Multidimensional measures of caregiver burden give a sensitive reading of caregivers' feelings and a sophisticated picture of caregivers' responses to the demands of care. This paper reports on the development of a 24-item, five-subscale Caregiver Burden Inventory (CBI) and demonstrates its use as a diagnostic tool for professional caregivers. It concludes with a discussion of several ways that professional caregivers can use this multidimensional measure of caregiver burden.

**Key Words:** Alzheimer's disease, Family support, Assessment

Application of a Multidimensional Caregiver Burden Inventory

Mark Novak, PhD, and Carol Guest, MA

The Development of a Measure of Caregiver Burden

Before professionals can give support to caregivers, they must be able to assess caregivers' needs. A number of researchers have developed measures of caregiver burden that calculate how much burden caregivers feel and suggest interventions to relieve their discomfort.

Ory et al. (1985) define burden as "the impact of the changes in cognition and behavior of the Alzheimer patient on the family, and the patient's subsequent need for care and supervision." Impact, here, refers to the caregiver's felt burden. This definition recognizes that behavioral or cognitive changes in the Alzheimer's patient do not have the same impact on all caregivers. The severity of the patient's cognitive impairment, the patient's inability to perform daily tasks, or the length of time a caregiver has been giving care, for example, do not adequately predict caregivers' sense of burden (Colerick & George, 1986; Novak & Guest, 1985; Zarit, Reever, & Bach-Peterson, 1980). Instead, caregivers' social supports and subjective perceptions of caregiving more closely predict feelings of burden (Novak & Guest, 1989a). Researchers have developed a number of burden scales that assess caregivers' subjective feelings of burden.

Measures of Caregiver Burden

A number of unidimensional burden scales have been developed (Morycz, 1985; Robinson, 1983; Zarit et al., 1980; Zarit & Zarit, 1982) that share common features. They focus on caregivers' feelings and experiences; they tap similar facets of burden — health status, financial strain, social activity, and disturbed feelings; and they produce total scores representing overall burden (George & Gwyther, 1986).

These measures of overall burden support the idea that caregiving affects many parts of caregivers' lives, but because these scales total all items in a single burden score, they do not permit distinctions between the dimensions of burden. George and Gwyther (1986) say that "reliance upon summary scores masks dimension-specific patterns of caregiving impact and precludes identification of the different antecedents or correlates of specific dimensions of caregiver burden." Niederehe and Fruge (1984) recommend that researchers use multidimensional measures of burden that reflect "various areas of caregiver's well-being and function that may be differentially affected by the dementia of the relative."

Montgomery et al. (1985), Niederehe et al. (1983), Niederehe and Fruge (1984), and Poulshock and Deimling (1984) all report the use of multidimensional measures of caregiver burden. But the generality of subscale concepts (Montgomery, Gonyea, & Hooyman, 1985), the large number of items to respondents (Niederehe et al., 1983), and the small number of subscales reported in studies to date (Poulshock & Deimling, 1984) limit either the reliability or the applicability of these scales. Kosberg and Cairl (1986) have produced a multidimensional "Cost of Care Index," but high intercorrelations among four of their five subscales raise the question of these scales' independence. "The task remains," Poulshock and Deimling (1984) say, "for social scientists who examine family caregiving to refine explicitly the measurement of burden and impact indicators so that a more complex and reality-oriented perspective on caregiving can inform further research."

The present paper describes a diverse, multidimensional instrument (the Caregiver Burden Inventory or CBI) that measures the impact of burden on caregivers. Based on the work of Guest (1986), it includes a variety of items, some selected from previously published scales, others devised for this study.
This measure extends the work of previous researchers, while it avoids some of the methodological problems with earlier work (like the high ratio of items to subjects).

We applied the CBI to a sample of 107 caregivers of cognitively impaired older people. Here we describe and analyze these caregivers' patterns of burden and conclude by describing the value of this scale for professionals who work with caregivers.

