

Respite Care and Differential Outcomes for Dementia and  
Nondementia Patients and Their Caregivers

by

Michael P. Burdz

A thesis  
presented to the University of Manitoba  
in partial fulfillment of the  
requirements for the degree of  
Master of Arts  
in  
Department of Psychology

Winnipeg, Manitoba

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NONDEMENTIA PATIENTS AND THEIR CAREGIVERS

BY

MICHAEL P. BURDZ

A thesis submitted to the Faculty of Graduate Studies of  
the University of Manitoba in partial fulfillment of the requirements  
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MASTER OF ARTS

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## ABSTRACT

An estimated 5% of those over 65 and 20% of those over 80 years of age are affected by chronic brain syndrome or senile dementia (Morycz, 1980). Dementia results in the progressive failure of the patient in the activities of everyday life, the failure of memory and intellect, and the disorganization of the personality (Roth and Myer, 1975). A person's intellectual impairment may lead to emotional changes, to deterioration in self-care, and even to delusions and hallucinations.

The majority of dementia patients rely on their families and natural support systems to provide essential and intense care (Zarit, Reeve, & Bach-Peterson, 1980). Even so, the vast majority of dementia patients living in the community are sufficiently disabled as to be eligible for a skilled nursing facility (Gurland, Dean, Gurland, & Cook, 1978). The caregiver often faces the prospect of social isolation; lack of time for self, family, and friends; career interruption; financial drain; and unrelieved heavy physical labor in caregiving (Archbold, 1982; Brody & Lang, 1982). Furthermore, witnessing the loss of social functioning in a family member requires psychological adaptation by individual members and role adjustment between members

(Gwyther & Blazer, 1984). These and other problems contribute to a subjective sense of burden experienced by many caregivers (Zarit et al., 1980).

Some advocates of family support system enhancement have favored the provision of respite care as a means of temporary escape from the sheer constancy of care provision and the resultant infringement upon personal time and privacy (Getzel, 1981; Shanas & Sussman, 1977). Respite care is designed to give short-term relief to persons caring for elderly individuals living with them at home by providing temporary nursing home stays for weekends or extended periods, though the typical respite stay is for two weeks. There are presently 20 respite beds and one emergency respite bed located throughout Winnipeg.

The purpose of the present study was to assess the impact of respite care on the dementia patient's functional level and the primary caregiver's level of burden. A comparison group, comprised of mentally alert respite users, was also included to assess the relative effect of respite care on the cognitive and physical functioning of dementia and nondementia patients. A similar comparison was made to evaluate the hypothesized differential effect of respite care on the level of burden reported by caregivers of dementia and nondementia patients.



## Hypotheses

Because of their failing memory, it was anticipated that dementia patients would be less disturbed while remaining in the security of a familiar and reassuring environment. Consequently, it was hypothesized that the transition from the community to the respite facility and subsequent return to the community, all in the span of two weeks, would be more stressful for dementia patients than for nondementia patients. The confusion created by relocation would result in an increase in the frequency of memory and behavior problems following respite care for the former group. Moreover, a reduction in the dementia patient's level of functioning was expected to increase caregiver burden and to worsen the perceived quality of the caregiver-patient relationship. No such sequence of events was expected to unfold for nondementia respite patients and their caregivers. Since they were mentally alert, it was presumed that nondementia patients would tolerate relocation better than dementia patients; thus, they were not expected to manifest any new memory and behavior problems following respite care.

## Method

### Participants

Participants were the caregivers of respite patients and were selected from a list provided by the Office of Continuing Care. The caregivers were first contacted by

their case coordinators, who explained the nature of the study and its requirements. After consent was obtained, the investigator contacted the caregiver to arrange an interview and to answer any questions.

An initial interview was completed by 40 respondents. Because the design required both a pretest and posttest score, respondents who had not completed both interviews, eight in all, were not included in the analyses. The final sample consisted of 32 caregivers: 18 providing care to a mentally alert but disabled adult about to enter respite care and 14 providing care to a dementia patient about to enter respite care. The primary diagnoses of patients were made by physicians and were obtained from the Manitoba Health Service Commission Assessment Form. To avoid possible experimenter bias, the interviewer remained blind to the diagnosis until data collection was completed.

### Instruments

The Memory and Behavior Problems Checklist and Burden Interview (Zarit & Zarit, 1983), and an investigator-designed instrument to gather descriptive information about the caregivers and the nature of their caregiving responsibilities, were administered to the primary caregiver on two separate occasions, 2-7 days prior to respite placement and 14-21 days following respite care. Both interviews were conducted in the caregiver's home and each interview required approximately 30 minutes to complete.

Before the first interview was conducted, a consent form was signed.

### Results

Internal consistencies for the Memory and Behavior Problems Checklist (Problems Scale) and the Burden Interview were good, and longitudinal stability approached the limits of reliability. Caregiver burden and the problems score were significantly related to each other at pretest,  $r(38) = .41$ ,  $p < .01$ , but not at posttest,  $r(32) = .27$ ,  $p < .13$ , though the direction of the relationship was the same on each occasion.

Since posttest scores are almost inevitably correlated with level of pretest scores (Cronbach & Furby, 1970), it becomes critical to determine if the two groups differ at pretest. Thus, a Hotelling's  $T^2$  test was conducted to see if dementia and nondementia patients differed on pretest burden and problems scores. Hotelling's  $T^2$  was significant at pretest,  $F(3,34) = 4.59$ ,  $p < .001$ , indicating that the groups were not initially comparable on the major variables of interest. The dementia group was significantly higher on the problems score,  $F(1,36) = 14.53$ ,  $p < .001$ , but not on caregiver burden  $F(1,36) = 1.84$ ,  $p < .18$ . To simply compare the two groups on change, i.e. on the raw difference between pretest and posttest scores, would be misleading, particularly for the Problems variable.

Multiple regression was used to predict problems scores at posttest after having adjusted for pretest differences. A diagnosis of dementia contributed significantly to posttest problems scores independent of pretest differences,  $t(29)=3.46$ ,  $p<.002$ . Diagnosis, however, did not contribute significantly to caregiver burden scores after removing the effects of pretest status,  $t(29)=.37$ ,  $p<.71$ .

The perceived worsening in the quality of the caregiver-dementia patient relationship was confirmed in caregiver responses on the questionnaire. More caregivers of dementia than of nondementia patients felt that there was a worsening in the dyadic relationship following respite care,  $\chi^2(2,N=32)=10.34$ ,  $p<.006$ . There was also a tendency for dementia caregivers to report more of a worsening in their overall condition and in the patient's overall condition following respite care than did the nondementia caregivers,  $\chi^2(2,N=32)=4.37$   $p<.11$  and  $\chi^2(2,N=32)=3.61$   $p<.16$ , respectively.

### Discussion

After adjusting for pretest differences, nondementia patients showed significantly fewer post-respite problems than did dementia patients. Yet on the Burden Instrument there was no significant decrease in caregiver burden in either group. Furthermore, caregivers of dementia patients reported a significant worsening in the quality of the dyadic relationship on the posttest interview item. One

issue, then, is the stability of the burden scores in the face of other reported changes.

Two explanations have been proposed for the stability of caregiver burden scores. First, Zarit and Zarit (1982) found that burden did not correlate with either frequency of memory and behavior problems or level of impairment. Consequently, one cannot infer a direct relationship between these two variables (i.e. lower problem scores do not automatically result in lower burden scores). Though the Burden Interview has had consistently high reliability, there are no norms and it may be clinically insensitive to change. Second, they contend that social supports do not mediate burden. Those who are feeling burdened are more likely to seek help from outside agencies, but receiving such help does not necessarily reduce burden.

Caregivers of dementia patients reported a significant worsening in the dyadic relationship. Providing care to such patients is both physically and emotionally taxing. The temporary relief may have made caregivers aware of what they were sacrificing in their own lives to care for their loved ones. It may be that caregivers of dementia patients are either unprepared or unwilling to resume caregiving after been relieved of the responsibility. There is a strong association between the perception by the caregiver of great difficulty in providing care to someone with dementia and the admission of the patient to a long-term-

care institution (Kraus, 1984). Case coordinators can play a major role in helping the caregiver resume caregiving. If such support is not forthcoming, the result may be premature institutionalization following respite care.

