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Burden in Caregivers of Cognitively Impaired Older Adults Living in the Community: Methodological Issues and Determinants

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ABSTRACT. Considerable burden is reported by informal caregivers of older individuals with cognitive impairment. Significant progress in the understanding of determinants of this burden has been achieved. However, further progress could be attained if we considered important methodological issues that may have limited our understanding of caregiver burden. These issues include subgroups of care recipients and caregivers, measurement issues, research design, and statistical techniques. Fifty-three studies published between 1980 and 1997 (inclusive) that focused on caregiver burden were abstracted to determine the extent to which the methodological issues discussed above were considered. Overall, we found considerable variability among the studies surveyed. Further understanding of the caregiving process and reductions in caregiver burden will depend on the attention to methodological issues and understanding of burden across the whole caregiving career.

For several decades, research into the experience of providing care to a family member with dementia has focused largely on a concept known as "caregiver burden." Caregiver burden is typically conceptualized as subjective factors such as feelings of stress or strain (Pearlin et al., 1990) and objective factors such as task burden and financial burden. It is well established that caregivers for cognitively impaired individuals experience considerable burden and are at greater risk of psychiatric and physical morbidity compared to population norms and control groups (Canadian Study on Health and Aging, 1994;

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Williamson & Schulz, 1993). Further, there is consistent evidence that behavioral disturbance plays an important role in explaining burden. Yet whether behavioral disturbance is the best predictor of burden throughout the spectrum of caregiving is unknown. There are likely other key variables involved; however, a clear understanding of these variables has been hampered by methodological concerns. To ease the distress of caregivers, future research should address these methodological concerns to clearly identify the causes of burden and interventions to alleviate it.

Methodological barriers that have limited the research potential in this field can be grouped into four main areas that require attention. These include problems related to subgroups, measurement, research design, and statistical analysis.

Subgroup Considerations

Recent reviews and editorials have expressed concerns regarding the neglect of subgroups in caregiving research (Pearlin et al., 1990). This neglect resulted in heterogeneous samples. Investigators often include any person they can recruit in order to achieve sufficient sample size and to develop complex models of caregiving (Zarit, 1989). Although some benefits are associated with this practice, such as acceleration in the recruitment of study participants and increased generalizability of the findings, there are also problems. The heterogeneity of the participants negatively affects statistical power because the specific characteristics of participants create different response patterns, resulting in increased between-participant variability. The increased noise-to-signal ratio leads to the dilution of any real statistical association; failure to consider the complexity of the caregiving situation will likely increase Type II errors (Montgomery, 1996).

From the literature and our own clinical experience, we have identified the following important subgroups: diagnosis, stage/duration of the condition, gender, and kinship. Diagnosis is an important subgroup in burden research because there are a wide variety of diagnoses causing cognitive impairment. In older adults, the major causes are Alzheimer's disease (AD) and vascular dementia. The symptomatology is often similar between these two conditions when examined at baseline (Swearer et al., 1988). However, brain lesions affecting AD patients and patients with vascular dementia differ (Eriksson, 1996), and differences between diagnostic groups surface over time (Bédard et al., 1997; Kurita et al., 1993). Other types of dementia (e.g., frontotemporal dementia) are also difficult to differentiate from AD (Mendez et al., 1998), and evidence of subgroups within AD is available (Mayeux et al., 1985). Thus, to avoid the introduction of variability, it is desirable to either use one diagnostic classification only, or to stratify according to the diagnosis at the design or analysis phase.

A similar issue to that of diagnosis is the stage/duration of the condition. The progression of dementia is neither uniform throughout the course of the condition (Stern et al., 1994) nor among individuals (Galasko et al., 1996; Hogan et al., 1994). Therefore, if determinants of burden vary over time, using patients at various stages might introduce variability.

Gender is another important aspect to consider in caregiving research. The impact of gender may originate in the gender of the caregiver, the gender of the care recipient, or an interaction of both. Female caregivers report more burden than their male counterparts (Bédard et al., 1999; Miller & Cafasso, 1992), but male caregivers may report larger reductions in burden following some interventions (Bédard et al., 1997). Furthermore, there are differences in the behavior patterns of cognitively impaired older men and women (Cohen et al., 1993b; Ryden, 1988), and the burden experienced by their caregivers in response to these behaviors is gender-specific (Bédard et al., 1999).

Kinship and living arrangements may affect perceived burden, but we know relatively little regarding their influence (Harper & Lund, 1990). Lower life satisfaction, lesser involvement in social activities, greater levels of depression, and higher use of psychotropic medications have been observed in caregivers living with care recipients compared to caregivers not living with them (Cohen & Eisdorfer, 1988; George & Gwyther, 1986). Differences between primary and secondary caregivers are also important. Primary caregivers often live with care recipients. Secondary caregivers are usually the children of the care recipient and have multiple commitments, the impact of which on caregiver burden is unclear (Young & Kahana, 1989). Until we understand the impact of caring for these subgroups, it may be desirable to not pool their data.

Measurement Issues

Many instruments are available to measure burden and its determinants. Unfortunately, the operationalization of these constructs is not consistent. Burden is sometimes defined as psychological, physical, social, or a combination of all three. Even in situations where the definitions are the same, the format and psychometric properties of the instruments are often different. These same problems apply to the measurement of potential predictors such as cognition, depression, and problem behaviors. This represents a formidable challenge when trying to synthesize the literature.

Research Design

The majority of research in the field utilizes cross-sectional designs. They provide an easy means to gather preliminary evidence regarding associations between variables. However, major drawbacks of the cross-sectional design include the inability to prove causal inferences and a limited insight into a progressive condition (Malonebeach & Zarit, 1995). To further our knowledge, an increased reliance on the more informative longitudinal designs has been proposed (Malonebeach & Zarit, 1995; Ory et al., 1985). Nevertheless, research using cross-sectional designs continues (Montgomery, 1996).

Statistical Issues

It has been stated that univariate (bivariate) statistical methods are inadequate when dealing with caregiver burden (Zarit, 1989). The multitude of variables that may have an impact on burden and the interrelationships between these variables make it essential to understand the unique (independent) contribution of each variable. If stratification at the design phase is not possible, researchers can use multivariate statistics to dissect the complex relationships between dependent and independent variables (Afifi & Clark, 1996; Cohen & Cohen, 1983).

Another statistical issue pertinent to longitudinal and intervention designs is the use of means and change scores. Means are frequently used to compare caregivers at two points in time (longitudinal) or two groups of caregivers given different types of interventions to reduce burden (interventions). However, relying on means can be misleading. If a number of caregivers have meaningful changes in burden, but in opposite directions, the overall mean will suggest that there is no change over time when in fact significant changes within subgroups are observed (Bédard et al., 1997).