The Sample

The sample for this study consisted of 107 caregivers of confused or disoriented older people — 28 men and 79 women. Caregivers' ages ranged from 25 to 87 years with a mean of 60.13 (13.06). On the average caregivers reported caring for their care receivers for 63.09 (49.25) months. The impaired care receivers' ages ranged from 56 to 93 years with a mean of 77.78 (9.04). The majority of caregivers in this sample lived in single unattached homes or their own apartments. All care receivers received free medical services through a provincial government health care plan, which included the cost of visits to physicians, hospital stays, and home care services.

Half of the caregivers (n = 54) cared for their care receivers in the community, half (n = 53) cared for someone in an institution. Of the community caregivers, two-thirds (n = 35) lived with the care receiver. Spouses made up 44.9% of the caregiver sample, children or spouses of children made up 48.8% of the sample. All but one of the other 6.3% of caregivers were relatives of the impaired person. All of the caregivers in this sample acted as primary caregivers to the impaired patient.

We obtained our sample from professionals in the community — directors of long-term care facilities, physicians in medical clinics, and case coordinators from the Manitoba Community Services and Home Care Division. Each agency or professional received a letter that stated: "The ill person should be assessed as having any one or more of the following — Alzheimer's disease, senile dementia, or organic brain syndrome. Clear and obvious cases of stroke or multiinfarct dementia (with no indication of Alzheimer's or related disorder) will not be included in the study. Dementia of doubtful origin will be included."

Physicians had diagnosed three-quarters (74.3%) of the care receivers in this study as having Alzheimer's disease or senile dementia. All of the other care receivers in this study were assessed as cognitively impaired by assessment teams of Manitoba Community Services and Home Care Division. These teams consist of nurses and social workers who visit clients in their homes. The division uses these assessments to determine a family's needs for home care, respite, and institutionalization.

All of the care receivers in this study, then, had been defined as suffering from Alzheimer's disease, senile dementia, or organic brain syndrome by health care professionals trained to recognize the symptoms and variations of symptoms of these disorders.

Construction of a Caregiver Burden Inventory (CBI)

Caregivers were interviewed in their homes using a questionnaire with open-ended and fixed-choice questions. Questions dealing with caregiver burden were drawn from previous studies (Zarit et al., 1980; Morycz, 1985; Robinson, 1983; Poulishock & Deimling, 1984; and others). Interviewees also answered a series of demographic questions. The interview took approximately two hours.

This study began with the work of Guest (1986), who carried out a factor analysis of 16 items based on responses from a sample of Alzheimer's Society members. These responses yielded a five-factor solution. However, one of the factors contained only three items and two of the factors contained only two items. The present study sought to expand the items in each factor and to enhance their interpretability.

We conducted a principal components analysis with orthogonal Varimax rotation on the selected items. The sample for this analysis consisted of 107 subjects from the current study and a further 64 subjects used in the previous study (Guest, 1986). Guest's study contained roughly the same types and proportions of caregivers as ours when compared on gender, age, and relation to the care receiver. The sample totaled 171 subjects.

Twenty-four items were entered into a factor analysis, including items from Guest's (1986) research plus new items selected from the burden literature to fit a multidimensional model. Each item ranged from 0 (not at all descriptive) to 4 (very descriptive). Five interpretable factors, each containing different high-loading items, resulted from the analysis. A subject's score on each factor could range from 0 to 20, except for Factor 3 (with only four items), where scores could range from 0 to 16. Factor 3 scores were adjusted by multiplying the obtained score out of 16 by 1.25 to give an equivalent score out of 20. Mean scores and standard deviations of the factors were: Factor 1 = 6.98 (SD 5.89); Factor 2 = 7.08 (SD 5.89); Factor 3 = 5.47 (SD 5.9) (adjusted); Factor 4 = 2.54 (SD 3.54); Factor 5 = 2.02 (SD 3.04).

These five factors accounted for 66% of the variance in the data set. All factors were of approximately equal importance. Each factor explained 9 to 12% of the variance. Internal consistency reliability (Coefficient Alpha) of the factors was good. Factors 1 and 2 obtained an Alpha value of 0.85 each. Factors 3, 4, and 5 had Alpha values of 0.86, 0.73, and 0.77 respectively. In all but one case, factors shared 23% or less of their variance.

