

# **PANEL ON CARE MANAGEMENT FOR CAREGIVERS**

## ***RESEARCH ON CAREGIVING ASSESSMENT***

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**TABLE 1: IDENTIFYING THE CAREGIVER & INTENSITY OF CAREGIVING**

**Background Characteristics of Care Receiver & Caregiver & Care Context**

- Relationship of care receiver & caregiver.
- Age, gender, race, education, marital status, & veteran status of care receiver & caregiver.
- Living arrangement of care receiver & caregiver.
- Family & household composition of care receiver & caregiver.
- Employment status of caregiver.
- Other caregiving demands & dependents of caregiver.
- Income & health insurance of care receiver & caregiver.
- Name of primary care physician & health plan, & date of most recent physician visit for care receiver & caregiver.
- Health & Functional Status of Care Receiver
  - Primary & secondary diagnoses; other health conditions.
  - Recent hospitalizations or emergency department visits (past six months or year).
  - Personal care & supervision task dependencies.
  - Instrumental activities of daily living dependencies.
  - Symptoms of physical disability.
  - Cognitive & behavioral symptoms of mental impairment.
  - Legal steps taken for care receiver (i.e. Power of attorney for health care).
- Intensity of Caregiver's Involvement
  - Amount of assistance caregiver provides with personal care tasks.
  - Amount of assistance caregiver provides with instrument daily living tasks.
  - Amount of assistance caregiver provides with health care tasks.
  - Amount of assistance caregiver provides with care management tasks.
  - Amount of assistance caregiver provides with supervision tasks
  - Amount of assistance caregiver provides with emotional support.

**TABLE 2: CAREGIVER WELL BEING & PERCEIVED NEGATIVE CAREGIVING CONSEQUENCES**

**General Well Being & Health**

- General self-rating of physical & emotional health.
- Health conditions &/or symptoms.
- Recent hospital admissions or emergency department visits.
- Depression.

**Caregiving Specific Negative Consequences**

- Perceived difficulty completing tasks or categories of tasks.
- Relationship strain with care receiver because of caregiving.
- Family relationship strain because of caregiving.
- Caregiving mastery or self efficacy.
- Emotional & physical health deterioration because of caregiving.
- Social isolation because of caregiving.
- Feeling trapped because of caregiving.
- Work strain because of caregiving.
- Use of prescription or over-the-counter medications to cope with caregiving.
- Excessive use of alcohol to cope with caregiving.
- Risk of elder abuse/neglect.

**TABLE 3: INFORMAL SUPPORT (OTHER THAN FROM CAREGIVER BEING ASSESSED) & FORMAL SERVICES USE BY CARE RECEIVER**

<b>Informal Support for Care Receiver</b>
<ul style="list-style-type: none"> <li>• Number of other informal helpers for care receiver.</li> <li>• Caregivers' perceptions of adequacy &amp; quality of informal support for care receiver.</li> </ul>
<b>Current &amp; Past Six Months/One Year Formal Service Use by Care Receiver</b>
<ul style="list-style-type: none"> <li>• Types &amp; amount of formal service use by care receiver in past six months/one year.</li> <li>• Current types &amp; amounts of formal service use by care receiver.</li> <li>• Satisfaction with formal services.</li> </ul>
<b>Perceived Barriers to Formal Service Use</b>
<ul style="list-style-type: none"> <li>• Inconvenient, too costly, family should care for their own, perceive that no one else can do as well, care receiver will not allow others to provide care, do not trust service providers in the home, do not feel there is need.</li> </ul>

**TABLE 4: INFORMAL SUPPORT & FORMAL SERVICES USE BY CAREGIVER**

<b>Informal Support for Caregiver</b>
<ul style="list-style-type: none"> <li>• Number &amp; relationship of informal helpers for caregiver.</li> <li>• Adequacy &amp; quality of informal help for caregiver.</li> </ul>
<b>Current &amp; Past Six Months/One Year Service Use by Caregiver</b>
<ul style="list-style-type: none"> <li>• Type &amp; frequency of services that give relief or a break from caregiving (respite service).</li> <li>• Type &amp; frequency of services that educate or provide information about illness, caregiving, or services (education programs/classes, written material, computer or video material).</li> <li>• Type &amp; frequency of services that provide emotional support (counseling, support groups, case management, telephone helpline).</li> <li>• Type &amp; frequency of services that help find, arrange, or monitor services for care receiver or caregiver (care management/care coordination, information &amp; referral).</li> </ul>
<b>Perceived Barriers to Caregiver Service Use</b>
<ul style="list-style-type: none"> <li>• Inconvenient times, too costly, family should care for their own, perceive that no one else can do as well, care receiver will not allow others to provide care, do not trust service providers in the home, do not feel they have need.</li> </ul>

**TABLE 5: SOME COMMON REASONS FOR NOT DOING OR USING  
A CAREGIVER ASSESSMENT**

- Takes too much time; Takes time away from direct service time.
- Adds paperwork, which is already excessive. Assessment is just something that funders or administration require in order to monitor or check up on service staff.
- The assessment is too long.
- Caregivers' problems are obvious so why gather unnecessary information.
- The assessment is cumbersome & duplicates the same information recorded elsewhere.
- Asking for lots of information scares off caregivers who are already reluctant to use services.
- Many parts of the assessment are irrelevant to the problems that lead caregivers to seek services.
- Interferes with developing the caregiver-service provider relationship.
- Interferes with the natural flow of the clinical interview.
- Asking for all this information unrealistically raises caregivers' expectations about the types & amounts of services that are available.
- Once the assessment is completed, it is not used for anything else such as developing care/service plans, follow-up contacts, or evaluating service effectiveness.

**TABLE 6: TIPS FOR DESIGNING & IMPLEMENTING AN ASSESSMENT THAT WILL BE USED**

- Allow some flexibility in the timing of when the information is collected.
- Allow flexibility in the method used to collect the information (structured questions, observation, extracted from a clinical interview, provided by a reliable informant).
- Eliminate redundant information, particularly if the care receiver has already completed an assessment with similar information. However, for issues that need to reflect perceptions, caregiver & care receiver may show important differences.
- Consider whether answer categories need to be simplified from versions of questions used in research.
- Consider whether it is adequate to include a subsample of questions extracted from a research tool.
- Control the length of the assessment by dividing it into sections with some parts gathered for all caregivers & other parts only for caregivers with certain characteristics.
- Consider whether certain parts of the assessment can be self-administered by caregivers.
- Find ways to analyze assessment information & provide results to those completing the information.
- Directly link the assessment, care plan, & reassessment so that assessment information is used to guide service delivery.
- Consider computer applications that streamline the process.