

Longitudinal Study on the Impact of Nursing-Home Respite on
Caregivers and Patients

by

Michael P. Burdz

A thesis
presented to the University of Manitoba
in fulfillment of the
thesis requirement for the degree of
Doctor of Philosophy
in
Department of Psychology

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RESPIRE ON CAREGIVERS AND PATIENTS

BY

MICHAEL P. BURDZ

A thesis submitted to the Faculty of Graduate Studies of
the University of Manitoba in partial fulfillment of the requirements
of the degree of

DOCTOR OF PHILOSOPHY

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ABSTRACT

Previous studies on the impact of nursing-home respite have produced mixed results. Moreover, some researchers have suggested that respite relocation may have a detrimental effect on dementia sufferers, resulting in increased caregiver burden and premature institutionalization. Therefore, the purpose of the present study was twofold: (a) to assess what effect nursing-home respite had on caregivers and patients, and (b) to assess what effect patient diagnosis (i.e., dementia vs. nondementia) had on respite outcome. Subjects were 33 predominantly female caregivers: 17 providing care to a mentally alert patient and 16 providing care to a cognitively impaired patient. Caregivers were interviewed in their own homes on 3 occasions: 1 week prior to respite admission, 1 week after respite discharge, and 1 month after the second interview. The interview schedule consisted of the Memory and Behavior Problems Checklist, Center for Epidemiologic Studies Depression Scale, Life Satisfaction Index-Z, and Family Impact Questionnaire. It was hypothesized that caregivers would be well rested after respite and would report improved psychological functioning. It was also hypothesized that respite patients, regardless of diagnosis, would be able to tolerate respite relocation and would manifest no decrement

in functioning. Moreover, nondementia patients were expected to improve following 2 weeks of nursing care. A 2 x 3 (Diagnosis x Time of Measurement) mixed-model-multivariate analysis of variance was used to analyze the longitudinal data, with repeated measures on all dependent variables. There was no significant main order effect, nor an interaction effect. The finding of no change in caregiver or in patient functioning is consistent with previous studies. Explanations are offered for the absence of the hypothesized improvement. One encouraging finding is that the patient's functional status was unaffected by respite relocation, indicating that caregivers can be periodically relieved of their caregiving duties without harming the patient. The present investigator believes that respite care is unlikely to prevent nursing-home placement, but it may prevent caregiver stress from reaching levels that would negatively affect the quality of care provided to the patient. Therefore, the criterion by which respite should be judged is whether the program delays nursing-home placement, not whether it prevents nursing-home placement.

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LONGITUDINAL STUDY ON THE IMPACT OF NURSING-HOME RESPIRE ON CAREGIVERS AND PATIENTS

A Brief Overview of Dementia

Etiology

Huppert and Tym (1986, p. 11) have described dementia as "the most serious psychiatric disorder of old age," with a prevalence rate of 5% among those over 65 years of age and 15% among those over 80 years of age. Recently, Evans and colleagues (1989) reported that the prevalence rate (of Alzheimer's disease) may actually reach 47.2% among those over 85 years of age. Although there may be some confusion surrounding the prevalence of dementia, the diagnostic criteria have been clearly outlined by the American Psychiatric Association ([APA], 1987, p.107). The hallmark of the disorder is loss of memory, both short term and long term. In addition to loss of memory, there must be impairment in one of the following areas: abstract thinking, judgement, cortical functioning (e.g., aphasia, apraxia, agnosia, "constructional difficulty"), or personality. The combined effect of all these deficits is impairment of social and occupational functioning. But before a diagnosis of dementia can be made, other treatable syndromes, such as delirium and depression, must be excluded by virtue of history, physical examination, and laboratory findings.

The leading cause of dementia is Alzheimer's disease, accounting for 40 to 60% of cases (Carnes, 1984, Table 2, p. 15). Because there is no diagnostic test presently available for Alzheimer's disease (Wurtman, 1985, p. 62), the examiner must consider the course of the disease when making a diagnosis. If symptoms emerge gradually and become progressively worse with time, then a diagnosis of Alzheimer's disease can be made, provided that other potential causes have been excluded (APA, 1987, p. 120; Terry & Katzman, 1983, p. 499). There are presently 300,000 Canadians suffering from Alzheimer's disease, and the number is expected to reach 550,000 within 30 years (Creighton, 1989, p. 27). The majority of these cases will be female (APA, 1987, p. 120).

The structural changes to the Alzheimer brain have been well described; they include neurofibrillary tangles, senile plaques, and granulovacuolar degeneration. Neurofibrillary tangles are twisted filaments found within the neuron, which disrupt the transport of neurotransmitters and, consequently, interfere with interneuronal communication (Storandt, 1983, p. 3). Senile plaques have an amyloid centre, which is encased by neuronal debris (Katzman, 1988, p. 73). It appears that amyloid escapes from blood vessels and attacks axon terminals (Rosenweig & Leiman, 1982, p. 112). Because amyloid is an antibody, some researchers have implicated the immune system in the disease process

(Storandt, 1983, p. 3). In Alzheimer's disease, tangles and plaques are found in both the hippocampus and the cortex, but in the healthy aged, tangles and plaques are found in smaller numbers and are largely restricted to the hippocampus (Tomlinson, Blessed, & Roth, 1970). The number of plaques and tangles has been positively correlated with the degree of impairment (Terry, 1985, p. 22).

Granulovacuolar degeneration affects pyramidal cells in the hippocampus; they become swollen with granular material (Tomlinson, et al., 1970). These three structural changes have been found in the hippocampus, cortex, and amygdala, thus producing a change in memory, cognition, and emotion (Gershon and Herman, 1982, p. 62).

There is also a neurochemical change associated with Alzheimer's disease. Specifically, there is 50 to 90% less choline acetyltransferase available to the neocortex and hippocampus (Terry & Katzman, 1983, p. 501). This enzyme is needed to produce the neurotransmitter acetylcholine, which is involved in memory and learning (Gershon & Herman, 1982, p. 62; Storandt, 1983, p. 4). This enzyme deficiency is attributed to the loss of cholinergic neurons in the basal nucleus of Meynert and in the septum, which project onto the neocortex and hippocampus, respectively (Joynt & Shoulson, 1985, p. 460; Lauter, 1985, p. 11). Researchers have attempted to correct the cholinergic deficiency by administering acetylcholine precursors (e.g., choline and

lecithin); however, these drugs have had no significant effect on memory or cognition (Lauter, 1985, p. 15; Terry & Katzman, 1983, p. 503). A second pharmaceutical approach has been to prevent the disintegration of acetylcholine by administering acetylcholinesterase inhibitors; however, these drugs are toxic (Terry & Katzman, 1983, p. 503).

The cause of Alzheimer's disease remains unknown (Wurtman, 1985, p. 62). After reviewing the six leading causal theories, Wurtman concluded that none could be viewed as definitive. These theories included genetic error, abnormal protein, slow-acting virus, environmental toxin, reduced blood flow, and acetylcholine deficiency.

A second cause of dementia is multi-infarct dementia, accounting for 10 to 15% of cases (Carnes, 1984, Table 2, p. 15). Dementia results from the loss of brain tissue due to blockage of cerebral arteries (Cummings, 1987, p. 124; Magee & Saper, 1981, p. 153). The two leading causes of blocked arteries are thrombosis (progressive blockage, such as arteriosclerosis) and embolus (abrupt occlusion attributed to a "floating clot") (Cummings, 1987, p. 124; Magee & Saper, 1981, pp. 153, 154). Multi-infarct dementia is usually caused by a series of strokes occurring over time rather than by a single stroke (APA, 1987, p. 122).

Unlike Alzheimer's disease, the symptoms of multi-infarct dementia usually emerge suddenly and progress in a

"stepwise" fashion (APA, 1987, p. 122). The symptoms of multi-infarct dementia depend on the location and the amount of infarcted tissue (Cummings, 1987, p. 124). Most strokes occur unilaterally along the middle cerebral artery and inside the internal capsule, producing symptoms on the side contralateral to the injury (Magee & Saper, 1981, pp. 155-156). Motor and sensory symptoms are more common than are psychiatric symptoms (Magee & Saper, 1981, p. 156; Perry, 1984, p. 91). Injuries approaching 50 ml in size may result in dementia, whereas injuries approaching 100 ml in size invariably result in dementia (Tomlinson et al., 1970).

There are two other major differences between multi-infarct dementia and Alzheimer's disease. First, multi-infarct dementia occurs at a younger age (APA, 1987, p. 122), having its highest prevalence between the ages of 40 and 60 (Gershon & Herman, 1982, p. 63). Second, men are more likely to develop multi-infarct dementia than are women (APA, 1987, p. 122).

Unlike Alzheimer's disease, the risk of multi-infarct dementia can be reduced by avoiding cigarettes and by monitoring one's hypertension, diabetes, blood lipids and triglycerides [i.e. fat intake], and body weight (Cummings, 1987, p. 124). Furthermore, in existing cases of multi-infarct dementia, the progression of the disease may be altered by observing these guidelines (Cummings, 1987, p. 124). To help distinguish multi-infarct dementia from

Alzheimer's disease, Hachinski and colleagues (1975, Table 3, p. 634) developed a 13-item scale. Those features most characteristic of multi-infarct dementia included abrupt onset, fluctuating course, history of strokes, focal neurological symptoms, and focal neurological signs. Molsa, Paljarvi, Rinne, Rinne, and Sako (1985) administered Hachinski's Ischaemic Score to 58 dementia patients. They used the following scoring system: 0 to 4 indicated Alzheimer's disease, 5 to 6 indicated a mixed diagnosis of Alzheimer's disease and multi-infarct dementia, and 7 or more indicated multi-infarct dementia. When those patients scoring 5 or more were collapsed into one diagnostic category, the Ischaemic Score was 73.3% successful in distinguishing vascular dementia from Alzheimer's disease. Additional support for the Ischaemic score was obtained from Bucht, Adolfsson, and Winblad (1984), who compared 19 Alzheimer patients to 20 multi-infarct patients. They found that focal neurological signs, abnormal electrocardiogram readings, and localized slow frequencies on the electroencephalogram were more frequently associated with multi-infarct dementia.

