

Using mixed methods to evaluate the use of a caregiver strain measure to assess outcomes of a caregiver support program for caregivers of older adults

Margaret Hellie Huyck^{1*}, Liat Ayalon² and Judy Yoder³

¹*Illinois Institute of Technology, IL, USA*

²*School of Social Work, Bar Ilan University, Israel*

³*Metropolitan Family Services, Chicago, IL, USA*

SUMMARY

Purpose Many assessment tools have been developed for evaluating caregiving programs, but the majority are too cumbersome for ongoing use. This study reports on a brief assessment tool used to monitor strain among family members caring for an impaired elder.

Design and methods Participants were enrolled in the SeniorCare program, a program funded by the Administration on Aging to provide care to family caregivers. The Caregiver Risk Screen (CRS) is a 12-item measure of strain, initially developed as part of an in-home assessment procedure. Its utility for use in practice settings over time was assessed using both quantitative and qualitative methodology.

Results Chronbach alpha levels for the CRS were 0.85 at intake and 0.84 at first follow-up. At the first follow-up, the overall index score and five of the 12 items showed statistically significant lessened strain. In subsequent follow-up evaluations, the average improvements were maintained but there was no additional decrease in strain. Individual variations in changes over time were identified by combining quantitative and qualitative information. Themes that emerged in qualitative data served to modify the measure for future use.

Implications The brief Caregiver Risk Screen tool appears to be a reliable and valid tool for use in practice settings. It is acceptable to clients and professional staff. Modifications have been made that may further enhance the suitability of this measure for other settings. Copyright © 2006 John Wiley & Sons, Ltd.

KEY WORDS— outcome evaluation; family caregiving; ethnicity; measurement; burden

INTRODUCTION

It is well established that providing care for an impaired older family member is a common experience, involving 25% of American families (Kaiser Family Foundation, 2002). Recognizing and supporting family caregiving is a central component of a comprehensive long-term care system.

While there is yet no common protocol for family caregiver support services, there are emerging guidelines (Feinberg, 2001). The common challenge for all programs is to identify tools for assessing impact that are user friendly and psychometrically sound. Many tools have been developed and used to assess care recipients, caregivers, situations, and responses (Family Caregiver Alliance, 2002; Feinberg, 2002; Schulz *et al.*, 2003). However, most are overly cumbersome for ongoing use in a practice setting. Thus, in this study, we evaluated the ability of a brief caregiving screen, the Caregiver Risk Screen (CRS; Guberman *et al.* 2001), to track the caregiver experience overtime.

*Correspondence to: Dr M. H. Huyck, Institute of Psychology, Illinois Institute of Technology, Chicago, IL 60616, USA.
E-mail: mhuyck@sbglobal.net

METHODS

The SeniorCare program

The SeniorCare program was designed to support family members caring for elders. SeniorCare had an array of core services provided by the lead social service agency, Metropolitan Family Services (MFS), which included information and assistance, linkage to services, educational workshops, support groups, individual and family counseling, respite camp, and overnight respite housing. Program staff provided presentations on caregiving to community groups, referrals to additional community respite services such as adult day care and homemaker programs, and financial, legal, and homeowner consultations. The service area was the Northwest section of Chicago, characterized by low income and high proportions of Latino and Polish heritage families. Over the three years of the project evaluated in this study, many clients were served. However, this report concerns only the 67 clients who completed an intake and a baseline survey of Caregiver Strain, and who received counseling or support group services from the agency; many of these clients also participated in other services. We do not have any direct assessment of how typical these core clients are of the larger group of caregivers.

Clients were recruited for services through a variety of ways: flyers, local newspaper advertisements (in English and in Spanish), referrals from other agencies, and word of mouth.

Outcome measures

Caregiver Risk Screen (CRS). The primary outcome measure is a 12-question measure which contains a set of statements reflecting domains which have been shown to indicate strain among caregivers. Respondents indicate whether the statement applies to them: 'Totally disagree, (0)', 'Somewhat disagree, (1)', 'Somewhat agree (2)', or 'Totally agree (3)'. Total scores can range from 0 (low strain) to 36 (highest strain) (Guberman *et al.*, 2001).