The small sample size and absence of a control group precludes firm conclusions from these findings. A control group consisting of dementia patients not using respite care is required to gauge the natural deterioration in their condition and its effect on caregiver burden. This study warrants replication with a larger sample and the inclusion of a control condition.

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RESPITE CARE AND DIFFERENTIAL OUTCOMES FOR  
DEMENTIA AND NONDEMENTIA PATIENTS AND THEIR  
CAREGIVERS

An estimated five percent of those over 65 and 20 percent of those over 80 years of age are affected by chronic brain syndrome or senile dementia (Morycz, 1980). According to several studies cited by Wells (1978), Alzheimer's disease accounts for approximately 51 percent of dementia cases, vascular disease for approximately 10 percent, a combination of Alzheimer's disease and vascular disease for eight percent, normal pressure hydrocephalus for six percent, alcoholism for six percent, and multiple other causes for less than 20 percent.

Dementias are unique diseases, not only because they are not presently curable, but because they cause a progressive impairment of memory and orientation with generalized deterioration in intellectual functioning and, eventually, in physical health. Roth and Myer's definition (1975) of dementia stresses the progressive failure of memory and intellect, and the disorganization of the personality. A person's intellectual impairment may lead to emotional changes, to deterioration of self-care, and even to delusions and hallucinations.

The majority of adults afflicted with dementia rely on their families and natural support systems to provide essential and intense care (Zarit, Reever, and Bach-Peterson, 1980). Even so, the vast majority of dementia patients living in the community are sufficiently disabled as to be eligible for a skilled nursing facility (Gurland, Dean, Gurland, & Cook, 1978). Not only is this situation of crucial importance to the home-care service system, but the demands of caring for a seriously disabled relative have been found to promote high rates of pervasive depression among family members who constitute the informal support system (Gurland, Dean, Gurland, & Cook, 1978).

Caregiving for the demented elderly is often extremely taxing and exhausting. The caregiver (usually the spouse or adult daughter) often faces the prospect of social isolation; lack of time for self, family, and friends; career interruption; financial drain; and unrelieved heavy physical labor in caregiving (Archbold, 1982; Brody & Lang, 1982). Furthermore, witnessing the loss of social functioning in a family member requires psychological adaptation by individual members, and role adjustment between members (Gwyther & Blazer, 1984). These and other problems contribute to a subjective sense of burden experienced by many caregivers (Zarit et al., 1980).

It is generally accepted that dementia is a public health problem of major importance. It is estimated that 60

percent of nursing home patients carry a diagnosis of some form of senility, and at least as many persons with similar problems reside in the community (Aronson & Lipkowitz, 1981). As Alzheimer's disease and other forms of dementia are most commonly found in those over 75--the fastest growing segment of the aging population--it is predicted that dementia will be a major public health dilemma by the turn of the century (Levine, Dustoor, & Gendron, 1983).

Institutionalization is frequently used to relieve the burden placed on families or other caregivers (Zarit et al., 1980). The gerontological literature has, however, stressed the importance of finding alternatives to institutionalization because of its negative effects, especially on the elderly afflicted with dementia. Some studies have reported especially high rates of mortality among relocated dementia patients compared to those remaining in the community (Blenkner, 1967). Furthermore, because of their inability to retain new information, dementia patients may show greater impairment in unfamiliar settings, while in their own home familiar cues can often trigger well-established habits (Plutzky, 1974).

To maintain the confused and disoriented adult in the community, intervention in the family support system is likely to be beneficial. Strengthening the morale, emotional well-being, and treatment skills of the care-providing family is perhaps the most important factor in

maintaining optimal health and functioning of the patient with early and middle stages of dementia (Barnes, Raskind, Scott, & Murphy, 1981). Advocates of family system enhancement have generally opted for more immediate relief measures designed to sustain burdened family members through periods of increasing need or mounting frustrations. Several investigators favor the provision of respite or day care services to informal caregivers as a means of temporary escape from the sheer constancy of care provision and resultant infringement upon personal time and privacy (Getzel, 1981; Shanas & Sussman, 1977). Others have advocated the bolstering of informal supportive services, including: home health aides, homemakers, and home maintenance programs (Getzel, 1981; Monk, 1979; Brody, 1978; Gross-Andrews and Zimmer, 1978; Johnson, 1978; Litwak, 1978; Sussman, 1977), or advocate counseling to help alleviate familial stress and upheaval on an as-needed basis (Poulshock & Silverstone, 1979). Unfortunately, a very few of the above suggestions appear in the literature as systematically designed, implemented, and evaluated programs, and so their utility in bolstering informal care provision networks remain, as yet, largely untested.

One exception is a longitudinal study which examined the impact of a day care program for dementia patients on the natural history of the disease and on the burden incurred by caregivers (Panella, Lilliston, Brush, & McDowell, 1984).

In this pilot study, eight patients with a diagnosis of Alzheimer's disease who had been attending the program consistently for 18 months and who had been regularly evaluated were studied. Evaluation centered on behaviors in the program and at home such as use of language, social interaction, attention, spatial orientation, motor coordination, bowel and bladder control, eating and nutrition, and dress and grooming measures. Numerical scores were obtained and were plotted to show the change in behavior and intellect. Upon entering the program, these patients showed a non-significant three-month period of slightly improved cognitive and physical functioning. Repeated evaluations after the initial three months showed a steady decline in functional abilities. The continued decline in evaluation scores indicated progression of dementia and did not support the possibility that day care for dementia halts or changes the downward decline and eventual death of these patients. The authors concluded, however, that the program allowed families to continue to provide care and to delay nursing home placement or the hiring of additional help at home. It was also cost-effective when compared with the general alternative of nursing home placement (Panella, Lilliston, Brush, & McDowell, 1984). The small sample size and the absence of any comparison group precludes firm conclusions from these findings, and further evaluation of suggested interventions is needed.

The purpose of the present study was to assess the impact of a locally active respite care program on dementia and nondementia patients and on the burden incurred by caregivers. Respite care in Winnipeg is designed to give short-term relief to persons caring for elderly individuals living with them at home by providing temporary nursing home stays for weekends or extended periods, though the typical respite stay is for two weeks. The purpose of the program is to prolong community based care, thus reducing the medical, mental, and emotional costs of institutionalization. The respite care program was started in 1977 in coordination with a few personal care homes within the city. The program was centralized in 1984 under the auspices of the Office of Continuing Care, an agency of the Provincial Department of Health. The cost to the respite user is \$16.60 per day, as is admission to a personal care home. There are 20 respite beds and one emergency bed located throughout Winnipeg. There are 300 referrals annually for the service and full occupancy between May and September (Lussier, 1986).

When it is determined that an individual's care can best be provided in a respite facility, an assessment to determine the individual's level of care is completed by a community social worker and nurse from the Office of Continuing Care. Level of care refers to a person's degree of dependency both on nursing staff time for activities of

daily living and on basic nursing care to maintain functioning, i.e. bathing and dressing, feeding, treatments, ambulation, elimination, and supervision.

Although the purpose of respite care is clear and the program is operational, there has been virtually no evaluation of the local program. Moreover, there is a dearth of literature available on similar programs elsewhere. A computerized literature search conducted by the Foundation for Long Term Care (1983) provided only two articles, each of which provided profiles of the respite user and caregiver. A major demonstration was undertaken by the Foundation for Long-Term Care (1983) in which respite care was provided to 134 individuals at the six long-term care facilities throughout New York State. Analysis of the data showed that of 134 participants, 15 (12%) were in long-term care facilities one month later. This is a much higher percentage than the commonly reported five percent for the elderly population in the United States at large. The authors conclude correctly that what is not known is whether the high rate of placement can be attributed to familiarization with the nursing home environment, to the deteriorating condition of the patient, or to the changing condition of the caregiver. It would have been beneficial had the researchers provided the diagnosis of the 15 participants who were eventually institutionalized -- inappropriate applicants would have been identified. A

prospective study which obtains information on patients and their caregivers prior to respite experience would be most informative.

Now that the respite care program is operational, attempts should be made to answer the questions raised by the Foundation for Long-Term Care. If respite care is to be viewed positively from a social policy perspective, the key factors will be: (1) its impact on reducing the stress of family caregivers and (2) its potential for helping these caregivers to avoid or delay institutional placement of their elderly relatives (Foundation for Long-Term Care, 1983). The purpose of the present study was to assess the impact of respite care on the dementia patient's functional level and the primary caregiver's level of burden. A comparison group, comprised of mentally alert respite users, was also included to assess the relative effect of respite care on the cognitive and physical functioning of dementia and nondementia patients. A similar comparison was made to evaluate the hypothesized differential effect of respite care on the level of burden by caregivers of dementia and nondementia patients.

