National Library of Canada
Acquisitions and Bibliographic Services Branch
395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale du Canada
Direction des acquisitions et des services bibliographiques
395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

Canada

The Affective Correlates of the Desire to Institutionalize in Caregivers to Relatives with Dementia

by

April V. R. D'Aloisio

Submitted in partial fulfillment of the requirements for the degree
of Doctor of Philosophy
at
Dalhousie University
Halifax, Nova Scotia
May, 1995

National Library
of Canada

Acquisitions and
Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale
du Canada

Direction des acquisitions et
des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

ISBN 0-612-05263-X

Name APRIL V.R. D'ALOISIO

Dissertation Abstracts International is arranged by broad, general subject categories. Please select the one subject which most nearly describes the content of your dissertation. Enter the corresponding four-digit code in the spaces provided.

PSYCHOLOGY

SUBJECT TERM

0 5 2 5

SUBJECT CODE

U·M·I

Subject Categories

THE HUMANITIES AND SOCIAL SCIENCES

COMMUNICATIONS AND THE ARTS

Architecture	0729
Art History	0377
Cinema	0900
Dance	0378
Fine Arts	0357
Information Science	0723
Journalism	0391
Library Science	0399
Mass Communications	0708
Music	0413
Speech Communication	0459
Theater	0465

EDUCATION

General	0515
Administration	0514
Adult and Continuing	0516
Agricultural	0517
Art	0273
Bilingual and Multicultural	0282
Business	0688
Community College	0275
Curriculum and Instruction	0727
Early Childhood	0518
Elementary	0524
Finance	0277
Guidance and Counseling	0519
Health	0680
Higher	0745
History of	0520
Home Economics	0278
Industrial	0521
Language and Literature	0279
Mathematics	0280
Music	0522
Philosophy of	0998
Physical	0523
Psychology	0525
Reading	0535
Religious	0527
Sciences	0714
Secondary	0533
Social Sciences	0534
Sociology of	0340
Special	0529
Teacher Training	0530
Technology	0710
Tests and Measurements	0288
Vocational	0747

LANGUAGE, LITERATURE AND LINGUISTICS

Language	
General	0679
Ancient	0289
Linguistics	0290
Modern	0291
Literature	
General	0401
Classical	0294
Comparative	0295
Medieval	0297
Modern	0298
African	0316
American	0591
Asian	0305
Canadian (English)	0352
Canadian (French)	0355
English	0593
Germanic	0311
Latin American	0312
Middle Eastern	0315
Romance	0313
Slavic and East European	0314

PHILOSOPHY, RELIGION AND THEOLOGY

Philosophy	0422
Religion	
General	0318
Biblical Studies	0321
Clergy	0319
History of	0320
Philosophy of	0322
Theology	0469

SOCIAL SCIENCES

American Studies	0323
Anthropology	
Archaeology	0324
Cultural	0326
Physical	0327
Business Administration	
General	0310
Accounting	0272
Banking	0770
Management	0454
Marketing	0338
Canadian Studies	0385
Economics	
General	0501
Agricultural	0503
Commerce-Business	0505
Finance	0508
History	0509
Labor	0510
Theory	0511
Folklore	0358
Geography	0366
Gerontology	0351
History	
General	0578
Ancient	0579
Medieval	0581
Modern	0582
Black	0328
African	0331
Asia, Australia and Oceania	0332
Canadian	0334
European	0335
Latin American	0336
Middle Eastern	0333
United States	0337
History of Science	0585
Law	0398
Political Science	
General	0615
International Law and Relations	0616
Public Administration	0617
Recreation	0814
Social Work	0452
Sociology	
General	0626
Criminology and Penology	0627
Demography	0938
Ethnic and Racial Studies	0631
Individual and Family Studies	0628
Industrial and Labor Relations	0629
Public and Social Welfare	0630
Social Structure and Development	0700
Theory and Methods	0344
Transportation	0709
Urban and Regional Planning	0999
Women's Studies	0453

THE SCIENCES AND ENGINEERING

BIOLOGICAL SCIENCES

Agriculture	
General	0473
Agronomy	0285
Animal Culture and Nutrition	0475
Animal Pathology	0476
Food Science and Technology	0359
Forestry and Wildlife	0478
Plant Culture	0479
Plant Pathology	0480
Plant Physiology	0817
Range Management	0777
Wood Technology	0746
Biology	
General	0306
Anatomy	0287
Biostatistics	0308
Botany	0309
Cell	0379
Ecology	0329
Entomology	0353
Genetics	0369
Limnology	0793
Microbiology	0410
Molecular	0307
Neuroscience	0317
Oceanography	0416
Physiology	0433
Radiation	0821
Veterinary Science	0778
Zoology	0472
Biophysics	
General	0786
Medical	0760

EARTH SCIENCES

Biogeochemistry	0425
Geochemistry	0996
Geodesy	0370
Geology	0372
Geophysics	0373
Hydrology	0388
Mineralogy	0411
Paleobotany	0345
Paleoecology	0426
Paleontology	0418
Paleozoology	0985
Palynology	0427
Physical Geography	0368
Physical Oceanography	0415

HEALTH AND ENVIRONMENTAL SCIENCES

Environmental Sciences	0768
Health Sciences	
General	0566
Audiology	0300
Chemotherapy	0992
Dentistry	0567
Education	0350
Hospital Management	0769
Human Development	0758
Immunology	0982
Medicine and Surgery	0564
Mental Health	0347
Nursing	0569
Nutrition	0570
Obstetrics and Gynecology	0380
Occupational Health and Therapy	0354
Ophthalmology	0381
Pathology	0571
Pharmacology	0419
Pharmacy	0572
Physical Therapy	0382
Public Health	0573
Radiology	0574
Recreation	0575
Speech Pathology	0460
Toxicology	0383
Home Economics	0386

PHYSICAL SCIENCES

Pure Sciences

Chemistry	
General	0485
Agricultural	0749
Analytical	0486
Biochemistry	0487
Inorganic	0488
Nuclear	0738
Organic	0490
Pharmaceutical	0491
Physical	0494
Polymer	0495
Radiation	0754
Mathematics	0405
Physics	
General	0605
Acoustics	0986
Astronomy and Astrophysics	0606
Atmospheric Science	0608
Atomic	0748
Electronics and Electricity	0607
Elementary Particles and High Energy	0798
Fluid and Plasma	0759
Molecular	0609
Nuclear	0610
Optics	0752
Radiation	0756
Solid State	0611
Statistics	0463

Applied Sciences

Applied Mechanics	0346
Computer Science	0984
Engineering	
General	0537
Aerospace	0538
Agricultural	0539
Automotive	0540
Biomedical	0541
Chemical	0542
Civil	0543
Electronics and Electrical	0544
Heat and Thermodynamics	0348
Hydraulic	0545
Industrial	0546
Marine	0547
Materials Science	0794
Mechanical	0548
Metallurgy	0743
Mining	0551
Nuclear	0552
Packaging	0549
Petroleum	0765
Sanitary and Municipal	0554
System Science	0790
Geotechnology	0428
Operations Research	0796
Plastics Technology	0795
Textile Technology	0994

PSYCHOLOGY

General	0621
Behavioral	0384
Clinical	0622
Developmental	0620
Experimental	0623
Industrial	0624
Personality	0625
Physiological	0989
Psychobiology	0349
Psychometrics	0632
Social	0451

DALHOUSIE UNIVERSITY

FACULTY OF GRADUATE STUDIES

The undersigned hereby certify that they have read and recommend to the Faculty of Graduate Studies for acceptance a thesis entitled "The Affective Correlates of the Desire to Institutionalize in Caregivers to Relatives with Dementia"

by April V. R. D'Aloisio

in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

Dated May 26, 1995

External Examiner

Research Supervisor

Examining Committee

[redacted]

DALHOUSIE UNIVERSITY

DATE: 6 July 1995

AUTHOR: April V. R. D'Aloisio

TITLE: The Affective Correlates of the Desire to Institutionalize in Caregivers to Relatives with Dementia

DEPARTMENT OR SCHOOL: Psychology

DEGREE: Ph.D. CONVOCATION: October YEAR: 1995

Permission is herewith granted to Dalhousie University to circulate and to have copies for non-commercial purposes, at its discretion, the above title upon the request of individuals or institutions.

[redacted]

Signature of Author

Dedication

This thesis is dedicated to my grandmother, Alice M. Reede. She was a model of strength of character, persistence, patience, and empathy. Through her wisdom and example, she taught me the importance of maintaining priorities in life, that it is possible to age successfully, and especially, that now is the time to be happy. Guided by her inspiration, I was able to begin, implement and complete this process.

Table of Contents

List of Tables

Abstract

The aim of the present study was to examine the emotional correlates of the desire to institutionalize in family caregivers of elderly persons diagnosed with dementia. Subjects were 75 female caregivers and their elderly relatives who were referred, within the last two years, to the Division of Geriatric Medicine in Camp Hill Hospital. All care recipients had a diagnosis of dementia made by a neuropsychologist or geriatrician according to the DSM III-R criteria. It was hypothesized that caregiver burnout would predict institutionalization over and above patient disability variables. It was predicted that caregiver burden would be correlated with the desire to institutionalize but would not predict desire to institutionalize over and above patient disability variables. Results indicated that severity of patient disability accounted for 23 per cent of the variance in caregivers' desire to institutionalize. As expected, caregiver burnout was a significant predictor accounting for an additional 9 per cent of the variance above and beyond that accounted for by patient disability. While burden was correlated with desire to institutionalize, when patient disability was statistically controlled, burden was not a significant predictor of desire to institutionalize. Discussion focuses on the need to include comprehensive measures of patient disability in studies addressing the role of psychological variables in caregiver stress. It is argued that resource depletion models of caregiver stress may provide a viable account of the processes involved in caregivers' decisions concerning the institutionalization of a care recipient.

Acknowledgments

Numerous individuals have provided the guidance and support that made this dissertation possible. I am very grateful to Mick Sullivan for his invaluable advice, encouragement, friendship and sense of humor. I would like to thank John Barresi for his constant support and advice. I am indebted to Ken Rockwood for his indispensable help in obtaining participants for the study and his feedback. For her advice, time and consideration I would like to extend my thanks to Grace Pretty. To my friend and unfailing mentor Allan Wilson, I would like to express my deep appreciation for his emotional support and his example of a caring, insightful clinician.

To Simon, I am thankful for his immeasurable support and patience and also his help with formatting the thesis. I would also like to thank my friends, Marie, Judith and Janet, who provided encouragement and helped keep this process in perspective. I am also grateful to my father and mother for their financial and emotional support.

Finally, my gratitude extends to the participants in this study, who not only took the time out of their 36 hour days to provide personal information concerning their experiences, but also through their hospitality, made this an enjoyable experience.

Chapter 1

Introduction

When elderly individuals are not able to care for themselves, family members often assume caregiving responsibility. It has been estimated that approximately 68% of individuals over the age of 85 live with their families, either with a spouse or other family members. The majority of these individuals require some degree of assistance (Gilford, 1988). There are indications that families may begin to consider institutional placement when they feel that the demands of caregiving become excessive. The primary aim of the present study was to examine the affective correlates of the desire to institutionalize in family caregivers of elderly diagnosed with dementia.

1.1 Aging and Disability

One of the most dramatic changes of the 20th century is the 'graying' of the population; never before in history have so many lived to such an old age. Not only are the numbers of older individuals increasing in absolute terms but also in relation to the total population. In Canada at the turn of the century approximately 2.5 million Canadians or 4% of the total population was over the age of 65 (McPherson, 1983). In 1991, the estimated 3.1 million individuals over the age of 65 comprised approximately 12% of the population. By the year 2036, it is projected that this proportion will increase to 25%. Within this elderly population, the fastest population growth rate is occuring in the over-75 age group. By 2036, these individuals will comprise 13% of the population, almost three times the proportion of 5% in 1991 (Health, & Welfare, 1991).