Table 1. Pearson Product Moment Correlations of Caregiver Burden Inventory Factors

<table>
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<th>Factor</th>
<th>1</th>
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<tr>
<td>2</td>
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<td>3</td>
<td>0.44</td>
<td>0.62</td>
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<td>4</td>
<td>0.06</td>
<td>0.26</td>
<td>0.18</td>
<td>0.19</td>
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<tr>
<td>5</td>
<td>0.43</td>
<td>0.47</td>
<td>0.48</td>
<td>0.19</td>
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Factor 1: Time-Dependence Burden
This factor describes the burden due to restrictions on the caregiver's time. Because persons with Alzheimer's disease often lose the ability to perform the activities of daily living, caregivers devote time and energy to helping them with daily tasks. Also, Alzheimer's patients may wander or hurt themselves, and caregivers have to increase their vigilance as the disease progresses. This constant vigilance and feeling of responsibility places stress on the caregiver. Items like, "My care receiver is dependent on me" or "I don't have a minute's break from my caregiving chores" reflect their feeling of burden.

Factor 2: Developmental Burden
This factor describes the caregivers' feelings of being "off-time" in their development with respect to their peers. Neugarten and Hagestad (1976, p. 45) conclude from their research that "... the age norm system ... also creates an ordered predictable life course, it creates timetables, it sets boundaries for acceptable behavior at successive life stages." Few people have prepared to become caregivers of a dementia patient. They receive almost no socialization for this role before they enter it and little support once they take it on.

Caregivers see their peers enjoying their later years as they expected, but they feel continued anxiety and strain. They often ask the existential question, "Why did this happen to me?" Items like, "I feel that I am missing out on life" and "I expected that things would be different at this point in my life" reflect this feeling of burden.

Factor 3: Physical Burden
These items describe caregivers' feelings of chronic fatigue and damage to physical health. Many studies report that caregivers run a high risk of physical illness due to caregiving. Items like, "I'm not getting enough sleep" and "Caregiving has made me physically sick" reflect caregivers' feelings of physical burden.

Factor 4: Social Burden
These items describe caregivers' feelings of role conflict. A caregiver may argue with a spouse or with other family members over how to manage the care receiver's needs. Caregivers sometimes feel unappreciated and neglected by others. They may also have to limit the time and energy that they invest in relationships or in their jobs. Items like, "I don't get along with other family members as well as I used to" and "I don't do as good a job at work as I used to" reflect caregivers' feelings of social burden.

Factor 5: Emotional Burden
These items describe caregivers' negative feelings toward their care receivers, which may result from the patient's unpredictable and often bizarre behavior. Caregivers may feel guilty about these socially unacceptable feelings. Items like, "I resent my care receiver" and "I feel angry about my interactions with my care receiver" reflect these feelings of emotional burden.

Because of the small sample size, it was impossible to test for factor invariance. But within-sample comparisons allowed us to see whether the CBI can discriminate between types of caregivers. We would predict that different types of caregivers (spouses versus children, caregivers for institutionalized versus community dwelling patients) would show different patterns of burden. Further work with the CBI found predictable differences between these caregiver types.

Novak and Guest (1989b) report that caregivers
who care for someone in an institution, compared to community caregivers, report less burden on all but one dimension of the CBI. Novak and Guest (1989b) also report that nonspouse caregivers, compared to spouse caregivers, report less burden on all dimensions of the CBI. Nonspouse caregivers with a care receiver in an institution report the least burden on all CBI dimensions; spouse caregivers with a care receiver in their own home report the highest burden on all but one CBI dimension. These findings support the interpretation of the factor structure presented here. They also give preliminary support to the idea that the factors retain their interpretability with different subsamples of caregivers.