A third cause of dementia is a joint diagnosis of Alzheimer's disease and multi-infarct dementia, accounting for 15 to 20% of cases (Carnes, 1984, Table 2, p. 15). The remaining 5 to 10% of cases are attributed to rarer neurological disorders such as Creutzfeld-Jacob disease,

Huntington's disease, Pick's disease, and Parkinson's disease (which results in dementia in approximately one third of cases) (Carnes, 1984, Table 2, p. 15; Jenike, 1986, p. 408). However, the true cause of dementia can only be established by performing a brain biopsy (Bucht et al., 1984, p. 495).

Treatable syndromes may also produce dementia symptoms, resulting in misdiagnosis. For example, the depressed aged may complain of memory loss and other cognitive deficits (APA, 1987, p. 106; Gershon & Herman, 1982, p. 64; Haggerty, Golden, Evans, & Janowsky, 1988, p. 65). Furthermore, their neuropsychological profile and mental-status score may suggest organic impairment (APA, 1987, p. 106). However, there are a number of differences between dementia and "pseudodementia." First, unlike dementia, the symptoms of pseudodementia usually emerge suddenly and progress rapidly (APA, 1987, p. 106). Second, dementia patients are often unaware of their memory loss or deny its existence, whereas the depressed aged are aware of their impairment and are concerned about it (Gershon & Herman, 1982, p. 64; Ware & Carper, 1982, p. 474). Third, the depressed aged are more likely to have a personal history of depression or a family history of mental illness (Haggerty et al., 1988, p. 67; Lauter, 1985, p. 4).

Cognitive functioning should improve following a trial of antidepressant medication or electroconvulsive therapy as depression lifts (APA, 1987, p. 106; Janowsky, 1982, p. 25).

However, approximately one quarter of Alzheimer sufferers have a coexisting depression (Terry & Katzman, 1983, p. 502). Depression may stem from one of two causes: either patients are aware of their intellectual decline, or it is a byproduct of altered neurochemistry (Gershon & Herman, 1982, p. 65). Depression only exacerbates cognitive impairment (Haggerty et al., 1988, p. 67). When antidepressants are prescribed, it is imperative that they not have anticholinergic properties, which would only aggravate cognitive impairment (Terry & Katzman, 1983, p. 502).

Delirium may also be mistaken for dementia. Older adults suffering from delirium may manifest memory impairment and other cognitive deficits (APA, 1987, pp. 100, 106). These deficits are commonly caused by a disruption in cerebral metabolism (Emery & Breslau, 1988, pp. 69-70). Unlike dementia, the symptoms of delirium emerge suddenly and fluctuate in intensity (APA, 1987, p. 100). The symptoms may be reversed if delirium is treated quickly; however, if treatment is delayed, delirium may result in dementia (APA, 1987, p. 102). Cases of coexisting delirium and dementia do occur, making the diagnosis of the latter more difficult (APA, 1987, p. 102).

There are other treatable conditions which may be mistaken for dementia. A partial list includes: chronic increased pressure (e.g., normal pressure hydrocephalus), infections (e.g., tuberculous meningitis), nutritional

disorder (e.g., pernicious anemia), drug toxicity (e.g., tranquilizers), environmental toxins (e.g., lead), brain lesion (e.g., tumors), endocrine diseases (e.g., hypothyroidism), and metabolic diseases (e.g., hepatic disease) (see Table 12-1, p. 165, of Magee & Saper, 1981, for a complete list). To prevent misdiagnosis, a complete assessment should be completed on the patient, including an interview, psychometric testing, a physical and neurological examination, and laboratory testing (see Table 12-2, p.166, of Magee & Saper, 1981, for a complete list).

Course

As described in the previous section, the onset and course of dementia depends on the underlying cause (APA, 1987, p. 105). In Alzheimer's disease, symptoms emerge gradually and become progressively worse with time (APA, 1987, p. 120), whereas in multi-infarct dementia, symptoms emerge suddenly and progress in a "stepwise" fashion (APA, 1987, p. 122). Not only is there variability between diagnostic categories, but also within categories (Whitehouse, 1987, p. 111). For example, the average duration of Alzheimer's disease is 6 to 10 years, but may range from 2 to 20 years (Jenike, 1986, p. 409).

Reisberg (1986) has identified seven stages in dementia. In stage 1, functioning is normal. In stage 2, occupational and social functioning appear normal to co-workers and

relatives, but the individual is aware of memory impairment. By stage 3, memory impairment begins to interfere with occupational and social functioning. By stage 4, instrumental activities of daily living, such as handling money, become impaired. By stage 5, basic activities of daily living, such as selecting appropriate clothes, become impaired, and supervision is required. In stage 6, the individual loses the ability to dress, bathe, and toilet independently, in chronological order. Incontinence is the result of nonresponse to brain signals. At this point, caregivers usually pursue nursing-home placement. Individuals may also manifest psychiatric symptoms, such as agitation, paranoia, and delusions. In the seventh stage, speech is replaced by nonintelligible utterances. The individual is unable to walk or to sit, and must be confined to bed. In the end, consciousness is lost and death occurs.

Impact on Family Caregivers

In recent years, the issue of caregiver burden has received a great deal of attention in the gerontological literature. The present literature review, however, will be restricted to those studies dealing with caregivers who lived with and provided care to dementia patients. Five studies will be reviewed.

Rabins, Mace, and Lucas (1982) interviewed 55 caregivers of dementia patients (8 of whom did not live with the patient). The three most common negative outcomes associated with caregiving were: feeling depressed, angry, or tired (87%); family discord (56%); and loss of time for self, as well as loss of friends and hobbies (55%) (Rabins et al., 1982, Table 3, p. 334).

Snyder and Keefe (1985) surveyed 117 caregivers who were either living with the patient or had recently relinquished their caregiving duties because of nursing-home placement or patient death. The cognitively impaired comprised 45% of the patient sample. Nearly 70% of caregivers reported poorer health as a result of caregiving. Furthermore, caregiving duties were usually assumed by one person, with only 28% of caregivers receiving help regularly from other relatives.

Haley, Levine, Brown, Berry, and Hughes (1987) compared 44 caregivers of dementia patients to 44 noncaregivers who were matched for age, sex, marital status, and race. Compared to noncaregivers, caregivers reported significantly: (a) poorer psychological functioning (i.e., depression, life satisfaction, quality of caregiver-patient relationship); (b) poorer health; (c) greater demand for health-care services (i.e., doctor visits and prescribed medication); and (d) more dissatisfaction with their support network (although the size of their network was not

significantly different from that of the comparison group) (Haley et al., 1987, Table 3, p. 409).

Cohen and Eisdorfer (1988) interviewed 46 relatives of 27 dementia patients. Caregivers were neither receiving respite services nor participating in a family support group. As part of the study, caregivers were interviewed by a psychiatrist. Twelve of the 22 caregivers residing with the patient were diagnosed as depressed using DSM-III criteria (5 suffered from unipolar depression and 7 suffered from adjustment disorder with depressive symptoms). Conversely, not one relative among the 24 living away from the patient was so diagnosed. Furthermore, depressed relatives experienced higher levels of distress and were perceived as coping more poorly. According to Houlihan (1987, p. 351), depression only exacerbates caregiver burden.

Pruchno and Potashnik (1989) surveyed 315 spousal caregivers of dementia patients on three occasions during a one year period. Caregivers' health status was compared to existing population norms, controlling for age and gender. Caregivers were more depressed, received more prescribed medication, and reported poorer physical health.

Houlihan (1987, p. 351) contends that providing care to a dementia patient is more burdensome than providing care to a physically frail patient. The reason for this becomes

clearer after reading Silliman and Sternberg (1988), who compared the caregiving demands of the physically frail (e.g., hip fracture) to those of the cognitively impaired. First, hip fracture patients do not require constant supervision; consequently, caregivers have greater flexibility in their schedules. Second, hip fracture patients can be expected to make a substantial recovery from their injury. Third, hip fracture patients are able to interact with their caregivers, and rarely resist their assistance. In contrast, caregivers of dementia patients have less flexibility in their schedules, face increasing dependency, and have no meaningful relationship with their relatives (see Ory et al., 1985, p. 629). Gwyther and Blazer (1984, p. 149) suggest that even the best functioning families find it difficult to provide care to a dementia patient.

In a recent study, Caserta, Lund, Wright, and Redburn (1987) surveyed 597 caregivers of dementia patients. They found that 50% of caregivers provided at least 16 hours of care daily. Despite these sacrifices, caregivers are generally reluctant to pursue nursing-home placement (Ory et al., 1985, p. 626). They would prefer to continue providing in-home care, but require some supplemental assistance (Snyder & Keefe, 1985, p. 12). One intervention recommended by gerontologists and caregivers is nursing home or hospital respite (e.g., Rabins et al., 1982, p. 335; Robertson &

Reisner, 1982, Table 5, p. 37; Snyder & Keefe, 1985, p. 9).
An overview of respite follows.

Overview of Respite

Scharlach and Frenzel (1986, p. 78) have defined "respite" as a service that allows caregivers to have a brief holiday from regular caregiving duties. It is intended to relieve caregivers and to prevent, or at least delay, nursing-home placement. Scharlach and Frenzel have identified three respite modalities: in-home (e.g., home attendant), day respite (e.g., adult-day care), and extended respite (e.g., nursing home). The present study will focus on nursing-home respite.

The nursing-home respite program in Winnipeg is administered by the Continuing Care Program (C. Lussier, personal communication, November 30, 1989). There are 26 respite beds located in various nursing homes throughout the city. The per-diem cost to the respite user is the same as that for a nursing-home resident, approximately one third of the total cost. From April 1, 1988 to March 30, 1989, 301 families used the program.

