Caregiver Assessment II: Practice Considerations for System Change

Edrena Harrison, Information Programs Specialist,
Family Caregiver Alliance, San Francisco, CA

Greg Link, Aging Services Program Specialist,
U.S. Administration for Community Living,
Washington, DC

Caregiver Assessment II: Practice Considerations for System Change

David W. Coon, PhD
Jo T. McCord, M.A.

Overview

- **Background and Justification**
- **Key Challenges for Caregiver Assessment**
- **Practical Issues in Administration**
- **Voice from the Field**
- **Outcome-driven Assessments**

Caregiver Assessment

A systematic process of gathering information

- Describes a caregiving situation
- Identifies the particular challenges & needs
- Uncovers the resources and strengths of the family caregiver
- Approaches issues from the caregiver's perspective and context
- Focuses on identifying what assistance the caregiver may need to maintain the caregiver's own health and well-being

Adapted from AARP Public Policy Institute Fact Sheet
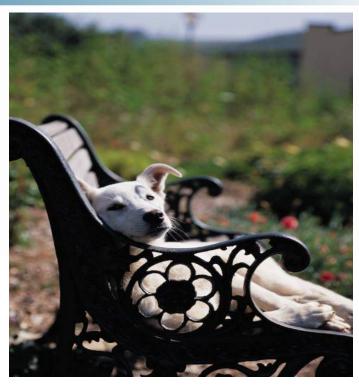
Caregiver - The Hidden Patient

AT RISK FOR:

– **Depression (>50% caregivers are depressed)**

– **Extreme fatigue, stress, anger/frustration**

– **Anxiety, upset, feeling overwhelmed**

– **Social isolation**

– **Financial loss**

– **Physical health problems/Morbidity**

– **Mortality**

Coon, Gallagher-Thompson & Thompson, 2003 (Eds.), *Innovative Interventions to Reduce Caregiver Distress,* Springer; Ory et al., 1999, *The Gerontologist, 37*, 804-815; Feinberg et al., *2012,Valuing the Invaluable: 2011 Update,* AARP Public Policy Institute; Schulz, et al, 1995. *The Gerontologist, 35*, 771-791; Schulz & Beach, 1999, *JAMA, 282*, 2215-2219

Value is Staggering

- In 2009, 42.1 million Americans provided unpaid care to another adult with ADL limitations at any given point and 61.6 million provided care at some time during the year.

- Economic value of their unpaid contributions = $450 billion. (Walmart sales = $409 billion)

- Family care is the most important source of assistance for people with chronic conditions who need LTSS. The "care coordinator."

- Without this "informal" workforce, the entire health care and LTSS system would be in jeopardy.

- Backbone or Bedrock--- either fits. And, caregiving doesn't end with placement.

All I ever needed to know…
I learned in kindergarten.

Robert Fulghum

I don't think Robert Fulghum was a family caregiver. Caregiver Assessment helps identify what assistance caregivers may need to maintain their own health and well-being, and sustain them in their roles.

D.W. Coon

Key Challenges in Expanding Assessment to Caregivers & Balancing Needs, Clinical Judgment, and Structured Assessments

Background Perspective

- **Many of the key points are drawn from:**
  - The Arizona Caregiver Assessment Tool (CAT) experience to date
  - The New Jersey Care Partner Support Pilot Program

- **However, points are quite similar to the experiences of others integrating caregiver assessment into systems**

- **Key issue: Assessment & service provision typically focused solely on the care recipient**

- **Arizona Caregiver Assessment Tool (CAT)**
  - To assist in respite allocation and identification of relevant services for the caregiver (Pilot in Lifespan Respite Grant)
    - Drawn from the scientific, practice and policy literatures
    - Measures with strong reliability and validity
    - Established use in diverse groups of caregivers
    - Sensitive to change
    - Tied to assessment of care recipient
    - Time constraints (everyone has a favorite domain)

  - Refined through focused discussions with service providers, administrators, family caregivers

  - Interviewer administered: Caregiving activities and impact (CR behavioral challenges); physical & emotional well-being; informal social support; negative coping strategies; and leisure time satisfaction. Project evaluation (post –only)