People with dementing illnesses often become excessively upset and may experience rapidly changing moods. Strange situations, confusion, groups of people, noises, being asked several questions at once, or being asked to do a task that is difficult for them can precipitate these reactions (Mace



& Rabins, 1981). When a situation overwhelms the limited thinking capability of brain-injured persons, they may overreact. They may weep, become agitated, angry, or stubborn. They may strike out at those trying to help them. They may cover their distress by denying what they are doing or by accusing other people of wrongdoings. Because of their failing memory, it was anticipated that dementia patients would be more disturbed in the respite environment than in the security of a familiar and reassuring environment. Consequently, it was hypothesized that the transition from the community to the respite facility and subsequent return to the community, all in the span of two weeks, would be more stressful for dementia patients than for nondementia patients. The confusion created by relocation would result in an hypothesized increase in the frequency of memory and behavior problems following respite care for the former group. Moreover, a reduction in the dementia patient's level of functioning was expected to increase caregiver burden and to worsen the perceived quality of the caregiver-patient relationship. No such sequence of events was expected to unfold for nondementia respite patients and their caregivers. Since they were mentally alert, it was presumed that nondementia patients would tolerate relocation better than dementia patients; thus, they were not expected to manifest any new memory and behavior problems following respite care.

One possible confounding variable in the present study is misdiagnosis. As many as 15 to 30 percent of those who present with dementia-like symptoms may actually have a reversible or non-progressive illness (Cohen, 1984). Depression in the elderly can so closely mimic Alzheimer's disease that Kiloh (1961) proposed the term pseudodementia. Depression in senescence is frequently overlooked because the clinical picture is often markedly different from depression in younger adults. Many of these manifestations are easily mistaken as evidence of dementia or Alzheimer's disease (Ware & Carper, 1982). Overdiagnosis is, however, more common in the United States than in Canada (Duckworth & Ross, 1975). While misclassification may work against the hypothesis, it is unlikely to outweigh the hypothesized effect. The value of the research overshadows the risk produced by misclassification.

The problem warrants investigation for three reasons: (1) given the known effects of institutionalization to the disabled elderly, other options must be investigated; (2) respite care, being one such alternative, has yet to be evaluated adequately in the literature; and (3) while the goals of respite care are to provide temporary relief from caregiving and to delay institutionalization, it may exacerbate the situation and result in premature institutionalization for some types of patients.

Three factors have allowed the present researcher to undertake such a study: (1) the existence of centralized medical files; (2) access to these files; and (3) the cooperation and encouragement of provincial health agencies. With this support it was possible to identify and contact the caregivers of elderly patients just before respite care was to begin and again five weeks later. Measures of patient functioning and caregiver morale could be assessed both before and after respite care, and the possibility of differential change in dementia and nondementia patients over the five-week period could be systematically considered. Change over the five-week interval could be due to the respite experience, or to changes within the patients which were not a result of respite care. Since both groups experienced the same treatment, any differential effects for the two groups would result from the interaction of respite care and diagnosis. More specifically, it was hypothesized that in comparison to their nondementia counterparts, dementia patients would show increases in various memory and behavior problems after respite care, the dementia caregivers would experience more burden and would report a worsening in the quality of the caregiver-patient relationship.

## Method

### Participants

Participants were the caregivers of respite patients and were selected from a list provided by the Office of Continuing Care. Interviews were completed by 40 respondents. Table 1 contains a summary of sample characteristics. Caregivers to dementia patients were approximately three and one-half years younger than caregivers to nondementia patients. Ninety percent of the caregivers interviewed were female, and the two largest groups were comprised of spouses (20%) and children (50%). As for the patients, 93 percent resided in the caregiver's home. Dementia patients were four and one-half years older than the comparison group, and had been in the care of their families for approximately two years longer than the nondementia group. Sixty-eight percent of all patients were female.

The primary diagnoses of patients were made by physicians and were obtained from the Manitoba Health Service Commission Assessment Form. To avoid possible experimenter bias, the interviewer remained blind to the diagnosis until data collection was completed. During the course of the interview, however, some caregivers did inadvertently mention the diagnosis. These cases remained in the analysis.

TABLE 1  
Summary of Sample Characteristics

Variable	Condition		
	Complete Sample (n=40)	Nondementia (n=22)	Dementia (n=18)
Mean age of patient	81.6	79.2	83.9
Sex of patient			
Female	27	13	14
male	13	9	4
Mean age of caregiver	54.9	56.6	53.2
Sex of caregiver			
Female	36	20	16
Male	4	2	2
Relationship			
Spouse	8	6	2
Son/daughter	20	9	11
Son/daughter-in-law	6	3	3
Brother/sister	2	2	0
Other	4	2	2
Mean number of months spent caregiving	56.7	68.4	44.9
Mean number of items that required assistance (e.g., bathing, feeding)	3.5	3.4	3.7

## Instruments

Memory and Behavior Problems Checklist. This Problems Scale (Zarit & Zarit, 1983) consists of 31 items on the type and frequency of memory and behavior problems exhibited by the patient (see Appendix A). Caregivers were asked to respond to a list of common memory and behavior problems such as "wandering or getting lost," "doing things that embarrass you," and "not recognizing familiar people." Then the respondent indicated how often the behavior occurred in the past week. Each item was rated on a five-point scale from 0 (never occurred) to 4 (occurs daily). After each item, the caregiver was asked to rate how much the problem upset them on a five point scale from 0 (not at all) to 4 (extremely). A score was generated by summing the frequency ratings of problems, thus providing a score which reflected the overall severity of the condition. This problems score could range from 0 to 124, with a high score reflecting more problems. The sum of reaction ratings provided a measure of how much difficulty caregivers were having in coping. The reactions score could also range from 0 to 124, with a higher score reflecting greater difficulty in coping. If a subject was unable or unwilling to answer a question, then the average of all completed items was substituted in place of the missing item before the final score was summed.

Burden Interview. The Burden Interview (Zarit & Zarit, 1983) consists of 22 items on feelings about caregiving and has a reported alpha reliability coefficient of .79.

Examples of items (see Appendix B) include: "Do you feel you don't have as much privacy as you would like because of your relative?" "Do you feel your social life has suffered because you are caring for your relative?" and "Do you feel your relative is dependent on you?". Each item was rated on a five-point scale from 0 (never) to 4 (nearly always). The caregiver burden score was the sum of all the responses and could range from 0 to 88, with higher scores associated with greater perceived burden. The procedure described for the Problems Scale was also used to handle missing items in the Burden Interview. Norms for the Burden Interview have not been published, but estimates of the degree of burden can be made from preliminary findings (Zarit & Zarit, 1983). These are 0-20 (little or no burden), 21-40 (mild to moderate burden), 41-60 (moderate to severe burden), 61-88 (severe burden).

Descriptive Information About Caregivers. A third instrument was used to gather descriptive information (see Appendix C). Some of the variables assessed were: relationship to patient, the caregiver's health status, the caregiver's perception of how caregiving had affected his or her health, and the presence or absence of a confidant for the caregiver. The patient's dependency on the caregiver was determined by summing the number of items that required assistance (i.e. bathing, dressing, feeding, medical treatment, ambulation, toilet needs, support and/or

supervision), and the maximum score was seven. At posttest, the caregiver's perceptions about respite care were assessed with the questions in Appendix D: (a) the benefit of respite care to the caregiver from 1 (not at all) to 5 (very); (b) the change in the caregiver's and the patient's overall condition following respite care from 1 (much worse) to 5 (much better); and (c) the change in the quality of the caregiver-patient relationship from 1 (worse) to 3 (better).

### Procedure

The coordinator of respite care provided each case coordinator (the social worker or nurse at the Office of Continuing Care responsible for the home care plan of the patient) with a list of his or her clients scheduled to enter respite care. Case coordinators were asked to contact the caregiver and to explain the nature of the study and its requirements. In a few cases, the case coordinator recommended that the caregiver not be contacted because the family was experiencing some crisis at the time of the study. These caregivers were not contacted. From the list of 66 caregivers, 61 percent (40) agreed to participate. After consent was obtained, the interviewer contacted the caregiver to arrange an interview and to answer any questions. Approximately 30 minutes were required to interview caregivers in their homes. Before the interview was conducted, a consent form was signed (see Appendix E).