Being relocated from one environment to another is a stressful experience for an older adult (Schulz & Brenner, 1977). After completing an exhaustive literature review, Bourestom (1984) concluded that relocation outcome was

largely mediated by four factors: (a) whether the individual moved voluntarily or involuntarily, (b) the degree of environmental change involved, (c) the individual's physical and mental health, and (d) whether the individual was prepared by staff for relocation. Elevated mortality rates and overall poor adjustment were more likely when the subject moved involuntarily, experienced a dramatic environmental change (e.g., community residence to nursing home), was physically or cognitively impaired, and was unprepared for relocation. Conversely, positive or neutral effects were more likely when the subject moved voluntarily, experienced a less dramatic environmental change (e.g., nursing home to nursing home), was healthier, and had been prepared for relocation.

Although respite relocation is only temporary, some researchers (Burdz, Eaton, & Bond, 1988; Seltzer et al., 1988) have expressed concern that it may have a detrimental effect on dementia patients, resulting in increased caregiver burden and premature institutionalization. To assess the validity of this concern, six studies on extended respite will be reviewed.

The Foundation for Long-Term Care (1983) surveyed 134 caregivers one month after respite discharge from one of six facilities. The condition of the respite patient was as follows: 26% had improved, 51% remained unchanged, and 23% had deteriorated (p. 15). Although 76% of patients still

resided at home, 12% were in nursing homes and 5% had died (p. 15). Mortality and placement rates were higher than existing population norms. Elevated rates were attributed to one of two causes: either respite was the final attempt at community care, or respite exposure had alleviated caregivers' concerns surrounding nursing-home placement. Although the majority of caregivers (78%) were very satisfied with the program (p. 20), it would have been beneficial had the authors attempted to identify those caregiver or patient characteristics associated with deteriorating health and nursing-home placement.

Scharlach and Frenzel (1986) surveyed 99 caregivers following respite care (where the average respite stay was 7 days). All caregivers were female and all patients were male. Caregivers were most likely to report improvement in their own health (72%), in their ability to continue providing care (64%), and in their relationship with the patient (56%). They were less likely to report change in the patient's physical (52%) or cognitive (65%) status. Caregivers were equally divided on the likelihood of nursing-home placement: 33% considered it less likely and 30% considered it more likely. A sizeable minority of caregivers (38%) reported deterioration in their relationship with the patient. Once again, although the majority of caregivers (70%) were very satisfied with the program, it would have been beneficial had the authors

attempted to identify those caregiver or patient characteristics associated with negative outcome.

Seltzer and colleagues (1988) provided a 2-week in-hospital respite to 37 Alzheimer patients (36 males and 1 female). These authors were initially concerned that patients would deteriorate following respite, resulting in increased caregiver burden and premature institutionalization. To test this hypothesis, patients' cognitive and physical functioning were assessed both at respite admission and at respite discharge. There was no significant change from pretest to posttest. When data were reanalyzed using patient's functional status at baseline as a covariate, poorer functioning patients were more likely to show improvement, whereas better functioning patients were more likely to show deterioration. The magnitude of improvement was small and largely confined to activities of daily living, with no change in cognitive functioning detected. A subsample of 24 caregivers was reinterviewed 2 and 4 weeks after respite discharge; these caregivers reported no change in patient functioning. The authors decided not to conduct additional interviews for fear of confounding results with the inherent deterioration of Alzheimer's disease. They concluded that the program had no appreciable effect on the course of Alzheimer's disease. Although the authors acknowledged that respite was designed primarily to relieve caregiver stress, no attempt was made to assess the program's effect on caregivers.

Burdz, Eaton, and Bond (1988) hypothesized that respite outcome would be mediated by the patient's mental status. Specifically, dementia patients were expected to deteriorate following respite care, resulting in increased caregiver burden. Conversely, mentally alert patients were not expected to deteriorate. There were 35 caregivers (89% female) in the respite condition, who were interviewed before and after respite, and 20 caregivers (75% female) in the waiting-list condition, who were interviewed on two occasions during a 5-week period. Both groups consisted of caregivers to the mentally alert and the cognitively impaired. Neither group reported change in caregiver burden. Caregivers in the respite condition did report improved patient functioning following respite, regardless of patient diagnosis. However, the authors were uncertain as to whether this improvement would be maintained beyond the short term.

Montgomery and Borgatta (1989) assessed what effect different combinations of respite and educational services (i.e., seminars for caregivers, support groups, and family consultation) had on caregiver burden and on the rate of nursing-home placement. After a baseline interview, 541 caregivers (79% female) were randomly assigned to either one of the five treatment groups or the control group, and then reinterviewed 12 months later. The cognitively impaired comprised 28% of the patient sample. Caregivers in the

respite condition were eligible for \$882 in medicare funds, which was equivalent to 14 days of nursing-home respite; however, they were free to choose their respite modality (i.e., in-home, day care, nursing home). Among those caregivers still providing care 12 months later, there was a significant decrease in subjective burden from baseline to posttest for all treatment groups, but not for the control group. Surprisingly, spousal caregivers in four of the treatment groups (including respite) had a higher rate of nursing-home placement when compared to spousal caregivers in the control group. The authors were encouraged by this finding because spousal caregivers are generally reluctant to pursue nursing-home placement. On the other hand, filial caregivers in the treatment groups had a lower rate of nursing-home placement relative to filial caregivers in the control group, though the trend was nonsignificant. Unfortunately, the authors never reported what effect each respite modality had on caregiver burden or on the rate of nursing-home placement. They found that families were generally reluctant to use caregiver services prior to a crisis. This trend was reflected in the high rate of attrition among patients: 15% were in nursing homes and 25% had died prior to the posttest interview. Consequently, it was difficult to test the preventive qualities of caregiver services. The authors contend that caregiver services must reach families sooner if they hope to achieve their stated goals, namely, "reduce burden, delay nursing home placement, and reduce costs" (p. 464).

Lawton, Brody, and Saperstein (1989) assessed the impact of three respite modalities: in-home, day, and nursing home. Following a baseline interview, 632 caregivers (79% female) of Alzheimer patients were randomly assigned to either the experimental or the control group, and then reinterviewed 12 months later. Respite patients spent 22 more days in the community than did control patients. However, the program had no effect on caregiver measures of well-being. Caregivers were generally reluctant to use respite care, often requesting assistance only after a crisis had occurred or the late stages of caregiving had been reached, thereby precluding testing the program's preventive qualities. Only one half of eligible caregivers used respite. Those that did, used it infrequently. For example, among the 48 caregivers who used nursing-home respite, the median stay was 11 days. This is equivalent to only one respite stay for the year (in Winnipeg), and may explain the lack of significant findings among caregivers.

In response to the Lawton et al. study, Callahan (1989) argued that additional studies will be required to establish the efficacy of respite care before government funding is provided to the program. There are, however, three additional points concerning the Lawton et al. study that should be noted. First, caregivers used respite care too infrequently for the program to have an effect. It is simply unrealistic to expect the equivalent of one nursing-

home stay for the year to have an appreciable effect on caregivers. Second, although the program was used infrequently, respite patients still managed to spend 22 more days in the community than did control patients. Third, caregivers often came forward only after experiencing a crisis, something this preventive program was never intended to handle.

The purpose of the present study was twofold: (a) to assess what effect nursing-home respite had on caregivers and patients; and (b) to assess what effect patient diagnosis (i.e., dementia vs. nondementia) had on respite outcome. The study warranted investigation because of the inconsistent findings reported elsewhere. For example, the Foundation for Long-Term Care (1983) found that a sizable minority of patients had deteriorated one month after respite, whereas other studies reported no decrement in functioning (Burdz et al., 1988; Seltzer et al., 1988). Furthermore, Montgomery and Borgatta (1989) reported a decrease in subjective burden following respite, whereas other researchers reported no change in caregiver measures (Burdz et al., 1988; Lawton et al., 1989).

In the present study, caregivers using nursing-home respite were interviewed on three occasions: 1 week prior to respite admission, 1 week after respite discharge, and 1 month after the second interview. At each interview, caregivers' psychological functioning (i.e., depression,

life satisfaction, quality of caregiver-patient relationship) and their perception of patient functioning were assessed. Two hypotheses were generated:

1. Caregivers would be well rested after respite and would report improved psychological functioning. These gains would be maintained at Posttest 2.
2. Respite patients, regardless of diagnosis, would be able to tolerate respite relocation and would manifest no decrement in functioning. Moreover, nondementia patients were expected to improve following 2 weeks of nursing care.

Unlike previous studies, the present study combined the following features: (a) it was longitudinal and prospective in nature; (b) it assessed the program's short-term effect both on caregivers and on patients; and (c) it considered the specific role of patient diagnosis (i.e., dementia vs. nondementia) in respite outcome.

Method

Subjects

Thirty-three primary caregivers who used nursing-home respite during the summer of 1988 were interviewed. Caregiver and patient characteristics appear in Table 1. The majority of caregivers was female (79%), with spouses (52%) and daughters (39%) constituting the two largest groups. Caregivers of dementia patients were approximately 6 years older than were caregivers of nondementia patients, and had been providing care for approximately 1 1/2 years longer. With one exception, all caregivers lived with the patient. The patient sample was predominantly female (61%). One third had been paneled for nursing-home placement, and 58% were intermittent users of respite. Dementia patients were approximately 1 year older than were nondementia patients. The patient's diagnosis was made by the family physician (see Table 2); however, the investigator remained blind to the diagnosis until data collection was completed. All participants were treated in accordance with the ethical standards of the American Psychological Association (1981).

