Caregiving for Vulnerable Populations

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COI

I have no conflicts of interest to disclose.

The Cycle of Caregiving

Story of Ms. O

- 56 yo Spanish-speaking woman
- In-Home Support Services (IHSS) primary caregiver for both her elderly parents
- Unable to see a doctor herself for years, while experiencing chronic back pain and caregiver burden
- Lost her source of income when both her parents passed
- Presented with severe depression, weight loss, dysphagia
- Diagnosed with advanced esophageal cancer
- Suffering from severe malnutrition, functional decline
- Adult daughter has become her primary caregiver

Learning Objectives

- To describe the urgent caregiving need for an aging and vulnerable U.S. population.
- To discern between different types of caregivers and caregiving services, both formal and informal.
- To develop ethical strategies for engaging family caregivers in patient care.
- To strategize ways to assess family (informal) caregiver burden and recognize its consequences.
- To understand resources and supports for family caregivers and their care recipients.
The Large Population of Americans with Disability

Disability: serious difficulty with hearing, vision, cognition, walking or climbing stairs, as well as difficulty with self-care and independent living.

- 40 million Americans with a disability in 2015 (12.6% of population)
- 13% with cognitive impairment
- About 25% of the population age 65 to 74 reported a disability
- Those ages 35 to 64 accounted for more disabled Americans – nearly 16 million in 2015 – than any other age group.

The Growing Need for Long-Term Services and Supports (LTSS)

LTSS: a broad range of services (institutional or community-based) by paid or unpaid caregivers that assist people who have limitations in their ability to care for themselves due to a physical, cognitive, or chronic health condition that is expected to continue for at least 90 days.

- ~11 million Americans use community-based LTSS each year; 1.8 million receive services in nursing homes
- A recent study projects that over half of adults who reach age 65 will someday require a high level of help with basic daily activities; 1 in 7 will need LTSS for more than five years

Source: Favreault M, Dey, J. Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief. 2015;
“Aging in Place” with In-Home Support Services (IHSS)

- Statewide program administered by each county under the direction of the California Department of Social Services.
- IHSS provides those with limited income services to help them remain safely at home or “Age in Place.”

**Eligibility Criteria:**

- SSI/SSP or Medi–Cal eligible.
- Blind, disabled, or ≥ 65 yrs old
- Living in a home, apartment or abode of their choosing (not a facility)
- Unable to live safely at home without care.

**IHSS Application Process**

- Submit an application that includes healthcare certification form.
- County caseworker is assigned.
- Caseworker needs assessment: home visit to determine types of services and number of hours (up to 283 hrs per month)
- Caregiver – friend, relative, or a worker in IHSS Registry.
- Client acts as employer, responsible for supervision and signing time sheets.
- Workers assist with a variety of activities, including personal care and paramedical services, household chores, and errands such as grocery shopping or going to medical appointments.
Formal vs Informal Caregivers

**Formal Caregiver** – a provider associated with a formal service system. Typically paid.

**Family (Informal) Caregiver** – any relative, partner, or friend who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. Typically unpaid.

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The committee calls for a transformation in the policies and practices affecting the role of families in the support and care of older adults, stating that today’s emphasis on person-centered care needs to evolve into a focus on person- and family-centered care.

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**Family Caregiving in the U.S.**

Types of Care Recipient Conditions

- Long-term physical condition: 66%
- Short-term physical condition: 35%
- Memory problem: 20%
- Emotional/mental health problems: 21%
- Behavioral issue: 7%
- Developmental/intellectual disorder, mental retardation: 4%

More than half of care recipients have been hospitalized in the last 12 months

- 39.8 million Americans are caregivers for an adult
- 60% of caregivers are women
- 1 in 10 caregivers are spouses/partners
- Higher hour caregivers 4x more likely to be spousal caregivers
- 25% of caregivers have been in their role 5+ years


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**Valuing the Invaluable: The Economic Value of Family Caregiving**

Informal caregiving saves the national economy between $221 and $642 billion annually.

HOW DOES FAMILY CAREGIVING COMPARE? 2013–2014 in billions

- Walmart Annual Sales $477
- Family Caregiving estimated value $470
- Combined Annual Sales $469
- Total Medicaid Expenditures $449

Apple, IBM, Hewlett Packard and Microsoft
### Caregiving for Racial/Ethnic Diverse Populations

- Caregiving workforce is increasingly diverse (21% Hispanic, 20% Asian, 20% Black).
- Racial/ethnic differences exist across caregiving experiences.
- Hispanic and African-American caregivers experience higher burdens from caregiving and spend more time caregiving on average than their White or Asian-American peers.
- African-American caregivers (41%) are more likely to provide help with more than three ADLs than white caregivers (28%) or Asian-Americans (23%).