Other important methodological considerations are sample size and sampling. Small sample sizes have less statistical power and generally preclude the use of multivariate statistics. Longitudinal studies require larger sample sizes because of attrition in the cognitively impaired population and to ensure equal groups at baseline for intervention studies. Also, researchers have noted that most studies have relied on convenience sampling, which may not be representative of the whole population, but rather reflects a population of more distressed caregivers who seek help (Malonebeach & Zarit, 1995). Furthermore, only some caregivers and care recipients will agree to participate in studies, further limiting the sampling process.

Attention to issues related to subgroups, measurement, research design, and statistical methods is important within research studies. However, the extent to which these areas have been addressed in the published literature is unknown. The purpose of this overview was to determine the prevalence of these methodological issues in the published literature. The review of these studies for methodological strengths and limitations also allowed us to identify the most significant determinant of caregiver burden.

METHODS

This overview included articles meeting the following criteria: published between January 1980 and September 1997 (inclusive), participants were older adults with cognitive impairment, care recipients were community-dwelling, and a measure of burden/strain in primary caregivers was used. Articles with caregivers' psychiatric symptoms as dependent variables were excluded. Although caregiver burden and psychiatric symptoms are often correlated, we preferred to avoid the additional variability that might be introduced by including measures of psychiatric illness. To identify published papers, we conducted literature searches using MEDLINE, Psychological Abstracts, Social Science Citation Index, and Sociological Abstracts with the key words Alzheimer's disease, dementia, burden, and caregiver. We reviewed the reference lists of the articles retrieved to identify potentially relevant references that might have been missed by literature searches. A total of 146 articles were evaluated, 53 of which met inclusion criteria and form the basis of this report.

Each study was abstracted to provide information on its methodology and results. We noted the year of publication and the number of participants (total for cross-sectional or longitudinal, smaller group size for intervention studies). The diagnosis of the participants was coded as AD, AD and related diseases, AD and related disease plus others (e.g., depressed), and not clearly defined. For studies using a mixture of diagnoses, we determined if some stratification (at the design phase or analysis) had been used to deal with different diagnoses.

We determined the duration of the condition in years by using either the number of years since onset of symptoms or the number of years of caregiving. Care recipients' impairment was sometimes available, usually with the Mini-Mental State Examination (MMSE; Folstein et al., 1975). Studies were classified according to the mean MMSE of the participants: less than 15, 15-20, greater than 20, otherwise moderate, or unclear. Attention to other subgroups was evaluated by determining if some stratification had been used for gender and kinship. These were coded as: some stratification, none, or undetermined.

The burden instrument used was classified as the Zarit if the original instrument (Zarit et al., 1980) or a derivative was used. The instrument was classified as unique if it measured burden but had been developed specifically for the study. A third category comprised the Screen for Caregiver Burden (SCB; Vitaliano et al., 1991a), and the last category included studies using other burnout, strain, or global measures of burden. We followed a similar procedure for instruments measuring cognition, mood, activities of daily living (ADL), and behavior problems.

The measurement of caregiver and external variables was dichotomized as present or absent. Caregiver variables included variables that may affect burden (e.g., education, financial resources, psychological profile). External variables included social supports and other variables outside the control of caregivers (e.g., help from relatives, formal supports). The dichotomization of caregiver and external variables reduced the sensitivity of the analyses but was necessary because so many different operationalizations of these variables were present in the studies abstracted.

The study design was classified as cross-sectional, longitudinal, or intervention. The use of multivariate statistics was classified as yes, some stratification, or no multivariate statistics or stratification used. For longitudinal and intervention studies, we determined if change scores were used to determine variables associated with changes in burden or if only comparison between means was offered. Other major methodological problems were noted.

Finally, the studies' outcomes were examined. For each study, the outcome measure that had the strongest relationship with burden (best predictor) was determined. The variable with the best correlation with burden was used for univariate correlational studies, the variable explaining the larger proportion of the variance was used for multivariate analyses, and the variable associated with the larger change score for intervention studies was selected.

RESULTS

Of the 53 studies abstracted, 23 (43%) studies were published between 1980 and 1989 (inclusive; Figure 1). Twelve (23%) studies used AD patients exclusively, 35 (66%) used a mixture of AD and other dementias, and 5 (9%) studies used a mix of patients with dementia and other psychiatric problems. In one study, the only diagnostic information provided was that patients were cognitively impaired. Some form of stratification was used in only 3 (7%) of the 41 studies using a mixture of diagnoses. Diagnoses and stratification of diagnoses are shown in Table 1.

The duration of the condition was available in 28 (53%) studies. The mean and median duration of symptoms were 4.0 years (range: 2.3 to 6.5 years). The 25th and 75th percentiles were respectively 3.3 and 4.8. An indication of the disease stage was available in 21 (40%) studies. In 7 (33%) of these studies the impairment was severe, in 12 (57%) it was moderate, and in 2 (10%) it was mild. The MMSE had been used in 17 (81%) of these 21 studies. In only 11 (21%) studies were the duration of symptoms and the stage provided. In 14 (26%) studies, neither the stage nor the duration of symptoms was given. Data on duration