The caregiver questionnaire was originally developed and validated by conducting thorough in-home assessments to see how well the questionnaire picked up risks assessed by the professionals, and by having a subset of clients complete standardized versions of domain assessment tools by (Guberman *et al.*, 2001). Because the tool has not yet been used sufficiently to have normative data that could indicate relative levels of risk, it has been used in this protocol merely to assess changes over time.

In the SeniorCare program, CRS responses were gathered as part of the initial intake interview by the social work staff. Follow up responses were obtained in telephone interviews by the evaluation staff at approximately 6-month intervals; often the first follow-up was sooner because it was given after respondents had completed a Caregiver Support Group program.

Other measures

Client Socio-demographic. This included age, marital status, ethnicity, education level, occupation, current employment status, residence, when 'caregiving' began, and others involved with care.

Care recipient data. This included age, gender, ethnicity, cognitive impairment as estimated by caregiver, and ADL-IADL measures.

Semi-Structured Individual Interviews with Caregivers. Telephone interviews were conducted by a member of the evaluation team with participants in support groups or respite camps within two weeks of completing the service; counseling clients were contacted approximately every 6 months. These data were used to interpret the changes in CRS scores. Participants were asked about their level of physical and emotional functioning since last evaluation, their care recipient condition, their participation in the SeniorCare program and the potential impact the SeniorCare program had on their lives and the lives of their loved ones.

Observer notes of support groups. One of the evaluation staff members attended each session of the support groups and took process notes. These were used as part of the qualitative data helping to interpret the CRS scores.

Hypotheses

We hypothesized that the items and the overall scale would be sensitive enough to pick up meaningful changes in caregiving responses over time. On the basis of prior research we anticipated that an effective caregiver support program would stabilize participants. The evidence is quite substantial that the 'natural course' of elder caregiving is that strain increases over time.

Analyses

Quantitative was conducted using SPSS. In order to identify clients showing different patterns of strain

over time, we first assessed the distribution of changes from the first to second assessment. The average (mean) amount of change was 3 points (on the 36-point CRS scale). Given this information, we determined that the 'expected' range of change would be to increase or decrease 3 points. Clients who increased in their CRS by 4 or more points were judged to show increased strain; and clients who decreased their CRS by 4 or more points were determined to have benefited from the program.

Patterns of change over time were assessed using a General Linear Model with repeated measures analysis in SPSS, with Total CRS scores (0–36) as the vertical axis and time of assessment (Baseline, 1, 2, 3 follow-up) on the horizontal axis. In this analytic model, only those clients who participated in successive waves of assessment were included. We had no prior expectations about the length of time clients would remain in contact with the agency. Clients were not available for assessment on successive waves for a variety of reasons (detailed below).

Qualitative data were analysed thematically using grounded theory methodology (Strauss and Corbin, 1990). We did not have predetermined hypotheses about the data, but instead used open coding to categorize interview data and to validate patterns identified in the quantitative analysis.

RESULTS

Sample characteristics are shown in Table 1. The majority of the caregivers were daughters or daughters-in-law, caring for a cognitively impaired care recipient. The majority of the sample was White (59%), mean age of the caregiver was 56 and mean age of care recipient was 82.

Baseline caregiver Risk Screen Scores for SeniorCare clients

The Baseline CRS scores for the 67 SeniorCare clients soon after they entered the program to receive either counseling or support group services was 17.0 (SD 7.8); the range was substantial—from 0–32 (out of a possible 36 points). The Chronbach alpha level for the intake CRS was 0.85 (and 0.84 at first follow-up).