Survival into the later years of life brings increasing chronic illness and disability. The definition of disability adopted by the World Health Organization (WHO) and the one used in this thesis is: "a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1981, p. 8). A chronic illness is considered to be a disability only if it interferes with an individual's ability to carry out "normal" activities. The prevalence of disability increases with age, ranging from 6% in individuals between the ages of 15-34, to 38.6% among the 65 and over group (Statistics Canada, 1990). The prevalence of disability increases dramatically among the older segments of the elderly population; over half (52%) of the 75-84 age group and 82% of those 85 and over are disabled (Statistics Canada, 1986).

1.2 Dementia

1.2.1 Statistics

Mental illness is a significant contributor to disability in the elderly. The findings of several epidemiological studies suggest that the prevalence of mental illness in individuals over the age of 65 ranges from 15 to 30% (Canadian Medical Association, 1987). Dementia constitutes a substantive proportion of mental problems in the elderly. Estimates of the prevalence of dementia range from 3.5% to 8.0% (Bland, Newman, & Orn, 1988; Canadian Study of Health and Aging, 1994; Jeans, Helmes, Mersey, Robertson, & Rand, 1987; Jorm, Korten, & Henderson, 1987; Robertson, Stolee, & Rockwood, 1989; Rockwood, & Stadnyk, 1994; Statistics Canada, 1987). The prevalence rate of dementia increases dramatically with age from 1.4% in the 65-69 age group to 38.6% in the 90 and over group. With the ever increasing growth rate in the older age groups the prevalence of the dementing illnesses is expected to continue to increase from 5.6% in 1981 to a projected 7.4% in 2006 (Statistics Canada, 1987). A recent study has estimated that approximately 253,000 people in Canada are currently affected by dementia and it is projected that this number will triple during the next 40 years to approximately 778,000 cases (Canadian Study of Health and Aging, 1994).

1.2.2 Criteria for the Diagnosis of Dementia

Dementia is a term which describes a constellation of symptoms associated with a number of organic brain diseases. The criteria for the diagnosis of dementia according to the revised third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III-R, American Psychiatric Association, 1987) are:

A. Demonstrable evidence of impairment in short- and long-term memory. Impairment in short-term memory (inability to learn new information) may be indicated by inability to remember three objects after five minutes. Long-term memory impairment (inability to remember information that was known in the past) may be indicated by inability to remember past personal information (e.g., what happened yesterday, birthplace, occupation) or facts of common knowledge (e.g., past Presidents, well-known dates).

B. At least one of the following:

(1) impairment in abstract thinking, as indicated by inability to find similarities and differences between related words, difficulty in defining words and concepts, and other similar tasks

(2) impaired judgment, as indicated by inability to make reasonable plans to deal with interpersonal, family, and job-related problems and issues

(3) other disturbances of higher cortical function, such as aphasia (disorder of language), apraxia (inability to carry out motor activities despite intact

comprehension and motor function), agnosia (failure to recognize or identify objects despite intact sensory function), and "constructional difficulty" (e.g., inability to copy three-dimensional figures, assemble blocks, or arrange sticks in specific designs)

(4) personality change, i.e., alteration or accentuation of premorbid traits.

C. The disturbance in A and B significantly interferes with work or usual social activities or relationships with others.

D. Not occurring exclusively during the course of Delirium.

E. Either (1) or (2):

(1) there is evidence from the history, physical examination, or laboratory tests of a specific organic factor (or factors) judged to be etiologically related to the disturbance

(2) in the absence of such evidence, an etiologic organic factor can be presumed if the disturbance cannot be accounted for by any non organic mental disorder, e.g., Major Depression accounting for cognitive impairment.

In sum, the essential components of dementia from the DSM-III-R criteria are memory and other cognitive impairments of probable organic origin and occurring without the presence of delirium. This broad definition of dementia includes a number of diseases, regardless of age or clinical course, and refers to both reversible and irreversible conditions.

1.2.3 Types of Dementia

The most common type of dementia is Alzheimer's Disease (AD). AD accounts for approximately 65% of all cases of dementing illness (Mortimer, 1983). There are a number of degenerative diseases of late life which are often clinically difficult to differentiate. As Moss and Albert (1988) have pointed out, due to the high prevalence of AD, often contradistinction of AD is made with other irreversible dementing disorders. A short description of these dementing illnesses is presented below to highlight the similarities and differences in presentation and pathogenesis that may bear on the differential diagnosis of AD. Although many types of dementia exist, this review will focus on a limited number of dementias specifically, vascular dementia, Pick's disease, frontal lobe-type dementia, diffuse Lewy-body disease, Parkinson's disease dementia, Creutzfeldt-Jakob disease, and normal pressure hydrocephalus, from which AD may be clinically differentiated. A detailed description of all dementing illnesses is beyond the scope of this thesis (for reviews of this area, see Emery, & Oxman, 1994).

In AD the most characteristic brain changes of the disease are, senile plaques and neurofibrillary tangles which are located throughout the cortex and in other areas such as the amygdala and hippocampus. Neurochemical changes, in particular loss of acetylcholinesterase (AChE) and choline acetyltransferase (CAT), have been consistently found in AD (Bartus, Dean, & Beer, 1982). The definite diagnosis of AD is virtually always made at the time of autopsy. Clinically, the diagnosis is one which is primarily based on exclusion of medical, neurological and psychiatric conditions which produce similar symptoms. An important consideration in the differential diagnosis of AD is the clinical course. While the nature and rate of decline of individuals with AD is highly variable (e.g., Reisberg 1983), AD is diagnosed when the individual's history reveals a uniformly progressive cognitive decline and all other possible causes for this decline have been excluded.

Recently several investigators have questioned the assumption that AD is a single disease, suggesting rather that AD may be a complex syndrome with marked heterogeneity (e.g. Chui, Teng, Henderson, & Moy, 1985; Khachaturian, 1992; Mayeux, Stern, & Sano, 1992). Specifically, the heterogeneity has been discussed in relation to age of onset, clinical course, patterns of neurological and psychiatric impairment and response to treatment. Distinctions have been made on the basis of age of onset (early versus late onset), familial verses sporadic AD, and language or motor impairments (Chui, et al., 1985; Mayeux, et al., 1992). Although, subtyping or the notion of heterogeneity has implications for theoretical conceptualizations of the disease, subtypes have yet to be incorporated within the standardized clinical classification, such as the DSM III-R (American Psychiatric Association, 1987). It has been suggested that one of the future challenges of clinical research on AD will be to expand efforts to refine diagnostic criteria in a manner that better reflects the heterogeneity of the disease (Khachaturian, 1992).

Jorm (1985) has challenged the subtype conceptualization of AD suggesting that what have been identified as different subtypes may actually reflect different stages of the disease. Jorm bases his argument primarily on methodological grounds arguing that the cross-sectional nature of the studies that have been cited in support of AD subtyping does not rule out the possibility that identified subtypes represent different stages of single disease.

A stage model of primary degenerative dementia has been proposed by Reisberg (1982). On the basis of symptom pattern, Reisberg has suggested that primary degenerative dementia progresses through a series of stages characterized by increasing impairment and disability. Reisberg's stages as measured by the Global Deterioration Scale (GDS, Reisberg, Ferris, de Leon, & Crook, 1982) are as follows: 1) no cognitive decline; 2) very mild cognitive decline; 3) mild cognitive decline; 4) moderate cognitive decline 5) moderately severe cognitive decline; 6) severe cognitive decline 7) very severe cognitive decline. Reisberg stages may be derived on the basis of scores on mental status function (Eisdorfer, Cohen, Paveza, Ashford, Luchins, Gorelick, Hirschman, Freels, Levy, Semla, & Shaw, 1992). Recent research has shown that psychiatric symptoms and functional impairments occur earlier than predicted by the GDS (Eisdorfer, et al., 1992). Based on this finding, Eisdorfer and associates suggested that separate scales measuring cognitive and functional impairments be used rather than the GDS.

The second most common cause of dementia in the elderly is vascular dementia which accounts for approximately 10 to 15% of all cases and coexists with AD in 25% of all cases of dementia (Tomlinson, Blessed, & Roth, 1970). Vascular dementia is often the result of multiple small vascular accidents or strokes, although several other pathological conditions may be responsible for this condition (Niederehe, & Oxman, 1994). Clinically, vascular dementia often may be distinguished from AD by the onset and progression, associated pathology, as well as the focal neurologic signs and symptoms. The onset of vascular dementia is usually sudden and the course often is characterized by step-wise deterioration, varying with the number and rate of strokes. In comparison, the onset of AD is described as insidious and the course is gradual and progressive. Pathology associated with vascular dementia includes all of the factors which predispose individuals to stroke, such as hypertension, transient ischemic attacks, heart disease, diabetes mellitus, obesity, cigarette smoking, and peripheral vascular disease. Vascular dementia is often clinically distinguishable from AD by frequently being accompanied by lability of affect and focal "stroke like" symptomatology (Hachinski, 1983; Hachinski, Lassen, & Marshall, 1974; Rosen, Terry, Fuld, Katzman, & Peck, 1980).

It has been suggested that the lack of specificity of the DSM III-R criteria for Primary Degenerative Dementia of the Alzheimer type may result in the inclusion of other degenerative diseases such as Pick's disease, frontal lobe dementia and diffuse Lewy body disease (Erkinjuntti, Hachinski, & Sulkava, 1994). Pick's disease is a rare type of dementia. The pathology of Pick's disease includes atrophy in the frontal and temporal lobes, inclusion bodies in the neurons called Pick's bodies, but not the senile plaques and neurofibrillary tangles characteristic of AD. In contrast to the course of AD, the early symptoms of Pick's disease are characterized by inappropriate social behaviour and mood which may occur before memory disturbance is apparent (Lishman, 1978).

Frontal lobe dementia is behaviourally similar to Pick's disease, with personality changes rather than cognitive impairments predominant in clinical presentation. The pathologically frontal lobe dementia has neither the histological changes characteristic of AD nor Pick's disease. The principal histological alteration is nonspecific neuronal degeneration, especially in the upper cortical layers (Cummings, & Benson, 1992). Diffuse Lewy-body disease (DLBD) is characterized by cytoplasmic inclusion bodies (Lewy bodies) in the cortex. Rigidity and gait disturbance in DLBD may occur before cognitive impairments. Neuropathological changes include, frontal cerebral atrophy, and cell loss in the substantia nigra and in Meynert's nucleus (e.g., Förstl, Burns, Luthert, Cairns, & Levy, 1993).

Parkinson's Disease dementia occurs in approximately 55% of Parkinson's Disease (PD) patients (Boller, Mizutani, Roessmann, & Gambetti, (1980). PD is a neurological disease that results from degeneration of neurons in the upper midbrain, mainly in the substantia nigra, with a large number of neurons with Lewy body inclusions and decreased amounts of the neurotransmitter dopamine.

The disorder is often distinguishable from AD by the characteristic rigidity, a resting tremor, bradykinesia and gait disorder. The clinical symptoms and course of deterioration of dementia in PD patients is indistinguishable from AD patients and a number may show similar neuropathological alterations of AD patients (Boller, et al., 1980). However some PD patients with dementia do not have neuritic plaques and neurofibrillary tangles associated with AD, but may have cell loss in the basal forebrain, and a decline in CAT (Chui, et al. , 1985; Hornykiewicz, & Kish, 1984).

A number of types of infectious dementia exist. Creutzfeldt-Jakob Disease (CJD) is one rare type of infectious dementia occuring usually in the sixth or seventh decade of life. CJD has been termed a 'transmissible virus dementia' and has been shown to be due to a slow acting viral infection. The neuropathology of CJD is characterized by neuronal degeneration, spongy appearance of the gray matter and the proliferation of astrocytes. CJD pathology does not reveal senile plaques and neurofibrillary tangles characteristic of AD, nor the atrophy characteristic of Pick's disease, nor the vascular problems of vascular dementia (Lishman, 1978). The onset of CJD is early and the course is one of rapid deterioration with severe neurological signs and symptoms (Siedler, & Malamud, 1963).