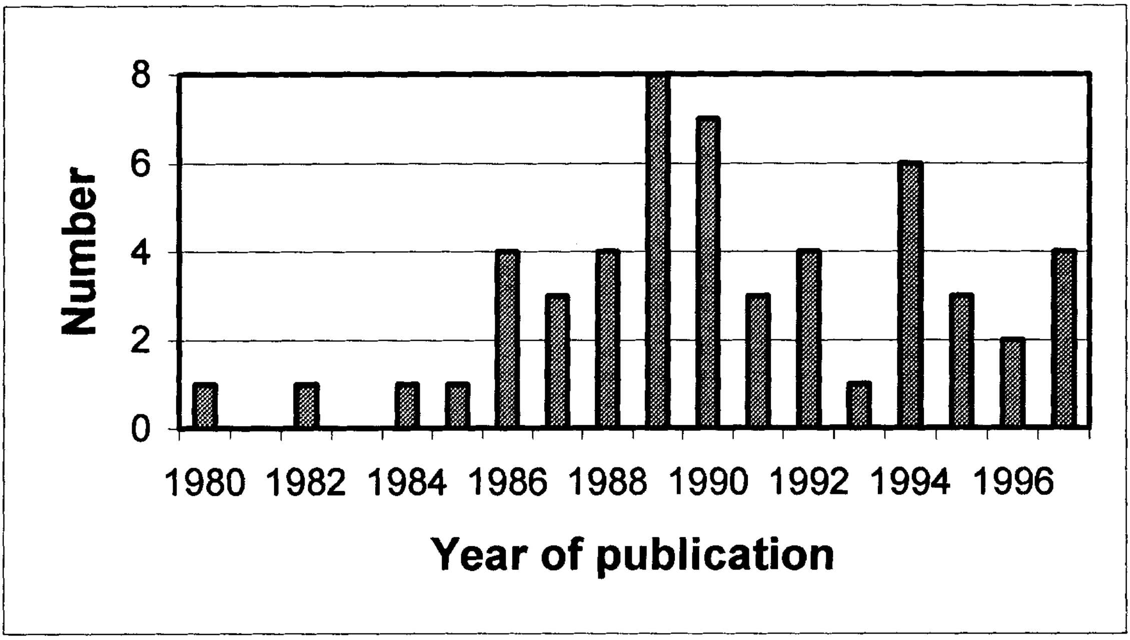

Figure 1. Number of caregiver burden publications for every year since 1980. Please note that 1997 includes studies for the first 9 months of the year only.

of symptoms and staging are also presented in Table 1.

Only 16 (30%) studies relied on stratification or multivariate analysis to control for gender (Table 2). There has not been an improvement in recent years; 56% of all studies considering gender were published after 1989, a proportion identical to that of all published studies. Similarly, kinship was considered in 24 (45%) studies (Table 2) by using only one type of kin (e.g., spouses only) or stratifying at the design or analysis phase. Thirteen (54%) of the studies considering kinship were published after 1989.

The instruments used are shown in Table 3. Twenty-five (47%) studies used a caregiver burden instrument based on that developed by Zarit and colleagues (1980). In 4 (8%) studies the SCB was used, and in the remaining 24 (45%) studies some burden, strain, or burnout measure, consisting mostly of global measures, was used.

Instruments measuring possible determinants of caregiver burden also varied. Twelve (32%) studies examining the relationship between cognition and burden used the MMSE (Folstein et al., 1975) or its standardized version (Molloy et al., 1991). Eight studies (21%) used the Memory and Behavior Problem Checklist (MBPC; Zarit et al., 1980) and 18 (47%) relied on other instruments. Fifteen studies (28%) did not examine cognition as a variable.

Only six studies examined the impact of the patient's depression symptomatology on burden. The Geriatric Depression Scale (Brink et al., 1982; Yesavage et al., 1983) was used in three, whereas less well-known instruments were used for the other studies.

TABLE 1. Diagnosis, Stratification of Diagnosis, Duration of Symptoms (Years), and Disease Stage of Participants

Study	Diagnosis	Stratification	Duration	Stage
Almberg et al., 1997	Dementia	No	—	—
Barusch & Spaid, 1989	Mixed	No	—	—
Bédard et al., 1997	Dementia	Yes	3.4	Mild
Brodaty et al., 1994	Dementia	No	4.8	Moderate
Burdz et al., 1988	Mixed	Yes	4.2	—
Deimling & Bass, 1986	Unclear	No	—	Moderate
Dillehay & Sandys, 1990	Dementia	No	—	—
Draper et al., 1992	Dementia	No	2.3	—
Drinka et al., 1987	Mixed	No	—	Unclear
Fitting et al., 1986	Dementia	No	—	Severe
Gallagher-Thompson et al., 1992	Dementia	No	—	—
Gilhooly, 1984	Dementia	No	4.9	—
Gold et al., 1994	Dementia	No	3.3	Severe
Goodman & Pynoos, 1990	Dementia	No	4.0	—
Grafström & Winblad, 1995	Dementia	No	—	Moderate
Grafström et al., 1994	Dementia	Yes	—	—
Grafström et al., 1992	Mixed	No	—	Moderate
Greene et al., 1982	Dementia	No	—	—
Haley et al., 1987	Dementia	No	5.0	Severe
Harper & Lund, 1990	Dementia	No	—	—
Hinrichsen & Niederehe, 1994	Dementia	No	4.5	Severe
Hooker et al., 1992	Dementia	No	—	—
Intrieri & Rapp, 1994	Dementia	No	—	—
Kahan et al., 1985	AD	—	—	—
Kinney & Stephens, 1989	AD	—	4.0	—
Kramer, 1997	Dementia	No	6.5	—
Lawton et al., 1989	Dementia	No	—	Moderate
Lawton et al., 1991	AD	—	—	—
Mangone et al., 1993	AD	—	4.5	Moderate
Mohide et al., 1990	Dementia	No	—	Severe
Molloy et al., 1996	Dementia	No	4.3	Moderate
Morris et al., 1988	Dementia	No	3.8	—
Morris et al., 1989	Dementia	No	3.7	—
Novak & Guest, 1989	Dementia	No	3.2	—
Nygaard, 1988	Dementia	No	4.7	Unclear
Pearson et al., 1988	Mixed	No	—	Mild
Pruchno & Resch, 1989a	AD	—	2.6	Unclear
Pruchno & Resch, 1989b	Dementia	No	3.0	—
Pruchno et al., 1990	Dementia	No	—	—
Pruchno, 1990	Dementia	No	—	—
Quayhagen & Quayhagen, 1989	AD	—	3.5	Unclear
Russo & Vitaliano, 1995	AD	—	—	Moderate

(continued)

TABLE 1. Continued

Study	Diagnosis	Stratification	Duration	Stage
Scott et al., 1986	Dementia	No	—	Severe
Seltzer et al., 1997	AD	—	3.5	Moderate
Stephens et al., 1997	Dementia	No	4.0	—
Stuckey et al., 1996	AD	—	—	—
Talkington-Boyer & Snyder, 1994	AD	—	5.5	—
Vitaliano et al., 1991b	AD	—	—	Moderate
Welleford et al., 1995	AD	—	3.4	Moderate
Williamson & Schulz, 1990	Dementia	No	2.3	Unclear
Zarit et al., 1987	Dementia	No	5.5	Severe
Zarit et al., 1980	Dementia	No	3.1	Moderate
Zarit et al., 1986	Dementia	No	5.7	Unclear

Note. AD = Alzheimer's disease only; Dementia = any dementia; Mixed = any dementia and other psychiatric diagnosis; Unclear = diagnosis not specified.

The measurement of ADL was included in 33 (62%) studies. Nine (26%) studies used an instrument derived from that of Lawton and Brody (1969). Four (12%) relied on the Barthel (Mahoney & Barthel, 1965), whereas three (9%) relied on instruments developed by Katz and colleagues (1963). The remaining 17 (50%) studies used other less well-known instruments.