Longitudinal data on strain

Longitudinal data are available on a subset of clients. Among the 67 clients who completed the CRS measure initially, 59 completed at least a second

measure. Of the eight who did not complete a second measure, four could not be contacted, three had only a single session by mutual agreement of the social worker and client, and one refused to cooperate. Of the 59, 41 completed three measures, and 19 completed four measures. Only two clients completed five measures during the study period. The primary reason

Table 1. Characteristics of seniorcare caregiver clients and care recipients

Characteristic	% Of clients (n = 67)	
Caregivers' characteristics		
Gender	Women	80.9%
Ethnicity	European American	58.8%
	Latino	26.5%
	African American	13.3%
	Asian American	1.5%
Languages	Spanish only (9)	
	Latvian only (1)	
	Pakistani only (1)	
	Croatian (1)	
Age	Mean	56 (SD 13)
	Range 17–87	
Education	Some high school or less	7.4%
	High school graduate	23.5%
	Some college	23.5%
	College graduate	30.9%
	Graduate, professional	5.9%
	Missing	8.8%
Employment status	Employed full time	35.3%
	Employed part time	11.8%
	Unemployed	27.9%
	Retired	22.1%
	Disabled	2.9%
	Missing	0.0%
Altered work involvement for caregiving	Yes	48.5%
	Yes	13.4%
Involved in volunteer work		
Living arrangements	With care recipient	30.9%
	With spouse/partner	51.5%
	Alone	8.8%
Care recipients' characteristics		
Relationship to caregiver	Mother/mother-in-law	65.9%
	Father/father-in-law	17.6%
	Spouse	16.2%
	Sibling	1.5%
Gender	Women	70.6%
	Yes	60.3%
Cognitive impairment		
Baseline IADL impairment	Mean 20.8/24 (SD 6.4)	Range 0–24
Baseline ADL impairment	Mean 8.6/18 (SD 4.9)	Range 0–18
Age	Mean 82 (SD 10.4)	Range 50–96

for 'dropping out' after the second assessment was death of the care recipient; 20 of the 59 dropped out for this reason over the course of the project. Since this project was not designed to follow-up on how they dealt with grief, they were not called for responses. Others could not be contacted, declined to cooperate (sometimes because of their own health problems), or were no longer receiving services and did not want to be questioned further. Clients who remained in the program to complete second (and subsequent) CRS measures were initially caring for individuals with greater ADL impairment levels, were more likely to have revised their work schedule to accommodate care giving, and were more likely to be working part time or be unemployed.

Among the 59 caregivers who have at least two CRS measures, there was a clear statistically significant decline in overall strain from intake to first follow-up. The overall index score and five of the items showed lessened strain, as shown in Table 2. The initial reductions in strain were maintained overall for the 41 individuals with three measures, as shown in Figure 1. The reductions were still evident for the 19 who were assessed four times, although strain was not significantly reduced further after the initial drop.

Individual differences in change

Individual differences in change over time were identified. Forty-two percent of the caregiver clients reported decreased strain (more than 3 points lower on

total CRS) from the first assessment to first follow up; 44% had no change; and 14% reported increased strain. There were *no* group differences in caregiver age, gender or ethnicity, or whether counseling or support group services had been utilized. Clients who showed the most decreases in strain (and, presumably received the most benefit from the program) were caring for less impaired elders, had the highest strain when entering the SeniorCare program, and actually used fewer services. Clients who remained stable were intermediate in their initial strain levels, the impairment of their care recipient, and their service use.

The minority who reported increased strain were caring for elders who had the highest levels of ADL impairments, although they were unlikely to report high strain when they entered the services. They used more services overall, and attended more caregiver support groups.

The use of qualitative analysis to identify patterns in change overtime

Qualitative analyses explored possible causes of increased strain, and provided a validity check on the CRS measure. One pattern identified through qualitative research showed objectively worsened caregiver situations. For example, 'Dan' was caring for his demented father; when he entered the support group he reported a CRS score of 11 (out of 36). His increased strain (to 24) reflected his sense that his own health was suffering, that he had no break and was

Table 2. Changes in caregiver Risk Screen Measure: baseline to first follow-up ($n = 59$)

