



# Web-based Psychosocial Assessment for Caregivers of Persons with Dementia: A Feasibility Study

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## Abstract

Over 5 million people live with dementia. Often family caregivers do not seek outside help due to care and time constraints. The purpose of this quasi-experimental study was to examine the experience of using a psychosocial assessment to understand caregivers' needs, in the assessment's original face-to-face interview format versus a new self-administered web-based format. This study integrates concepts from Friedemann's framework of systemic organization that portrays people as open systems striving for balance/congruence in their lives. Ten family caregivers (5 male; 5 female) from one mid-west state were randomized to a face-to-face interview or web-based group. Participants in the interview group had the assessment administered by one nurse in a face-to-face format. Participants in the web-based group accessed the study's web site and completed the assessment online, which was then reviewed by a second nurse. Participants in both groups, as well as the nurses, completed a paper/pencil Survey to capture their perception of the assessment experience and descriptive statistical and content analyses were applied. Overall the caregivers rated the assessment as excellent or very good; thought it was easy to complete; and captured their real needs. There did not appear to be any significant differences between the two groups. All participants reported that every caregiver should have access to this assessment. One theme that emerged from the written comments was that the Survey helped participants in assessing their own needs, which they tend to deny or ignore. Nurses administering the assessment reported that the web-based format was very easy to use, while the face to face format was difficult to use. Web based assessment of caregiver needs is an effective method for healthcare professionals to analyze caregivers needs, providing a means for planning appropriate interventions to promote balance/congruence in caregivers' lives.

## Background

- More than 5 million people in the United States are currently living with Alzheimer's Disease (AD) (Alzheimer's Association, 2011).
- Family caregivers provide the majority of care and experience tremendous physical and emotional consequences relate to:
  - personality and cognitive changes in their loved one,
  - years of providing constant, loving attention, and
  - demands of bathing, dressing, and other caregiving duties (ADEAR, 2004).
- Caregivers of persons with AD are less likely to seek outside help due to care and time constraints.
- Efficient assessment of caregivers' problems and needs is important (Wancata et al., 2005).
- Internet technology can facilitate problem solving and offer support for family caregivers (NAC/AARP, 2009).
- Therefore, a web-based psychosocial assessment of caregivers' needs would be useful, allowing for individualized planning and intervention.

## Purpose

The purpose of this quasi-experimental study was to examine the experience of using a psychosocial assessment to understand caregivers' needs, comparing a face-to-face interview format and a self-administered web-based format.

## Methods

### Assessment Tool

A psychosocial assessment tool, developed by Wancata et al. (2005)\*, was used to identify and understand caregivers' needs. The tool

- included 18 problem areas, with descriptive prompts, that caregivers were asked to rate as they relate to their own situation.
- provided space to type additional problems.
- was originally developed as a face-to-face interview.
- was adapted for self-administered, web-based use.

### Examples of Problem Areas include:

- Are you sufficiently informed about the illness, it's symptoms, and its course?
- Do you have financial difficulties because of the patient? Are you aware of financial benefits you or the patient are entitled to?
- Does the patient sometimes behave toward you in ways that burden you?

### Assessment Implementation and Evaluation

Ten family caregivers from a midwest state were randomized into 2 groups: an interview and a web-based group.

- The interview group had the assessment administered face-to-face by an advanced practice nurse.
- The web-based group accessed the study's web site and completed the assessment online.
  - The completed web-based assessment was then reviewed by a second advanced practice nurse.