The interview schedule was administered to the caregiver on two separate occasions: 2-7 days prior to respite placement and 14-21 days following respite care.

### Hypotheses

Translation of the general hypothesis into the specific measures used results in the following specific hypotheses:

1. The post-respite problems score was expected to be greater for dementia patients than for nondementia patients;
2. the post-respite burden score for those providing care to dementia patients was expected to be higher than the burden score for the comparison group; and
3. the post-respite perception questions were expected to be rated more negatively by the dementia group than by the nondementia group.

Multiple regression was used to test hypotheses 1 and 2, whereas a chi-square analysis was used to test hypothesis 3.

### Results

Sample shrinkage. Because the design required both a pretest and posttest score, respondents who had not completed both interviews, eight in all, were not included in the analysis. Six of the eight caregivers were unavailable at posttest for the following reasons: death of

patient (one nondementia patient), hospitalization of patient during respite care (one dementia patient), admission of patient to a personal care home (one patient in each condition), refusal of caregiver to be interviewed (one patient in each condition). Two caregivers (one in each condition) were also deleted because they were interviewed three days after respite care instead of the required two weeks. This happened because an error was made in scheduling the interview. The final sample consisted of 32 caregivers: 18 providing care to a mentally alert but disabled adult about to enter respite care and 14 providing care to a dementia patient about to enter respite care.

Reliability. Once again, the problems score was generated by summing the frequency ratings in the problems scale, while the caregiver burden score was the sum of all the responses in the Burden Interview. Cronbach's alpha reliability coefficient is a general formula for estimating the reliability of a scale consisting of items on which two or more scoring weights may be assigned to answers. In order to measure Cronbach's alpha, all 31 items in the Problems Scale and all 22 items in the Burden Interview had to be completed. If a subject was unable or unwilling to answer a question, then the item was coded as missing. It was infrequent that more than one item per scale was coded as missing. One missing item would, however, preclude the inclusion of the interview in an analysis of reliability.

The Cronbach's alpha reliability coefficients for the Problems and Burden Scales are presented in Table 2. As inspection of Table 2 reveals, internal consistency for each was good, and longitudinal stability approached the limits of reliability. Such longitudinal results do not preclude change over time, though the high stability coefficients mean that an individual high relative to others on the pretest, in all likelihood remained high relative to others at the posttest. This high level of longitudinal stability may be due to the short time interval of five weeks.

Dependent variable relationships. Caregiver burden and problem scores were significantly related to each other only at pretest,  $r(38)=.41$ ,  $p<.01$ , but not at posttest,  $r(32)=.27$ ,  $p<.13$ , though the direction of the relationship was the same on each occasion. The present results contrast with those of Zarit and Zarit (1983), who found that burden did not correlate with either frequency of memory and behavior problems or level of impairment. They also found that the caregiver's reaction ratings were a much better predictor of burden than were frequencies of the same variable. In the present study, the caregiver's reaction ratings were significantly correlated with burden at pretest,  $r(37)=.43$ ,  $p<.008$ , and at posttest,  $r(31)=.73$ ,  $p<.001$ . These data suggest that the reaction part of the Problems Scale is more strongly related to perceived burden than is the frequency of the problems, though problem frequency and burden are positively related.

TABLE 2  
Reliability Coefficients

Instrument	Alpha		
	Pre-respite administration	Post-respite administration	Test-retest correlation
Problems Scale	.76 (19)	.91 (27)	.86***
Burden Interview	.89 (35)	.89 (44)	.89***

Note: Numbers in parentheses indicate the number of subjects with completed data on every item in the scale. Additional caregivers were interviewed following respite care, thus accounting for 44 participants at post-respite.

\*\*\*  $p < .0001$ .

Initial level and change. Since posttest scores are almost inevitably correlated with level of pretest scores (Cronbach and Furby, 1970), it becomes critical to determine if the two groups differ at pretest. Means and standard errors on the Problem and Burden variables are presented in Table 3 for both dementia and non-dementia groups as well as for the drop-outs from the study. Thus, a Hotelling's  $T^2$  test was conducted to see if dementia and nondementia patients differed on pretest burden and problems scores. Hotelling's  $T^2$  was significant at pretest,  $F(3,34)=4.59$ ,  $p<.001$ , indicating that the groups were not initially comparable on the major variables of interest. The dementia group was significantly higher on the problems score,  $F(1,36)=14.53$ ,  $p<.001$ , but not on caregiver burden,  $F(1,36)=1.84$ ,  $p<.18$ . To simply compare the two groups on change, i.e. on the raw difference between pretest and posttest scores, would be misleading, particularly for the Problems variable. The more appropriate analysis is to compare the posttest scores for the two groups after removing the influence of pretest scores. In other words, posttest scores are predicted from pretest scores, and the residuals are then compared for the two groups to see if one group changed more or less than expected given their initial positions.

Adjusting for pretest differences. Multiple regression was used to predict problems scores at posttest after adjustments for pretest differences were made. Diagnosis

TABLE 3

Mean Scores and Standard Error of the Mean at Pretest and Posttest by Condition

Occasion	Condition							
	Nondementia				Dementia			
	Longitudinal Sample		Drop-outs		Longitudinal Sample		Drop-outs	
	(n=18)		(n=4)		(n=14)		(n=4)	
	$\bar{X}$	SE	$\bar{X}$	SE	$\bar{X}$	SE	$\bar{X}$	SE
Pretest								
Problems score	25.3	3.4	24.8	4.5	49.9	6.2	35.1	4.7
Burden score	30.6	3.6	24.0	5.9	36.3	4.9	38.3	6.6
Posttest								
Problems score	18.5 <sup>a</sup>	3.0			47.6 <sup>b</sup>	4.6		
Burden score	29.3	4.0			35.9	5.0		

<sup>a</sup> Paired pretest-posttest comparison t-test within group,  $p < .002$

<sup>b</sup> Paired pretest-posttest comparison t-test within group,  $p < .55$

(dementia vs. non-dementia) contributed significantly to posttest problems scores independent of pretest differences,  $t(29)=3.46$ ,  $p<.002$  (See Figure 1). Diagnosis, however, did not contribute significantly to caregiver burden scores after removing the effects of pretest status,  $t(29)=.37$ ,  $p<.71$  (see Figure 2). Caregivers reported a moderate degree of burden (where a score of 21-40 indicates mild to moderate burden). Since Zarit and Zarit (1982) reported that the caregiver's reaction ratings were a better predictor of burden than were frequencies of the same variable, a multiple regression was also performed on reaction ratings. The findings were insignificant,  $t(29)=1.29$ ,  $p<.21$ .

The perceived worsening in the quality of the caregiver-dementia patient relationship was confirmed,  $\chi^2(2,N=32)=10.39$ ,  $p<.006$  (see Table 4). More caregivers of dementia patients believed that there was a worsening in the dyadic relationship following respite care. No such deterioration was reported in the other caregiver group. Caregivers also perceived a worsening in their overall condition and the dementia patient's overall condition following respite care, but they did not reach statistical significance,  $\chi^2(2,N=32)=4.37$ ,  $p<.113$ ,  $\chi^2(2,N=32)=3.61$ ,  $p<.164$ , respectively (see Tables 5 and 6). Respite care, however, was perceived as being very beneficial to 94 percent of the caregivers themselves (see Table 7).

