Principles of Dementia Caregiver Assessment: From Assessment Bloat to Tailoring Strategies

Joseph E. Gaugler, PhD
Long-Term Care Professor in Nursing
Center on Aging
University of Minnesota

Specific Aims

- Identify the recommended dimensions of dementia caregiver assessment
- Recognize common tools that will allow professionals to effectively assess dementia caregivers
- Think about ways to potentially move beyond assessment of everything, to the effective tailoring of services

Question

- What is assessment? How is it different from measurement?

Defining Assessment

- “Assessment refers to the collection of data to describe or better understand an issue”
- “Measurement is the process of quantifying assessment data”
- From Huit, Hummel, & Kaeck, 2001
Assessment Bloat

- Not a technical term: something I have witnessed
- The need to make everyone on a team happy: assess everything that everyone thinks is important
- Can lead to:
  - Overly long assessment tools
  - Data that are not useful to the provider or client
  - Zombie like assessment tools

Importance of Caregiving Assessment

- Families Caring for an Aging America: 2016 Report from the National Academies of Science, Engineering, and Medicine:
- Recommendations
  - “The focus of the nation’s health care reforms should change from person-centered care to person- and family-centered care.
  - The Secretary of HHS, working with the Secretaries of Labor and Veterans Affairs, and others should create and implement a National Family Caregiver Strategy that includes mechanisms to ensure that family caregivers are routinely identified in delivery of services to older adults who rely on help (1a)”

What are the Principles You Use to Guide Caregiver Assessment?

- Do you assess family caregivers?
- If so, what principles guide your assessment approach?

Box 1

The 7 principles of family caregiver assessment

1. Because family caregivers are a core part of health care and long-term care, it is important to recognize, respect, assess, and address their needs.
2. Caregiver assessment should embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver.
3. Caregiver assessment should result in a care plan (developed collaboratively with the caregiver) that indicates the provision of services and intended measurable outcomes.
4. Caregiver assessment should be multidimensional in approach and periodically updated.
5. Caregiver assessment should reflect culturally competent practice.
6. Effective caregiver assessment requires assessors to have specialized knowledge and skills. Practitioners and service providers’ education and training should equip them with an understanding of the caregiving process and its effects, as well as the benefits and elements of an effective caregiver assessment.
7. Government and other third-party payers should recognize and pay for caregiver assessment as a part of care for older people and adults with disabilities.

From Gaugler, Potter, & Pruinelli, 2014
**Who Should You Assess?**

**Assessment Perspectives**
- May require a system perspective
  - Caregiver
  - Person receiving assistance
  - Other family members involved in the care process
  - Environment/context of family care
  - Services used
  - Feasibility concerns

---

**Assessment Perspectives**

**Goals**
- Ascertain the emotional and psychological well-being of the caregiver and care recipient
- Determine what challenges the care recipient’s chronic illness, condition, or disability places on both the primary caregiver as well as other family members or care providers
- Identify whether there are precipitating factors, or triggers, which result in either positive or negative outcomes on the part of the caregiver or care recipient

---

**What Do You Assess?**
Recommended Assessment Domains

- Background of the caregiver and the caregiving situation
- The caregiver's perception of the health and functional status of the care recipient
- The caregiver's values and preferences
- The health and well-being of the caregiver
- The consequences of caregiving on the caregiver
- Care provision requirements
- Resources to support the caregiver
- See https://www.caregiver.org/caregivers-count-too-s3-caregiver-assessment-table

From: Family Caregiver Alliance/National Center on Caregiving

Recommended Assessment Domains

- Although a caregiving assessment may include these 7 domains, content or questions may vary as a result of:
  - When the assessment is administered
  - Whether the caregiving situation is new or has been ongoing for some time
  - Whether an acute episode, such as a fall or hospital discharge, has led to a change in the caregiving situation; and
  - Whether the care recipient is living at home, in a residential setting, or is receiving some other arrangement of services
- See https://www.caregiver.org/caregivers-count-too-s3-caregiver-assessment-table