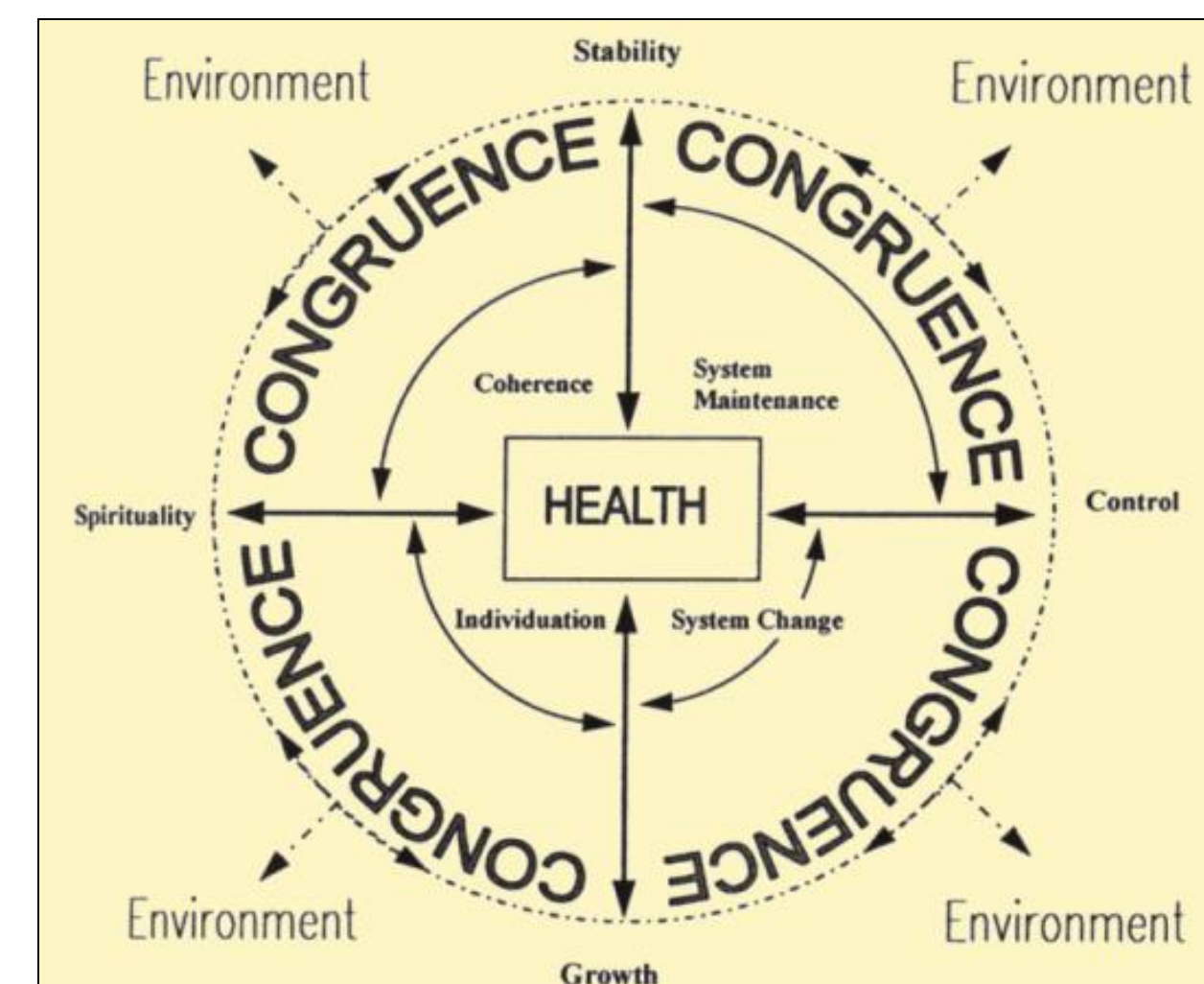
Participants in both groups, as well as the nurses, completed a paper/pencil Survey to capture their perception of the assessment experience.

- The caregivers' Survey had 9 closed and open ended questions, evaluating the ease / time of completion, question difficulty, impact on understanding of their needs, as well as their general opinion.
- The nurses' Survey had 4 closed and open ended questions, evaluating the ease / time of completion and their ability to identify caregivers' needs based on the information obtained.

\* Wancata, J., Krautgartner, M., Berner, J., Alexandrowicz, R., Unger, A., Kaiser, G., ... Weiss, M. (2005). The carer's needs assessment for dementia (CNA-D): Development, validity and reliability. *International Psychogeriatrics*, 17(3), 393-406.

## Friedemann's Framework

"The four targets of control, spirituality, stability and growth interact with each other along the system periphery to form a dynamic equilibrium through which the healthy system continuously adjusts to find congruence" (Friedemann, 2011).



- Problems in caring and unmet needs create imbalance and incongruence in caregivers' lives, impacting their health and well being.
- Consequently, caregiving signifies a continuing struggle to readjust the four targets and balance them against each other and the environment.

## Results

### Family Caregivers

- The interview group included 3 males / 2 females (2 African American / 3 White), in fair to good health, whose average age was 67 years with 13 years of schooling.
  - They cared for a person with dementia at home for > 4 years and whose average age was 76 years.
- The web-based group included 2 males / 3 females (1 African American / 4 White), in fair to very good health, whose average age was 58 years with 14 years of schooling.
  - They cared for a person with dementia at home for > 3 years and whose average age was 73 years.
- Participants in both groups:
  - rated the assessment as excellent or good.
  - reported it was easy to complete.
  - thought that all caregivers should have access to such as assessment.
- The participants in the web-based group reported with greater frequency that:
  - there were difficult questions to answer.
  - the real needs of caregivers were captured in the assessment.
  - their understanding of their own needs or situation was impacted by completing the assessment.
- Despite differences in response frequencies, no statistically significant differences (p > .05) were found between the two groups based on analyses appropriate for small sample sizes.
- Comments included:
  - "Raises questions on where you stand to seek more help."
  - "I didn't realize how much of my day revolves around my dad."