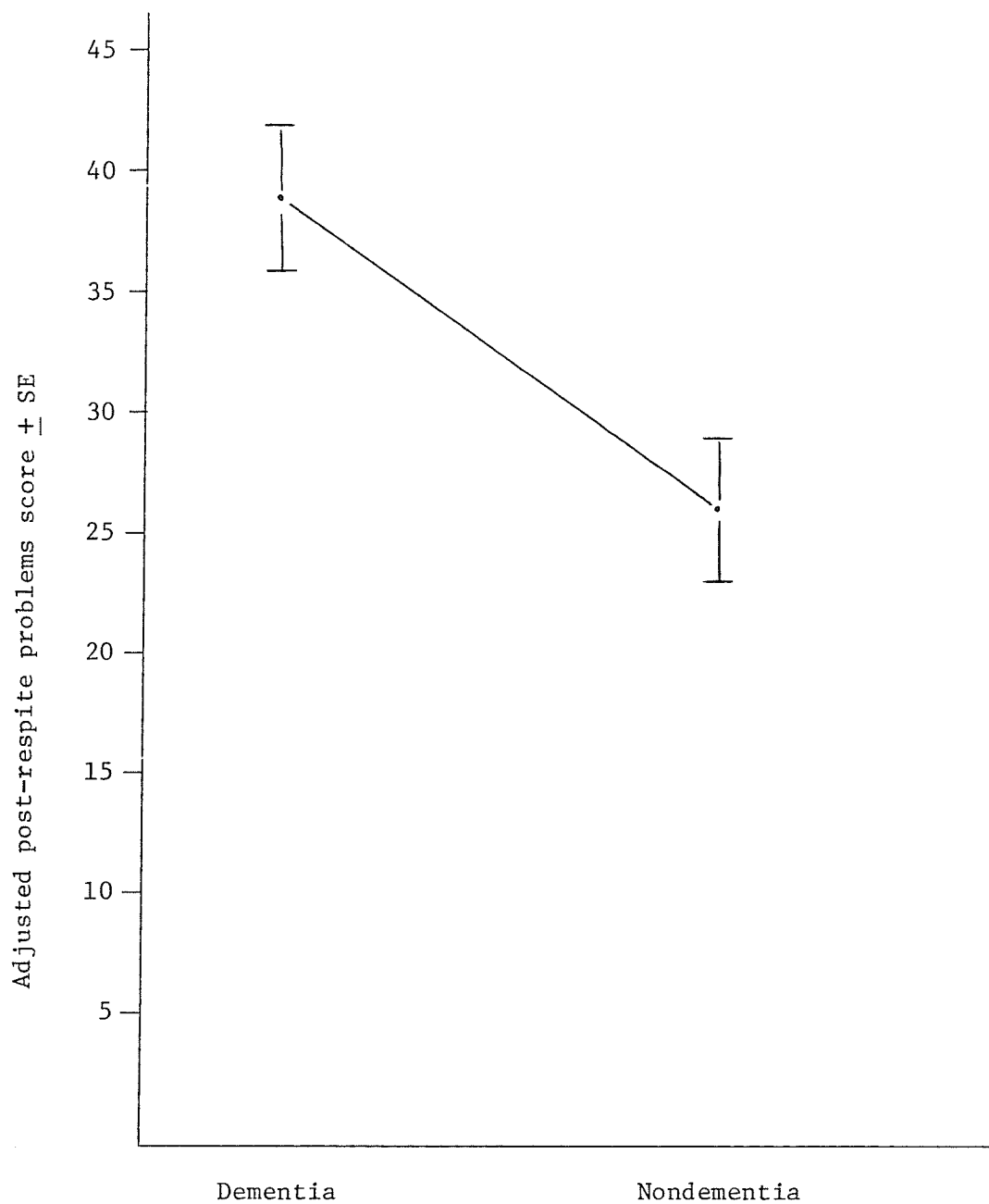


Figure 1. Adjusted post-respite problems score  $\pm$  SE for dementia and nondementia patients.



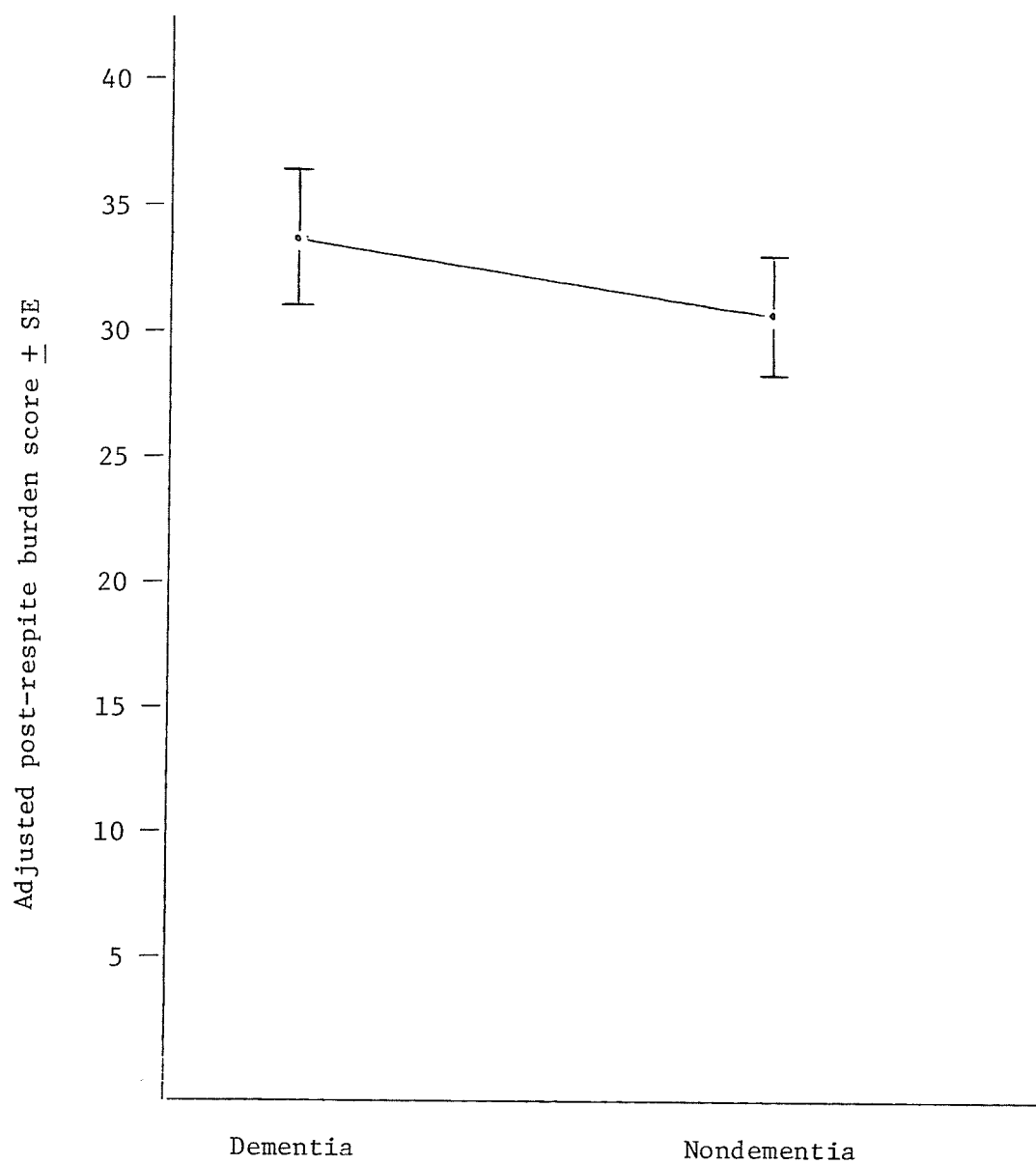


Figure 2. Adjusted post-respite burden score  $\pm$  SE for dementia and nondementia patients.

TABLE 4

Quality of Caregiver-Patient Relationship Since Respite Care

Quality of relationship	Condition	
	Nondementia (N=18)	Dementia (N=14)
Worse	0	5
Same	13	9
Better	5	0

Chi-square test,  $p < .01$

TABLE 5  
Condition of Patient Since Respite Care

Condition	Condition	
	Nondementia (N=18)	Dementia (N=14)
Worse	4	8
Same	10	5
Better	4	1

Chi-square test,  $p < .113$

TABLE 6  
Condition of Caregiver Since Respite Care

Condition	Condition	
	Nondementia (N=18)	Dementia (N=14)
Much worse/worse	2	4
Same	13	10
Better/much better	3	0

Chi-square test,  $p < .164$

TABLE 7  
Perceived Benefit of Respite Care to Caregiver

Benefit	Condition	
	Nondementia (N=18)	Dementia (N=14)
Not at all/not too beneficial	0	1
Somewhat beneficial	1	0
Beneficial/very beneficial	17	13

## Discussion

The purpose of the present study was to assess the impact of a respite care program on the cognitive and physical functioning of dementia and nondementia patients and on the burden incurred by caregivers. It was hypothesized that dementia patients would be less able to tolerate the relocation incurred in respite care because of their diminished mental capacity. The anticipated reduction in their level of functioning following respite care was expected to result in a reported increase in caregiver burden and a reported worsening in the quality of the caregiver-dementia patient relationship. No such sequence of events was anticipated to unfold for mentally alert respite users.