Not all caregivers contacted agreed to participate. Of the 45 caregivers initially contacted, 39 (87%) agreed to participate. The six caregivers who refused were female, and two were caregivers of a dementia patient. Their reasons for refusing were: one caregiver could not speak English, one caregiver cited a negative experience with a

TABLE 1
Characteristics of the Longitudinal Sample

Variable	Total sample (N=33)	Diagnosis	
		Nondementia (n=17)	Dementia (n=16)
Mean age of patient	79.2	78.6	79.7
Sex of patient			
Female	20	11	9
Male	13	6	7
Mean age of caregiver	65.1	62.1	68.3
Sex of caregiver			
Female	26	16	10
Male	7	1	6
Relationship			
Spouse	17	6	11
Son/daughter	13	9	4
Son/daughter-in-law	1	0	1
Brother/sister	1	1	0
Other	1	1	0
Mean number of months spent caregiving	54.8	45.8	64.4
Paneled for nursing home			
Yes	11	5	6
No	22	12	10
Respite use			
One time	14	8	6
Intermittent	19	9	10

TABLE 2
Etiology by Diagnosis

Diagnosis	
<hr/>	
Dementia (n=16)	
Alzheimer's disease	10
Multi-infarct dementia (MID)	3
Parkinson's disease	2
Mixed Alzheimer's and MID	1
Nondementia (n=17)	
Cerebrovascular accident	4
Multiple sclerosis	2
Congestive heart failure	2
Rheumatoid arthritis	2
Chronic renal failure	1
Peripheral vascular disease	1
Hypoparathyroidism	1
Parkinson's disease	1
Cerebral palsy	1
Oral cancer	1
Hip replacement	1

previous study, and four caregivers felt unable to meet the demands of three interviews.

Of the 39 caregivers interviewed at pretest, 6 were unavailable at Posttest 1, and were therefore excluded from the data analysis. They were unavailable for the following reasons: one patient had died, one patient was hospitalized during respite, one patient was admitted to a nursing home, one caregiver canceled respite, and two caregivers refused to be reinterviewed.

Of the 33 caregivers interviewed at Posttest 1, 11 were unavailable at Posttest 2. They were unavailable for the following reasons: one patient was readmitted to respite, one patient had died, two patients were hospitalized, two caregivers refused to be reinterviewed, and five patients were admitted to nursing homes.

Instruments

One major criticism of earlier studies on the impact of dementia has been their reliance on the multidimensional construct of "burden," rather than assessing the caregiver's response in greater detail (Niederehe & Fruge, 1984, pp. 38-39). This criticism could also be extended to the present investigator's earlier study of respite (Burdz et al., 1988). In that study, only one global measure of caregiver burden was used. It is plausible that change did

occur among caregivers, but that it was not detected. Therefore, this study reexamined the impact of respite by using a range of measures which were found to be sensitive to the caregiver's experience by Haley and colleagues (1987). The reader will recall that these authors compared 44 caregivers of dementia patients to 44 matched noncaregivers. Among the items assessed were psychological functioning; specifically, depression, life satisfaction, and quality of caregiver-patient relationship. They found that caregivers reported significantly poorer psychological functioning. The same psychological measures were used with one modification: The Beck Depression Inventory was replaced by the Center for Epidemiologic Studies Depression Scale because of the latter's greater emphasis on depressed mood. Each scale will now be reviewed.

Memory and Behavior Problems Checklist. Zarit and Zarit's scale (cited in Zarit, Orr, & Zarit, 1985, pp. 78-79; see Appendix A) consists of 29 memory and behavior problems commonly associated with dementia. Examples include: "Asking the same question over and over again," "Losing or misplacing things," and "Doing things that embarrass you." Each item was read to the caregiver, who was provided a card containing response categories. Caregivers were asked to indicate how frequently the problem occurred during the past week on a 5-point scale, from never occurred (0) to occurs daily or more often (4). The

Frequency score could range from 0 to 120, with higher scores indicating lower patient functioning. If the problem did occur, caregivers were asked to indicate how upsetting it was to them on a 5-point scale, from not at all (0) to extremely (4). The Reaction score could range from 0 to 120, with higher scores indicating less acceptance. A third score was generated by this scale; specifically, the cross product of each frequency and reaction rating (Zarit, Todd, & Zarit, 1986, p. 262). The Cross-Product score could range from 0 to 480, with higher scores indicating greater caregiver stress. Quayhagen and Quayhagen (1988, p. 392) reported a reliability coefficient alpha of .78 for the Cross-Product Scale.

Center for Epidemiologic Studies Depression Scale. This scale consists of 20 items assessing depressive symptomatology, with stress given to depressed mood (Radloff, 1977, Table 1, p. 387; also cited in Corcoran & Fischer, 1987, p. 119; see Appendix B). It was validated with a sample of 3574 white subjects from the general population (1422 of whom were retested) and a sample of 105 psychiatric patients (Radloff, 1977, Table 2, p. 389). Examples include: "I did not feel like eating, my appetite was poor," "I felt that everything I did was an effort," and "My sleep was restless." Each item was read to the caregiver, who was provided a card containing response categories. Caregivers were asked to indicate how often they felt or behaved this

way during the past week on a 4-point scale, from rarely or none of the time (0) to most or all of the time (3).

Because four items were positively worded (4, 8, 12, 16), they required reverse scoring. The Depression score could range from 0 to 60, with higher scores indicating more depressive symptoms. A score of 16 has been used repeatedly as the clinical cut-off for depression (Husaini, Neff, Harrington, Hughes, & Stone, 1980; Mahard, 1988; Radloff, 1977). The scale distinguished a general population sample from a psychiatric sample (Radloff, 1977, p. 393).

Reliability coefficient alpha for the general population and the psychiatric samples was .85 and .90, respectively (Radloff, 1977, p. 391). Because the scale was intended to measure current level of symptomatology, its developers expected test-retest correlations to be in the moderate range (Radloff, 1977). When tested over 2 to 8 weeks, correlations ranged from .51 to .67 (Radloff, 1977, Table 4, p. 392).

Life Satisfaction Index-Z. This scale consists of 13 items assessing life satisfaction (Wood, Wylie, & Sheafor, 1969, pp. 467-468; see Appendix C). It was validated with a sample of 100 older adults, ranging in age from 63 to 92 (Wood et al., 1969). Examples include: "As I grow older, things seem better than I thought they would be," "This is the dreariest time of my life," and "The things I do are as interesting to me as they ever were." Each item was read to

the caregiver, who could either agree with the statement, disagree, or indicate "don't know." The scoring system was as follows: a "right" answer received a score of 2, a "don't know" answer received a score of 1, and a "wrong" answer received a score of 0. The Life-Satisfaction score could range from 0 to 26, with higher scores indicating more life satisfaction. The scale has a reliability coefficient alpha of .79 (Wood et al., 1969, p. 467).

Family Impact Questionnaire. This scale consists of 11 items assessing the quality of the caregiver-patient relationship (Haley et al., 1987; see Appendix D). The items were originally developed by Poulshock and Deimling (1984), who factor analyzed the responses of 614 caregivers. These items were converted to a questionnaire format by Haley and colleagues (1987), and used in the present study. Examples include: "I feel angry toward my family member," "I wish my family member and I had a better relationship," and "I feel pressured between giving in to my family member and others in the family." Each item was read to the caregiver, who was provided a card containing response categories. Caregivers were asked to indicate how strongly they agreed with the statement during the past week on a 4-point scale, from not at all (0) to extremely (3). Item 8 was positively worded and therefore required reverse scoring. The Family-Impact score could range from 0 to 33, with a higher score indicating a more negative caregiver-patient relationship.

If any item was not answered, then the average of all completed items was substituted in place of the missing item, thus allowing a summary score to be generated. Reliability coefficient alpha for the scale has not been reported in the literature.

Demographic and Descriptive Information. Except where indicated, these questions were adapted from the Philadelphia Geriatric Center Caregiver Assessment Instrument (e.g., Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; see Appendix E). Questions concerning the respite patient included age, sex, marital status, education, occupation, and number of months receiving care. Questions concerning the caregiver included age, sex, marital status, relationship to patient, household composition, occupation, and self-rated health. A support network grid was also included, listing all those who provided respite to the caregiver. It was adapted both from the Philadelphia Geriatric Center Caregiver Assessment Instrument and from Trute and Hauch (1988).

Caregiver's Perceptions of Respite. At Posttest 1, caregivers were asked to indicate what effect respite had on the following variables: (a) caregiver health, (b) patient health, (c) quality of caregiver-patient relationship, (d) ability to continue providing care, and (e) likelihood of nursing-home placement. Each question was rated on a 5-point scale (see Appendix F). These questions were

adapted from the headings in the Scharlach and Frenzel (1986) article. The questions were readministered at Posttest 2.

Procedure

The investigator was not allowed to contact caregivers directly, but had to rely on case coordinators. Case coordinators are employed by the Continuing Care Program to manage the home-care services received by families. The investigator made a brief presentation to case coordinators, describing the requirements of the study. They were asked to contact those caregivers scheduled to use nursing-home respite between June and September. Although 139 respite stays were scheduled during this period, including one-time and intermittent users, only one half of eligible case coordinators referred caregivers to the investigator. When the caregiver agreed to participate, the case coordinator contacted the investigator, who then arranged an interview with the caregiver.

Prior to the first interview, a consent form was signed by the caregiver (see Appendix G). The interview schedule consisted of Zarit and Zarit's Memory and Behavior Problems Checklist (cited in Zarit et al., 1985), Center for Epidemiologic Studies Depression Scale (Radloff, 1977), Life Satisfaction Index-Z (Wood et al., 1969), and Family Impact Questionnaire (Haley et al., 1987). The interview schedule

was administered to the caregiver on three occasions: 1 week prior to respite admission, 1 week after respite discharge, and 1 month after the second interview. All interviews were conducted in the caregiver's home, each requiring approximately 30 to 45 minutes to complete. Once data collection was completed, the investigator contacted case coordinators to obtain the patient's diagnosis.