### Average Time to Complete the Assessment

- |            | Caregivers: | Nurses:    |   |
|------------|-------------|------------|---|
| Interview: | 42 minutes  | 43 minutes | Caregiver and nurse together during assessment.   |
| Web-based: | 31 minutes  | 27 minutes | Caregiver completes and nurse reviews separately. |

Table 1. Frequency of Responses on Caregiver Post-Assessment Survey

QUESTIONS	INTERVIEW (n=5)				WEB-BASED (n=5)			
	Excellent / Good OR Easy (n) / %	Neutral (n) / %	YES (n) / %	NO (n) / %	Excellent / Good OR Easy (n) / %	Neutral (n) / %	YES (n) / %	NO (n) / %
General opinion of the assessment (excellent to poor)	(5) 100%				(5) 100%			
Assessment captured the real needs of the caregivers (excellent to poor)	(3) 60%	(2) 40%			(5) 100%			
Easy or difficult to complete the assessment (easy to difficult)	(5) 100%				(5) 100%			
Repetitive questions (yes / no)			(1) 20%	(4) 80%				(5) 100%
Difficult questions (yes / no)				(5) 100%			(2) 40%	(3) 60%
Assessment had an impact on understanding of own needs or situation (yes / no)			(2) 40%	(3) 60%			(3) 60%	(2) 40%
All caregivers should have access to such an assessment (yes / no)			(5) 100%				(5) 100%	

## Results cont.

### Advanced Practice Nurses

- The nurse reviewing the web-based format thought the assessment was easy to use.
- The nurse interviewing caregivers thought it was difficult to identify caregivers' needs from the assessment.
- Comments included:
  - "Top needs [on web-based format] relatively easy to correlate to the problems."
  - "Interview format was difficult to complete and time consuming."

Table 2. Frequency of Responses on Nurse Post-Assessment Survey

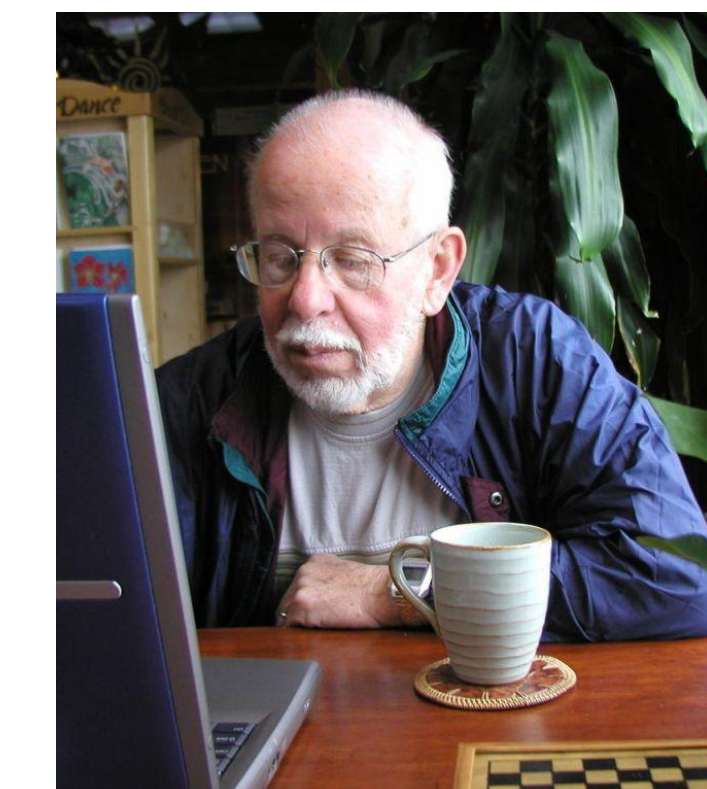
QUESTIONS	INTERVIEW			WEB-BASED		
	Easy	Neutral	Difficult	Easy	Neutral	Difficult
Easy or difficult to use the assessment tool		20%	80%	100%		
Easy or difficult to identify needs for the caregiver	20%	20%	60%	60%	40%	

## Conclusions

### Web-based assessment of caregivers' needs:

- is an effective method for healthcare professionals to use.
- is less time intensive than a face-to-face interview assessment.
- helps caregivers identify their own needs, which they tend to ignore / deny.
- makes caregivers realize the impact of caring for their significant other.
- provides a means for targeting appropriate interventions to promote balance / congruence in caregivers' lives.

The researchers are implementing a web-based intervention that provides individualized education, support, guidance and care planning assistance for caregivers of persons with dementia.



- This web-based assessment tool was incorporated into the intervention website to provide information on caregivers' specific needs.

### Acknowledgement:

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