Behavior problems were examined in 38 (72%) studies. The MBPC was used in 12 (32%) of these reports. However, the cognition and behavior subscales were reported separately in only one study. Various other rating tools were used in the remaining 26 (68%) studies.

Caregiver and external variables were examined in 33 (63%) and 24 (45%) of the studies, respectively (see Table 4). The operationalization of caregiver and external variables included global indices or summary scores derived from various scales, subjective variables, and objective variables. Most measures used self-reporting, and some of these operationalizations appeared circular. Examples of caregiver variables included: education, self-reported coping skills, satisfaction with social life, positive outlook, subjective health, number of visits to physicians, medications taken, financial resources, personality traits, depression, and anxiety. Examples of external variables included: number of times or hours formal and informal supports were used over a fixed period of time, frequency of contact with relatives, number of people available to help, satisfaction with formal support, presence of a confidant, and use of respite programs.

Thirty-six (68%) studies were cross-sectional (Table 5). In keeping with the overall proportion of studies published before 1990, 16 (44%) of all cross-sectional studies were reported until 1989 and the remainder after. Overall, 23 (43%) studies did not use multivariate statistics or some stratification, a proportion similar for all types of designs. However, 15 (65%) of all studies limited to univariate statistics were published prior to 1990, and the last reported study using such analytical techniques was published in 1996.

We found that 11 (65%) of 17 longitudinal and intervention studies relied exclusively on means; the remaining 6 (35%) used change scores. The sample sizes used varied considerably across studies. Cross-sectional studies averaged 130 participants,

TABLE 2. Attention to Gender of Patients and Caregivers, and Kinship

Study	Gender	Kinship
Almberg et al., 1997	No	No
Barusch & Spaid, 1989	Yes	Unknown
Bédard et al., 1997	Yes	Yes
Brodaty et al., 1994	No	No
Burdz et al., 1988	No	No
Deimling & Bass, 1986	No	No
Dillehay & Sandys, 1990	No	No
Draper et al., 1992	No	No
Drinka et al., 1987	No	No
Fitting et al., 1986	Yes	Yes
Gallagher-Thompson et al., 1992	No	No
Gilhooly, 1984	No	No
Gold et al., 1994	Yes	No
Goodman & Pynoos, 1990	No	No
Grafström & Winblad, 1995	No	No
Grafström et al., 1994	Yes	Yes
Grafström et al., 1992	Yes	Yes
Greene et al., 1982	No	No
Haley et al., 1987	No	No
Harper & Lund, 1990	Yes	Yes
Hinrichsen & Niederehe, 1994	Yes	Yes
Hooker et al., 1992	No	Yes
Intrieri & Rapp, 1994	No	Yes
Kahan et al., 1985	No	No
Kinney & Stephens, 1989	No	No
Kramer, 1997	Yes	Yes
Lawton et al., 1989	No	No
Lawton et al., 1991	No	Yes
Mangone et al., 1993	No	No
Mohide et al., 1990	No	No
Molloy et al., 1996	No	No
Morris et al., 1988	No	Yes
Morris et al., 1989	No	Yes
Novak & Guest, 1989	No	Yes
Nygaard, 1988	Yes	Yes
Pearson et al., 1988	No	No
Pruchno & Resch, 1989a	No	Yes
Pruchno & Resch, 1989b	Yes	Yes
Pruchno et al., 1990	Yes	Yes
Pruchno, 1990	No	No
Quayhagen & Quayhagen, 1989	No	Yes
Russo & Vitaliano, 1995	No	Yes

(continued)

TABLE 2. Continued

Study	Gender	Kinship
Scott et al., 1986	No	No
Seltzer et al., 1997	No	No
Stephens et al., 1997	No	No
Stuckey et al., 1996	No	No
Talkington-Boyer & Snyder, 1994	No	No
Vitaliano et al., 1991b	No	Yes
Welleford et al., 1995	No	Yes
Williamson & Schulz, 1990	Yes	No
Zarit et al., 1987	Yes	Yes
Zarit et al., 1980	Yes	Yes
Zarit et al., 1986	Yes	Yes

but ranged from 20 to 614. Longitudinal studies had a mean number of 96 participants (range: 19 to 315), whereas the smallest group within any intervention study averaged 55 participants per group (range: 6 to 315).

In four (8%) studies, community-dwelling and institutionalized study participants were mixed. In 12 (23%) studies, the analytic plan was not set up to clearly determine the relationship between independent variables and burden. In two (4%) studies there was a mix of caregivers living with and living separately from care recipients. In one (2%) study, correlation values were not given; only p values were presented. Finally, in four (8%) studies the dropout rate exceeded 25%, and in three of nine intervention studies the groups differed significantly at baseline.

Among the 38 studies providing a clear indication of the best burden predictor, 20 (53%) found behavior problems as the best predictor. Five (13%) found some other care recipient variable, 10 (26%) a caregiver variable (e.g., personality attributes), and 3 (8%) found an external variable (e.g., formal supports) to be the best predictor of burden. Data on predictors are presented in Table 6.

The predominance of behavior problems as the best predictor of burden prompted us to examine the importance of behavior in studies that included it. In 27 (51%) studies, behavior problems were among the variables examined. In 20 (74%), behavior problems emerged as the best predictor of burden. Other care recipient variables, caregiver variables, and external variables were the best predictors in one (4%), four (15%), and two (7%) studies, respectively.

The association between cognition and burden was examined in 25 (47%) studies. A relationship was found in 3 (12%) but not found in 17 (68%), and the results were unclear in 5 (20%) studies. In all three studies with associations, correlations were less than .4 ($r^2 < .2$) and no multivariate statistics were used. Among studies with unclear results, behavior problems were included in measures of cognition in three studies, and ADL limitations were included in the remaining two. The relationship between changes in cognition and changes in burden was examined in four (8%) studies, but no associations were found.