Only partial confirmation for hypothesis 1 was obtained. Mentally alert respite users did show significantly fewer post-respite problems than dementia patients, but dementia patients, who were expected to show an increase in problems following respite care, showed no change. Hypothesis 2 was not confirmed since caregiver burden remained unchanged in both groups. Hypothesis 3 was confirmed in that caregivers to dementia patients reported a significant worsening in the quality of the caregiver-dementia patient relationship.

The finding that dementia patients showed slight nonsignificant improvement on the mean problems score from

pre- to post-respite administration is encouraging. While some symptoms, such as memory loss, have no known treatment, many of the behaviors distressing to families are responsive to good medical care and pharmacotherapy, which were available at the respite facility. In the Panella et al. study (1984), dementia patients showed a nonsignificant three-month period of slightly improved cognitive and physical functioning following the introduction of day care. Repeated evaluations after the initial three months showed a steady decline in functional abilities. The continual decline in evaluation scores indicated progression of dementia and did not support the possibility that day care for dementia halts or changes the downward decline and eventual death of these patients; however, it provided families with a much needed rest. It is also unlikely that respite care can prevent the inevitable deterioration, but it serves some ameliorative purpose, as indicated by caregivers' belief that respite care was beneficial. On the other hand, the improvement could be the result of repeated testing. Untreated control subjects are needed to assess the validity of this alternative explanation.

Although problem scores declined for nondementia patients, caregiver burden remained unchanged. Zarit and Zarit (1982) offer two possible explanations for this finding. First, they found that burden did not correlate with either frequency of memory and behavior problems or

level of impairment. They caution that one cannot infer a direct relationship between these two variables (i.e. lower problem scores do not automatically result in lower burden scores). Though the Burden Interview has had consistently high reliability, there are no real norms and it may be clinically insensitive to change in problems scores. Second, they contend that social supports do not mediate burden. Those who are feeling burdened are more likely to seek help from outside agencies, but receiving such help does not necessarily reduce burden. The latter explanation is the more plausible since we found that burden and problem scores were significantly correlated at pretest.

Caregivers to dementia patients reported a significant worsening in the dyadic relationship. Caring for the mentally impaired causes more problems and strains than caring for old people who are physically infirm (Isaacs, Livingstone, and Neville, 1972). Significant impairment in self-care skills and the presence of behavioral problems of more than a mild degree make support and surveillance necessary 24 hours a day, seven days a week (Robertson and Reisner, 1982). Such intensive and extensive caregiving is emotionally and physically draining. The temporary experience of relief may have made caregivers aware of what they were sacrificing in their own lives to care for their loved ones. It may be that caregivers to dementia patients are either unprepared or unwilling to resume caregiving after having been relieved of the responsibility.



The perceived worsening of the dyadic relationship has important implications. There is a strong association between the perception by the caregiver of great difficulty in providing care to someone with dementia and the admission of the patient to a long-term-care institution (Kraus, 1984). Case coordinators should be alerted to this finding and should help prepare the caregiver to resume caregiving. If such support is not forthcoming, the result may be early institutionalization following respite care.

One way of averting the potential danger is with educational and other intervention programs. These programs should be designed to increase caregivers' confidence in problem solving, to provide caregivers help in redefining situations, and to teach them how to marshal social support (Pratt, Schmall, Wright, & Cleland, 1985). Since effective problem solving and reframing of problems often require experience, programs need to provide opportunities for caregivers to practice these skills in a nonthreatening way. A preliminary evaluation of a community training program for families of elderly (Karusa, Joss, Nowak, & Brice, 1983) supports the value of such an educational approach. Participation in an educational service was associated with increase confidence and comfort in caregiving, decreased caregiver stress, increased tolerance of elderly care recipients, increased skills in caregiving, improved family relationships, and more effective interaction with health

professionals. While the program did not specifically address caregivers for dementia patients, similar results may be possible for these caregivers.

One such educational program is the day care for dementia patients as described by Panella et al. (1984). The program is conducted four days a week. The four primary areas of activity in which all participants take part are memory training and reminiscence, physical activity, social interaction, and family support. The program did not alter the steady progression of intellectual decline; however, it provided the families with a much needed rest. It also helped to maintain an intact family structure. A biweekly family support group provided a forum for joint problem solving, the sharing of management techniques, and the discussion of the caregiver's experience. Many families believed that the knowledge obtained from staff training and support group allowed them to take an active role in preventing institutionalization.

Correlational analyses by others has revealed that home help service is related to morale and mental health. Those receiving the most support have the highest morale and better mental health (Gilhooly, 1984). Robertson and Reisner (1982) reported, however, that more than one-half of the caregivers providing support to dementia patients expressed the need for day hospital, day care, and intermittent relief services, but these services were used

by few patients. There is considerable unmet need for community relief services for the dependent elderly and their supporters in Canada (Robertson & Reisner, 1982). It is, however, unlikely that community support services can prevent the inevitable deterioration and institutionalization of dementia patients. Krause (1984) contends that when dementia becomes sufficiently severe and its behavior manifestations sufficiently disturbing, existing community services do not prevent the provision of needed care from becoming difficult for the family and do not prevent the institutionalization of the afflicted person.

In summary, dementia patients' problems scores indicate less improvement than nondementia patients; however, there is little change on perceived caregiver burden in either group. Caregivers to dementia patients do perceive a worsening in the caregiver-patient relationship following respite care. This question warrants further investigation, but requires larger sample sizes. A control group of dementia patients not using respite care is also required to gauge the natural deterioration in their condition and its effect on caregiver burden. The small sample size and absence of a control group precludes firm conclusions from these findings. As Gilhooly indicated (1984), the often commented upon increase in the number of the very old -- those at most risk of becoming demented -- makes it

imperative that we find out more about the factors mediating the impact on the relative who will be expected to give care.

## REFERENCES

- Archbold, P. G. (1982). All-consuming activity: The family as caregiver. Generations, 7, 12-13.
- Aronson, M. K., & Lipkowitz, R. (1981). Senile dementia Alzheimer's type: The family and the health care delivery system. Journal of the American Geriatrics Society, 29, 568-572.
- Barnes, R. F., Raskind, M. A., & Murphy, C. (1981). Problems of families caring for Alzheimer's patients: Use of a support group. Journal of the American Geriatrics Society, 29, 80-85.
- Blenkner, M. (1967). Environmental change and the aging individual. Journal of Gerontology, 7, 101-105.
- Brody, E. (1978). Long-term care of older people: A practical guide. New York: Human Sciences Press.
- Brody, E. M., & Lang, A. (1982). They can't do it all: Aging daughters with aged mothers. Generations, 7, 18-20.
- Cantor, M. H. (1983). Strain among caregivers: A study of experience in the United States. Gerontologist, 23, 597-604.

- Cohen, G. D. (1980). Prospects for mental health ageing.  
In J. E. Birren & R. B. Sloane (Eds.), Handbook of mental health and aging. Englewood Cliff: Prentice-Hall.
- Cohen, G. D. (1984). The mental health professional and the Alzheimer patient. Hospital and Community Psychiatry, 35, 115-123.
- Cronbach, L. J., & Furby, L. (1970). How should we measure "change" -- or should we? Psychological Bulletin, 74, 68-80.
- Duckworth, G. S., & Ross, H. (1975). Diagnostic differences in psychogeriatric patients in Toronto, New York, and London. Canadian Medical Association Journal, 112, 847.
- Foundation for Long-Term Care. (1983). Respite care for the frail elderly: A summary report on institutional respite research. New York: The Center for the Study of Aging.
- Getzel, G. (1981). Social work with family caregivers to the aged. Social Casework, 26, 201-209.
- Gilhooly, M. L. M. (1984). The impact of care-giving on care-givers: Factors associated with the psychological well-being of people supporting a dementing relative in the community. British Journal of Medical Psychology, 57, 35-44.