Results

Sample Attrition

As mentioned previously, 39 caregivers were initially interviewed at pretest, but 6 were unavailable at Posttest 1. A chi square was computed to determine whether dropping out of the study was associated with patient diagnosis (i.e., dementia vs. nondementia). Because two of the four cells in the chi-square table had expected values of less than 5, Yates' correction was used (Cody & Smith, 1987, p. 56). There was no association between patient diagnosis and dropping out of the study, Yates' correction (1, $N = 39$) = 0.06, ns. At Posttest 1, 33 caregivers were interviewed: 17 providing care to a nondementia patient and 16 providing care to a dementia patient.

Of the 33 caregivers interviewed at Posttest 1, 11 were unavailable at Posttest 2. Once again, a chi square was computed to determine whether there was an association between patient diagnosis and dropping out of the study. There was no association, chi square (1, $N = 33$) = 0.24, ns. At Posttest 2, 22 caregivers were interviewed: 12 providing care to a nondementia patient and 10 providing care to a dementia patient.

Reliability of Scales

Cronbach's coefficient alpha is a measure of internal consistency for scales with three or more response categories; it is the mean for all conceivable split-half reliabilities (Golden, Sawicki, & Franzen, 1984, pp. 29-30). In order to have been included in the analysis, all the items in the scale had to be completed. Alpha values appear in Table 3. The internal consistency for each scale was generally good and comparable to those values reported by other investigators (see the Instruments section).

Test-retest correlations measure the stability of scores between interviews (Golden et al., 1984, p. 28). For example, a large correlation coefficient would indicate that subjects who scored relatively high at pretest also scored relatively high at posttest. In the present study, test-retest correlations ranged from moderate to strong (from .54 to .93). Only the Center for Epidemiologic Studies Depression Scale had a reported test-retest correlation, which ranged from .51 to .67 over a 2- to 8-week period (Radloff, 1977). A comparable range was found in the present study (.58 to .67 over a 4- to 8-week period).

TABLE 3
Reliability of Scales

Scale	Internal reliability (Cronbach's alpha)			Test-retest ^a reliability		
	Time 1 (N=39)	Time 2 (N=33)	Time 3 (N=22)	T1-T2 (N=33)	T2-T3 (N=22)	T1-T3 (N=22)
FREQ	.84	.80	.77	.92	.92	.93
XPROD	.87	.81	.88	.54*	.75	.80
CESD	.84	.90	.87	.67	.61*	.58*
LSIZ	.69	.81	.83	.64	.92	.79
FIQ	.80	.66 ^b	.80 ^c	.72	.72	.81

Note. FREQ = Frequency Scale; XPROD = Cross-Product Scale; CESD = Center for Epidemiologic Studies Depression Scale; LSIZ = Life Satisfaction Index-Z; FIQ = Family Impact Questionnaire.

^a

All correlation coefficients are significant at the $p < .001$ level, except where indicated.

^b

$N = 31$ (2 subjects had missing items).

^c

$N = 21$ (1 subject had a missing item).

* $p < .01$.

Correlations Between Dependent Variables

Intuitively, it seems reasonable to expect an inverse relationship to exist between the dementia patient's functional status and caregiver burden. However, Zarit, Reever, and Bach-Peterson (1980) found no significant relationship between these variables. In a later study, Zarit, Todd, and Zarit (1986) found that the Cross-Product score (Frequency x Reaction) was more strongly related to caregiver burden.

To see whether these findings would be replicated in the present study, Pearson correlation coefficients were computed between the Memory and Behavior Problems Checklist and caregiver measures. The results for each diagnostic group are presented separately in Tables 4 and 5. Table 4 indicates that there was no relationship between the dementia patient's Frequency score and caregiver measures, and that only sporadic relationships existed between the Cross-Product score and caregiver measures. The former finding was consistent with Zarit et al. (1980), but the latter finding was inconsistent with Zarit et al. (1986). The correlations between the Memory and Behavior Problems Checklist and caregiver measures were stronger in the nondementia sample (see Table 5).

Means and standard deviations for each scale are presented in Table 6. Caregiver scores at pretest were

TABLE 4

Significant Correlations Between the Memory and Behavior Problems Checklist and Caregiver Scales for the Dementia Sample at Time 1, 2, and 3

Scale	Memory and Behavior Problems Checklist					
	FREQ1	FREQ2	FREQ3	XPROD1	XPROD2	XPROD3
CESD1	.12	.12	.22	.12	.67**	.29
CESD2	.22	.17	.30	.05	.53*	.50
CESD3	.18	.34	.30	.12	.53	.72*
LSIZ1	-.38	-.26	-.40	-.56*	-.19	-.20
LSIZ2	-.15	-.04	-.01	-.29	-.18	.01
LSIZ3	-.15	-.07	-.08	-.45	-.19	-.19
FIQ1	-.28	-.17	-.11	-.04	-.07	-.01
FIQ2	-.15	-.02	.09	.06	-.10	.07
FIQ3	-.01	.09	.00	.06	.47	.23

Note. FREQ = Frequency Scale; XPROD = Cross-Product Scale; CESD = Center for Epidemiologic Studies Depression Scale; LSIZ = Life Satisfaction Index-Z; FIQ = Family Impact Questionnaire; N = 16 at Time 1 and 2; N = 10 at Time 3.

*p < .05. **p < .01.

TABLE 5

Significant Correlations Between the Memory and Behavior Problems Checklist and Caregiver Scales for the Nondementia Sample at Time 1, 2, and 3

Scale	Memory and Behavior Problems Checklist					
	FREQ1	FREQ2	FREQ3	XPROD1	XPROD2	XPROD3
CESD1	.53*	.37	.64*	.72**	.55*	.83***
CESD2	.55*	.58*	.52	.27	.46	.26
CESD3	.64*	.53	.71**	.63*	.54	.63*
LSIZ1	-.60*	-.48	-.69*	-.50*	-.48	-.54
LSIZ2	-.40	-.33	-.31	.01	-.23	-.02
LSIZ3	-.57	-.61*	-.58	-.28	-.60*	-.28
FIQ1	.41	.16	.57	.61**	.46	.89***
FIQ2	.27	.31	.41	.27	.50*	.37
FIQ3	.71**	.54	.70*	.68*	.84***	.79**

Note. FREQ = Frequency Scale; XPROD = Cross-Product Scale; CESD = Center for Epidemiologic Studies Depression Scale; LSIZ = Life Satisfaction Index-Z; FIQ = Family Impact Questionnaire; N = 17 at Time 1 and 2; N = 12 at Time 3.

*p < .05. **p < .01. ***p < .001.

TABLE 6
Means and Standard Deviations for Caregiver Scales by
Diagnosis

Occasion	Nondementia		Dementia	
	M	SD	M	SD
Pretest				
Frequency score	42.6	14.8	57.2	20.2
Cross-Product score	35.2	51.0	25.3	28.3
Depression score	10.6	11.5	10.7	7.5
Life-Satisfaction score	14.8	5.5	16.7	4.3
Family-Impact score	9.4	5.2	7.8	4.6
Posttest 1				
Frequency score	44.4	15.1	55.9	18.8
Cross-Product score	34.9	38.8	27.8	27.1
Depression score	13.8	13.4	13.2	10.8
Life-Satisfaction score	14.8	6.4	17.5	5.3
Family-Impact score	9.3	4.7	8.4	3.9
Posttest 2				
Frequency score	45.7	16.4	55.4	15.4
Cross-Product score	48.1	58.9	31.1	24.7
Depression score	14.6	12.5	8.0	6.8
Life-Satisfaction score	13.7	6.7	17.8	5.3
Family-Impact score	11.8	6.0	8.2	4.2

Note. N = 33 at pretest and Posttest 1; N = 22 at Posttest 2. Both the Cross-Product score and the Depression score are reported in their original units of measurement because they remained positively skewed even after logarithmic transformation.

comparable to those reported for 44 caregivers in the Haley et al. (1987) study. In that study, the mean scores for the Beck Depression Inventory, Life Satisfaction Index-Z, and Family Impact Questionnaire were 9.4, 16.0, and 9.3, respectively (Haley et al., 1987, Table 3, p. 409). The mean score on the Beck Depression Inventory never reached the clinical cut-off of 11. In the present study, the mean Depression score also failed to reach its clinical cut-off of 16. Radloff (1977, Table 2, p. 389) reported a range of 7.94 to 9.25 for the general population on the Center for Epidemiologic Studies Depression Scale. However, the present sample of dementia patients had a higher Frequency score than reported elsewhere. For example, Zarit et al. (1986, Table 4, p. 263) reported a mean Frequency score of 45.72 for their sample of 32 dementia patients living at home.

Sample Comparability

To test sample comparability, two multivariate analyses of variance (MANOVA) were computed: (a) to test whether dementia and nondementia caregivers differed at baseline, and (b) to test whether those caregivers who dropped out of the study were different from those who completed the study. Both MANOVAs used the following pretest variables: Frequency score, Depression score, Life-Satisfaction score, Family-Impact score, caregiver age, patient age, and months

of caregiving. Neither comparison was significant: (a) the dementia sample was not different from the nondementia sample at baseline, $F(7, 25) = 1.97$, ns, and (b) those subjects who dropped out of the study were not different from those who completed the study, $F(7, 25) = 0.76$, ns.

Repeated-Measures Analysis of Variance

A 2 x 3 (Diagnosis x Time of Measurement) mixed-model-multivariate analysis of variance was used to analyze the longitudinal data, with repeated measures on Frequency score, Depression score, Life-Satisfaction score, and Family-Impact score. The results appear in Table 7. There was neither a significant main-order effect nor an interaction effect. The only significant univariate finding was that dementia patients had a higher Frequency score than did nondementia patients, $F(1, 31) = 4.44$, $p < .05$. Because the Cross-Product score (Frequency x Reaction) was found to be more strongly correlated with caregiver measures, the data were reanalyzed using the Cross-Product score rather than the Frequency score. The results were nonsignificant (see Table 8).

