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SUPPORTING CAREGIVERS THROUGH ASSESSMENT

Identifying
Caregivers'
Aspirations, Realities
and Expectations

The C.A.R.E. Tool



This work was supported by a grant from the Alzheimer's Association



EVALUATING THE C.A.R.E. TOOL ~ A RESEARCH PROJECT

"From Research to Practice: Assessing Caregivers of Persons with Alzheimer's Disease" (2003—2007)

Goal

To evaluate the impact of the C.A.R.E. Tool on caregivers of persons with and without Alzheimer's Disease and Related Disorders (AD) and on home care organizations to determine whether its use leads to changes in the caregiving situation, caregiver well being and home care practice.

Methodology

Three hundred and forty nine caregivers were selected for involvement in the study through home care practitioners at participating publicly-funded home care agencies in four Canadian provinces.

They participated in two telephone interviews four months apart. Approximately half were selected to receive an assessment using the C.A.R.E. Tool to determine whether the assessment results in a change in caregiver well being.

Findings

The findings on the following pages show results for Alzheimer's Disease and Related Disorders (AD) versus non-Alzheimer's Disease and Related Disorders (No AD), examining in particular the impact of assessment on caregiver well being, self-assessed positive change and identified areas of difficulty for caregivers.

Participants

Caregivers: 80% women; average age- 61 years. Almost one-half (45%) were daughters/daughters-in-law.

Care Receivers: Mostly female, average age- 82 years, approximately half had AD.

15 Areas of Difficulty Experienced by Caregivers*

Most Common

- 1) Future planning- 48%
- 2) Crisis planning- 47%
- 3) Emotional health- 46%
- 4) Physical health- 40%
- 5) Supervision/Support- 36%
- 6) Juggling responsibilities-34%
- 7) Help received- 32%
- 8) Housework- 31%

Less Common

- 9) Relationship with care receiver- 27%
- 10) Relationship with family-21%
- 11) Physical care- 21%
- 12) Coordination- 19%
- 13) Housing- 14%
- 14) Financial costs- 13%
- 15) Relationship with formal service providers- 7%

*Percentages represent caregivers in the intervention group who reported at least some difficulty, n=183



Funding Agency:
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WHAT WE FOUND

Impact on Caregiver Well Being

On average, scores for both components of well being—**activities of daily living** and **basic needs**—decreased between interviews for both the assessment and non-assessment groups, as well as for cases where AD was present and where AD was not present. While these results were not statistically significant, they indicate a decline in well being.

Table 1. Changes in Caregiver Well Being (n=349)

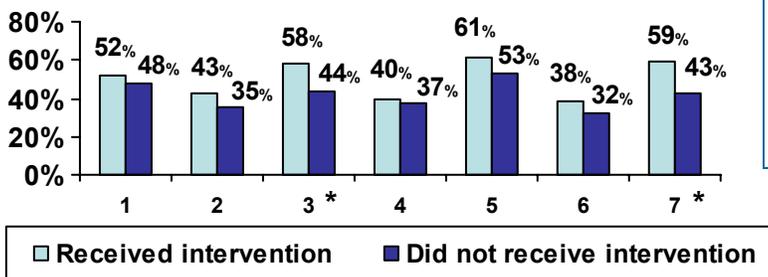
Activities of Daily Living- Change in Average Scores		Basic Needs- Change in Average Scores	
Assessment -1.95	No Assessment -1.12	Assessment -1.50	No Assessment -1.83
Alzheimer's Disease Present		Alzheimer's Disease Present	
Assessment -1.61	No Assessment -1.97	Assessment -1.78	No Assessment -2.23
No Alzheimer's Disease		No Alzheimer's Disease	
Assessment -2.26	No Assessment -.61	Assessment -1.24	No Assessment -1.59

The null findings may be due to:

- *The sample*— the care receivers (CR) had high level care needs and most caregivers were providing care for 2 or more years. Expecting significant improvement in well being while caregiving needs are likely intensifying may not be reasonable.
- *The study design*— all practitioners received comprehensive training, leading to increased sensitivity to caregivers in general, and to the application of the Tool, which may have benefited caregivers.
- *Other variables*— variables such as gender, relationship, etc., that have yet to be specifically examined, may help explain the null findings.

Impact on Caregivers' Role, Awareness, Support and Recognition

Figure 1. Caregivers' self-assessed positive change, 4-months post contact, n=349



* Indicates statistical significance

- Caregivers who were assessed by the C.A.R.E. Tool (the intervention group) reported positive change for variables 3 and 7.

Key to variables

- 1— Information about CR condition
- 2— Involved in decisions regarding care
- 3— Service providers more aware of CG role
- 4— Change in service allocation
- 5— More aware of services available
- 6— Choice in involvement of care of CR
- 7— Greater recognition as a caregiver

AD vs. Non-AD

Within the No AD group, caregivers who received the intervention were significantly higher in variables 5 and 7, while in the AD present group, variables 3 and 7 were significant.