Another syndrome which may lead to dementia is normal pressure hydrocephalus (NPH). NPH is characterized by enlarged cerebral ventricles with normal cerebrospinal fluid (CSF) pressure. Individuals with NPH show a rapid onset of gait disturbance, urinary incontinence and, similarly to AD patients, dementia. In many cases NPH occurs secondary to lesions, but NPH may occur as the result of head injury or subarachnoid hemorrhage (Adams, Fisher, Hakim, Ojemann and Sweet, 1965; Katzman, 1978). Although CSF pressure is normal approximately half of NPH patients respond to shunting which further reduces CSF pressure (Katzman, 1978) and in these cases dementia is reversible.

In general, the prognosis for individuals with dementia is considered to be poor. Individuals with dementia are much more likely to develop conditions which are a consequence of being unable to care for themselves, often resulting in lower life expectancy (Kraus & McGeer, 1982). The leading cause of death in individuals with dementia is bronchopneumonia (Burns, Jacoby, Luthert, & Levy, 1990). Also, conditions such as skin ulceration, due to lack of circulation in the limbs of those chair or bedridden, lead to medical emergencies and may end in death (Reisberg , 1983). Other acute events which may lead to death are myocardial infarct, cerebrovascular accident and pulmonary embolus (Katzman, 1976). On average the length of the disease from onset to death is about 5 to 8 years. Due to the variability of decline between individuals the range of the disease from onset to death is from under 2 to over 20 years (Katzman, 1976).

1.2.4 Cognitive Deficits and Behavioural Disturbances Associated with Dementia

The classical view of dementia and in particular AD, is one of homogeneity of cognitive deficits. However, recent evidence suggest that in AD, cognitive impairments in the early and middle stages of the disease may be heterogeneous, while changes in the later stages of the disease appear to be similar (Schwartz, 1990). The following brief description of losses in dementia, based on this classical view, is a general and simplified discussion of dementia, however, it must be noted that the heterogeneity of AD is well documented in research on cognitive manifestations of dementia (for a review, see Joanette, Ska, Poissant, & Béland, 1992).

In general, cognitive impairments in dementia are characterized by loss of memory, slowed reaction time, impaired visuospatial praxis, language disturbance, abstract problem solving, attention/concentration and learning. Memory loss is the most commonly reported deficit. Individuals with dementia perform poorly on tests of verbal and visual recent memory such as paired associates, recall of paragraphs and word lists, face recognition, name-face associates and memory for designs (for a review see Flicker, Ferris, Crook, Bartus, & Reisberg, 1985). Until the later stages of the disease, there appears to be some sparing of performance on tasks requiring the immediate recall of verbal material (Flicker, et al., 1985). Remote memory losses have also been demonstrated in tests requiring the recall of news items or famous faces and, in the severely demented, a loss of personal information is also apparent (Wilson, Kaszniak, & Fox, 1981).

Often individuals with dementia also show performance deficits on visuospatial tasks as measured by drawing, construction and perception tests (Flicker, Ferris, & Reisberg, 1993). One of the questions that has been addressed in this area is whether performance decrements in visuospatial tasks reflect actual impairments in visuospatial ability. On time limited visuospatial tasks reaction time is confounded with performance. Although studies have indicated that dementia patients are slower than normals on both simple and complex reaction time tasks, even on tasks without time limitations dementia patients' performance is impaired (Ferris, Crook, Sathananthan, & Gershon, 1986). Reaction time must be taken into consideration on any time limited task, since lower scores may only reflect decreased psychomotor speed associated with dementia.

Dementia also results in impaired performance on tests of object naming and category instance fluency. However, it has been suggested that underlying loss of secondary memory may account for observed performance decrements on these tasks, as well as on tasks of abstract-problem solving (Flicker, Ferris, Crook, & Bartus, 1986) attention/concentration (Caird, & Inglis, 1961), and learning (Miller,1973; Flicker, et al., 1985). Due to the heterogeneity of dementia, dysphasia may occur early, preceding complaints of memory loss, however in many cases dysphasia has been reported as absent. Dysphasia, when reported as part of the symptomatology, in the latter stages of the disease may reduce speech production to grunts and screams (Reisberg, Ferris, de Leon, & Crook, 1982; Sim, & Sussman, 1962).

Cognitive changes in dementia are often associated with behavioural changes (Reisberg, 1983). However, cognitive impairments progress in a generally predictable linear manner, whereas behavioral disruptions may appear and disappear in a much less predictable fashion (Pruchno, & Resch, 1989). For example, one study found that the frequency of behavioural disruptions was greater in individuals with dementia of mild to moderate severity than individuals with severe dementia (Haley, & Pardo, 1989). It has been suggested that the cognitive and physical impairments associated with severe dementia may interfere with the individual's ability to enact disruptive behaviors.

Swearer, Drachman, O'Connell and Mitchell (1988) found the 83% of their sample of 126 individuals with dementia displayed one or more disruptive behaviours. Studies that have examined behavioural disturbances have found dementia to be characterized by nocturnal wakefulness, incontinence, angry outbursts, repetitive gestures and questions, hoarding, paranoid ideas, wandering, and inappropriate sexual behaviour (e.g., Mace, & Rabins, 1981;

Rabins, Mace, & Lucas, 1982; Argyle, Jestice, & Brook, 1985). For example, Baumgarten, Becker and Gauthier (1990) in a sample of 96 individuals with dementia, found that the most common behavioural disturbances, as assessed by the patient's primary caregiver, were repetitive questions (reported by 72% of the sample), losing or hiding things (65%), lack of interest in daily activities (51%), nocturnal wakefulness (34%), unwarranted accusations (33%), excessive daytime sleeping (29%), and pacing (27%).

Rabins and colleagues, (Rabins, et al., 1982) examined the most frequent and most serious behavioural disturbances in 55 patients with irreversible dementia. Caregivers reported that the most frequent behavioural disturbance was catastrophic reactions. Catastrophic reactions were defined as an exaggerated emotional reactions to stress situations such as outbursts of anger, physical blows, arguing, crying and care resistance. Demanding/critical behaviour, night waking and hiding things were rated as a significant behaviour problems. The most serious problem reported by caregivers was violence in response to care.

As cognitive and behavioural problems associated with dementia become more severe an individual's ability to engage in basic activities of daily living may be compromised. After a moderate increase in disability an elderly individual may move closer to or live with children or relatives. A number of studies have examined the role of impairment in predicting the transition from independent living and/or living with family support to institutionalization. With major changes in disability, transition may be to an institution (Longino, Jackson, Zimmerman & Bradsher, 1991; Litwak & Longino, 1987; Speare, Avery & Lawton, 1991). According to Lawton (1982) the transition from independent to more dependent living arrangements involves two factors: environmental press and personal competence. Environmental press refers to an environmental stimulus or context, which may be comprised of physical, interpersonal and social forces, with the potential for eliciting a particular behavioural outcome. Competence refers to physical, mental and emotional resources. A transition is predicted to occur when the person's disability increases, or competence decreases, to the point of not being able to deal with the current living situation or the challenges of the environment increase.

1.3. Characteristics of the Elderly Individual as Predictors of Institutionalization

1.3.1 Statistics

Statistics on institutionalization indicate that approximately 2.5 million elderly individuals reside in nursing homes in North America and the rate of new admissions is approximately 1.1 million a year (Liu, & Manton, 1983). By 1995 the rate of institutionalization is expected to increase by almost 50% to 1.9 million a year (Doty, Liu, & Weiner, 1985). Approximately, 23% to 38% of the elderly are projected to spend time in a nursing home at some point in their lives (Liu, & Palesch, 1981; Ingram, & Barry, 1977; Kastenbaum, & Candy, 1973). The majority of the institutionalized elderly have been diagnosed with dementia. Fifty-five percent of geriatric patients in general hospital psychiatric wards and approximately 50 to 68% of nursing home samples are diagnosed with dementia (Kramer, Taube, & Redick, 1973; Pfeiffer, 1977).

In recent years there have been indications of an increase in the age of admission to institutions. Forbes, Jackson and Kraus (1987) suggested, that the increase in the age of admission may be due to a trend for elderly individuals have better health, more community services, and more financial resources than in the past. Forbes et al. (1987) also speculate that increased age of admission may occur due to difficulties in gaining admission to an institution.

1.3.2 Demographic Variables

Demographic variables have been examined as antecedents to institutionalization. Studies examining demographic variables have often failed to account for substantive variance in the prediction of institutionalization. Nursing home availability (Greene, & Ondrich, 1990) and financial feasibility of placement (e.g., Colerick, & George, 1987; Greenburg, & Ginn, 1979; Palmore, 1976; Hammel, Gold, Andres, Reis, Dastoor, Grauer, & Bergman, 1990) are antecedents which make placement an option. Among the demographic variables examined, age and sex are the most consistent risk factors for institutionalization. Many studies have found that age is associated with the risk of institutionalization (e.g., Branch, & Jette, 1982; Cohen, Tell, & Wallack, 1986; Cohen, Tell, & Wallack, 1988; Dolinsky, & Rosenwaike; 1988; Ford, Roy, Haug, Folmar, & Jones, 1991; Hanley, Alecxih, Wiener, & Kennell, 1990; Liu, & Manton, 1983; Morris, Sherwood, & Gukin, 1988; Shapiro, & Tate, 1988; Weissert, & Cready, 1989), with the probability of institutionalization increasing dramatically with age from 35% in the 65-74 age group to 68% of those over the age of 85 (Vicente, Wiley, & Carrington, 1979).

Women are also more likely to be institutionalized than men (e.g., Kane, & Matthias, 1984; Ford et al., 1991; Morris et al., 1988; Shapiro, & Webster, 1984; Shapiro, & Tate, 1988; Smallegan, 1985). According to the National Center for Health Statistics (1983) women are twice as likely as men to live in nursing homes, which is in part due to the longer life expectancy of women (Hing, Sekscenski, & Strahan, 1989). Consequently, women out number men in the oldest- old age category when institutionalization rates are the highest. Although sex has been found to be associated with placement, as Wingard, Jones and Kaplan (1987) point out, when sex is considered as a risk factor in studies that use multivariate analyses, and therefore, take into account the shared variance among factors, the relationship between sex and institutionalization is either no longer significant or diminished. Likewise, it is important to note that neither age nor sex are explanatory variables. Rather they are best considered markers for processes related to health status, functional impairment, and presence or absence of an informal caregiver.

1.3.3 Health status

In research examining the relation between health status and institutionalization, a distinction has been drawn between physical health status and functional health status. Physical health status is typically defined in relation to the medical diagnosis given for a certain condition. Functional health status refers to the daily tasks that an individual can perform. It is typically assessed by observer rated measures of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). ADL measures assess basic physical self-maintenance activities such as toileting, feeding, dressing, grooming, locomotion and bathing. IADL instruments measure more complex behaviours such as, telephoning, shopping, food preparation, housekeeping, laundering, use of transportation, use of medicine and financial behaviour.