TABLE 3. Instruments Used to Measure Caregiver Burden and Care Recipients' Cognition, Mood, ADL, and Behavior Problems

Study	Burden	Cognition	Mood	ADL	Behavior
Almberg et al., 1997	Other	None	None	None	None
Barusch & Spaid, 1989	Zarit	None	None	Other	Other
Bédard et al., 1997	Zarit	MMSE	GDS	Lawton	Other
Brodaty et al., 1994	Zarit	Other	None	None	MBPC
Burdz et al., 1988	Zarit	MBPC	None	None	MBPC
Deimling & Bass, 1986	Own	Other	Other	Other	Other
Dillehay & Sandys, 1990	Zarit	MBPC	None	Other	MBPC
Draper et al., 1992	Other	None	Other	Barthel	Other
Drinka et al., 1987	Zarit	Other	Other	Barthel	None
Fitting et al., 1986	Zarit	None	None	Other	None
Gallagher-Thompson et al., 1992	Other	MMSE	None	None	Other
Gilhooly, 1984	Other	Other	None	Lawton	Other
Gold et al., 1994	Zarit	MMSE	None	None	Other
Goodman & Pynoos, 1990	Zarit	MBPC	None	None	MBPC
Grafström & Winblad, 1995	Own	MMSE	None	None	Other
Grafström et al., 1994	Other	Other	None	Katz	Other
Grafström et al., 1992	Other	None	None	None	None
Greene et al., 1982	Other	Other	None	Lawton	Other
Haley et al., 1987	Other	MMSE	None	Lawton	MBPC
Harper & Lund, 1990	Zarit	Other	None	Other	Other
Hinrichsen & Niederehe, 1994	Zarit	MBPC	None	Barthel	MBPC
Hooker et al., 1992	Other	None	None	Other	None
Intrieri & Rapp, 1994	Zarit	MBPC	None	None	MBPC
Kahan et al., 1985	Zarit	None	None	None	None
Kinney & Stephens, 1989	Other	Other	None	Other	Other
Kramer, 1997	SCB	MBPC	None	Katz	MBPC
Lawton et al., 1989	Other	Other	None	None	Other
Lawton et al., 1991	Zarit	Other	None	Other	Other
Mangone et al., 1993	Zarit	MMSE	None	Lawton	Other
Mohide et al., 1990	Other	MMSE	None	Barthel	MBPC
Molloy et al., 1996	Zarit	MMSE	GDS	Lawton	Other
Morris et al., 1988	Other	None	None	None	Other
Morris et al., 1989	Other	None	None	None	Other
Novak & Guest, 1989	Zarit	Other	None	Other	Other
Nygaard, 1988	Other	Other	None	Other	Other
Pearson et al., 1988	Own	Other	GDS	Katz	Other
Pruchno & Resch, 1989a	Own	None	None	None	Other
Pruchno & Resch, 1989b	Other	None	None	Other	Other
Pruchno et al., 1990	Other	None	None	Lawton	None
Pruchno, 1990	Zarit	None	None	Lawton	None
Quayhagen & Quayhagen, 1989	Zarit	MBPC	None	None	MBPC
Russo & Vitaliano, 1995	SCB	MMSE	None	Other	None

(continued)

TABLE 3. Continued

Study	Burden	Cognition	Mood	ADL	Behavior
Scott et al., 1986	Zarit	MMSE	None	None	None
Seltzer et al., 1997	Zarit	Other	None	Other	None
Stephens et al., 1997	Other	Other	None	Other	Other
Stuckey et al., 1996	Own	Other	None	None	Other
Talkington-Boyer & Snyder, 1994	Other	MBPC	None	Other	MBPC
Vitaliano et al., 1991b	SCB	MMSE	None	Other	None
Welleford et al., 1995	SCB	MMSE	None	None	None
Williamson & Schulz, 1990	Zarit	None	None	Other	None
Zarit et al., 1987	Zarit	None	None	None	None
Zarit et al., 1980	Zarit	Other	None	Lawton	MBPC
Zarit et al., 1986	Zarit	Other	None	None	Other

Note. ADL = activities of daily living; Zarit = caregiver burden instrument based on that developed by Zarit and colleagues (1980); MMSE = Mini-Mental State Examination; GDS = Geriatric Depression Scale; Lawton = instrument derived from that of Lawton and Brody (1969); MBPC = Memory and Behavior Problem Checklist; Barthel = Barthel instrument (Mahoney & Barthel, 1965); Katz = instrument developed by Katz and colleagues (1963); SCB = Screen for Caregiver Burden.

DISCUSSION

This overview revealed considerable differences between studies on critical methodological issues. These methodological issues need to be addressed in future research. Attention to these methodological issues, including the need for longitudinal designs and subgroup differences, will enable us to move towards a comprehensive theoretical understanding of caregiving.

Subgroups

We found considerable pooling of data from different subgroups; not enough attention was paid to diagnosis, staging, gender, and kinship. Future studies should recruit over longer periods of time, and use multiple sites if necessary to permit the enrollment of a larger number of participants and allow for the control of subgroups. Attention to this issue will assist in accurately determining the predictors of burden by controlling unnecessary variability and decreasing the likelihood of Type II error.

Also, we need to clarify if differences in clinical manifestations, progression of cognitive impairment, and caregiver burden exist across diagnoses. If critical differences emerge across diagnoses, the interpretation of many studies may need to be revisited. Only 3 of 41 studies using a mix of diagnoses controlled for them.

It is also important to provide a clear indication of disease staging to facilitate comparison of cross-sectional studies, and to provide better linkages between changes in caregiver burden and disease stage in longitudinal and intervention studies. We found staging to vary considerably across studies, and it was not determined in 26%. Staging can be indexed by screening tests or duration of symptoms or duration of the caregiving. Screening tests are preferable because they provide more standardized indices of staging, whereas determination of time since symptoms' onset or diagnosis may depend on caregivers' perception and resilience, the referral process, and clinicians' practices. Furthermore, spousal caregivers may not see caregiving begin as early as nonspousal caregivers (George & Gwyther, 1986).

TABLE 4. Attention to Caregiver Variables and External Variables

Study	Caregiver	External
Almberg et al., 1997	Yes	No
Barusch & Spaid, 1989	Yes	Yes
Bédard et al., 1997	Yes	Yes
Brodaty et al., 1994	Yes	No
Burdz et al., 1988	No	No
Deimling & Bass, 1986	No	No
Dillehay & Sandys, 1990	Yes	Yes
Draper et al., 1992	Yes	No
Drinka et al., 1987	Unclear	Unclear
Fitting et al., 1986	Yes	No
Gallagher-Thompson et al., 1992	No	No
Gilhooly, 1984	Yes	Yes
Gold et al., 1994	Yes	No
Goodman & Pynoos, 1990	No	Yes
Grafström & Winblad, 1995	No	Yes
Grafström et al., 1994	No	No
Grafström et al., 1992	Yes	No
Greene et al., 1982	No	No
Haley et al., 1987	Yes	No
Harper & Lund, 1990	Yes	Yes
Hinrichsen & Niederehe, 1994	Yes	Yes
Hooker et al., 1992	Yes	No
Intrieri & Rapp, 1994	Yes	No
Kahan et al., 1985	Unclear	Unclear
Kinney & Stephens, 1989	No	Yes
Kramer, 1997	Yes	No
Lawton et al., 1989	No	Yes
Lawton et al., 1991	Yes	Yes
Mangone et al., 1993	Unclear	Unclear
Mohide et al., 1990	Yes	Yes
Molloy et al., 1996	No	No
Morris et al., 1988	Yes	No
Morris et al., 1989	No	Yes
Novak & Guest, 1989	Yes	No
Nygaard, 1988	No	No
Pearson et al., 1988	No	No
Pruchno & Resch, 1989a	No	No
Pruchno & Resch, 1989b	Yes	Yes
Pruchno et al., 1990	Yes	No
Pruchno, 1990	No	Yes
Quayhagen & Quayhagen, 1989	No	No
Russo & Vitaliano, 1995	Yes	Yes