- **NJ Care Partner Support Pilot Program**
  - To improve the knowledge and skills of family caregivers caring for adults in Medicaid programs
    - Self-administered designed to guide I&R to meet the needs of caregivers
    - Care needs and behaviors
    - Caregiver physical and emotional health
    - Informal and formal assistance available
  - Not intended to be an intervention that resulted in behavior change; Pilot to make care managers more aware of the caregiver needs and promote good professional practice
  - Provided packet of materials and referrals
  - Follow-up phone call
  - Follow-up mail survey

Challenging Wish List

- **User Friendly & Staff Ready**
- **Less "intensive" and less "time away"**
  – Reality of case management
- **Clinical Judgment and Structured Assessments**
  – I know what they think, want and need vs. an integrated approach
  – Forced choice
  – Open-ended endings?
- **Appeal to & be effective with caregivers from diverse backgrounds**

Complexity in the Context of Care

- **Sociocultural Influences on Caregiving**
  - The meaning of illness
  - Who is "family" and decision-making patterns
  - Values and attitudes; views of help and authority
  - Style and patterns of communication
  - Definitions of acceptable behavior and coping strategies
- **Less vs. More Challenging Caregiving Contexts**
  - CR sicker and released quicker
  - Personality style and complicated situations
  - Multigenerational households
  - Financial stress and strain

Challenging Wish List

- **Married with existing programs**
  - Easily identifies which referrals are needed: Respite, care management, support groups, psychoeducational skill-building classes, etc.
- **Evidence based; empirically supported**
- **Reality: Caregiver assessment is multidimensional; needs periodic review and update; needs to reflect culturally responsive practice**

Addressing Practical Issues

- **Technology versus Art**
  - Training and Coaching

- **Privacy and phone CAT administration**
  - Calling back, but response sets can shift
  - Concern about a care recipient's reaction to caregiver's response

- **Self versus Interviewer administered**
  - Time (with either type of administration)
  - Frequent requests for assistance (NJ pilot)
  - Literacy; lack of clarity about a question

- **Help the caregiver see assessment as worthwhile; an opportunity to express their views**

- **Matter-of-fact approach: the goal is to obtain accurate, valuable information**
- **Relax and be yourself, even if the questions are challenging (e.g., negative coping). Introduction to a sensitive topic can be scripted.**
  - Ask questions as worded and in the order presented (provide feedback to continue to revise)
  - Ask without embarrassment, apology or criticism (of self, caregiver, tool). Ok to acknowledge topics can be sensitive, but useful to help identify quality services to address their needs
  - Ask for clarification as needed without "pitching" a response
- **Most caregivers welcome the attention and support; particularly if described as supporting them in their role and helping them to provide care**

Examples of CAT Interview Tips

Challenge	Prompt
Trouble choosing between two answers	*"Which comes closest to…?"* *"I understand, but I only have these choices, which fits best for you?"* (*offer to make a note of their suggestion*)
Unclear about what the caregiver means	*"Would you tell me a little more?"* *"Would you please explain that a little?"*

Examples of CAT Interview Tips

Challenge	Prompt
Lost the focus of the question and you must get the caregiver back on track	*"You are bringing up some very important issues, but I also want to be respectful of your time. So let's complete these questions first, and we can try to discuss more about XYZ later."*
Caregiver wants to tell his/her story in an unfocused way, or caregiver goes on about some matter that is tangential.	*"Perhaps we can talk about that later. Right now it is important for me to get all your responses to these questions to see what would be most helpful for you."*

Voice from the Field: Experiences Using the CA CRCs' Uniform Assesssment Tool

Jo McCord, M.A., Family Consultant, Bay Area Caregiver Resource Center, San Francisco, CA

- **Challenges and Approaches: Invasion of Privacy and Multiple Caregivers; Importance of Dialogue and Timing**

- **Insights: Significance of Clinical Judgment and Context**

- **Suggestions/Recommendations for Staff Training, Reassessments and Follow-up**

Moving Toward Outcome-Driven Assessments

Many now consider the stress of caregiving to be a public health priority of national concern.
(CDC & Kimberly-Clark, 2008)

Outcomes: What? When?