The CBI's subscales differ from previous multidimensional scales based on principal factors analysis. Niederehe and Fruge (1984) describe two dimensions of caregiver burden — subjective strain and impact on family. Poulschock and Deimling (1984) report two dimensions of impact of caregiving on caregivers: changes in the caregiver's relationship with family members and with the care receiver, and restrictions of activities. Kosberg and Cairl (1986) produced a multidimensional “Cost of Care Index (CCI)” with five dimensions: personal and social restrictions, physical and emotional health, value, care recipient as provocateur, and economic costs.

How do these instruments compare to the CBI? Neither Niederehe and Fruge (1984) nor Poulschock and Deimling (1984) produced scales that cover a wide range of caregiver problems or that a professional caregiver can easily use in practice. Kosberg and Cairl (1986) produced a useful and interpretable scale, but included in their study those who cared for physically as well as cognitively impaired patients. Thus, it is unclear how well their findings specifically fit caregivers of cognitively impaired patients.

The CBI provides a unique set of subscales designed to assess caregivers of cognitively impaired older people. It shows good internal reliability, moderate intercorrelations of subscales, and high factor loadings. Taken together the subscales cover a wide range of problems reported by caregivers of these patients. This makes the CBI a practical tool for assessing and responding to caregiver burden.

Construction of a Caregiver Burden Profile (CBP)

We constructed a Caregiver Burden Profile (CBP) for each of our 107 subjects based on their CBI scores. These profiles enabled us to graphically display each subject's burden scores and, by comparing the burden scores among subscales, to compare different individuals' patterns of burden. We first constructed profiles of subjects' raw scores. (For Factor 3, with only four items, we adjusted the raw scores. We multiplied the Factor 3 raw score by 1.25 to obtain an equivalent score out of 20.)

The raw score CBPs underscore the necessity of using a multidimensional measure of caregiver burden. A look at one case will make this point.

Case No. 93, Mr. Warner, a 73-year-old husband, shows that the degree of burden varies on each subscale. He has a total adjusted burden score of 38.25. The line on this chart shows a high level of burden on subscale 2 (developmental burden), and moderate burden on subscale 3 (physical burden) and subscale 4 (social burden). Mr. Warner reports no burden on subscale 1 (time dependence) and subscale 5 (emotional burden). Unidimensional measures that produce only a total burden score overlook these differences in the types of burden caregivers experience.

Mr. Warner's total raw score of 38.25 was somewhat above the sample mean. But, because his wife lived in a nursing home, he felt no burden from time dependence. He also showed no negative emotions toward his wife. He did, however, show the highest possible score (20) on Factor 2 (developmental burden). This subscale measures a person's sense of being trapped and out of phase with their expectations about this time in their life.

During his interview, Mr. Warner expressed great distress over his wife's deterioration and a sense of hopelessness about the future. He reported a decrease in his economic situation due to nursing home expenses, extreme unhappiness due to separation from his wife, and feelings of guilt and sadness about institutionalizing her. Further study of this sample found that high levels of developmental burden are highly correlated with depression ($r = .70$, $p < .001$) (Guest & Novak, 1987). This man reported a number of symptoms of depression — "crying easily," "a feeling of being trapped or caught," and "feeling lonely and blue." Mr. Warner's profile suggests the need for psychological counseling. But he reported receiving no counseling at the time of the interview.

A comparison of the two cases on Chart 1 shows that the use of total burden scores alone could lead to a misleading conclusion about caregivers' needs. Case No. 70, Mrs. Franklin, a 49-year-old daughter, has a total adjusted burden score of 20 (roughly half...
of Mr. Warner’s total score). But she scores lower than Mr. Warner on only some factors. She shows a lower adjusted raw burden score than does Case No. 93 on Factor 2 (developmental burden), Factor 3 (physical burden) and Factor 4 (social burden). But, on Factor 5 (emotional burden) they show the same score and on Factor 1 (time dependence) Mrs. Franklin shows a much higher raw score than Mr. Warner (Case No. 93).

This finding fits with other data from our study. Mrs. Franklin cares for her mother in her home, while Mr. Warner cares for his wife in a nursing home. High time dependence almost always accompanied care for a care receiver in the caregiver’s home; low time dependence accompanied institutionalization. Note, however, that Mr. Warner, who had placed his wife in an institution, still shows a high level of burden on Factor 2 (developmental burden), Factor 3 (physical burden) and Factor 4 (social burden). This case shows that burden does not always disappear when a care receiver enters an institution.