### Caregivers for Patients with Limited English Proficiency (LEP) are Heavily Relyed Upon During Care Transitions

**Key Findings:**
- 158 caregivers for patients with LEP recently discharged from hospital for acute stay interviewed.
- 69% of caregivers were adults caring for parents or grandparents.
- 43.7% of caregivers had LEP; only 12% of patients had access to professional interpreters at the time discharge instructions were provided.
- 40% reported moderate/high levels of perceived caregiving stress.
- Caregivers for Chinese-speaking patients were most likely to report moderate/high levels of perceived stress.


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### Caregiver Roles and Responsibilities

- Caregivers help, on average, with 4.2 out of 7 Instrumental Activities of Daily Living (IADLs).
- 59% help with at least one Activity of Daily Living (ADL).
- About 6 in 10 caregivers assist with “medical/nursing tasks,” (i.e. injections, tube feedings, catheter and colostomy care).
- Caregivers interact with various providers, agencies, and professionals on their care recipient’s behalf.
- 2 out of 3 monitor their care recipient’s condition to adjust care.
- 63% communicate with health care professionals, and
- 50% advocate for their recipient.

Barriers to Reaching out to Caregivers for Patients

- Professional code of ethics emphasizes obligations towards the patient and offers little guidance in engaging their caregivers.
- Electronic health records provide limited options for identifying and tracking involved caregivers.
- Reimbursement structures focus on the patient, providing limited direct incentives for engaging their caregivers.
- Medical training focuses on individual patient treatment and management, creating a lack of provider comfort with family-centered care.

Why Engage Patients’ Family Caregivers?

- Engage patient in self-management strategies
- Prevent adverse events
- Improve patient disease outcomes
- Gain information to inform care management
- Overcome communication barriers with patients
- Ease care transitions

4 in 10 caregivers want to have more conversations with providers about patient care.

Figure 1 Caregiver-reported roles assisting patients with LEP post-hospitalization.

Applying fundamental values in bioethics to engaging patients' family caregivers

<table>
<thead>
<tr>
<th>Ethical value</th>
<th>Definition</th>
<th>Application to caregivers</th>
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<tbody>
<tr>
<td>Autonomy</td>
<td>Right to self-determination</td>
<td>Determine with patient and caregiver (1) balance between safety and well-being, (2) patient’s capability for independent decision making, and (3) when and how to involve the caregiver.</td>
</tr>
<tr>
<td>Beneficence</td>
<td>Making decisions and taking action in best interest of patient</td>
<td>Provider must reach out to caregiver to assess their well-being and capacity to provide care as this is in patient's best interest.</td>
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<td>Nonmaleficence</td>
<td>Pursuing actions that minimize harm</td>
<td>Provider needs to reach out to caregiver with support and resources in order to minimize harm to caregiver and patient.</td>
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<tr>
<td>Truth-telling</td>
<td>Communicating openly and honestly</td>
<td>Provider needs to inform patient of importance of involving caregiver in decision making and is obligated to share the truth about the patient's capacity.</td>
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Domain Specific Strategies

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<th>Specific Strategies</th>
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<tr>
<td>Ask strategic questions about caregiving</td>
<td>1. Ask about caregivers’ own health and well-being. 2. Recommend keeping a journal of care. 3. Recommend listing decision-making challenges that can be discussed in future encounters.</td>
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<tr>
<td>Engage in active listening</td>
<td>1. Provide reassurance. 2. Validate caregiver efforts 3. Show empathy 4. Reaffirm ethical dilemmas caregivers experience</td>
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Strategies for reaching out to family caregivers for patients

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<th>Specific Strategies</th>
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<tr>
<td>Offer resources</td>
<td>1. Provide ongoing education on patient disease. 2. Recommend caregivers talk with their own physician. 3. Refer caregivers to specialists (e.g., counselor, geriatric care manager) as needed. 4. Refer caregivers to support groups and information.</td>
</tr>
<tr>
<td>Prepare office &amp; office staff</td>
<td>1. Integrate family education &amp; support in office practices 2. Ask if a patient receives help from a family member as part of medical history taking 3. Ask the family member what care responsibilities he or she has and how he or she is doing. 4. Provide education to office staff about caregiving. 5. Develop office protocol that recognizes and includes caregiver as part of the medical encounter.</td>
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“I had to do everything for them (parents); It was hard work. Nobody else could help.”
~ Ms. O

Caregiver Burden: The extent to which caregivers perceive that caregiving has an adverse effect on their emotional, social, financial, physical, and spiritual functioning.