#	Question (range 0 'Disagree Completely' to 3 'Agree Completely')	Mean (SD) intake	Mean (SD) second measure
1	Caring for my ___ has negative effects on my physical health	1.87 (1.1)	1.7 (1.1)
2	I am not coping well with the present situation	1.8 (1.0)	1.3 (1.1)***
3	I am more cut off from my usual social activities than before	2.2 (1.0)	1.9 (1.5)
4	Caring for ___ puts a strain on my family relationships	1.9 (1.2)	1.6 (1.0)
5	I will not be able to continue caring for ___ much longer	0.8 (1.1)	0.7 (1.0)
6	Taking care of my ___ has put a strain on my relationship with him/her	1.8 (1.1)	1.3 (1.0)***
7	Taking care of ___ is no longer worth the effort	0.3 (0.8)	0.3 (0.8)
8	I don't have a minute's break from caregiving	1.3 (1.1)	0.9 (1.1) **
9	I do more than my share of caring compared to others in my family or support system	2.2 (1.2)	2.0 (1.2)
10	I feel depressed	2.0 (1.1)	1.4 (1.0) ***
11	I feel I am losing control over my life because of my present situation	1.5 (1.2)	1.1 (1.1) *
12	In the past few months, I have increased my intake of alcohol, drugs, or cigarettes	0.4 (0.9)	0.3 (0.8)
Total	Total Scale Mean	1.5 (0.6)	1.2 (0.6) ***

Mean scores for two groups are statistically different

*($p < 0.05$)

** $p < 0.01$

*** $p < 0.001$

Copyright: Measure developed by Nancy Guberman (School of Social Work, IQAM, Montreal) and Janice Keefe (Mount St Vincent University, Halifax, Nova Scotia). Used with permission.

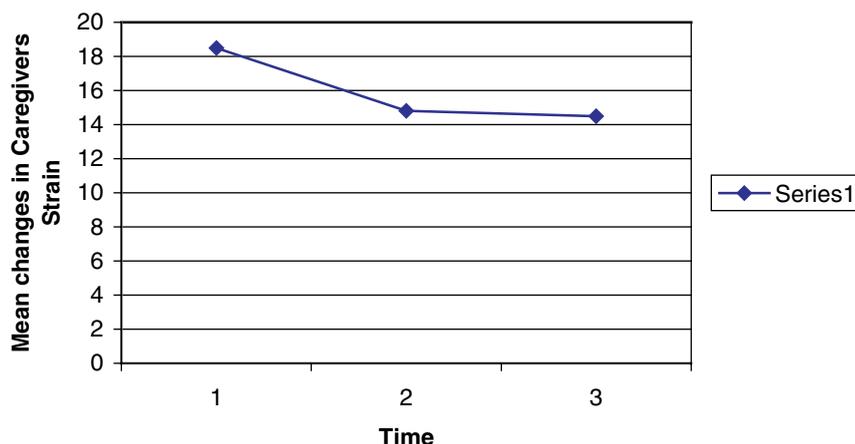


Figure 1. Changes in caregiver strain from intake (Time 1) to follow-ups 1 and 2 (Time 2 and 3) ($n = 41$ clients)

doing more than his share of caring, that he had lost control of his life, that he could not continue, and that he had resumed smoking to cope with anxiety. Another theme identified in clients reporting increased strains was that support groups provide 'permission' to acknowledge strain. 'Dee' is a black woman living with her mother, age 77; at intake she had a CRS score of two. She had stopped working for pay to care for her father three years ago (now dead) and wanted to resume employment. When she first contacted the SeniorCare program, the only stress she indicated was that she was more cut off from her regular social activities. At the end of the support group, she had a score of 10. She reported that she realized that it was reasonable to feel stressed, and that she did not need to 'fake feeling normal' with the support group.

The qualitative analyses also validate the reduced strain reported by some clients. Probably the most dramatic decline in strain was reported by 'Marie', who indicated a score of 32 (out of 36) when she first encountered the program. She was living with her mother, who seemed to be forgetful, demanding, and depressed. After the social worker met with both of them, the mother admitted she had been very grouchy and demanding, and inconsiderate of her daughter. Marie reported that her mother had started going for walks, remembering things, and become interested in accompanying Marie on excursions. After only two months of family counseling sessions, Marie's strain score decreased to four.