- **Symptomatology/Quality of life**
  - Caregiver depression, caregiver burden, patient memory/behavior problem impact, caregiver self-efficacy, target complaints, positive/adaptive coping, negative coping, and informal support

- **Social validity**
  - Caregiver perceptions of the utility of project services (e.g., ability to continue to provide care at home); post evaluation

- **Social significance**
  - Cost of implementation, amount of service utilization

- **Timing**
  - Pre/Post (3 months)
  - Maintenance: Post (6 and 12 months)

Challenges & Opportunities for Paradigm Shift

- **Care Management and Behavior Change**
  - Professionals vary in the prior training, theoretical frame, interest, what counts at work
  - Outcomes often depend on caregiver behavior change and provider behavior change skills
  - Opportunity to learn/do more vs. negative "add-on"
  - May become critical for sustainability of programs

Challenges & Opportunities for Paradigm Shift

- **Training/Fidelity Model:** *Say, Show, Do, Review*
  - **Structure and Process of Assessment Training**: initial training, observation, supervised delivery and consultation
  - **Structure and Process for Programs with Behavior Change**: education/skill introduction, home practice/coaching, and integration, monitoring and boosters

Additional Questions

- **Who will administer, collect, compile and utilize?**
  - The referring agency or the agency that conducts the program or service? How is information shared to improve the quality of life of both care recipients and caregivers?

- **What programs, services, interventions exist and what are their targeted outcomes?**
  - Ongoing need to update resource guides; identify & fill service gaps

- **Who will pay for them?**
  - Without funding or reimbursement, organizations may not be able to commit to caregiver assessment, information & referral, much less additional programs needed to assist family caregivers

Reducing costs through supporting caregivers in their role

- Better workplace policies (e.g. on-site education & support)

- Integrate caregiver assessment into publicly funded HCBS programs, hospital discharge planning, chronic care coordination, care transitions, new models of care under the Affordable Care Act

- Expand funding for the National Family Caregivers Support Program and Lifespan Respite Act

- Encourage health and social service professionals to integrate informal caregivers into the care team as partners

- Refer caregivers to supportive services

MEDICAL HOME

- *Family/Informal support is essential to remaining at home/in the community*

- *Better assessment and response to caregiver needs through public programs that provide LTSS needs to be a public policy priority at both the state and federal levels*

  – *AARP Public Policy Report (Feinberg et al., 2012)*

Ethic of Care

- **An ethic of care is viewed in a relationship as a balance of self (e.g. family caregiver) and a constellation of caring others (e.g., care recipient, other family members, and direct care workers)**

- **It is not conceptualized as an initial position of self-concern versus other-concern**

An Ethic of Care

…maximizes the quality of life of both care partners

…may better capture the full range of a caring community and lead us toward healthy aging communities where care recipients and their care partners are more psychologically and socially integrated into our society
(Coon et al., 1999; Noddings, 1984)

- **Caregiver Assessment is a fundamental building block in this Ethic of Care that supports the quality of life of both care recipients and their caregivers.**

- **When the caregiver is at risk, so is the care recipient. Taking care of the caregiver is critical work.**

References

- Centers for Disease Control (CDC) and Prevention and the Kimberly-Clark Corporation (2008). Assuring healthy caregivers, a public health approach to translating research into practice: The RE-AIM Framework. Neenah, WI: Kimberly-Clark Corporation.

- Coon, D., Gallagher-Thompson, D. & Thompson, L. (Eds.)(2003). Innovative interventions to reduce caregivers' distress: A sourcebook and clinical guide. New York: Springer.

- Coon, D. W., Davies, H., McKibbin, C., & Gallagher-Thompson, D. (1999). The psychological impact of genetic testing for Alzheimer's disease. Genetic Testing, 3, 121-132.

References (cont'd)

- Feinberg, L. & Houser, A. (2012). Assessing family caregiver needs: Policy and practice considerations. AARP Public Policy Institute Fact Sheet. Washington, DC: AARP.

- Feinberg, L., Reinhard, S., Houser, A. & Choula, R. (2011). Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving. AARP Public Policy Institute Insight on the Issues 51. Washington, DC: AARP.

- Noddings, N. (1984). Caring: A feminist approach to ethics and moral education. Berkeley and Los Angeles, CA: University of California Press.

References (cont'd)

- Ory, M., Hoffman, R., Yee, J. Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. The Gerontologist, 37, 804-815.

- Schulz , R. & Beach, S. (1999). Caregiving as a risk factor for mortality. Journal of the American Medical Association, 282 (23) 2215-2219.

- Schulz, R., O'Brien, A., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. The Gerontologist, 35, 771-791.