- Gross-Andrew, S., & Zimmer, A. (1978). Incentives to family caring for disabled elderly: Research and demonstration project to strengthen the natural support system. Journal of Gerontological Social Work, 1, 119-133.
- Gurland, B., Dean, L., Gurland, R., & Cook, D. (1978). Personal time dependency in the elderly of New York City: Findings from the U.S.-U.K. cross-national geriatric community study in dependency in the elderly of New York City. Report of a Research Utilization Workshop, 9-44.
- Gwyther, L. S., & Blazer, D. G. (1984). Family therapy and the dementia patient. Journal of Family Practice, 29, 140-156.
- Hayter, J. (1980). Helping families of patients with Alzheimer's disease. Journal of Gerontological Nursing, 8, 81-86.
- Isaacs, B., Livingstone, M., & Neville, Y. (1972). Survival of the unfittest: A study of geriatric patients in Glasgow. London: Routledge & Kegan Paul.
- Jacobs, J. W., Bernhard, J. R., Delago, A., & Strain, J. J. (1977). Screening for organic mental syndromes in the medically ill. Annals of Internal Medicine, 86, 40-46.
- Johnson, E. (1978). "Good" relationships between older mothers and their daughters: A causal model. Gerontologist, 18, 301-306.

- Kapust, L. K. (1982). Living with dementia: The ongoing funeral. Social Work in Health Care, 7, 79-91.
- Karusa, J., Joss, D., Nowak, C., & Brice, G. (1983). Evaluation of a community training program for families of the elderly. Paper presented at the annual meeting of the Gerontological Society of America, San Francisco.
- Kiloh, L. G. (1961). Pseudo-dementia. Acta Psychiatrica Scandinavica, 37, 336.
- Kraus, A. S. (1984). The burden of care for families of elderly persons with dementia. Canadian Journal on Aging, 3, 45-51.
- Levine, N. B., Destoor, D. P., & Gendron, C. E. (1983). Coping with dementia: A pilot study. Journal of the American Geriatrics Society, 31, 12-18.
- Lezak, M. D. (1978). Living with the characterologically altered brain injured patient. Clinical Psychology, 39, 592-598.
- Litwak, E. (1978). Planning care for the elderly: Coordination of formal organization and primary groups. Paper presented at the 31st annual meeting of the Gerontological Society of America, Dallas.
- Lussier, C. (1986). Personal communication, April 21.



- Mace, N. L., & Rabins, P. V. (1981). The 36-hour day: A family guide to caring for persons with Alzheimer's disease, related dementing illnesses, and memory loss in later life. Baltimore: Johns Hopkins University Press.
- Monk, A. (1979). Family supports in old age. Social Work, 24, 533-538.
- Morycz, R. K. (1980). An exploration of senile dementia and family burden. Clinical Social Work Journal, 8, 16-27.
- Panella, J. J., Lilliston, B. A., Brush, D., & McDowell, F. H. (1984). Day care for dementia patients: An analysis of a four-year program. Journal of the American Geriatrics Society, 32, 883-886.
- Plutzky, M. (1974). Principals of psychiatric management of chronic brain syndrome. Geriatrics, 29, 120-127.
- Poulshock, S., & Silverstone, B. (1979). Caring for elders and the mental health of family members: An overview of the study. Unpublished manuscript, Benjamin Rose Institute.
- Pratt, C. C., Schmall, V. L., Wright, S., & Cleland, M. (1985). Burden and coping strategies of caregivers to Alzheimer's patients. Family Relations, 34, 27-33.
- Rabins, P. V., Mace, N. L., & Lucas, M. J. (1982). The impact of dementia on the family. Journal of the American Medical Association, 248, 333-336.

- Robertson, D., & Reisner, D. (1982). Management of dementia in the elderly at home: Stress and the supporter. Canada's Mental Health, 30, 36-38.
- Robinson, B. C. (1983). Validation of a caregiver strain index. Journal of Gerontology, 38, 344-348.
- Roth, M., & Myers, O. H. (1975). The diagnosis of dementia in contemporary psychiatry (Vol. 9). Edited by T. Silverstone & B. Barraclough. Ashford, Kent, England: Headley Brothers.
- Sanford, R. A. (1975). Tolerance of debility in elderly dependents by supporters at home: Its significance for hospital practice. British Medical Journal, 23, 471-473.
- Shanas, E., & Sussman, M. (1977). Family bureaucracy and the elderly. Durham, NC: Duke University Press.
- Soldo, B. J., & Myllyluoma, J. (1983). Care-givers who live with dependent elderly. Gerontologist, 23, 605-611.
- Teusink, J. P., & Mahler, S. (1984). Helping families cope with Alzheimer's disease. Hospital and Community Psychiatry, 35, 152-160.
- Ware, L. A., & Carper, M. (1982). Living with Alzheimer's disease patients: Family stresses and coping mechanisms. Psychotherapy: Theory, Research, and Practice, 19, 472-482.

- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980).  
Relatives of the impaired elderly: Correlates of feelings  
of burden. Gerontologist, 20, 649-655.
- Zarit, J. M., & Zarit, S. H. (1982). Measuring burden and  
support in families with Alzheimer's disease elders.  
Paper presented at the 35th annual Scientific Meeting of  
the Gerontological Society of America, Boston.
- Zarit, S. H., & Zarit, J. M. (1983). The memory and  
behavior problems checklist and the burden interview.  
Unpublished manuscript.

Appendix A

MEMORY AND BEHAVIOR PROBLEMS CHECKLIST

## MEMORY AND BEHAVIOR PROBLEMS CHECKLIST

## INSTRUCTIONS TO INTERVIEWER:

You want to describe as accurately as possible how often problems occur.

## INSTRUCTIONS TO CAREGIVER:

"I am going to read you a list of common problems. Tell me if any of these problems 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 ratings are printed.

## FREQUENCY RATINGS

- 0 = never occurred
- 1 = has occurred infrequently  
(and 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
- 5 = occurred frequently in past, but no longer occurs.
- 7 = would occur, if not supervised by caregiver (e.g., wandering except door is locked).

## 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. Asking the same question over and over again.	0	1	2	3	4	5	0	1	2	3	4	
2. Trouble remembering recent events (e.g., items in the newspaper, on T.V.)	0	1	2	3	4	5	0	1	2	3	4	
3. Trouble remembering significant events from the past.	0	1	2	3	4	5	0	1	2	3	4	
4. Losing or misplacing things.	0	1	2	3	4	5	0	1	2	3	4	
5. Wandering or getting lost.	0	1	2	3	4	5	7	0	1	2	3	4
6. Unable to find way about indoors.	0	1	2	3	4	5	0	1	2	3	4	
7. Unable to find way about familiar streets.	0	1	2	3	4	5	0	1	2	3	4	
8. Not recognizing a familiar place.	0	1	2	3	4	5	0	1	2	3	4	
9. Not recognizing familiar people.	0	1	2	3	4	5	0	1	2	3	4	
10. Not recognizing a familiar object.	0	1	2	3	4	5	0	1	2	3	4	

BEHAVIORS	FREQUENCY							REACTION				
11. Forgetting what day it is.	0	1	2	3	4	5	0	1	2	3	4	
12. Starting, but not finishing things.	0	1	2	3	4	5	0	1	2	3	4	
13. Difficulty concentrating on a task.	0	1	2	3	4	5	0	1	2	3	4	
14. Hiding things (money, jewelry, etc.)	0	1	2	3	4	5	0	1	2	3	4	
15. Being suspicious or accusative.	0	1	2	3	4	5	0	1	2	3	4	
16. Destroying property.	0	1	2	3	4	5	0	1	2	3	4	
17. Doing things that embarrass you.	0	1	2	3	4	5	7	0	1	2	3	4
18. Waking you up at night.	0	1	2	3	4	5	0	1	2	3	4	
19. Being constantly restless.	0	1	2	3	4	5	0	1	2	3	4	
20. Spending long periods of time inactive.	0	1	2	3	4	5	0	1	2	3	4	
21. Being constantly talkative.	0	1	2	3	4	5	0	1	2	3	4	
22. Talking little or not at all.	0	1	2	3	4	5	0	1	2	3	4	
23. Appears sad or depressed.	0	1	2	3	4	5	0	1	2	3	4	
24. Appears anxious or worried.	0	1	2	3	4	5	0	1	2	3	4	
25. Engaging in behavior that is potentially dangerous to others or self.	0	1	2	3	4	5	7	0	1	2	3	4
26. Dwelling on the past.	0	1	2	3	4	5	0	1	2	3	4	
27. Reliving situations from the past.	0	1	2	3	4	5	0	1	2	3	4	
28. Seeing or hearing things that are not there (hallucinations or illusions)	0	1	2	3	4	5	0	1	2	3	4	
29. Eating sweets excessively.	0	1	2	3	4	5	0	1	2	3	4	
30. Not eating at all.	0	1	2	3	4	5	0	1	2	3	4	
31. Any other problems (specify):	0	1	2	3	4	5	0	1	2	3	4	