Although the mixed-model-multivariate analysis of variance provides greater statistical power than does MANOVA, the sphericity assumption of homogeneous variances and covariances is often violated in repeated-measures designs, resulting in an inflated Type I error rate (Hertzog

TABLE 7
Results of Repeated-Measures Analysis of Variance

Source	Multivariate <u>F</u>	Univariate <u>F</u>			
		FREQ	CESD	LSIZ	FIQ
^a Between					
Diagnosis	2.55	4.44*	0.37	2.15	1.57
^b Within					
Time	0.92	0.12	1.75	0.62	0.86
Time x Diagn.	0.86	0.86	1.25	0.45	1.82

Note. FREQ = Frequency Scale; CESD = Center for Epidemiologic Studies Depression Scale; LSIZ = Life Satisfaction Index-Z; FIQ = Family Impact Questionnaire.

^a

Degrees of freedom for multivariate F (Pillai's Trace) are 4 and 28, whereas degrees of freedom for univariate F are 1 and 31.

^b

Degrees of freedom for multivariate F (Pillai's Trace) are 8 and 98, whereas degrees of freedom for univariate F are 2 and 51.

*p < .05.

TABLE 8

Results of Repeated-Measures Analysis of Variance Using the
Cross-Product Scale

Source	Multivariate F	Univariate F			
		XPROD	CESD	LSIZ	FIQ
^a Between					
Diagnosis	0.75	0.62	0.37	2.15	1.57
^b Within					
Time	0.93	0.28	1.75	0.62	0.86
Time x Diagn.	0.67	0.06	1.25	0.45	1.82

Note. XPROD = Cross-Product Scale; CESD = Center for Epidemiologic Studies Depression Scale; LSIZ = Life Satisfaction Index-Z; FIQ = Family Impact Questionnaire.

^a
Degrees of freedom for multivariate F (Pillai's Trace) are 4 and 28, whereas degrees of freedom for univariate F are 1 and 31.

^b
Degrees of freedom for multivariate F (Pillai's Trace) are 8 and 98, whereas degrees of freedom for univariate F are 2 and 51.

& Rovine, 1985). Greenhouse-Geisser epsilon and Huynh-Feldt epsilon are two statistics used to test the sphericity assumption (Cody & Smith, 1987, p. 171). Hertzog and Rovine (1985, p. 793) recommended using a mixed-model F test when epsilon is greater than .9 (where perfect sphericity equals 1); however, when epsilon falls belows .75, they recommended using MANOVA tests or adjusted F tests. In the present study, the Life-Satisfaction score failed to meet this .9 criteria (Greenhouse-Geisser epsilon and Huynh-Feldt epsilon were .63 and .69, respectively). Because the sphericity assumption was violated, the investigator decided to reanalyze the data using the MANOVA procedure, as suggested by Tabachnick and Fidell (1983, p. 228). The results remained nonsignificant; that is, respite had no effect on the dependent variables.

A total of 9 caregivers (4 in the dementia sample and 5 in the nondementia sample) scored in the clinically significant range for depression at pretest (i.e., a score of 16 or greater). To see what effect respite had on caregivers' depression scores, the investigator computed a repeated-measures MANOVA test on the 33 caregivers who completed the Posttest 1 interview. There was no Time of Measurement x Diagnosis interaction, $F(1, 31) = 0.04$, ns, indicating that the program had no effect on depression scores for either group of caregivers.

Caregiver's Perceptions of Respite

Caregivers' perceptions appear in Table 9. Because of the small sample size, the original 5-point scale was collapsed into a 3-point scale (i.e., better, same, worse). At Posttest 1, caregivers were most likely to report improved personal health (45%) and increased capacity to continue caregiving (48%). The majority of caregivers reported no change in the patient's health (61%), nor in the quality of the caregiver-patient relationship (88%). Among the 22 caregivers who had yet to pursue nursing-home placement, 41% (9) viewed it as more likely and 32% (7) as less likely. The overwhelming majority of caregivers (88%) was very satisfied with the program. When these questions were readministered at Posttest 2, the majority of caregivers reported no change from Posttest 1 (see Table 9).

Chi-square analysis was performed to see whether patient diagnosis was associated with caregivers' responses. There was only one significant finding: caregivers of nondementia patients reported deteriorating health at Posttest 2, chi square (2, $N = 22$) = 7.30, $p < .05$. Because four of the six cells in the chi-square table had expected values of less than 5, this statistic may not have been valid. Therefore, the question was reanalyzed using Goodman-Kruskal lambda (Berenson, Levine, & Goldstein, 1983, pp. 484-486). The 95% confidence interval for lambda ranged from -.26 to .92. The fact that the confidence interval covered zero indicated

TABLE 9
Perceived Impact of Respite

Occasion	<u>N</u>	Perception		
		Better	Same	Worse
Posttest 1				
Caregiver health	33	15	14	4
Patient health	33	8	20	5
Caregiver-patient relationship	33	3	29	1
Ability to continue providing care	33 ^a	16	16	1
Likelihood of nursing-home placement	22	9	6	7
Posttest 2				
Caregiver health	22	1	13	8
Patient health	22	1	13	8
Caregiver-patient relationship	22	1	18	3
Ability to continue providing care	22 ^b	0	16	6
Likelihood of nursing-home placement	17	8	3	6

^a Eleven patients were already paneled for nursing-home placement. The direction of scoring is reversed for this question (i.e. "better" indicates greater likelihood of nursing-home placement).

^b Five patients were already paneled for nursing-home placement. The direction of scoring is reversed for this question.

that lambda was not statistically significant. Consequently, the investigator concluded that there was no relationship between caregiver health and patient diagnosis at Posttest 2.

Caregivers spent respite in one of two ways: they either went on holidays (55%) or stayed at home (45%). Those caregivers that stayed at home spent their time visiting friends and relatives, relaxing, and attending to personal matters. It is unlikely that caregivers would have been able to engage in these activities without respite; for example, 67% of caregivers reported receiving no relief from relatives or friends. For one caregiver it was the first holiday in 9 years. Only 24% of caregivers offered suggestions for improving the program. Their two major recommendations were: (a) that the nursing-home staff make a greater effort to engage the respite patient in social and recreational activities at the facility, and (b) that caregivers be allowed greater flexibility in scheduling respite.

Discussion

The purpose of the present study was to assess what effect nursing-home respite had on caregivers and patients, with special attention paid to the role of patient diagnosis in respite outcome. It was hypothesized that caregivers would report improved psychological functioning (i.e., depression, life satisfaction, quality of caregiver-patient relationship) following respite. It was also hypothesized that patients, regardless of diagnosis, would show no decrement in functioning following relocation, and that nondementia patients might actually show some improvement following respite. However, the first hypothesis was not confirmed, and the second hypothesis only partially confirmed.

The finding of no change on caregiver measures is consistent with previous studies (Burdz et al., 1988; Lawton et al., 1989). There was, however, one exception. Montgomery and Borgatta (1989) found that caregivers reported a decrease in subjective burden (a 4-item scale measuring caregiver stress) following respite. Although respite was provided in three different modalities (i.e., in-home, day care, nursing home), there was no comparison between modalities on reducing subjective burden.

Previous studies have also reported no change in the functional status of dementia patients (Seltzer et al.,

1988). However, the anticipated improvement among nondementia patients was not found. Improvement had been anticipated based on the investigator's earlier study (Burdz et al., 1988), which reported improved Frequency scores following respite, especially in the nondementia sample. However, the present sample of nondementia patients was more impaired, thus reducing the likelihood of detecting improvement. For example, the previous nondementia sample had a pretest Frequency score of 24.6 ($N = 20$), whereas the present sample had a pretest score of 42.6 ($N = 17$).

Caregivers' perceptions of respite resemble those reported by Scharlach and Frenzel (1986). Following respite, caregivers in both studies were most likely to report: (a) improved personal health and increased capacity to continue caregiving, (b) no change in the patient's health, and (c) a division of opinion on the likelihood of nursing-home placement. There was, however, one major difference. In the Scharlach and Frenzel study, 56% of caregivers reported improvement in the quality of the caregiver-patient relationship, whereas 38% reported deterioration. In the present study, 88% reported no change, and only 3% reported deterioration.

The absence of a respite effect on caregiver measures may be attributed to the measures that were used. In a earlier study, Montgomery, Gonyea, and Hooyman (1985, p. 21) drew a distinction between objective and subjective burden. They

defined the former as the degree of disruption in the caregiver's daily life, and the latter as the caregiver's feelings about caregiving. They found that the two variables were weakly correlated ($r = .34$), with only 12% overlapping variance. Consequently, they suggested that a single intervention was unlikely to affect both variables equally. Because subjective burden was inevitable for some caregivers, they thought that an intervention was more likely to have an ameliorative effect on objective burden. However, the caregiver measures used in the present study--depression, life satisfaction, family impact--actually assessed subjective burden, which, according to these authors, was less likely to change. Therefore, future respite studies should include measures of objective burden (see Montgomery et al., 1985, Appendix A, p. 26).

According to Lawton et al. (1989, p. 15), the most relevant outcome measure is the caregiver's direct evaluation of the program. In the present study, 88% of caregivers were very satisfied with respite. Moreover, 45% reported improved personal health and 48% reported increased capacity for caregiving following respite.

The fact that patients' Frequency scores did not change following respite relocation is encouraging, for it indicates that caregivers can be periodically relieved of their caregiving duties without harming the patient. When one considers their high Frequency scores, it is surprising

that patients were not negatively affected by respite relocation. One obvious mitigating factor is that respite relocation is only temporary. However, there are two additional factors which may have reduced the potential harm to patients. First, case coordinators typically visit families prior to the introduction of respite, thus preparing the patient for relocation. Second, intermittent users of respite are usually readmitted to the same facility, thus allowing the patient to become familiar with the facility and the staff. Using the Bourestom (1984) framework, it appears that the risk associated with respite relocation has been reduced by: (a) allowing patients to express their opinions, (b) preparing them for respite, and (c) making relocation less dramatic.