A large number of studies have found health status indicators of declining or poor health, functional limitations and cognitive impairments to be important in the prediction of institutionalization (e.g., Branch, & Jette, 1982; Hanley, et al., 1990; Greenberg, & Ginn, 1979; Kraus, Spasoff, Beattie, Holden, Lawson, Rodenburg, & Woodcock, 1976; McCoy, & Edwards, 1981; Shapiro, & Tate, 1985; Shapiro, & Tate, 1988; Vicente et al., 1979). For example, 1982-1984 National Long-Term Care survey indicated that community dwelling elderly with twc ADL limitations had a 13% greater probability of institutionalization over a two year period, than the non- disabled elderly (Hanley et al., 1990). Similarly, McCoy and Edwards, (1981) found that ADL was a significant predictor of institutionalization in a sample of elderly welfare recipients. Individuals who reported difficulty with physical mobility were three times as likely to be institutionalized than those without this limitation. In a sample of elderly admitted to an acute-care Veterans Administration hospital, Narain, Rubenstein, Wieland, Rosbrook, Strome, Pietruszka and Morley (1988) examined predictors of immediate and 6-month nursing home admission. They found that individuals with decreased functional status were almost three times as likely to be admitted to a nursing home 6 months after the initial hospital admission than those with less ADL impairment. In a six year prospective study, Branch and Jette (1982) examined predictors of institutionalization in community dwelling elderly. Although, ADL was not predictive of later institutionalization, IADL was significantly related to institutionalization.

Studies have also indicated that cognitive function or a diagnosis of dementia are important factors in predicting institutionalization (e.g., Branch & Jette, 1982; Greene, & Ondrich, 1990; Kane, Matthias, & Sampson, 1983; Kraus, et al., 1976; Lamont, Sampson, Matthias, & Kane, 1983; Glazebrook, Rockwood, Stolee, Fisk, & Gray, 1994; Wachtel, Fulton, & Goldfarb, 1987). For example, a recent case control study of institutionalized and community dwelling elderly in Nova Scotia, which examined risk factors for institutionalization, found that the presence of dementia was the strongest predictor of institutionalization (Glazebrook et al., 1994).

While research has been relatively consistent in showing a relationship between health status and institutionalization, often the magnitude of the relationship has been modest. For example, in a Canadian study, Shapiro and Tate (1988) examined various combinations of high risk characteristics for institutionalization among elderly individuals. ADL limitation increased the odds of institutionalization by less than 3% and having a mental impairment increased the odds of institutionalization by less than 2%.

A number of studies have examined risk factors of institutionalization among those diagnosed with dementia (e.g., Heyman, Wilkinson, Hurwitz, Helms, Haynes, Utley, & Gwyther, 1987; Hutton, Dippel, Loewenson, Mortimer, & Christians, 1985; Knopman, Kitto, Deinard, & Heiring, 1988; Steele, Rovner, Chase, & Folstein, 1990). In a five year prospective study, Heyman and colleagues (1987) found that cognitive impairment, language impairment and overall severity of dementia were predictive of later institutionalization. Age had a modifying effect on these variables. Younger individuals with a more severe level of cognitive and language impairment and greater overall severity of dementia were at higher risk for institutionalization than older individuals with a similar level of impairment. Similarly, Knopman et al., (1988) found that mental status was predictive of institutionalization over a two year period. In addition, ADL limitations and behavioural disturbance, specifically nocturnal wandering and irritability, were predictive of institutionalization. Steele et al., (1990) also found functional limitations were significantly more likely in individuals who were institutionalized than those who remained in the community. Also those who were institutionalized were more likely to be experiencing psychiatric symptoms of depression, hallucinatory and suspicious behaviour and behaviour disturbances such as agitation, wandering, combativeness and resisting caretaking efforts. Mental status did not differentiate between institutionalized and community dwelling individuals with dementia.

Studies that have examined both caregiver and dementia patient variables, have found the role of health status and other patient variables is not as consistent in predicting institutionalization as those studies that have not considered the caregiving relationship (Colerick, & George, 1986; Zarit, Todd, & Zarit, 1986). Zarit and colleagues (1986) examined predictors of institutionalization in a two year longitudinal study of wives and husbands caring for spouses with dementia. They found that the objective indicators of mental status, and memory and behaviour problems did not differentiate those caregiving spouses who later chose institutionalization from those that had not. The findings were similar in a larger one year longitudinal study of caregivers to Alzheimer's patients. Colerick and George (1986), found that the objective indicators of illness duration, symptoms and their severity were not important predictors of institutionalization. Similarly, Lieberman and Kramer (1991) found that mental status and behaviour problems were not predictive of later institutionalization.

Nygaard (1991) examined predictors of institutionalization in demented elderly considering their caregivers over a one year period. In contrast to previous work, behavioural disturbance was significantly associated with institutionalization. Individuals who wandered and were disoriented at home, were approximately nine times as likely to be institutionalized than those without these disturbances. Likewise, Chenoweth and Spencer (1986) found that behavioural disturbance, specifically combativeness or angry outbursts, were cited by caregivers to relatives with dementia as reasons for institutionalization. Pruchno, Michaels and Potashnik (1990) examined both predictors of actual institutionalization and desire to institutionalize in caregivers to demented spouses. Significant patient predictors of institutionalization included the ADL level (specifically whether or not the individual was incontinent) and forgetful, asocial and disoriented behaviour. The best predictor of later actual institutionalization was the caregiver's stated desire to institutionalize.

A number of studies have also examined predictors of the desire to institutionalize in caregivers to elderly relatives. Gonyea (1987) examined the relationship among a number of patient and caregiver variables and the desire to institutionalize in caregivers to elderly relatives. The desire to institutionalize was conceptualized as a three-stage process involving recognition, discussion and implementation. Patient functional health accounted for less than 5% of the variance in the implementation stage of institutionalization. Deimling and Poulshock (1985) found, in caregivers to elderly relatives, that the elder's health was not a predisposing factor in the caregivers decision to institutionalize. In caregivers to dementia patients, Morycz (1985) found that functional and behavioural deficits accounted only for 5% of the variance in the desire to institutionalize. Hammel, et al. (1990) examined aggressive behaviour in dementia patients. They found that caregivers who were caring for more aggressive individuals with more behavioural and memory problems were more likely to be planning to institutionalize. Pruchno et al., (1990) in a study of caregivers to spouses with Alzheimer Disease, found that among patient health status variables only forgetful behaviour of the recipient was a significant predictor of the desire to institutionalize.

From this review it is evident that a number of studies have found health variables, in particular functional and cognitive impairments, to be significant predictors of institutionalization in community dwelling elderly. In samples of demented elderly, behavioural disturbances, in addition to functional and cognitive impairments, are found to be significant predictors of institutionalization in many studies. The findings are less consistent in studies that have focussed on elderly with caregivers. In an attempt to reconcile these discrepant findings, it is necessary to consider differences in sample and measurement. In the studies that reported a modest relationship between ADL and institutionalization, it is possible that the samples were comprised of more heterogeneous groups with elderly living both independently and being cared for by family. Health factors may be more important predictors of institutionalization when the individual is moving from independent living to institutionalization. It is likely that the difference between the range of disability in these studies may be a factor in the degree of importance of health predictors. In studies that examined only patient characteristics, the samples may be more heterogeneous and a wide range of disability is possible; whereas, for studies that have selected elderly based on having a caregiver present, it is likely that a smaller range of disability exists. It is possible that when the individual is being supported by the family the range of disability may be more restricted in the sample. Consequently, this restriction, decreases the probability that a significant relationship will be found between institutionalization and health variables.

1.3.4 Family Support

A number of studies have found that elderly who lack an informal caregiver are at greater risk for institutionalization: elderly individuals who live alone, being separated or never married, and having few or no children are at greater risk for institutionalization (e.g., Branch, & Jette, 1982; Cohen et al., 1986; Greene, & Ondrich, 1990; Kraus, et al., 1976; Liu, & Manton, 1983; Shapiro, & Tate, 1985; Shapiro, & Tate,1988; Palmore, 1976; Glazebrook et al., 1994; Wan, & Weissert, 1981). Studies have shown the importance of the role of family in delaying or preventing institutionalization (e.g., Bergmann, Foster, Justice, & Matthews, 1978; Brody, 1966; Greenberg, & Ginn, 1979; Liu, & Manton, 1983; Morris, & Sherwood, 1983; Prohauska, & McAuley, 1983; Tobin, & Kulys, 1981; Vicente, et al., 1979; York, & Calsyn, 1977). For example, in a recent prospective study, assessing elderly at risk for institutionalization, Shapiro and Tate (1988) found that not having a spouse at home was the most important predictor of later institutionalization. Likewise, Maddox (1975) suggested that presence/absence of family is a crucial factor for elderly at high risk for institutionalization. Similarly, Barney (1977) found that individuals were more likely to be prematurely institutionalized if they lacked strong family and economic supports. Townsend (1965) also found that fewer elderly individuals who had family were institutionalized.

An examination of community dwelling elderly has shown that the majority of the severely functionally disabled are not institutionalized due to family support (Newman, Struyk, Wright, & Rice, 1990). These elderly are often as functionally impaired as elderly residing in nursing homes (Brody, Poulshock, & Masciocchi, 1978; Lowenthal, Berkman, & Associates, 1967). Similarly, 90% of those with chronic mental disability reside in the community with the support of the family (Kay, Beamish, & Roth, 1964). As noted by Forbes, et al. (1987), Kraus (1984) observed "that some seriously demented elderly persons continue to live at home despite severe physical, mental and behavioural problems and needs for care that one would ordinarily expect to have resulted in institutionalization. This tends to occur if the key caregiving relative feels strongly about keeping the dementia victim at home and out of the institution." (p. 42). Thus, at any point in time, the majority of individuals with cognitive and/or physical impairments live in the community and the majority of assistance to these individuals comes from the family (Chappell, 1989).

Recent research has suggested, that the characteristics of the caregiver may be a more important determinant of institutionalization than characteristics of the recipient (e.g., Colerick, & George, 1986; Zarit et al., 1986). As noted earlier, several studies have shown that in samples of elderly being cared for in the home, health status variables are, at best, modest predictors of institutionalization (e.g., Shapiro, & Tate, 1988). Based on clinical observation, Zarit suggested that caregivers differ in their ability to meet the emotional demands of caregiving (Zarit, et al., 1986). Similarly, Chenoweth and Spencer (1986) found that those caregivers who appraise their relative's needs as being too great for their informal care may be more likely to discontinue care, putting their elder at a higher risk for institutionalization.

1.3.5 Kinship and Gender

One of the most ubiquitous findings in the caregiving literature is that the task of caregiving is performed mainly by female caregivers. In a national caregiver survey Stone, Cafferata, & Sangl (1987) found that approximately 75% of family caregivers are female. Among spousal diads, 67% were wives providing care to husbands. Among adult child caregivers, 80-90% are daughters.

Both demographic and psycho-social explanations have been advanced to account for the disproportionate representation of women in the caregiving population. For example, women tend to marry older men and tend to have longer life expectancies. Consequently, men are more likely than women to require care as a function of age-related disability and are more likely to have a spouse who can provide care. When women require help for an age related disability, it is likely that they are widows (Lee, 1992).

Three explanations are typically cited for why females are more likely to be primary caregivers than males; the traditional role of women in assuming nurturing tasks, stronger attachment to the family, and the traditional division of labour which allows women homemakers to have flexible time to assume caregiving responsibilities (e.g. Moen, Robison, & Fields, 1994). Also it has been argued that caregiving is more consistent with a female rather than male gender role orientation. According to sociological and psychological theory, gender role orientation occurs through the process of socialization. The outcome of these socialization patterns is more affiliative behaviour in women, and more autonomous and instrumental behaviours in men. For example, women have been socialized to be the nurturers and traditionally, within the context of parenting, women are more likely than men to be the primary caregiver. In-spite-of women's recent move into the paid work force, caregiving or the role of the nurturer continues to remain normative behaviour and a central self-concept for women (Abel, 1986; Walker, 1992). Thus, for women the adoption of the caregiving role to elderly parents or spouses may be viewed as an extension of their traditional female roles as family nurse and household manager (Allen, 1994).