Likewise, Mrs. Franklin shows that community care does not always produce high levels of burden on all dimensions. Mrs. Franklin reports good health and good support from her family (her husband and three children in their twenties who live with her). She also has a friend she can talk to about her feelings. She seems to cope well with caregiving, though she feels burdened by the constant attention her mother demands. This profile suggests that a specific intervention, like respite care, might reduce her time dependence (Factor 1) burden score.

These two profiles suggest that caregivers have unique needs, depending on their social, psychological, and physical resources. A multidimensional measure of burden like the CBI can target caregivers’ specific needs for intervention.

The next two cases further illustrate the importance of using a multivariate method to measure burden.

These two cases both have almost the same total adjusted burden score (Case No. 25 had a score of 52.75 and Case No. 32 had a score of 53.25), both well above the sample total burden mean of 22.14 (16.30). Each case shows a different pattern of burden.

The first subject, Ms. Adamchuk (Case No. 25) is a 26-year-old woman. She is caring for her 62-year-old mother, who has lived in a nursing home for the past 10 months. She shows a moderate burden score on Factor 3 (physical burden) and high burden scores on Factors 1 (time dependence), 2 (developmental burden), and 4 (social burden). Ms. Adamchuk reports strain between herself and her fiance, worry about her mother, and trouble keeping a job. Caregiving has led to declines in all parts of this woman’s life and she reports extreme unhappiness. Yet she receives little social support from either formal or informal sources. As with Mr. Warner, this case shows that burden can continue at a high rate even after the care receiver’s institutionalization.

The second subject (Case No. 32) is a 74-year-old woman, Mrs. Carstairs, who cares for her husband at home. She scores high on Factors 2 and 3 and she shows extremely high burden on Factors 1 (time dependence) and 5 (emotional burden). Mrs. Carstairs reports that her husband interrupts people in the supermarket to tell them about his physical problems. He also urinates in the backyard in front of the neighbors. These behaviors disturb and embarrass Mrs. Carstairs and she no longer has either friends or visitors. She reports feeling “hopeless about the future” and “extremely unhappy” since her husband became ill. She has put her husband on a waiting list for a nursing home and may get some relief from her feelings of emotional burden when her husband enters the home. She will have more time and energy for her social life and she may feel less embarrassed about his behavior in an institutional setting. Until then, Mrs. Carstairs’ feelings of burden and unhappiness will probably increase. A day sitter, respite care, or attendance at support group meetings might help Mrs. Carstairs cope with her emotional burden.

These two cases show that caregivers with the same total burden scores can have markedly different patterns of burden. These different patterns point to caregivers’ different social and psychological needs. They also point to the need for different intervention methods in order to relieve different kinds of burden.

### The Practical Value of Caregiver Burden Profiles

These findings have policy implications. The absence of a reliable and sensitive measure of burden makes it impossible to adequately evaluate the effects on caregivers of nursing home care, respite care, adult day care, or homemaker programs. It also leads to gaps in the services available to caregivers. For example, little research has focused on caregivers after the institutionalization of their care receivers. We know little about caregivers’ needs after a patient has entered an institution and we provide
little (or no) services to those caregivers. Unidimensional measures of burden in general show an overall lower burden score for caregivers of institutionalized care receivers. But our study shows that many caregivers with care receivers in a nursing home report high levels of developmental, physical, and social burden. These caregivers may need individual counseling, family therapy, or continued informal support (Colerick & George, 1986) to help them overcome the social barriers that caregiving may have created (a loss of friends, an interrupted career, or a decrease in community contacts). They may also need advice on how to allow staff to take over the work of caregiving.

Ory and colleagues (1985) say that “we need to know how and in what ways different family members are affected by a relative with AD and whether certain effects can be predicted based on age, sex, or level of responsibility” (p. 637). The CBI moves toward this goal by offering a multidimensional measure and a multidimensional view of caregiver burden.

References