It may be unrealistic to expect improvement in patients' Frequency scores, especially when one considers the Hasselkus and Brown (1983) study. These authors administered the Barthel Self-Care Index to 19 respite patients. This scale measures the degree of dependency for 10 items of daily living (e.g., dressing, bathing, toileting). The score can range from 0 (dependent) to 100 (independent). New nursing-home admissions had a mean score of 65.55, whereas respite patients had a mean score of 65.79, thus indicating that respite patients were on the verge of nursing-home placement. This trend was also reflected in the present study, where one third of the

patient sample was awaiting nursing-home placement. Furthermore, only 22 of the original 39 caregivers interviewed were able to complete all three interviews over the relatively brief period of 2 months. Most caregivers dropped out because the patient was either hospitalized, institutionalized, or dead.

Two additional factors reduced the likelihood of detecting improvement in respite patients. First, caregivers appear to be reluctant to use respite prior to the late stages of caregiving or until a crisis occurs (Lawton et al., 1989, p. 15; Montgomery & Borgatta, 1989, p. 463). Second, others have stressed that respite was designed to relieve caregivers and was never intended to be a treatment for patients, especially those suffering from dementia (Miller, Gulle, & McCue, 1986, p. 469; Seltzer et al., 1988, p. 123).

Recently, Callahan (1989) has argued, based on the lack of significant findings in the Lawton et al. (1989) study, that the efficacy of respite care has yet to be established and this precludes government funding for the program. As indicated on page 20, the Lawton et al. results must be placed in their proper context. Moreover, there are three additional studies which indicate that there is a need for an intervention such as respite.

Haley and colleagues (1987) compared 44 caregivers of dementia patients to 44 matched noncaregivers. Caregivers reported significantly poorer physical and psychological functioning, as well as more doctor visits and more prescribed medication. These authors suggested that the hidden cost of caregiving may be poorer health and a concomitant increase in demand for medical services.

Cohen and Eisdorfer (1988) interviewed 46 relatives of 27 dementia patients. Caregivers were neither receiving respite services nor participating in a family support group. Twelve of the 22 caregivers residing with the patient were clinically depressed, whereas not one relative living away from the patient was so diagnosed. These authors suggested that those caregivers providing in-home care needed an intervention (i.e., environmental and social supports) if they were to avoid becoming depressed in the process.

Hu, Huang, and Cartwright (1986) compared the cost of nursing-home care for 25 dementia patients to the cost of community care for 19 dementia patients. A nurse or a family caregiver kept a daily log for 2 weeks, recording expenses and the time spent caregiving. Dementia patients required 36% more nursing care than did the average nursing-home resident. The average annual cost of nursing-home care was projected to be \$22,458. Caregivers provided an average of 6.28 hours of care daily. Using a nursing aide's hourly

salary of \$4.64 as the criterion, the authors estimated the average annual cost of in-home care to be \$11,735. However, this figure most likely underestimated the true cost because medical and emotional costs were excluded from the calculation. Nevertheless, it appears that community-based care is cost effective when compared to nursing-home care.

Scharlach and Frenzel (1986) suggested that future investigators must not only identify which participants benefit from respite, but they must also decide how benefit is to be measured. They identified three measures of benefit: "cost effectiveness, reduced caregiver burden, or improved quality of care" (p. 81). Respite care appears to be cost effective because it prolongs community-based care (Lawton et al, 1989, reported that respite patients spent 22 more days in the community than did control patients.) However, the program appears to have little effect on caregiver burden (Burdz et al., 1988; Lawton et al., 1989). Future studies should include an interview with the caregiver during respite to see whether there is a decrease in the level of caregiver burden. One area which awaits future investigation is what effect the program has on the quality of care provided to the patient. The reader will recall that Montgomery et al. (1985) drew a distinction between objective and subjective burden, and suggested that an intervention was more likely to affect the former. Quality of care may be one such measure of objective burden,

and should be addressed in future respite studies. Future studies assessing relocation trauma among patients should include physiological indicators of stress (Bourestom, 1984, p. 86). One study which awaits future investigation is what effect respite exposure has on the patient's adjustment to eventual nursing-home placement.

Overall, the results reported in the present study are quite consistent with those reported elsewhere. Caregivers reported no change in their psychological functioning, nor in the patient's functional status. Although respite care does not appear to harm patients, the small sample size precludes drawing strong conclusions. The present investigator believes that nursing-home placement is almost inevitable in the late stages of caregiving. Therefore, I concur with Scharlach and Frenzel's (1986, p. 81) suggestion that respite is not an alternative to nursing-home placement, but that it does prevent caregiver stress from reaching levels that would undermine "their ability to provide high quality long-term care." Consequently, the criteria by which respite should be judged is not whether the program prevents nursing-home placement, but whether it delays nursing-home placement.

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Appendix A

MEMORY AND BEHAVIOR PROBLEMS CHECKLIST

Memory and Behavior Problems Checklist

Instructions to Interviewer

This checklist has two parts. Part A measures the frequency with which problems occur. Part B determines to what degree the behavior upsets the caregiver. Begin by asking if a problem has occurred and, if so, how often. When you find it has occurred, then go immediately to Part B, and determine the caregiver's reaction to that problem when it occurs.

Instructions to Caregiver

Part A. "I am going to read you a list of common problems. Tell me if any of these have occurred during the past week. If so how often have they occurred? If not, has this problem ever occurred?" Hand the subject the card on which the frequency and reaction ratings are printed.

Part B. "How much does this problem bother or upset you at the time it happens. The subject indicates his/her typical reaction on the card on which the frequency and reaction ratings are printed. Reaction is how the person reacts when the problem occurs.

Frequency Ratings

- 0 = never occurred
- 1 = has occurred, but not
in past week
- 2 = has occurred 1 or 2 times
in past week
- 3 = has occurred 3 to 6 times
in past week
- 4 = occurs daily or more often

Reaction Ratings: How much does this bother or upset you when it happens?

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = very much
- 4 = extremely

Behaviors

Frequency

Reaction

1. Wandering or getting lost	0 1 2 3 4	0 1 2 3 4
2. Asking the same question over and over again	0 1 2 3 4	0 1 2 3 4
3. Hiding things (money, jewelry, etc)	0 1 2 3 4	0 1 2 3 4
4. Being suspicious or accusative	0 1 2 3 4	0 1 2 3 4
5. Losing or misplacing things	0 1 2 3 4	0 1 2 3 4
6. Not recognizing familiar people	0 1 2 3 4	0 1 2 3 4
7. Forgetting what day it is	0 1 2 3 4	0 1 2 3 4
8. Starting, but not finishing things	0 1 2 3 4	0 1 2 3 4

9. Destroying property	0 1 2 3 4	0 1 2 3 4
10. Doing things that embarrass you	0 1 2 3 4	0 1 2 3 4
11. Waking you up at night	0 1 2 3 4	0 1 2 3 4
12. Being constantly restless	0 1 2 3 4	0 1 2 3 4
13. Being constantly talkative	0 1 2 3 4	0 1 2 3 4
14. Talking little or not at all	0 1 2 3 4	0 1 2 3 4
15. Engaging in behavior that is potentially dangerous to others or self	0 1 2 3 4	0 1 2 3 4
16. Reliving situations from the past	0 1 2 3 4	0 1 2 3 4
17. Seeing or hearing things that are not there (hallucinations or illusions)	0 1 2 3 4	0 1 2 3 4
18. Unable or unwilling to dress self (either partly or totally, or inappropriate dress compared to previous standards)	0 1 2 3 4	0 1 2 3 4
19. Unable or unwilling to feed self	0 1 2 3 4	0 1 2 3 4
20. Unable or unwilling to bathe or shower by self	0 1 2 3 4	0 1 2 3 4
21. Unable to put on make-up or shave by self	0 1 2 3 4	0 1 2 3 4
22. Incontinent of bowel or bladder	0 1 2 3 4	0 1 2 3 4
23. Unable to prepare meals	0 1 2 3 4	0 1 2 3 4
24. Unable to use the phone	0 1 2 3 4	0 1 2 3 4
25. Unable to handle money (e.g., to complete a transaction in a store; do not include being unable to manage finances)	0 1 2 3 4	0 1 2 3 4
26. Unable to clean house	0 1 2 3 4	0 1 2 3 4
27. Unable to shop (to pick out adequate or appropriate foods)	0 1 2 3 4	0 1 2 3 4

28. Unable to do other simple tasks 0 1 2 3 4 0 1 2 3 4
 which he/she used to do
 (e.g., put away groceries, simple
 repairs)
29. Unable to stay alone by self 0 1 2 3 4 0 1 2 3 4
30. Are there any other problems? 0 1 2 3 4 0 1 2 3 4

Note. Adapted from The Hidden Victims of Alzheimer's Disease: Families Under Stress (pp. 78-79) by S. H. Zarit, N. K. Orr, and J. M. Zarit, 1985, New York: New York University Press. Copyright 1983 by Steven H. Zarit and Judy M. Zarit. Available from Dr. Steven H. Zarit, Gerontology Center, Pennsylvania State University, University Park, PA 16802. Earlier version obtained from Dr. Steven H. Zarit in 1985.

Appendix B

THE CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION
SCALE

CES-D

Using the scale below, indicate the number which best describes how often you felt or behaved this way -- DURING THE PAST WEEK.