(continued)

TABLE 4. Continued

Study	Caregiver	External
Scott et al., 1986	Yes	Yes
Seltzer et al., 1997	Yes	Yes
Stephens et al., 1997	No	Yes
Stuckey et al., 1996	Yes	No
Talkington-Boyer & Snyder, 1994	Yes	No
Vitaliano et al., 1991b	Yes	Yes
Welleford et al., 1995	Yes	No
Williamson & Schulz, 1990	Yes	No
Zarit et al., 1987	Unclear	Unclear
Zarit et al., 1980	No	Yes
Zarit et al., 1986	Yes	Yes

Despite mounting evidence that gender and kinship may affect burden, there has been no improvement in the control of these variables. Future studies will have to examine the independent contribution of care recipients' gender, caregivers' gender, and the interaction of both on burden. Gender may have an impact on the measurement of burden and the efficacy of interventions (Bédard et al., 1997). Both qualitative and quantitative differences in the burden experience need further study.

Similarly, not enough data are available on comparisons of caregivers living with care recipients compared to those not living with care recipients, and in some studies these were mixed. Little is known regarding the impact of other commitments (e.g., work) on burden. The issue of secondary caregivers has not been well explored (Malonebeach & Zarit, 1995); the needs of primary and secondary caregivers may be different.

The issue of subgroups remains open for debate and further study. We must identify what subgroups need to be controlled for (likely there are more than those identified here), and also their respective contribution to burden, in isolation or interaction, across the duration of the condition. In addition to the subgroups examined for this review, cultural or ethnic subgroups may show different responses to the aging process and cognitive impairment (Valle, 1994), and need to be researched. Caring for older adults may take many forms. We have the opportunity to enrich our conceptual views of the caregiving process by studying differences between cultures.

Measurement Issues

Further research improvement could also be accomplished by focusing on measurement issues. Reliance on the Zarit instrument (Zarit et al., 1980) has promoted caregiving research and facilitated comparison of studies. However, the Zarit scale is unidirectional and may introduce acquiescence bias (Dillehay & Sandys, 1990). In general, the validity of burden instruments is unclear because they were developed using heterogeneous samples (Vitaliano et al., 1991c) and may not generalize to subgroups of caregivers. Furthermore, the responsiveness of burden instruments to change over time has not been demonstrated. Very few intervention studies have demonstrated improvement in caregiver

TABLE 5. Sample Size (Total or Per Group if Intervention), Type of Design, Use of Multivariate Statistics, and Use of Change Scores (Delta) to Predict Changes in Caregiver Burden

Study	Sample	Design	Multivariate	Delta
Almberg et al., 1997	52	Cross-sectional	Yes	—
Barusch & Spaid, 1989	131	Cross-sectional	Yes	—
Bédard et al., 1997	111	Longitudinal	Yes	Yes
Brodaty et al., 1994	26	Intervention	Yes	Yes
Burdz et al., 1988	35	Intervention	No	No
Deimling & Bass, 1986	614	Cross-sectional	Yes	—
Dillehay & Sandys, 1990	19	Longitudinal	No	No
Draper et al., 1992	99	Cross-sectional	No	—
Drinka et al., 1987	127	Cross-sectional	No	—
Fitting et al., 1986	54	Cross-sectional	No	—
Gallagher-Thompson et al., 1992	35	Longitudinal	Some	Yes
Gilhooly, 1984	37	Cross-sectional	No	—
Gold et al., 1994	131	Cross-sectional	Yes	—
Goodman & Pynoos, 1990	31	Intervention	No	No
Grafström & Winblad, 1995	219	Cross-sectional*	Yes	—
Grafström et al., 1994	209	Cross-sectional	Yes	—
Grafström et al., 1992	110	Cross-sectional	Yes	—
Greene et al., 1982	38	Cross-sectional	No	—
Haley et al., 1987	9	Intervention	No	No
Harper & Lund, 1990	409	Cross-sectional	Yes	—
Hinrichsen & Niederehe, 1994	152	Cross-sectional	Yes	—
Hooker et al., 1992	51	Cross-sectional	No	—
Intrieri & Rapp, 1994	44	Cross-sectional	Yes	—
Kahan et al., 1985	18	Intervention	No	No
Kinney & Stephens, 1989	60	Cross-sectional	No	—
Kramer, 1997	74	Cross-sectional	Yes	—
Lawton et al., 1989	315	Intervention	Yes	Yes
Lawton et al., 1991	272	Cross-sectional	Yes	—
Mangone et al., 1993	25	Cross-sectional	Yes	—
Mohide et al., 1990	20	Intervention	Yes	No
Molloy et al., 1996	108	Cross-sectional	Yes	—
Morris et al., 1988	20	Longitudinal	No	No
Morris et al., 1989	20	Cross-sectional	No	—
Novak & Guest, 1989	30	Cross-sectional	Yes	—
Nygaard, 1988	46	Cross-sectional	No	—
Pearson et al., 1988	46	Cross-sectional	Yes	—
Pruchno & Resch, 1989a	262	Cross-sectional	Some	—
Pruchno & Resch, 1989b	315	Cross-sectional	Yes	—
Pruchno et al., 1990	315	Longitudinal	Yes	Yes
Pruchno, 1990	315	Cross-sectional	No	—
Quayhagen & Quayhagen, 1989	6	Intervention	Some	No
Russo & Vitaliano, 1995	175	Cross-sectional	Yes	—

(continued)

TABLE 5. Continued

Study	Sample	Design	Multivariate	Delta
Scott et al., 1986	23	Cross-sectional	No	—
Seltzer et al., 1997	40	Cross-sectional	Yes	—
Stephens et al., 1997	60	Cross-sectional	Yes	—
Stuckey et al., 1996	129	Cross-sectional	No	—
Talkington-Boyer & Snyder, 1994	110	Cross-sectional	No	—
Vitaliano et al., 1991b	79	Longitudinal	Yes	Yes
Welleford et al., 1995	36	Longitudinal	Yes	No
Williamson & Schulz, 1990	151	Longitudinal	No	No
Zarit et al., 1987	36	Intervention	No	No
Zarit et al., 1980	29	Cross-sectional	No	—
Zarit et al., 1986	64	Cross-sectional	No	—

*Longitudinal component of study was ignored because it included institutionalized participants.

burden, and responsiveness has not been validated against other indices of caregiver burden. Furthermore, the operationalization of burden varies across studies, often in ways that blur the distinction between burden and psychiatric/psychological symptoms (e.g., depression, anxiety).