Bonds of attachment or affection have also been posited as an explanation for the disproportionate number of female caregivers. Strong affectional bonds have been shown to be important antecedents of caregiving (Cicirelli, 1989). Evidence has indicated that these bonds are stronger between daughters and their parents, than sons and their parents, and are strongest between daughters and mothers (Lee, 1980; Rossi, & Rossi, 1990). A related explanation for the preponderance of female caregivers posits that gender consistency may be an important factor. Research by Lee, et al. (1993) suggested that adult children were more likely to provide care to a parent of the same gender and that care was more likely to be received from a same gender child. This tendency towards gender consistency results in a large predominance of caregiving daughters since most parents requiring care are mothers. When a father required care daughters were not as likely to care for fathers as for mothers. It is speculated that kinship ties which are strongest between daughters and mothers (Lee, 1992; Rossi, & Rossi, 1990) may account for gender consistency in determining who provides and receives care.

The findings on role of kinship and gender in determining the pattern of care, i.e. amount and type of care, and use of formal services, appear somewhat inconsistent. Studies have indicated that spouses provide more comprehensive and extensive care than adult child caregivers (Cantor, 1983; Horowitz, 1985; Johnson, 1983; Shanas, 1979; Soldo, & Myllyluoma, 1983; Stevens, & Christianson, 1986; Stone et al., 1987). However, a number of recent studies have pointed to the importance of co-residence rather than kinship as more important in determining the type and extent of care provided by caregivers. These studies have found that the amount of care provided, and type of care was related to living arrangement (Chappell, 1991; Noelker, & Wallace, 1985; Stevens, &

Christianson, 1986). In a study examining both kinship and co-residence in patterns of care to frail elders, co-residence of the caregiver rather than kinship determined level of instrumental care (Tennstedt, Crawford, & McKinlay, 1993).

In a recent meta-analysis of gender differences in caregiving Miller and Cafasso (1992) concluded that there is little compelling evidence to support the position that men and women differ in their patterns of caregiving or the outcome of their caregiving efforts. They highlighted that most research on gender differences has used inadequate sample sizes to effectively examine gender differences, and when differences have been observed, they have not been interpreted within the context of guiding theoretical frameworks. In the absence of methodological refinement or theoretical development, Miller and Cafasso have questioned the utility of additional studies addressing gender differences in caregiving. Thus, while women may represent the majority of caregivers, their experience of the caregiving situation may not differ meaningfully from that of men.

Findings have been inconsistent concerning the relationship between institutionalization and the role of kinship of the caregiver. Some studies have found that those most likely to desire to institutionalize their relative are adult children or younger caregivers (often children)(e.g., Morycz, 1985) while others have found that kinship or sex of the caregiver is unrelated to wanting to institutionalize (e.g., Hinrichsen, & Neiderehe, 1994). Likewise studies which have looked at actual institutionalization have found that children are more likely to place their relative than spouses (e.g., McFall & Miller, 1992). However, several studies have found that the kinship relationship did not predict institutionalization (e.g., Hassinger, 1985).

The present study, as with most of the work in this area, examined processes related to caregiving in a sample of female caregivers. Unlike many studies in this area, co-residence was controlled in order to maximize the homogeneity of the sample with respect to the type and amount of care provided. In specifying these criteria it was possible to obtain data from those comprising the majority group of caregivers, while limiting the heterogeneity of the sample by specifying gender and co-residence.

1.4. *Models of Caregiver Stress and Institutionalization*

A considerable body of research addressing the emotional, behavioural correlates and outcomes of caregiving has accumulated. The stress and coping framework proposed by Lazarus and Folkman (1984) has provided the conceptual base for much of the theoretical and empirical developments in this area. This transactional model views individuals as engaged in a dynamic interchange with the environment. In Lazarus and Folkman's (1984) General Stress and Coping Model, stress is defined as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). In Lazarus' model the stressor or the environmental situation is appraised by the individual as to whether it is a threat or not (primary appraisal). If the stressor is deemed threatening, harmful, or challenging, the individual may invoke coping mechanisms to manage the stressful situation. Secondary appraisal then commences in which the individual evaluates his or her ability to cope, which includes an assessment of, the availability, the effectiveness and the outcome of coping options. The subsequent intensity of the stress reaction is a function of the interaction between primary and secondary appraisal.

An important component of the Lazarus' transactional model is that stress is viewed as a subjective phenomena. In other words, since an event must be appraised as stressful in order to yield a stress response, the processes involved in appraisal are central in defining a stressor. A stressor is defined only in relation to the probability that it evokes a stress response. This conceptualization of stress has been criticized by several theorists for circularity of reasoning (e.g., Hobfoll, 1989; Dohrenwend, Dohrenwend, Dodson, & Shrout, 1984; Kasl, 1978). It has been suggested that the conceptualization of stress in this model blurs the distinction between stimulus and response.

Zarit (1990) has proposed a modified stress and coping model to account for emotional and behavioural outcomes of caregiving. Both Lazarus, Folkman and Zarit proceed from the basic assumption that an individual's primary task is to appraise and effectively manage stressors to minimize their impact on emotional well-being. Lazarus and Folkman (1984) argue that individuals are motivated to minimize their experience of stress, and will engage in coping strategies to achieve this goal. In this model, coping is classified into two main categories; problem-focussed coping and emotion-focussed coping. Problem focussed coping serves to manage or alter situations that have been appraised as stressful. Emotion-focussed coping is directed at regulating an emotional response to a situation that has been appraised as stressful.

Zarit's model is primarily distinguished from Lazarus' model in that he specifically addresses the caregiving relationship. In Zarit's (1990a) framework, the stresses or demands of caregiving may include the care-recipient's level of cognitive impairment, functional disability, behavioural disturbance, and the duration, amount and type of care which is required (e.g., Cantor, 1983; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Poulshock, & Deimling, 1984). The stressfulness of caregiving demands is determined by the appraisals made by the caregiver. If the caregiving situation is appraised as threatening (primary appraisal), the process of secondary appraisal is initiated in which the caregiver evaluates the available resources which may be drawn upon in order to deal with the stress.

1.4.1 Burden

Several studies have examined the relationship between the subjective appraisal caregiver stress and emotional outcomes. Burden has been discussed as one measure of an evaluative response to the demands of caregiving that mediates the relationship between the primary objective stressor and negative emotional outcomes (Lawton et al., 1989). Items on measures of burden typically reflect individuals' subjective evaluations of the stress and strain associated with various caregiving demands. Lawton (Lawton et al., 1989) suggested that the assessment of burden refers to all appraisals of caregiving stress and thus involves both primary and secondary appraisal processes.

In the caregiving literature a significant relationship between measures of caregiving burden and depression has been well documented (e.g., Jenkins, Parham, & Jenkins, 1985; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Pruchno, & Resch, 1989). Pruchno and Resch (1989) examined spousal caregiving to demented patients, and found that depression and burden were moderately correlated. Similarly, Lawton et al. (1991) found that depression and burden were significantly correlated in adult child and spousal caregivers to dementia patients. Using path analytic techniques they found that caregiver burden predicted severity of depression beyond the variance accounted for by patient disability.

Although a consistent relationship has been demonstrated between burden and depression, the burden construct has been criticized by a number of researchers. First, operational definitions and measurement procedures have varied widely across studies. Caregiver burden has been defined as "the physical, psychological, or emotional, social, and financial problems that can be experienced by family members caring for older adults" (George, & Gwyther, 1986, p. 253). Other definitions range from emotional costs (Thompson, & Doll, 1982) to number of tasks performed (Farthingham, Skelton, & Hoddinott, 1972).

Poulshock and Deimling (1984) have questioned whether the notion of burden as a unified construct has enough precision to be useful. George and Gwyther (1986) challenged the usefulness of the burden construct citing a number of problems. Since the burden construct is applicable only to caregivers it is not possible to compare noncaregiving groups on level of burden. Therefore it is not possible to compare relative effects of caregiving with other life stresses. Thus, the burden measure has limited comparability with noncaregiving groups and with normative data. Another more basic criticism is that burden measurement confounds stressor and outcome by requiring that caregivers relate caregiving to its effects. Since the burden measure is based on Lazarus' model of general stress and coping, which has also been criticized for circularity, it is not surprising that this measure suffers from the same flaw.

In defense of the utility of the burden construct, it can be argued that objective measures of health in care recipients suffering from Alzheimer disease do not adequately capture the most distressing aspects of the disease from the caregiver's perspective. It is difficult, for example, to assess objectively such aspects of Alzheimer disease as the 'loss of personality', or the impact of the inability of their relative to recognize them, or the impact of the odd, dangerous or disruptive behaviours exhibited by the recipient. Thus it is possible that subjective measures of burden, while not directly assessing these aspects of caregiving, provide an indirect reflection of the degree of severity of the condition.

Recently, Coyne and Fiske (1992) have proposed that viable accounts of stress and coping need to place greater emphasis on social contextual factors. Coyne and Fiske (1992) use the term relationship-focussed coping to emphasize that relationship maintenance may be as much a goal of coping as minimizing personal emotional distress. They provide data suggesting that the coping efforts of the caregiver may improve the emotional status of the recipient of care but at the same time, have deleterious effects on the caregiver's emotional status. In other words, caregiving may be maintained even though caregiving may increase rather than minimize the caregiver's distress. While the concept of relationship-focussed coping has not been developed into a comprehensive framework, it highlights the importance of distinguishing between coping efforts aimed at maintaining emotional well-being and efforts to maintain the caregiver relationship. The desire to institutionalize can be conceptualized as the caregiver's decision to end the caregiving relationship.

Some investigators have discussed decisions to institutionalize as a multistage process. According to Gonyea (1987) caregivers first recognize the need to consider institutionalization. Recognition may be followed by discussion of possible institutionalization options, the initiation of behaviours that have institutional placement as their goal. Actual placement is viewed as the final step of the institutionalization process. There is evidence to suggest that desire to institutionalize is significantly correlated with actual placement (Morycz, 1985; Pruchno et al., 1990). Zarit (1990a) discusses institutionalization as one of several possible outcomes of caregiver stress. Implicit within this model is that the caregiver may consider institutionalization when the demands of caregiving exceed available resources or call for coping skills that are not within the caregiver's repertoire. A critical point in stress appraisal may be reached leading to the decision to terminate the caregiving relationship. In a two-year longitudinal study, Zarit et al. (1986) assessed predictors of nursing home placement in 64 spousal caregivers of Alzheimer patients. They found that the group in which nursing home placement had occurred scored significantly higher on initial levels of caregiver perceived burden, even though there was no difference between groups on the objective measures of dementia severity.

Hassinger (1985) in a one year longitudinal study, examined the subcomponents of the burden measure as predictors of institutionalization in 169 caregivers to relatives with dementia. A factor analysis of the Burden Interview revealed six distinct factors of global physical/emotional distress, anger at patient, patient dependency, social discomfort, guilt, and lack of privacy. She found that the participants scoring highly on the factors of anger, dependency, and lack of privacy for the caregiver, were more likely to institutionalize their relatives. Of these factors, anger showed the strongest correlation with institutionalization.

Drawing upon a subset of data from the 1982-1984 National Long-Term Care survey, McFall and Miller (1992) examined the importance of burden and functional limitations for the risk of institutionalization in 940 elderly individuals with spouse or adult child caregivers in 1982. A comparison of those later admitted to a nursing home with those still residing in the community revealed that those admitted had caregivers who reported high levels of burden, more ADL and IADL limitations and greater cognitive impairments. The results indicated that burden was a more powerful predictor of nursing home admission than patient disability variables. Similarly, Brown, Potter and Foster (1990) found that caregiver burden was the more powerful predictor of institutionalization than health status variables.

Somewhat inconsistent findings are evident in a study by Gonyea (1987) who examined factors that influence family members' decisions to institutionalize their elderly relative. Caregivers were asked to rate the degree to which they had 1) thought of placing their elderly relative in an institution during the past year, 2) discussed with others the possibility of placing their elder, and 3) taken any action towards placing their elder. The results indicated that burden was significantly correlated with caregivers' degree of recognition and discussion concerning institutionalization. However, the relation between burden and implementation was not significant. The main predictor across all three stages of decision-making was an index of functional disability; burden did not contribute significant variance to any stage of decision-making once functional disability was controlled.