- 32% of caregivers nationally report high caregiver burden.
- Caregiver burden is associated with a 63% increased risk of caregiver mortality.
- Caregiver burden can lead to caregiver depression and anxiety, poor self-care.
- Caregiver burden can also lead to worse patient physical and mental health outcomes.
## Risk Factors for Caregiver Burden

<table>
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<tr>
<th>Domain</th>
<th>Risk Factor</th>
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<tbody>
<tr>
<td>Caregiver demographics</td>
<td>Female, Spousal caregiver, Low education, Living with care recipient, unemployed</td>
</tr>
<tr>
<td>Caregiver psychosocial</td>
<td>Depression, lack of coping strategies, perceived patient distress, social isolation, anxiety</td>
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<tr>
<td>Caregiving context</td>
<td>Longer duration of caregiving, more hours spent caregiving, financial stress, lack of choice in becoming a caregiver, medical/nursing responsibilities</td>
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<td>Care recipient factors</td>
<td>Mental health issues, dementia, long-term physical condition</td>
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## Catalysts for Discussing Caregiver Burden with Patients’ Caregivers

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<tr>
<th>Domain</th>
<th>Catalyst</th>
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| Caregiver Health        | 1. To provide the very best patient care, I find I need to also pay attention to my patients’ caregivers. Can you tell me a bit about how you are feeling/doing?  
2. We know that caregivers often neglect their own health. When was the last time you saw your physician? Is she he aware of your caregiving situation? |
| Quality of Life         | 1. I know that many family caregivers find the role to be very stressful. How are you coping with these responsibilities?  
2. How often do you get out?  
3. What do you do for fun? |
| Support                 | 1. Many caregivers don’t want to burden others. Are there times when you really need help but don’t ask for fear of being a burden?  
2. Who gives you support? How helpful is this support?  
3. Caregiving is a very hard job and the best way to do it well is to take advantage of some of the resources available for help. May I help you with a referral? |

### Caregiver Burden Assessment Tools:
- 35 general and 19 disease specific (mostly for dementia) instruments. Lacking culturally and linguistically tailored instruments.
  - Appraisal of Caregiving Scale (ACS)
  - Zarit Burden Inventory and Short Form Burden Interview (ZBI; ZBI-12)
  - Caregiver Burden Scale (CBS)
  - Caregiver Strain Index (CSI)
  - Caregiver Stress Scale (CSS)
  - Caregiver Reaction Assessment (CRA)
  - Cost of Care Index (CCI)

### Zarit Burden Short Form (ZBI-12)

<table>
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<tr>
<th>Question</th>
<th>Response Options</th>
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<tr>
<td>Q1. You don’t have enough time for yourself?</td>
<td>0=Never; 1=Rarely; 2=Sometimes; 3=Quite Frequently; 4=Nearly Always</td>
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<td>Q2. Stressed between caring and meeting other responsibilities?</td>
<td></td>
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<td>Q3. Angry when around your relative?</td>
<td></td>
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<td>Q4. Your relative affects your relationship with others in a negative way?</td>
<td></td>
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<tr>
<td>Q5. Strained when are around your relative?</td>
<td></td>
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<tr>
<td>Q6. Your health has suffered because of your involvement with your relative?</td>
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<td>Q7. You don’t have as much privacy as you would like, because of your relative?</td>
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<tr>
<td>Q8. Your social life has suffered because you are caring for your relative?</td>
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<tr>
<td>Q9. You have lost control of your life since your relative’s illness?</td>
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<tr>
<td>Q10. Uncertain about what to do about relative?</td>
<td></td>
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<tr>
<td>Q11. You should be doing more for your relative?</td>
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<td>Q12. You could do a better job in caring for your relative?</td>
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Interventions to Support Caregivers and Patients

- Support groups or psychoeducational interventions for caregivers of individuals with dementia are modestly effective.
- Pharmacologic interventions (including anticholinergic or antipsychotic medications, treating the patient’s dementia or dementia-related behaviors) reduce caregiver burden.
- Many studies showed improvements in symptoms associated with caregiver burden (e.g., mood, coping, self-efficacy) even when caregiver burden itself was not substantially improved.
- Given these broad effects on many distressing caregiver symptoms, attempts at lower-risk (i.e., nonpharmacologic) interventions are probably warranted, even when impact on burden is modest.

Practical Interventions to Reduce Caregiver Burden

- Encourage the caregiver to function as a member of the care team.
- Encourage caregivers to improve self-care and maintain their health.
- Provide education and information (e.g., emergency response systems, online support groups).
- Use the support of technology (e.g., electronic health record patient portals).
- Coordinate/refer for assistance with care (e.g., Alzheimer’s Association, home health, housekeeping, meal delivery services, transportation).
- Encourage caregivers to access respite care (e.g., hospice, adult day programs, PACE – Program of All inclusive Care for the Elderly).

Online Resources for Caregivers

- Family Caregiver Alliance (FCA), http://www.caregiver.org/
- The Caregiver Action Network (CAN), http://caregiveraction.org/about/
- eCare diary, http://www.ecarediary.com
- Aging Care, http://www.agingcare.com

“There are four kinds of people in the world: Those who have been caregivers; Those who are currently caregivers; Those who will be caregivers; And those who will need caregivers.”

- Rosalyn Carter, Former First Lady of the United States
Questions