contexts of care
Goals and Challenges for Future Research
(cont’d)

• Include under-researched groups
  • older,
  • non-cancer,
  • non-dementia (especially heart and lung disease),
  • ethnic minorities,
  • male,
  • non-traditional relationships

• Evaluate interventions: efficacy, effectiveness, cost-effectiveness