Pruchno, et al. (1990) examined predictors of both the desire to institutionalize and actual institutionalization in 220 caregivers to spouses with dementia. Measures of functional disability, caregiver depression and caregiver burden were significantly correlated with the desire to institutionalize. However burden and depression did not predict desire to institutionalize over and above patient disability measures.

Findings showing that burden predicts institutionalization over and above patient disability indicators, are consistent with the position that individual differences in the appraisal, coping repertoire or coping resources have a significant influence on decisions to terminate the caregiving relationship. However, some investigators have shown that burden does not contribute unique variance to the prediction of institutionalization. Critical examination of the literature suggests that the degree to which burden predicts institutionalization varies as a function of the comprehensiveness of the index of patient disability. For example, Zarit et al. (1986) used measures of cognitive impairments and behavioural disturbance as their measure of patient disability but did not consider the patient's functional impairments. Zarit et al, found that burden, but not patient disability was a significant predictor of institutionalization. In addition to measures of cognitive and behavioral disturbance, Pruchno et al (1990) included measures of functional impairment in a composite index of patient disability, and found that burden did not predict institutionalization over and above patient disability.

Another possible reason for the lack of consistency in findings addressing the relation between burden and institutionalization may concern the heterogeneity of the burden construct. As defined by Zarit, caregiver burden may vary both as a function of an inadequate skill repertoire or the lack of coping resources. Zarit's discussion of burden highlights the repertoire demands of the stress situation and the "resource consuming" properties of stress. Resources have been defined as "strengths either within the person or in the external environment" (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991, p.181). A number of resources have been examined in the caregiver literature such as, caregiver physical health, income, education, social support and coping behaviours (e.g. Pratt, Schmall, Wright, & Cleland, 1985; Zarit, et al., 1980; Zarit, et al., 1986). Within Zarit's model, caregiving situations may be experienced as stressful when they call for skills not within the individual's repertoire or when they exceed available coping resources.

A more homogeneous construct, reflecting specifically the caregiver's resource depletion, may be a better predictor of institutionalization than burden. Recent conceptualizations of stress have moved away from the view that individuals meet the demands of their environment with a repertoire of coping skills, to the view that individuals have limited adaptational resources available to them. This view is most explicitly stated in Hobfoll's resource conservation model of stress (Hobfoll, 1989). Hobfoll defines psychological stress as "a reaction to the environment in which there is (a) the threat of a net loss of resources, (b) the net loss of resources, or (c) a lack of resources gain following the investment of resources". (Hobfoll, 1989, p. 156). According to Hobfoll, resources are the personal characteristics, objects, conditions or energies which are valued by the individual or aid in the acquirement of valued resources. The goal of the individual within this model is the retention, attainment and protection of resources.

Romeis (1989) has emphasized the importance of resource depletion in the caregiver's decision to institutionalize. In this model caregiver strain is conceptualized as "a bio-psycho-social reaction of a primary caregiver resulting from an imbalance of care receiver demands relative to caregiver resources" (p. 191-192). In this model caregiver strain is predicted to occur when the elder's physical, functional and psycho-social demands exceed the caregiver's personal, informal and formal resources. As the gap widens between care receiver demands and the caregiver resources and strain increases, so does the probability of the caregiver deciding to institutionalize. The model predicts that institutionalization will occur when care receiver demands are excessive and resources are depleted.

1.4.2 Burnout

Romeis' (1989) model of caregiver strain describes a process leading to institutionalization using terminology similar to discussions in the literature on burnout. Burnout has been conceptualized as a negative emotional outcome of the stress process and occurs when resources have been depleted (Maslach, 1978; Brill, 1984). Burnout has mainly been studied among formal caregivers such as nurses, physicians, social workers, psychiatrists and psychologists (Enzmann, & Kleiber, 1990). The earliest work on burnout was conducted by Bradley (1969) who noted that this phenomenon was found especially in the helping professions. It was Freudenberger (1974), however, who sparked interest in the psychological community. Freudenberger (1974) described burnout in terms of physical signs of fatigue and exhaustion, irritability, mistrustfulness and stubbornness, a negative and cynical attitude towards work and clients, and as occurring with depression.

The bulk of recent research has suggested that environmental factors, such as work setting and organizational factors (e.g., demographics and personality variables) are significant predictors of burnout (e.g., Burke, Shearer, & Deszca, 1984; Golembiewski, & Scicchitano, 1983; Leiter, & Maslach, 1988; Maslach, 1978; Maslach and Jackson, 1984). Among the significant environmental factors are various aspects of job conditions, such as caseload, role in communication networks, greater role conflict, work pressure, and lack of promotion opportunity (see review in Maslach, & Jackson, 1986).

Maslach and Jackson (1986) have proposed a three dimensional process model of burnout. The burnout construct is conceptualized as consisting of three separate but related factors: emotional exhaustion, depersonalization, and diminished personal accomplishment. Emotional exhaustion refers to the stress and tedium a person is experiencing in a human service occupation. Depersonalization refers to a callous and unfeeling response to the recipients of one's care, and reduced personal accomplishment to a decline in feelings of success and competence in one's work achievements with people.

The process of burnout has been described by Leiter and Maslach (1988) as an attempt by workers to deal with feelings of exhaustion (which is the immediate emotional reaction to stress) by depersonalizing, or losing their personal relationship with their clients. As the depersonalization process occurs, feelings of accomplishment diminish resulting in a state of exhaustion, isolation and discouragement, in short, burnout.

Although no research has examined burnout in informal caregivers, a number of researchers have speculated that informal caregivers become burned out in their caregiving roles (e.g., Green, & Monahan, 1987; DeLongis, & O'Brien,1990; Prohaska, & McAuley, 1983; Young, & Kahana, 1989). Also, in a review by DeLongis and O'Brien (1990) on stress and coping in caregivers to relatives with Alzheimer disease, the authors not only refer to burnout, but also speculate on the processes which may lead to burnout.

> "As the patient's dementia progresses, caregivers may have difficulty understanding their ill family members, and they may consequently disengage and reduce attempts to emotionally connect and relate to the family member.

> This lack of emotional relatedness can lead to more depersonalized caregiving and to fewer rewards for sustaining care. Conversely, those caregivers who become over-involved with their afflicted relative, losing their sense of self-other differentiation, may neglect themselves and become burned out by focusing their energies exclusively on caregiving. Burnout may be more likely in caregiving with Alzheimer's patients because caregivers often feel reluctant or guilty about asking for or accepting help or about seeking respite care (Quayhagen, & Quayhagen, 1988)" (DeLongis, & O'Brien, 1990, p. 231).

A relationship between burnout and caregiving is further suggested by research findings showing that depression is prevalent in the caregiving population. Several studies, using standardized diagnostic criteria, have shown elevated rates of depression among caregivers when compared with age and gender-based population norms or noncaregiving samples. Copple, Burton, Becker, & Fiore (1985) used the schedule for Affective Disorders and Schizophrenia interview (SADS; Endicott, & Spitzer, 1978) assessed depression in 68 caregivers to Alzheimer patients. They found that 47% of caregivers were currently depressed and 40% had met the criteria for depressive disorder during an earlier phase of the recipients illness. Dura, Stukenberg and Kiecolt-Glaser (1990) found 30% of caregivers to demented patients were depressed, while only 1% of matched noncaregiver controls were classified as depressed. Gallagher et al. (1989a) found that 46% of the sample of 51 caregivers to relatives with Alzheimers disease met the criteria for either major, minor, or intermittent depression.

Using DSM-III criteria, Cohen and Eisdorfer (1988) reported that 27 out of 46 caregivers (55 %) to relatives with dementia met the criteria for major depression. No relative living away from the patient met the criteria for clinical depression. Drinka, Smith, & Drinka (1987) found 83% of their sample of caregivers to dementia patients met the DSM-III criteria for major depression.

Overall, research suggests that rates of major depression in caregivers may range from 30-83%. In the general population prevalence rates of depression have been reported to range 4-9% (Boyd, & Weissman, 1981). It appears therefore, that, compared to general population estimates, the risk for major depression may be approximately 9 times higher in caregivers.

Numerous studies have also found the caregivers of Alzheimers patients score higher compared with non-caregiving samples on self-report measures of depression (e.g., Dura, Haywood-Niler, & Kiecolt-Glaser, 1990; Fiore, Becker, & Coppel, 1983; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989a; Gallagher, Wrabetz, Lovett, Del Maestro, & Rose, 1989b; Haley, Levine, Brown, Berry, & Hughes, 1987; Kiecolt-Glaser, Glaser, Shuttleworth, Dyer, Ogrocki, & Speicher, 1987). Schulz, Visintainer and Williamson (1990) concluded from their review that the more severely impaired the recipient of care, the greater the level of depressive symptomatology in the caregiver.

A number of investigators have suggested that burnout may not be distinct from depression. For example, Wentzel's (1984) commented that burnout, may be "...analogous to old fashioned depression related to stressful working conditions". Many of the features of burnout appear to overlap with the DSM-III-R criteria for both Major Depression and Dysthymia. Cognitive descriptions of depression in terms of negative views of the self, the future and the world are similar to descriptions of burnout in terms of negative attitudes towards oneself, towards the situation and towards life as a whole (Beck, Rush, Shaw, & Emery, 1979; Pines, Aronson, & Kafry, 1981). Learned helplessness theory has been used to account for both depression (e.g. Peterson, & Seligman, 1984) and burnout (Cherniss, 1980). When one compares the two most widely used measures of each of these constructs - the Maslach Burnout Inventory (MBI) and Beck Depression Inventory (BDI), the overlap appears clear. Many of the items in the two measures are similar. For example, one item on the MBI, I feel fatigued when I get up in the morning and have to face another day on the job, is very similar to the BDI items, I get tired from doing almost anything and I am too tired to do anything.

Several studies have provided data consistent with the notion that burnout overlaps significantly with depression. Belcastro, and Hays (1984) found that burned out teachers were more likely than nonburned out teachers to be, or have been, diagnosed with depression. Similarly, quantitative comparisons have generally found moderate zero-order correlations (typically in the .4 to .6 range) between burnout and depression. Meier (1984) reported a correlation of .57 between burnout and two self-report measures of depression. Meier (1984) suggests that these findings indicate that burnout and depression are similar constructs.

Maslach and Jackson (1986) state that conclusions from Meier's study should be made cautiously because Meier (1984) did not treat the different components of the MBI as separate scales. Rather Meier (1984) used a total burnout score. A number of studies support the finding that burnout, as measured by the MBI, is a multidimensional construct comprised of three separate but related subscales (e.g. Maslach & Jackson, 1981) and consequently should not be treated as a unidimensional construct. Additionally, Leiter and Maslach's (1988) research suggests that burnout is a process and the temporal contribution of each subscale differs depending on the stage of development of the syndrome, therefore summing the subscale would obscure understanding of this process. Enzman and Kleiber (1990) examined the relation between the BDI and subscales of the MBI in 130 human service professionals. Significant correlations were obtained between depression and emotional exhaustion (r = .40), personal accomplishment (r = -.41), and depersonalization (r =.15). Although these findings are consistent with Meier (1984), suggesting overlap between burnout and depression, these correlations are small to moderate, and, therefore, a considerable amount of the variance must be contributed by factors not common to burnout and depression.

In a factor analytic study of 200 nurses, Firth, McKeown, McIntee, and Britton (1987) looked at burnout, measured by the MBI, and 'professional depression', measured by adapting items from the BDI to assess depression related to work. Firth et al. (1987) refer to professional depression as "generalized changes in mood, motivation, and, very likely, behavior in the work setting". Findings indicated that the emotional exhaustion subscale was significantly correlated with professional depression (r = .59).