The use of consistent instruments to index cognitive impairment, ADL, and problem behaviors across studies would also be desirable to facilitate comparison. Selection of a preferred instrument remains a contentious issue. The MMSE is considered the most widely used screening instrument (Manandhar, 1995; Wade, 1992) and the standard (Fleming et al., 1995).

In contrast, there is no standard ADL or behavior instrument. A new ADL scale is currently under development for use in international settings (Lehfeld et al., 1997) and may be suitable if it has good psychometric properties. As many as 100 instruments are currently available to measure problem behaviors in geriatric patients (Zaudig, 1996). Current instruments often combine behavior, cognition, and/or ADL limitations. In many, aggression and sexual dysfunction are poorly examined despite their burden potential. Thus, potentially key variables are not being assessed and will limit the ability to intervene appropriately. Furthermore, the weight given to different types of behavior varies across scales, rendering the combined interpretations of the various studies complicated.

To minimize these measurement problems, new instruments to measure caregiver burden and other critical variables could be developed. The instruments would require consensus on their operationalization, be adaptable to different languages and cultures, and have measurement properties (validity, reliability, and responsiveness) comparable for the different subgroups. An alternative to the development of new scales, or refinement of existing ones, would be to rely on measures of caregiver's objective burden (e.g., time spent caregiving, metabolic changes) (Davis et al., 1997; Vitaliano et al., 1996). However, operationalization of objective burden is a problem, and from a clinical perspective, subjective burden should remain the intervention target.

The impact of care recipient depression symptoms has been the subject of little investigation. Although the evidence linking

TABLE 6. Best Predictor of Caregiver Burden Overall and When Behavior Problems Were Included, and Relationship Between Cognition and Changes in Cognition (Delta) and Caregiver Burden

Study	Best Predictor Overall	Behavior Included	Cognition	Delta
Almberg et al., 1997	Caregiver	—	—	—
Barusch & Spaid, 1989	Behavior	Behavior	—	—
Bédard et al., 1997	Behavior	Behavior	No	No
Brodaty et al., 1994	Unclear	—	—	—
Burdz et al., 1988	Behavior	Behavior	—	—
Deimling & Bass, 1986	Behavior	Behavior	No	—
Dillehay & Sandys, 1990	Unclear	—	—	—
Draper et al., 1992	Behavior	Behavior	—	—
Drinka et al., 1987	Function	—	No	—
Fitting et al., 1986	Unclear	—	—	—
Gallagher-Thompson et al., 1992	Behavior	Behavior	Yes	No
Gilhooly, 1984	Caregiver	Caregiver	Unclear	—
Gold et al., 1994	Behavior	Behavior	No	—
Goodman & Pynoos, 1990	Unclear	—	—	—
Grafström & Winblad, 1995	Behavior	Behavior	—	—
Grafström et al., 1994	Behavior	Behavior	No	—
Grafström et al., 1992	Unclear	—	—	—
Greene et al., 1982	Behavior	Behavior	No	—
Haley et al., 1987	Unclear	—	—	—
Harper & Lund, 1990	Unclear	—	—	—
Hinrichsen & Niederehe, 1994	Caregiver	Caregiver	—	—
Hooker et al., 1992	Caregiver	—	—	—
Intrieri & Rapp, 1994	Caregiver	Caregiver	Unclear	—
Kahan et al., 1985	Unclear	—	—	—
Kinney & Stephens, 1989	Behavior	Behavior	Yes	—
Kramer, 1997	Behavior	Behavior	Unclear	—
Lawton et al., 1989	Unclear	—	—	—
Lawton et al., 1991	External	External	—	—
Mangone et al., 1993	Behavior	Behavior	—	—
Mohide et al., 1990	Unclear	—	—	—
Molloy et al., 1996	Behavior	Behavior	No	—
Morris et al., 1988	Caregiver	—	—	—
Morris et al., 1989	External	—	—	—
Novak & Guest, 1989	Caregiver	Caregiver	Unclear	—
Nygaard, 1988	Unclear	—	No	—
Pearson et al., 1988	Behavior	Behavior	No	—
Pruchno & Resch, 1989a	Behavior	Behavior	—	—
Pruchno & Resch, 1989b	Unclear	—	—	—
Pruchno et al., 1990	Caregiver	—	—	—
Pruchno, 1990	Unclear	—	—	—
Quayhagen & Quayhagen, 1989	Function	—	—	—
Russo & Vitaliano, 1995	Caregiver	—	No	—

(continued)

TABLE 6. Continued

Study	Best Predictor Overall	Behavior Included	Cognition	Delta
Scott et al., 1986	Unclear	—	No	—
Seltzer et al., 1997	Function	—	No	—
Stephens et al., 1997	Behavior	Behavior	No	—
Stuckey et al., 1996	Behavior	Behavior	Yes	—
Talkington-Boyer & Snyder, 1994	Behavior	Behavior	No	—
Vitaliano et al., 1991b	Function	Function	No	No
Welleford et al., 1995	Function	—	No	No
Williamson & Schulz, 1990	Caregiver	—	—	—
Zarit et al., 1987	Unclear	—	—	—
Zarit et al., 1980	External	External	No	—
Zarit et al., 1986	Behavior	Behavior	Unclear	—

depression symptoms to caregiver burden is sparse, some data show a contribution of depression to burden, independent of problem behaviors (Molloy et al., 1996). Also, depression can cause cognitive impairment (Benedict et al., 1999), potentially resulting in misclassification. However, it is recognized that assessment of depression in mid- to late-stage AD may be difficult. The use of established depression measures may be problematic for this population. Nonetheless, some attempt must be made to control for depression symptoms.

The measurement of caregiver and external variables lagged behind the measurement of care recipient cognition, both in the proportion of studies accounting for these variables and in the quality of measurement. The measurement of caregiver and external variables was generally composed of measures obtained through self-report, with a focus on subjective (sometimes objective) components, and sometimes with poor or circular operationalization. In general, the validity and reliability of these measures have not been demonstrated.