FINDINGS, CONTINUED

Areas of Difficulty Experienced by Caregivers

Figure 2. Percentage of caregivers experiencing difficulty with financial costs, intervention group only, n= 183

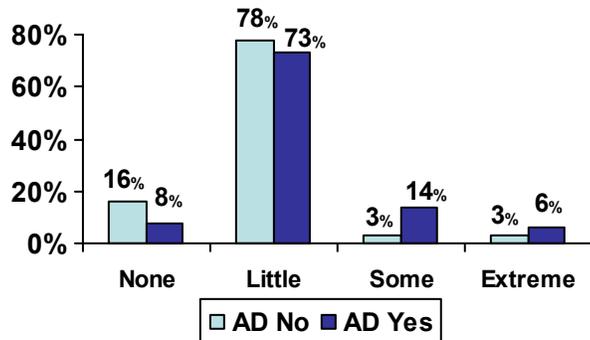
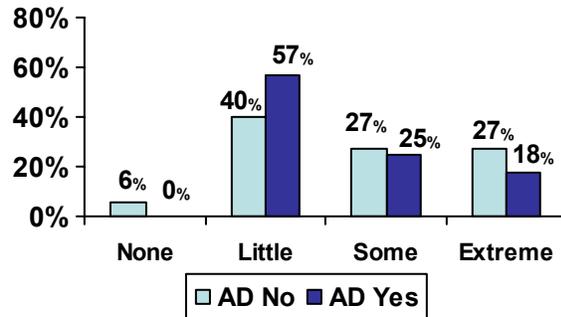


Figure 3. Percentage of caregivers experiencing difficulty with future planning, intervention group only, n= 183



Caregivers in AD vs. Non-AD groups were not significantly different in 13 areas of difficulty, with exceptions being Financial Difficulty and Future Planning. More AD caregivers experience difficulty with financial costs, possibly because of lost income and increased medication and service costs. More Non-AD caregivers experience difficulty with future planning, possibly because CR's prognosis may not be as evident as for the AD group.

Prerequisites to Successful Implementation

Focus groups and interviews with agency staff revealed key factors to ensure successful implementation of the C.A.R.E. Tool:

- Caregivers have an explicit status in policy and practice.
- Agency philosophy is compatible with concepts of caregiver assessment and the role and responsibility of family caregivers as partners in the care delivery.
- Agency buy-in occurs at all levels from management to front-line staff.
- Practitioner training ensures a common conception of assessment. *Once caregivers are designated as an agency priority and their status has been clarified, it is important that all agency personnel arrive at a common understanding of the purpose and use of an assessment tool.*

KEY MESSAGES

Assessment has Many Positive Impacts on Caregivers and Practitioners

- Caregivers who received the C.A.R.E. Tool intervention reported greater recognition and increased awareness from service providers.
- These results did not translate into significant differences in well being between the intervention and non-intervention group.
- Assessment increased practitioners' understanding of what it means to be a caregiver. In turn, this can lead to improved accessibility and appropriateness of services to caregivers.



Tips for Successful Implementation

- Know who should be assessed; When? By whom?
- Integrate the tool with existing tools
- Ensure training and on-going supervision
- Rethink work organization and allocate resources required for caregiver assessment



THE C.A.R.E. TOOL

What is the C.A.R.E. Tool?

An assessment of **C**aregivers' **A**spirations, **R**ealities and **E**xpectations. The C.A.R.E. Tool is a comprehensive, psychosocial assessment to be used by practitioners with family caregivers.



Why was it Developed?

Caregivers make significant contributions in the care of persons with long-term health conditions and need to be supported in individualized ways requiring personal assessment.

The Assessment Process

The C.A.R.E. TOOL Includes 10 Sections

- Demographic information
- Caregiving work
- Informal and formal support
- Living arrangements
- Other responsibilities
- Financial contribution
- Physical and emotional health
- Family relations
- Crisis and long-term planning
- Service support



The Caregiver and Assessor discuss the caregiving situation, guided by the 10 sections



Outcomes

- Areas of difficulty are summarized
- Services and support needs are identified
- A proposed care plan is recommended

User Feedback...



"I think I see caregivers' lives in a whole new light now... I see more clearly how it is 24 hours a day"

- Practitioner



"It (the assessment) made me feel better to know that someone cares or is interested in my needs"

- Caregiver

"I had the facts, but I didn't have the explanation. I didn't have the context. And I feel that greatly influences our way of intervening"

- Practitioner



ADDITIONAL RESOURCES

Additional Tools

The C.A.R.E. Tool Short Version (2006)

- Developed in response to concerns about the time required to administer the original C.A.R.E. Tool, the Short Version contains the same 10 sections as the C.A.R.E. Tool, but with fewer questions and without user information.

The Caregiver Risk Screen (2001)

- The Risk Screen is designed for use at intake by home care practitioners to assess the level at which caregivers' physical and/or emotional health may be at risk and to determine whether the care being provided is adequate.

Publications

Keefe, J., Fancey, P., Guberman, N., Barylak, L., & Nahmiash, D.; The C.A.R.E. Tool: Caregivers' Aspirations, Realities, and Expectations; *Journal of Applied Gerontology*; in press.

Guberman, N., Keefe, J., Fancey, P., & Barylak, L.; "Not Another Form": Lessons from implementing carer assessment in health and social service agencies; *Health & Social Care in the Community*; 2007; 15(6): 577-587.

Guberman, N., Keefe, J., Fancey, P., Nahmiash, N., & Barylak, L.; Screening and assessment tools for informal caregivers: Identifying services to meet the needs of these potential Clients; *Rehab and Community Care Management*; 2001; Spring: 24-26.

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