- 0 = Rarely or none of the time (less than 1 day)
- 1 = Some or a little of the time (1-2 days)
- 2 = Occasionally or a moderate amount of time (3-4 days)
- 3 = Most or all of the time (5-7 days)

DURING THE PAST WEEK:

- _____ 1. I was bothered by things that usually don't bother me.
- _____ 2. I did not feel like eating; my appetite was poor.
- _____ 3. I felt that I could not shake off the blues even with help from my family or friends.
- _____ 4. I felt that I was just as good as other people.
- _____ 5. I had trouble keeping my mind on what I was doing.
- _____ 6. I felt depressed.
- _____ 7. I felt that everything I did was an effort.
- _____ 8. I felt hopeful about the future.
- _____ 9. I thought my life had been a failure.
- _____ 10. I felt fearful.
- _____ 11. My sleep was restless.
- _____ 12. I was happy.
- _____ 13. I talked less than usual.
- _____ 14. I felt lonely.
- _____ 15. People were unfriendly.
- _____ 16. I enjoyed life.
- _____ 17. I had crying spells.
- _____ 18. I felt sad.

_____ 19. I felt that people disliked me.

_____ 20. I could not get "going."

Note. From "The CES-D Scale: A Self-Report Depression Scale for Research in the General Population" by L. S. Radloff, 1977, Applied Psychological Measurement, 1, p. 387. Copyright 1977 by the West Publishing Company. Reprinted by permission of Lenore Sawyer Radloff.

Appendix C
LIFE SATISFACTION INDEX-Z

Life Satisfaction Index-Z

I am going to read you a list of statements about life in general that people feel differently about. If you agree with the statement, indicate "agree". If you do not agree with the statement, indicate "disagree". If you are not sure one way or another, indicate "don't know".

	AGREE	DISAGREE	?
1. As I grow older, things seem better than I thought they would be.	X		
2. I have gotten more of the breaks in life than most of the people I know.	X		
3. This is the dreariest time of my life.		X	
4. I am just as happy as when I was younger.	X		
5. These are the best years of my life.	X		
6. Most of the things I do are boring or monotonous.		X	
7. The things I do are as interesting to me as they ever were.	X		
8. As I look back on my life, I am fairly well satisfied.	X		
9. I have made plans for things I'll be doing a month or a year from now.	X		
10. When I think back over my life, I didn't get most of the important things I wanted.		X	
11. Compared to other people, I get down in the dumps too often.		X	

12. I've gotten pretty much
what I expected out of
life.
13. In spite of what people
say, the lot of the average
man is getting worse,
not better.

X

X

Note. From "An Analysis of a Short Self-Report Measure of Life Satisfaction: Correlation with Rater Judgements" by V. Wood, M. L. Wylie, and B. Sheafor, 1969, Journal of Gerontology, 24, pp. 467-468. Copyright 1969 by Gerontological Society. Adapted by permission of Dr. Vivian Wood.

Appendix D

FAMILY IMPACT QUESTIONNAIRE

Family Impact Questionnaire

Below are listed a number of statements concerning your relationship with your family member. For each of these items, rate your amount of agreement by selecting one of the numbers. Think about how your relationship has been over the past week.

	NOT AT ALL	SOMEWHAT	VERY	EXTREMELY
1. I feel angry toward my family member.	0	1	2	3
2. My relationship with my family member makes me depressed.	0	1	2	3
3. My relationship with my family member is strained.	0	1	2	3
4. I am resentful of my family member.	0	1	2	3
5. My family member has had a negative affect on my relationship with others.	0	1	2	3
6. My family member tries to manipulate me.	0	1	2	3
7. I wish my family member and I had a better relationship.	0	1	2	3
8. My relationship with my family member gives me pleasure.	0	1	2	3
9. My family member makes more requests of me than is necessary.	0	1	2	3
10. I feel pressured between giving in to my family member and others in the family.	0	1	2	3

11. My family member has	0	1	2	3
only me to depend on.				

Note. From "Family Impact Questionnaire" by W. E. Haley, E. G. Levine, S. L. Brown, J. W. Berry, and G. H. Hughes, 1987, unpublished scale. Copyright 1987 by W. E. Haley, E. G. Levine, S. L. Brown, J. W. Berry, and G. H. Hughes. Adapted by permission of Dr. William E. Haley. Available from Dr. William E. Haley, Department of Psychology, University of Alabama at Birmingham, Birmingham, Al 35294.

Appendix E

DEMOGRAPHIC AND DESCRIPTIVE INFORMATION

Demographic Information on Care Recipient (CR)

1. ID: _____
2. Age: _____
3. Sex: _____
4. Marital status:
 1. never married
 2. married
 3. widowed
 4. separated
 5. divorced
5. What was the highest grade of school (CR) completed? _____
6. What kind of work did (CR) do most of his/her life?
7. When did (CR) first start living with you? _____ months ago

month/year
8. When did you start giving (CR) special help
and care because of his/her condition? _____ months ago

month/year
- ^a
9. How many respite stays is (CR) expected to have this year? _____
 1. one-time user
 2. intermittent user
- ^a
10. Does (CR) have a history of depression?
 1. no
 2. yes
- ^a
11. How many prescription medications is (CR) taking currently?
 1. zero
 2. 1-2
 3. 3-4
 4. 5 or more

Demographic Information on Caregiver (CG)

1. Age: _____
2. Sex: _____
3. Marital status: 1. never married
2. married
3. widowed
4. separated
5. divorced
4. You are (CR's) (relationship): 1. spouse
2. son/daughter
3. son/daughter-in-law
4. brother/sister
5. friend
6. neighbor
7. other (specify)
- 5A. How many people, if any, live here with you? _____
- B. Who are they?

Relationship to (CR)	Age
1.	_____
2.	_____
3.	_____
4.	_____
5.	_____
6.	_____
7.	_____

6A. What kind of work did you do most of your working life?

B. Do you work now?

1. no
2. yes

Now working

C. How many hours a week do you work? _____

D. Have you cut back on your working hours because of the time you give caring for (CR)?

1. no
2. yes

Not now working

E. Why did you stop working (probe)? Any other reason?

Ask all

F. Are you actively seeking more work now?

1. no
2. yes

Now a few questions about your health.

7. How would you rate your overall health at the present time?

1. poor
2. fair
3. good
4. excellent

b

8. How many physician visits did you make for yourself in the past year?

1. zero
2. 1-2
3. 3-4
4. 5 or more

b

9. How many prescription medications are you taking currently?

1. zero
2. 1-2
3. 3-4
4. 5 or more

^a
10. Do you feel that the most difficult aspect of caregiving is being confined within one's own home?

1. disagree
2. uncertain
3. agree

Support Network

Are there any relatives or friends from whom you can get respite care or a break from your caregiving duties (e.g., in-home respite, day respite, extended respite)?

If so, how frequently do they provide respite care?

Frequency Code

1. semi-annually or more often
2. once a month or more often
3. once a week or more often

name	relationship	sex	respite care	frequency
1.				
2.				
3.				
4.				
5.				

Note. From "Philadelphia Geriatric Center Caregiver Assessment Instrument" by M. P. Lawton and co-workers. Adapted by permission of Dr. M. Powell Lawton. Available from Dr. M. Powell Lawton, Director of Research, Philadelphia Geriatric Center, 5301 Old York Road, Philadelphia, PA 19141.

a

Question inserted by the investigator.

b

From "Psychological, Social, and Health Consequences of Caring for a Relative With Senile Dementia" by W. E. Haley, E. G. Levine, S. L. Brown, J. W. Berry, and G. H. Hughes, 1987, Journal of the American Geriatrics Society, 35, p. 406.

Appendix F
CAREGIVER'S PERCEPTIONS OF RESPITE CARE

Caregiver's Perceptions of Respite Care at Posttest 1

1. What were you able to do while your relative was receiving respite care that you would not otherwise have been able to do?
2. What effect has respite care had on your physical or mental well-being?
 1. much worse
 2. worse
 3. same
 4. better
 5. much better
3. What effect has respite care had on your relative's physical or mental well-being?
 1. much worse
 2. worse
 3. same
 4. better
 5. much better
4. What effect has respite care had on your relationship with your relative?
 1. much worse
 2. worse
 3. same
 4. better
 5. much better
5. What effect has respite care had on your ability to continue to provide care?
 1. much worse
 2. worse
 3. same
 4. better
 5. much better

6. What effect has respite care had on the likelihood of placing your relative in a nursing home?

1. very unlikely
2. unlikely
3. uncertain
4. likely
5. very likely
9. already paneled

7. Overall, how satisfied are you with respite care?

1. not at all satisfied
2. not too satisfied
3. somewhat satisfied
4. satisfied
5. very satisfied

a

8. What recommendations do you have for improving respite care?

Note. Adapted from the headings in "An Evaluation of Institution-Based Respite Care" by A. Scharlach and C. Frenzel, 1986, The Gerontologist, 26, 77-82.

a

Question inserted by the investigator.

Caregiver's Perceptions of Respite Care at Posttest 2

1. Compared to when I last spoke to you, how would you describe your current physical or mental well-being?
 1. much worse
 2. worse
 3. same
 4. better
 5. much better
2. Compared to when I last spoke to you, how would you describe your relative's current physical or mental well-being?
 1. much worse
 2. worse
 3. same
 4. better
 5. much better
3. Compared to when I last spoke to you, how would you describe your current relationship with your relative?
 1. much worse
 2. worse
 3. same
 4. better
 5. much better
4. Compared to when I last spoke to you, how would you describe your current ability to continue to provide care?
 1. much worse
 2. worse
 3. same
 4. better
 5. much better
5. Compared to when I last spoke to you, what is the present likelihood of placing your relative in a nursing home?
 1. very unlikely
 2. unlikely
 3. uncertain
 4. likely
 5. very likely
 9. already paneled

Appendix G
CONSENT FORM

Consent to Participate

I agree to participate in a study on the impact of respite care conducted by Michael Burdz. I understand that the results will be used by the Office of Continuing Care in future planning and by the principal investigator, Michael Burdz, towards his doctoral thesis. I understand that I am under no obligation to participate and I may withdraw from the study at any time. My refusal to answer any question will in no way jeopardize any current or future use of home-care service. Confidentiality has been assured.

Date

Signature

If you have any questions feel free to call me at .
Thank you for your participation.