Furthermore, external variables may only predict burden in interaction with other variables. For example, work commitments may increase burden whereas the financial security some types of work provide may decrease burden by enabling the acquisition of external supports. Socioeconomic status has not been well examined and may have an impact because of its importance regarding the provision of formal support (Malonebeach & Zarit, 1995). Base work to standardize the measurement of caregiver and external variables is imperative.

Research Design

Attention to subgroups and utilization of appropriate instruments will yield optimal results if design and statistical issues are addressed. Further study of the mechanisms underlying burden can progress with cross-sectional studies. These, however, should be limited to the testing of new hypotheses. Otherwise, the focus should be shifted towards longitudinal and intervention studies, which allow us to test causal linkages between determinants and burden. The research community has yet to embrace these more informative designs fully.

Longitudinal designs also enable us to examine patterns of change in caregiver burden over time. It has been shown that some caregivers experience increases in burden over time whereas others report decreases (Bédard et al., 1997). These data support both the "wear and tear" and "adaptation" hypotheses. Characteristics of the care recipients and caregivers may differ in those who report decreases in burden compared to those who report increases.

Statistical Issues

The call for longitudinal designs also means the consideration of relevant statistical issues. The statistical analysis of longitudinal data can be complex because of the correlation between repeated measurements of the same participants (Hirdes & Brown, 1994; Matthews & Farewell, 1996). Although strategies to account for repeated measurements are available (e.g., regression models) (Liang & Zeger, 1986; Zeger & Liang, 1986), one analytical difficulty remains the simultaneous consideration of the cohort, cross-sectional, and longitudinal effects of the same data (Wassertheil-Smoller, 1990). The complexities inherent to some longitudinal designs highlight the need for appropriate statistical consultation.

The majority of longitudinal and intervention studies reviewed used group means. However, means may mask the dynamic nature of burden because of the inclusion of various subgroups (in clinical trials, one may refer to responders and nonresponders). Attention to individual responses, and not group means, will allow us to determine potential determinants of these different response patterns. This information is crucial in developing effective interventions.

A better understanding of the determinants of burden also relies on multivariate statistics. It is impossible to study totally homogeneous samples given the number of variables that may influence results. However, multivariate statistics provide us with a tool to control for these variables (Afifi & Clark, 1996; Cohen & Cohen, 1983). Since 1990, there has been an increase in the number of studies relying on some form of stratification or multivariate statistics; multivariate statistics must become an integral part of caregiving research.

However, multivariate statistics require large sample sizes, and attrition rates are a logistic problem and considerable threat to the generalizability of results. Recruitment of samples and full completion of research protocols would benefit from in-home assessments. In-home assessments are as equally valid and reliable as in-clinic ones, yet can facilitate recruitment and have the potential to reduce dropout rates (Bédard et al., 1999; Bédard et al., 1995). Using in-home assessments may allow investigators to increase sample sizes while providing better control for subgroups. Generalizability of the results would be increased by the inclusion of care recipients and caregivers who might otherwise not participate, while reducing demands on study participants (Bédard et al., 1998).

Predictors of Caregiver Burden

Assessing methodological strengths and limitations also provided us with the opportunity to determine the most significant predictor of burden. Among the variety of studies examined, problem behaviors associated with cognitive impairment were the most consistent predictor of caregiver burden. It is possible that the predominance of behavior as the best predictor of burden is an artifact of the number of cross-sectional studies conducted with mild and moderately impaired individuals. Behavior problems may decline in more impaired individuals (Reisberg et al., 1996), whereas problems with basic ADL (e.g., continence) increase over time (Haley & Pardo, 1989) and may be more critical as the disease progresses. The limited number of longitudinal studies does not allow us to determine whether behavior problems would remain the best predictor throughout the whole functional spectrum of dementia.

Some behaviors, despite their high frequency (e.g., repeating over and over), have little impact on burden (Molloy et al., 1996). Other behaviors can have a stronger influence on burden. In an earlier study, physical violence was reported as a problem in 23 of 55 caregivers and noted as serious in 18 of these 23 (75%; Rabins et al., 1982). In a subsequent study, correlations between hassles and caregiver strain were stronger when problem behaviors only, rather than the full hassles scale, were used (Kinney & Stephens, 1989). In a more recent study, 59% of the variability in the burden of female spousal caregivers was accounted for by frustrated and aggressive behaviors (Bédard et al., 1999).

Implications for Interventions

There is sufficient evidence regarding the impact of problem behaviors on burden to suggest that interventions should target care recipients. However, because problem behaviors and burden may be exacerbated by caregivers' responses, formal and informal caregivers should not be ignored. Problem behaviors may stem from physiological or environmental causes, but because of cognitive impairment, the causes are not easily communicated by care recipients if at all (Cohen-Mansfield, 1996).

Behavior may be modified through environmental and pharmacological interventions (Rabins et al., 1982). Pharmacological interventions to control behavior may be especially useful in aggressive care recipients. Although the sedative properties of some drugs may have an adverse effect on cognition, changes in cognition are not associated with changes in burden (Bédard et al., 1997). This may represent an acceptable trade-off for caregivers if substantial reductions in burden are achieved and if environmental interventions are not successful.

Until recently, the focus of clinical trials in dementia was on the cognitive function of care recipients, without much consideration of caregiver burden (Hollister & Gruber, 1996). However, drugs that improve cognition may actually increase behavior problems by raising care recipients' awareness of their condition. Interventions aimed at demented individuals must include caregiver burden as a main outcome variable.

Further, few randomized controlled trials of nonpharmacological interventions have been conducted (Mittelman & Ferris, 1996). Nonpharmacological interventions to increase sleep quality (e.g., exercise) and mood (e.g., reminiscence) and otherwise improve care recipients' environments may be beneficial and cost-effective. Such interventions require further study, but should be limited to variables that can be altered with sufficient magnitude to bring about a reduction in burden.

For informal caregivers, interventions may provide emotional support, focus on instrumental needs (e.g., meals), and further the development of skills (e.g., communication, management) to control problem behaviors. Improvement of communication skills alone may improve caregivers' attitudes towards care recipients (Ripich, 1994). These strategies may delay or prevent institutionalization (Cohen et al., 1993a; Mittelman et al., 1993). Formal caregivers need to be trained to interact with care recipients in a fashion that will not aggravate problem behaviors and if possible will reduce them. Formal caregivers also need to be sensitive to the emotions of caregivers while promoting the caregivers' management of the situation.

Conclusion

Research on burden has contributed significantly to the understanding of caregiving; however, we continue to face challenges concerning the causes of burden throughout the caregiving career and appropriate interventions. In order to further our understanding, we need to overcome the methodological barriers highlighted in this article. These changes will allow us to further understand the complexity of caregiver burden and move beyond what we already know.

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