From: Gaugler, Potter, & Pruinelli, 2014

Assessment Guidelines

- Valid and reliable (measurement quality)
- Short
- Measures that have been used in care settings that are similar to the clinician’s/provider’s
- Direct (i.e., reduced response categories)
- Using language that is appropriate to the cultural or socioeconomic contexts of family caregivers

Zarit Assessment Framework

- Assessment
  - Who are you seeing today?
  - Who is the primary caregiver?
  - Today's problem
  - History of the problem
  - Assessment of the identified care recipient
  - Living situation
  - Evaluate the family system
  - Assess the caregiver’s reaction

From: Zarit, 2009; pp. 114-125
Taking the Next Step: From Assessment to Tailoring

- How do you move from assessment to tailoring?

Care to Plan

- [http://www.caretoplan.org](http://www.caretoplan.org)
- See also Minnesota Long-Term Care Navigator

---

Initial Interview

- Presenting Problem
- Cognitive Symptoms
- Functional Problems (daily, gain, incontinence)
- Problems with vision
- Problems with hearing
- Born & raised (where)
- Education
- Vocational (and reference)
- Marital/Single/Divorced/Widowed
- Children
- Current living situation
- Family Medical and psychiatric history
  - Father
  - Mother
  - Siblings
- Family history of cognitive disorders/dementia
- Personal medical history
- Neurological history (imaging or prior testing)
- Current Medications
- Drug & Alcohol
  - Alcohol
  - Tobacco
  - Caffeine
  - Other substances (including over-the-counter medications)

From: Zarit, 2009; Table 6.1, p. 118

From: Kwak et al., 2011
A Clinical Framework to Assess and Treat Caregivers

- Intervention
- Information
- The problem-solving method
  - Generate a list of problem behaviors
  - Generate solutions
  - Trial and error
  - Providing support

From: Zarit, 2009, pp. 125-130

Money and Behavior Problems Checklist

<table>
<thead>
<tr>
<th>Problem</th>
<th>0 = never occurred</th>
<th>1 = less than once a month</th>
<th>2 = 1 to 3 times a month</th>
<th>3 = 3 to 4 times a month</th>
<th>4 = daily or more often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No interest in things</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Engaging in inappropriate behaviors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tardiness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor hygiene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor dressing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems taking medicines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal appearance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal hygiene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor nutrition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor hygiene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal hygiene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor nutrition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor hygiene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal hygiene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor nutrition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor hygiene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal hygiene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor nutrition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor hygiene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor personal hygiene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor nutrition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

From: Zarit, 2009

Caregiving Gapsgram

<table>
<thead>
<tr>
<th>CAREGIVER</th>
<th>GENETIC</th>
<th>Cardiac care</th>
<th>Neurocognitive</th>
<th>Emotional support</th>
<th>Social support</th>
<th>Physical care</th>
<th>Family care</th>
<th>Financial care</th>
<th>Communication</th>
<th>Recreation</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dying</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cooking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Money</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

From: Zarit, 2009, p. 123, Table 6.3

Problem List

<table>
<thead>
<tr>
<th>Time of Day</th>
<th>Problem</th>
<th>What You Do Next</th>
<th>What Happened After</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

From: Zarit, 2009, p. 127, Table 6.4
Assessment Resources

- Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners
- The Risk Appraisal Measure (Czaja et al., 2009)
  - The RAM
  - Supporting journal article
- American Psychological Association Caregiver Briefcase
  - Assessment

Questions?

Joseph E. Gaugler, PhD
Long-Term Care Professor in Nursing
School of Nursing, Center on Aging
University of Minnesota
6-153 Weaver-Densford Hall
308 Harvard Street S.E.
Minneapolis, MN  55455-1331
Phone: 612-626-2485
Email: gaug0015@umn.edu