Appendix B  
BURDEN INTERVIEW

## BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
4. Do you feel embarrassed over your relative's behavior?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
5. Do you feel angry when you are around your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
7. Are you afraid what the future holds for your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
8. Do you feel your relative is dependent on you?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
9. Do you feel strained when you are around your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always



10. Do you feel your health has suffered because of your involvement with your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
11. Do you feel that you don't have as much privacy as you would like, because of your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
12. Do you feel that your social life has suffered because you are caring for your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
13. Do you feel uncomfortable about having friends over, because of your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
16. Do you feel that you will be unable to take care of your relative much longer?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
17. Do you feel you have lost control of your life since your relative's illness?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
18. Do you wish you could just leave the care of your relative to someone else?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
19. Do you feel uncertain about what to do about your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

20. Do you feel you should be doing more for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

Appendix C

DESCRIPTIVE INFORMATION ABOUT CAREGIVERS AND THE  
NATURE OF THEIR CAREGIVING RESPONSIBILITIES



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

B. Do you work now?

Yes	2
No	1
DK	9

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)?

Yes	2
No	1
DK	9

Not Now Working

E. When did you work last? Months ago \_\_\_\_\_

\_\_\_\_\_  
Month/Year

F. Why did you stop working? (probe:) Any other reasons?

Ask All

G. Are you actively seeking (more) work now?

Yes	2
No	1
DK	9

-----

4. A. Do you help (CR) with (task):

\_\_\_\_\_ Bathing

\_\_\_\_\_ Toilet needs

\_\_\_\_\_ Dressing

\_\_\_\_\_ Support and/or supervision  
(managing financial affairs)

\_\_\_\_\_ Feeding

\_\_\_\_\_ Taking medication or with medical treatment at home.

\_\_\_\_\_ Getting about the house

B. About how many hours a day do you estimate you are actually doing things with or for (CR)?  
\_\_\_\_\_

Now, a few questions about your physical health.

5. How would you rate your overall health at the present time:

<u>excellent</u>	<u>4</u>
<u>good</u>	<u>3</u>
<u>fair</u>	<u>2</u>
<u>poor</u>	<u>1</u>
<u>DK</u>	<u>9</u>

6. Is your health now better, about the same, or not as good as it was three years ago?

<u>better</u>	<u>3</u>
<u>same</u>	<u>2</u>
<u>not as good</u>	<u>1</u>
<u>DK</u>	<u>9</u>

7. Do your health problems stand in the way of your doing the thing you want to do?

<u>not at all</u>	<u>3</u>
<u>a little</u>	<u>2</u>
<u>a great deal</u>	<u>1</u>
<u>DK</u>	<u>9</u>

8. Would you say that your health is better, about the same, or not as good as most people your age?

<u>better</u>	<u>3</u>
<u>same</u>	<u>2</u>
<u>not as good</u>	<u>1</u>
<u>DK</u>	<u>9</u>

9. About how many days have you spent in a hospital during the past twelve months?

---

Now, a few questions about your physical health.

23. How would you rate your overall health at the present time:

excellent	4
good	3
fair	2
poor	1
DK	9

24. Is your health now better, about the same, or not as good as it was three years ago?

better	3
same	2
not as good	1
DK	9

25. Do your health problems stand in the way of your doing the thing you want to do?

not at all	3
a little	2
a great deal	1
DK	9

26. Would you say that your health is better, about the same, or not as good as most people your age?

better	3
same	2
not as good	1
DK	9

27. About how many days have you spent in a hospital during the past twelve months?

- 28A. Have you been involved in any caregiver support or self-help groups in the last year?

Yes	2
No	1
DK	9

- B. Has any other family member been involved in any caregiver support or self-help groups in the last year?

Yes	2
No	1
DK	9

29. Have you been in therapy or received counselling in the past year?

Yes	2
No	1
DK	9

32A. When did (CR) first start living with you? Months ago \_\_\_\_\_

Month/Year

B. When did you start giving (CR) special help  
and care because of (her) condition? Months ago \_\_\_\_\_

Month/Year



FAMILY SUPPORT OF CAREGIVING ACTIVITIES

1A. Is there anyone in particular in whom you confide or talk to about your problems?

Yes	2
No	1
DK	9

B. Who is that person?

C. About how often do you talk with that person on the phone and see him/her in person?

First Name	Relationship to CG	Phone	See

Frequency Code

never	0
3 x yr. or less	1
4-10 x yr	2
1 x month	3
2-3 x month	4
1 x week	5
2-4 x week	6
5 x week or more	7
DK	9

2. Overall, what would you say was the quality of your relationship to (CR) prior to the onset of his/her need for care?

excellent	5
good	4
fair	3
poor	2
none	1
DK	9

3. Overall, what would you say is the quality of your current relationship to (CR):

excellent	5
good	4
fair	3
poor	2
none	1
DK	9

4. Overall, what would you say is the quality of the relationship of your (spouse) to (CR):

excellent	5
good	4
fair	3
poor	2
none	1
DK	9

5. Overall, how would you describe your (spouse's) attitude toward the help you give?
- |                     |   |
|---------------------|---|
| very supportive     | 5 |
| mostly supportive   | 4 |
| neutral             | 3 |
| mostly unsupportive | 2 |
| very unsupportive   | 1 |
| DK                  | 9 |
6. Overall, what would you say is the quality of the relationship of your children to (CR):
- |           |   |
|-----------|---|
| excellent | 5 |
| good      | 4 |
| fair      | 3 |
| poor      | 2 |
| none      | 1 |
| DK        | 9 |
7. Overall, how would you describe your children's attitude toward the help you provide (CR):
- |                     |   |
|---------------------|---|
| very supportive     | 5 |
| mostly supportive   | 4 |
| neutral             | 3 |
| mostly unsupportive | 2 |
| very unsupportive   | 1 |
| DK                  | 9 |
8. How stressful is it (to live alone with CR) (to have # others in your household)?
- |                    |   |
|--------------------|---|
| not stressful      | 1 |
| somewhat stressful | 2 |
| usually stressful  | 3 |
| DK                 | 9 |
9. How stressful is it to have children under 18 years of age in your household?
- |                    |   |
|--------------------|---|
| not stressful      | 1 |
| somewhat stressful | 2 |
| usually stressful  | 3 |
| DK                 | 9 |
10. How stressful is it for you to work in addition to caring for (CR)?
- |                    |   |
|--------------------|---|
| not stressful      | 1 |
| somewhat stressful | 2 |
| usually stressful  | 3 |
| DK                 | 9 |

Appendix D  
CAREGIVER'S PERCEPTION OF RESPITE CARE

## Caregiver's Perception of Respite Care

1. Has there been any change in the quality of your relationship with the carereceiver (CR) since I last spoke to you -- is it the same, better, or worse?
  - a) worse
  - b) same
  - c) better
2. How beneficial, if at all, was this respite to you?
  - a) not at all beneficial
  - b) not too beneficial
  - c) somewhat beneficial
  - d) beneficial
  - e) very beneficial
3. What is (CR's) overall situation since leaving respite care?
  - a) much worse
  - b) worse
  - c) same
  - d) better
  - e) much better

4. What is your overall situation since (CR) has returned home from the personal care home?
- a) much worse
  - b) worse
  - c) same
  - d) better
  - e) much better

Appendix E  
CONSENT TO PARTICIPATE

Consent to Participate

I agree to participate in a study on the impact of respite care conducted by Michael Burdz of the Department of Health and the Psychology Department, University of Manitoba. I understand that I am under no obligation to participate and I may withdraw from the study at any time.

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Date

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Signature

I would/would not like to receive summary information on the results of the study.

Address to which results should be sent:

If you have any questions, feel free to call me at 786-7241. If I am not in, leave a message for me at 786-7173 and I will return your call.