Although, studies have indicated significant overlap between burnout and depression, other work has provided data in support of the discriminant validity of these two constructs. For example, Evans and Fischer (1989), performed a factor analysis of the MBI items and a measure of transient depressed mood. Results revealed three separate factors for burnout and a fourth for depression. On the basis of these findings it was argued that the components of burnout were distinct from depressed mood. In addition, two studies found no difference in the incidence of depression in burned out and non-burned out teachers (Belcastro, 1982; Belcastro, & Gold, 1983).

Finally, Haack (1988) examined the relation between burnout and depression in a two year longitudinal study of nursing students. He found that burnout increased over two years while depression tended to decrease as students became more advanced in their program of study (Haack, 1988). This decrease in depressive symptomatology corresponded to the increase in burnout scores. Haack (1988) suggested that as students become more unfeeling towards patients they become less depressed.

Burnout can also be distinguished from depression on conceptual grounds. Burnout may differ from depression in terms of underlying attributional processes. Measures of depression require subjects to report on generalized symptoms of current distress. Measures of burnout also require subjects to report symptoms of distress but, only within the context of caregiving. In others words, measures of burnout require the subject to identify the caregiving situation as the cause of their current distress. Discussions of attributional processing in depression suggest that depressed individuals may be more likely to consider internal rather than situational determinants of their distress (Abramson, Seligman, & Teasdale, 1978).

The attributional distinction between burnout and depression may have consequences for caregiver's behaviour. Depressed caregivers, considering themselves to be the cause of their current distress may be less likely to examine situational or environmental factors in efforts to alleviate their distress. By identifying the caregiving situation as the cause of distress, caregivers who report symptoms of burnout may be more likely to engage in behaviour aimed at reducing the demands of the caregiving situation.

1.5 The present study.

The primary hypothesis addressed by the current research is that burnout will be a significant predictor of the desire to institutionalize. The hypothesis is consistent with Romeis' model suggesting that when caregivers have depleted their resources they will report that they desire to institutionalize their relative. It is also hypothesized that burnout will be a better predictor of the desire to institutionalize than depression. As noted above, the external attributional orientation of burnout may be more likely to increase the probability of action aimed at ending the caregiving role. Consistent with this perspective it is interesting to note that in helping professionals burnout is associated with the intention to quit one's job (Maslach, & Jackson, 1981; Maslach, & Jackson, 1986).

As discussed earlier, research has indicated that burden may be related to institutionalization. However, it was also argued that the heterogeneity of the burden construct may reduce its power as a predictor of the desire to institutionalize. Burden has been conceptualized as the caregiver's assessment of the stressors associated with caregiving, as well as, the evaluation of the resources they have available to manage the effects that caregiving demands have had on their lives. Caregivers experiencing high levels of burden may still have resources to manage their situation. It was predicted that burden would be a less powerful predictor of the desire to institutionalize than burnout.

The present work will also examine the relationship between burnout and depression, by assessing the ability of these constructs to predict the desire to institutionalize. Evidence of the discriminant validity of these constructs will be provided if one construct is a significantly more powerful predictor of the desire to institutionalize than the other. Based on the review of the depression and burnout literature, it is predicted that the emotional exhaustion scale of the MBI will be related to depressive mood as measured by the BDI.

The present study focussed on the predictors of the desire to institutionalize not actual institutionalization. As noted earlier actual institutionalization has been discussed as a multistage process that may span several years. The desire to institutionalize has been discussed as an important component of actual institutionalization. The theory of attitude-behavioural relations (Ajzen, & Fishbein, 1980; Fishbein, & Ajzen, 1975) indicates that intended behaviour is highly correlated with actual behaviour. Empirical work has also indicated that the desire to institutionalize is significantly correlated with actual institutionalization (Colerick, & George, 1986; Morcyz, 1985; Pruchno, et al., 1990).

A number of secondary questions were also addressed by the present research. Leiter and Maslach (1988) have discussed the process of burnout as one that begins with emotional exhaustion followed by depersonalization and ending with reduced personal accomplishment. The positive correlation between emotional exhaustion ($r = .49, p < .05$) and depersonalization, the inverse correlation between depersonalization and personal accomplishment ($r = -.30, p < .05$) and the lack of a relationship between emotional exhaustion and personal accomplishment have been used as support for their position ($r = -.15, p > .05$). However an important distinction between the professional helpers studied in previous research and the caregivers studied in the present research concerns their emotional involvement with their recipient of care. It is possible that differences in emotional involvement may influence the processes involved in burnout.

Experimental hypotheses can be summarized as follows:

1a) burnout will be a significant predictor of the desire to institutionalize

1b) burnout will predict desire to institutionalization over and above patient disability variables

2a) burden will be a significant predictor of the desire to institutionalize

2b) burden will not predict desire to institutionalize over and above patient disability variables

3a) depression and anger will be a significant predictors of the desire to institutionalize

3b) depression and anger will not predict desire to institutionalize over and above patient disability variables

While the relations among the different subscales of the burnout measure will be examined, and issues associated with the discriminant validity of burnout will be addressed, no predictions were made.

Chapter 2

Method

2.1 Subjects

Subjects were 75 female caregivers and their impaired relatives who were referred, within the last two years, to the Division of Geriatric Medicine in Camp Hill Hospital. Subjects were drawn consecutively from hospital patient files and new referrals until a sample of 75 primary caregivers residing with relatives who had been diagnosed with dementia was obtained. Forty-six subjects were wives caring for spouses ranging age from 52 years to 89 years (*M* = 69.65; *SD* = 8.68). Twenty subjects were daughters caring for mothers and 9 were daughters caring for fathers. Daughters ranged in age from 28 years to 65 years (*M* = 46.12 ; *SD* = 7.6). Due to the small number of daughter-father diads, daughter-father diads and daughter-mother diads were combined for all analyses. The following inclusion criteria were employed:

1) a diagnosis of dementia must have been made by a neuropsychologist or geriatrician according to the DSM III-R criteria for dementia

2) caregivers must have been self identified as the main person caring for their relative

3) caregivers must have been daughters or wives to the relative with dementia

4) caregivers must have been residing in Nova Scotia and in the community with their relative at the time of the interview

A total of 103 individuals were contacted to participate in the study. Of those contacted 17 were not eligible to participate due to death or institutionalization of their relative and 11 refused to participate. The hospital charts of the individuals with dementia do not contain information concerning the demographic characteristics of caregivers, and thus it was not possible to compare the subject sample to caregivers who refused to participate on variables of interest in this study.

Power analysis was included to ensure that sample size was adequate to test the primary hypothesis. The primary hypothesis would be tested with one covariate (patient disability index) and three predictor variables (emotional exhaustion, depersonalization, and lack of personal accomplishment). On the basis of previous research addressing emotional distress in caregivers a modest to moderate effect size was expected. The power analysis was conducted as follows:

number of covariates = 1

number of predictors = 3

sample size = 75

effect size = .15

alpha = .05

subject to variable ratio = 15:1

:$f2 = .15/(1-.10) = .167$

:$df = 75 - 2 - 1 = 72$

: $\lambda = .167\ (2 + 72 + 1) = 12.53$

with an alpha =.05 and n=75, power is estimated to exceed .75 (Cohen, 1988). The subject to variable ratio is significantly high to control for spurious inflation of R^2. The above analysis could also be performed with n = 60 without significant reduction in power.

2.2 *Measures*

Measures of patient and caregiver demographics (see Appendix A), cognitive status, functional ability, behavioural disturbance, burnout, burden, depression, anger, desire to institutionalize and social desirability were administered during the assessment interview. All measures except for the cognitive status measure were completed by the primary caregiver. The cognitive status measure was administered by the principal investigator.

2.2.1 Patient Disability Measures

Cognitive Status. The Mini Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) is a widely used instrument used to assess general cognitive status. The MMSE contains 11 items covering orientation, memory, attention, and the ability to name, to follow verbal and written commands, to write a sentence spontaneously, and to copy a figure (see Appendix B). Total MMSE score (ranging between 0-30) is obtained by summing the points assigned to each successfully completed item. As a screening instrument, scores of 23 or less out of a possible 30 indicate impairment. The instrument has high interrater and test-retest reliability, ranging from .83 to .99 in neurologic, psychiatric and mixed-diagnoses patient samples (e.g. Anthony, LeResche, Niaz, VonKorff, & Folstein, 1982; Folstein et al., 1975; Nelson, Fogel, & Faust, 1986). The MMSE was reported to have high specificity (.82) and sensitivity (.87) in patients admitted to a general medical unit (Anthony, et al., 1982). In the present study internal consistency of the MMSE was estimated by Cronbach's coefficient alpha. The reliability for the MMSE was .87.

Activities of Daily Living. Functional disability was measured by the Physical Self-Maintenance Scale (PSMS; Lawton, & Brody, 1969). This scale addresses six domains of functioning: toileting, feeding, dressing, grooming, physical ambulation and bathing. Responses are made on five-point scales ranging from total independence (1) to total dependence (5) (see Appendix C). According to Lawton and Brody's (1969) scoring method total scores are obtained by dichotomizing the scale into total independence (1) and requires assistance and/or dependence (0). Lawton and Brody (1969) suggest that the six domains form a Guttman Scale. In the present study total scores were obtained by maintaining the five point scale. This scoring system was adopted in order to retain the sensitivity of the scale to various levels of dependence. The Instrumental Activities of Daily Living Scale (IADL; Lawton, & Brody, 1969) assesses whether the individual can perform activities in seven domains: ability to use the telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medication, and ability to handle finances. Responses are made on three to five-point scales and range from total independence (1) to total dependence (3-5) (see Appendix D). Similar to the scoring of the PSMS, Lawton and Brody (1969) dichotomized the scale. In the present study the range of scores were retained in order to maintain sensitivity. High internal consistency (.87), high interrater reliability (.91), and comparison with physician's rating of function (r =.51, p <.01) indicate that both the PSMS and the IADL are valid and reliable measures. The internal consistency, as measured by Cronbach's alpha, for the PSMS and the IADL scale was .87 and .86, respectively.

Behavioural Disturbance. The Dementia Behavior Disturbance Scale (BDS; Baumgarten et al. 1990) was used as a measure of specific observable behaviour disturbance. The instrument contains 28 items often associated with dementia: passivity, agitation, eating disturbances, aggressiveness, diurnal rhythm disturbances, and sexual misdemeanor (see Appendix E). The scale has high internal consistency (.84) and moderate test-retest reliability (.71). A correlation of .73 between the Behaviour and Mood Disturbance scale (Greene, Smith, Gardiner, & Timbury, 1982) and the DBD indicated that the construct validity of the DBD was supported. The internal consistency for the BDS in the present study was alpha = .80.

Patient Disability Index. For the purpose of the present study a global index of patient's severity of disability was computed by adding the total score on the MMSE (reversed), ADL scale, IADL scale and the BDS. To determine the degree to which the four scales contributed to the overall Patient Disability Index (PI), item to total correlations were calculated. In the current sample, high scores on the PI were characterized primarily by disruptions in instrumental activities of daily living (r = .68) and basic activities of daily living (r = .57). Cognitive status (r = .40) and behavioural disturbance (r = .29) contributed less to PI than the functional measures. The internal consistency for the patient index scale was alpha = .90.

2.2.2 Caregiver Characteristic Measures

Burden Self-Report. The Zarit Burden Interview (ZBI, Zarit et al., 1980) was used as a self-report measure of burden. This instrument contains 22-items focussing on the affect of the caregiver in response to recipient functional/behaviour impairments and the home situation (see Appendix F). Items were obtained from clinical and research experience with caregivers to dementia patients. Ratings are made on a 5-point Likert-type scale ranging from never to nearly always present. The measure has high internal consistency (alpha = .91) and high test-retest reliability (alpha = .71). The ZBI is the most widely used measure of burden in caregiving studies. In the present study, the internal consistency of the ZBI was alpha = .89.