Modifications of the Caregiver Risk Screen. Initial reports of use of addictive substances such as alcohol, drugs, and cigarettes were very low on the CRS, and

there was no change overtime. From interview data it is likely that: (a) there is some or much denial involved in the reporting, and/or (b) the 'comfort substances' of choice are food, rather than the ones mentioned. Other themes that emerged in qualitative interviews were the importance of expectations or lack of expectations about caregiving services, and the role of anxiety and hope as important determinants of caregivers' strain. As a result, a modified version of the CRS, based on themes that emerged in qualitative research is presented in Appendix 1 for future evaluation. We have re-named this modified measure the Caregiver Strain.

DISCUSSION

Using both quantitative and qualitative methods has enabled us to make a better assessment of the SeniorCare program, and of the potential usefulness of the very brief strain measure. The Caregiver Risk Screen measure shows promise for field use to assess changes in caregiver experiences while caring for an older family member.

On the basis of results obtained with the SeniorCare measure, and literature emerging since the initial conceptualization of that measure, we have modified the measure for future use. Our revision includes food as one of the supportive substances; a general question about anxiety; a question about expectation that the services offered would be helpful; and a question that there is hope for the future. We will continue to assess the usefulness of this tool for tracking changes over time in this population.

Last, this study is limited by its relative small sample size and high attrition rate in subsequent follow-up evaluations. However, we believe that it provides an initial step in the evaluation of the CRS as a useful tool for the assessment of caregivers' strain over time.

ACKNOWLEDGEMENTS

The SeniorCare project was funded by the Administration on Aging to Metropolitan Family Services of Metropolitan Chicago. Nambury Raju, Distinguished Professor in the Institute of Psychology at IIT, was the consultant on statistical analyses. Results from these analyses were presented at the International Association of Gerontology meetings in Rio de Janeiro, Brazil, June, 2005.

REFERENCES

- Family Caregiver Alliance. 2002. *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners*. Family Caregiver Alliance: San Francisco, CA.
- Feinberg LF. 2001. Systems development for family caregiver support services. (issue brief). *The National Family Caregiver Support Program: From Enactment to Action*. US Administration on Aging Conference: Washington, DC.
- Feinberg LF. 2002. *The State of the Art: Caregiver Assessment in Practice Settings*. Family Caregiver Alliance, National Center on Caregiving: San Francisco, CA.
- Guberman N, Keefe J, Fancey P, et al. 2001. Development of Screening and Assessment Tools for Family Caregivers. Final Report NA 145 to Health Transition Fund, Health Canada.
- Kaiser Family Foundation, Harvard School of Public health, United Hospital fund of New York, Visiting Nurse Service of New York. 2002. *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*.
- Schulz R, Belle S, Czaja S, et al. 2003. Introduction to the special section on resources for enhancing Alzheimer's caregiver health (REACH). *Psychol Aging* 18(3): 357–360.
- Strauss A, Corbin J. 1990. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Sage Publications: Newbury Park, CA.

APPENDIX

Please read each statement below and indicate how much the statement applies to you over the last month. There are no right or wrong answers. Do not spend too much time on any statement.

[Response options are Almost Always, Often, About half the time, Rarely, Never]

1. Caring for my _ has negative effects on my physical health.
2. Taking care of my _ has put a strain on my family relationships.
3. I engage in regular activities that are important to me.
4. I feel I don't know how to deal with the problems in my life.
5. I find that food, cigarettes, alcohol, or drugs help me deal with my problems.
6. I feel there is a lot of stress in my life.
7. I feel anxious.
8. I feel depressed.
9. I feel I am losing control over my life.
10. Taking care of _ has put a strain on my relationship with him/her/them.
11. I am doing more than my share of caring compared to other family members or other members of my support system.
12. I will not be able to continue caring for _ much longer.
13. I feel that meeting the needs of _ is no longer worth the effort.
14. I expect that the services offered by MFS will help me cope with my problems.
15. I see hope for the future.

Copyright of *International Journal of Geriatric Psychiatry* is the property of John Wiley & Sons Ltd. 1996 and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.