Zarit Anger Self-Report. An anger subscale of the ZBI was used as a measure of caregiver anger. The factor analysis performed by Hassinger resulted in six factors, accounting for 53.5 percent of the variance (Hassinger, 1985). The anger subscale is comprised of seven items from the ZBI, (see Appendix G). In the factor analysis of burden reported by Hassinger (1985) anger toward the patient accounted for the largest percentage of variance (22.4 percent) in the factor solution. The other subscales were, labeled by Hassinger (1985) were as follows: global physical/emotional stress (see Appendix H); dependency of the patient (see Appendix I); social discomfort over the patient's condition (see Appendix J); lack of caregiver privacy (see Appendix K) and guilt over inadequacy in meeting the caregiving role (see Appendix L).

Burnout Self-Report. The Maslach Burnout Inventory was modified for the present sample of caregivers (MBI; Maslach, & Jackson, 1986). The MBI contains 22 items written in the form of statements about personal feelings and attitudes.

Ratings are made on a 7-point Likert-type scale ranging from never (0) to everyday (6) present. The scale is comprised of three separate but related factors: emotional exhaustion (9 items), depersonalization (5 items), and diminished personal accomplishment (8 items). The emotional exhaustion subscale is a general measure of the amount of stress and tedium a person is experiencing. Depersonalization refers to a callous and unfeeling response to the recipients of one's care, and reduced personal accomplishment to a decline in feelings of success and competence in one's role. Maslach and Jackson (1986) reported reliabilities of .90 for Emotional Exhaustion, .79 for Depersonalization , and .71 for Personal Accomplishment subscales of the MBI. In order to make the items of the MBI applicable to caregivers the item content was modified (see Appendix M). For example, items from the MBI were modified by replacing words, such as, "work", "job", or "my work" to "taking care of my mother/father/husband" or "being a caregiver". Referents of "people" or "recipient" were changed to "mother/father/husband". Internal consistency of the modified MBI for the total scale was alpha = .86. The reliability for the MBI subscales were: .95 for Emotional Exhaustion; .62 for Depersonalization; and .66 for Personal Accomplishment.

Depression Self-Report. The Beck Depression Inventory (BDI, Beck Ward, Mendelson, Mock & Erbaugh, 1961) was used as a self-report measure of depressive symptomatology. This instrument contains 21 items describing various symptoms associated with depression (see Appendix N). The scale has been standardized on psychiatric and non-psychiatric samples (Beck, Steer & Garbin, 1988). In a recent study of caregivers, a BDI cutoff score of 10 yielded sensitivity and specificity values of .70 and .79, respectively, suggesting that the BDI is a good predictor of clinical depression (Gallagher et al., 1989a). The BDI is also the most widely used measure of depression reported in caregiving studies (Schultz, Visintainer and Williamson, 1990). In the present study the internal consistency of the BDI was alpha = .86.

Desire to Institutionalize. The measure of caregiver desire to institutionalize their relative is based on Gonyea's (1987) work in which the process of "institutional decision-making" was conceptualized as having four stages: recognition, discussion, implementation, and placement. Caregivers were asked to endorse items reflecting different stages of institutional decision making. These stages included 1) thinking, 2) discussing and 3) taking action. The measure is composed of 6-items: whether they had thought of placing their elderly relative in an institution during the past year, whether they had discussed with others the possibility of placing their elder, and whether they had taken any action towards placing their elder in the form of telephone inquiries, visitation or application for admission (see Appendix O). Due to the infrequency of endorsement, item number 4, concerning patient visitation, was dropped from the scale. Caregivers' responses to the remaining five items were combined to form a Guttman scale. The resulting scale was as follows: do not desire to institutionalize=0; have thought and have discussed institutionalization = 1; have thought, discussed, and called the institution = 2; have thought, discussed, called and applied for institutionalization = 3.

Social Desirability. The Marlowe-Crowne Social Desirability Scale (M-CSDS: Crowne, & Marlowe, 1960) is a 33-item measure which assesses an individual's bias to answer in a socially desirable manner (see Appendix P). The measure of social desirability was included as a control measure. Social desirability may act as a suppressor variable, in that it is not correlated with the criterion variable but if included in a multiple regression equation it will increase the value of the multiple correlation coefficient (e.g. Jackson, & Messick, 1958). A recent study by Cappeliez (1989) found that the M-CSDS correlates with the BDI. Based on these findings Cappeliez suggested that those who were more likely to respond in a socially desirable manner may under report scores on a self- report measure of depressive symptomatology. Internal consistency of the M-CSDS was estimated by Cronbach's coefficient alpha. The reliability for the M-CSDS in the present study was .80.

2.3 Procedure

All participants were initially sent a letter by the attending geriatrician (see Appendix Q, example letter from Dr. Rockwood). Subjects interested in participating contacted the Division of Geriatric Medicine in Camp Hill Hospital and were then contacted by the principal investigator (April D'Aloisio) to further determine eligibility for the study. Subjects who met the criteria and agreed to participate were visited in their home by the principal investigator and asked to complete several questionnaires. All participants were made aware that their participation was completely voluntary and that they could withdraw at any time. They were told that agreement or refusal to participate would not influence their or their relative's current or future treatment at Camp Hill Medical Centre. Participants were informed that their responses would be kept confidential and accessible only to the investigators and assistants on the project. All participants after being informed of all the procedural details of the study were asked to sign a consent form (see Appendix R) and asked to complete the questionnaires during one interview (approximately 1 1/2 hours). The questionnaires included information on demographics, behavioral and functional capacity of the Dementia patient, self-report measures of burden, anger, depression, burnout and social desirability.

Chapter 3

Results

3.1 Descriptive statistics

The data on measures of disability in the present study were compared to previous studies using similar disability measures. The mean cognitive status score, as measured by the MMSE was, *M* =14.0. Mean scores on the ADL and IADL were *M* =12.2, *M* =24.5, respectively. The mean score on the Behavioural Disturbance Scale was, *M* = 26.8 compared to (*M* = 17.4) reported by Baumgarten et al. (1990). Mental status scores in the present study were comparable with a similar study by Hassinger (1985) who described her sample as moderately to severely impaired. It is somewhat difficult to make comparisons based on functional disability since past studies have used many different measures with numerous methods of scoring those scales. Based on the possible range of scores, mean scores on IADL and ADL in the present indicated that patients were respectively, severely and moderately impaired.

Patients were also categorized by severity of dementia based on Reisberg's stages as measured by the Global Deterioration Scale (GDS, Reisberg, Ferris, de Leon, & Crook, 1982) and dervived on the basis of scores on mental status function (Eisdorfer, et al. 1992). Patient distribution by stage was as follows: 5 patients were at stage 2 (very mild cognitive decline); 14 patients were at stage 3 (mild cognitive decline); 10 patients were at stage 4 (moderate cognitive decline); 18 patients were at stage 5 (moderately severe cognitive decline); 24 patients were at stage 6 (severe cognitive decline); 4 patients were at stage 7 (very severe cognitive decline).

Table 1 presents the means for demographic variables for patients cared for by either wives or daughters. Significant differences between patients cared for by daughters and wives emerged for patient age, ADL, IADL, and patient index. Relatives being cared for by daughters were significantly older than relatives being cared for by wives ($F(1,73) = 14.54$, $p < .001$). Daughters, compared to wives, also rated their relatives as more impaired with respect to activities of daily living ($F (1,73) = 6.64$, $p < .01$) and instrumental activities of daily living ($F(1,73) = 5.39$, $p < .05$.). Relatives being cared for by daughters also obtained higher scores on composite index of impairment than those cared for by wives ($F(1,73) = 7.16$, $p < .01$). Relatives being cared for by daughters and wives did not differ on time since diagnosis, cognitive status or behavioural disturbance.

Previous research has shown that daughter and spouse caregivers may differ on a number of demographic and psychological variables. As shown in Table 2, a number of demographic characteristics distinguished between spouse and daughter caregivers. Daughters were younger ($F(1,73) = 142.12$, $p < .001$), had more years of education ($F(1,73) = 8.78$, $p < .01$), were likely to have others residing with them ($\chi^2 = 4.29$, $p < .05$), were more often employed ($\chi^2 = 78.92$, $p < .01$) and received more formal services than wives ($F(1,73) = 7.59$, $p < .01$).

As shown in Table 3 wives and daughters did not differ on burnout, depression, anger, and burden. However, daughters desired to institutionalize their relative more than did wives, $F(1,73) = 6.11$, $p < .05$. Since a significant difference was found between daughters and wives on the primary dependent variable zero order correlations were computed among the dependent variables

Table 1: Demographic and Clinical Characteristics of Patients, N=75

	Spouses	Daughters
Patient Age		
Mean	72.46	79.97***
SD	9.63	5.53
Time since diagnosis (years)		
Mean	1.67	1.65
SD	1.71	1.93
Cognitive Status[a]		
Mean	15.04	12.48
SD	8.44	7.16
ADL[b]		
Mean	10.58	13.79**
SD	5.65	4.53
IADL[c]		
Mean	23.11	25.93*
SD	5.73	3.97
Behavioural Disturbance[d]		
Mean	23.71	29.93
SD	15.14	11.94
Patient Index[e]		
Mean	73.37	88.17**
SD	25.78	18.71

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

[a] Folstein Mini Mental Status Exam (MMSE) - score is number correct out of 30.

[b] Activities of Daily Living (ADL)- score ranges from independence (6) to dependence (30).

[c] Instrumental Activities of Daily Living (IADL) - score ranges from independence (8) to dependence (31).

[d] Behavioural Disturbance Scale (BDS) - score ranges from never occurs (0) to all of the time (112).

[e] Patient Index - is a composite score comprised of: (1- MMSE) + ADL + IADL + BDS score ranges from 14 to 203.

Table 2: Major Demographic Characteristics of Caregivers, N=75

	Spouses	Daughters
Caregiver Age		
Mean years	69.65	46.27***
SD	8.69	7.65
Caregiver Education		
Mean years	11.13	13.10**
SD	2.56	3.17
Caregiver Health		
Mean	2.13	1.83
SD	.95	.76
Caregiver's Change in Health		
Mean	2.20	2.03
SD	.54	.57
Duration of Caregiving		
Mean months	45.17	32.28
SD	9.79	33.34
Mean Time Caregiving		
Mean hours per day	6.50	6.83
SD	5.48	4.08
Others Residing with Dyad		
yes	10	27*
no	36	2
Employed		
yes	5	14**
no	41	15
Formal Services	45.2	146.4***

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

Table 3: Major Characteristics of Caregivers, N=75

	Spouses	Daughters
Maslach Burnout Inventory		
Mean	39.13	41.31
SD	26.69	16.05
Emotional Exhaustion		
Mean	18.76	23.31
SD	17.97	12.88
Depersonalization		
Mean	4.47	3.41
SD	6.26	3.43
Personal Accomplishment		
Mean	15.89	14.59
SD	9.65	7.46
Beck Depression Inventory		
Mean	10.00	8.55
SD	8.27	7.35
Zarit Burden Inventory		
Mean	30.07	36.07
SD	16.05	12.12
Anger Subscale of ZBI		
Mean	4.39	4.89
SD	3.31	2.73
Desire to Institutionalize		
Mean	.70	1.28*
SD	.94	1.07

*$p < .05$

Maslach Burnout Inventory (MBI) - total scores range from 0-132
Emotional Exhaustion (EE) - High 27+; Moderate 17-26; Low 0-16
Depersonalization (DEP) - High 13+; Moderate 7-12; Low 0-6
Personal Accomplishment (PA) - Low 39+; Moderate 32-38; High 0-31
Beck Depression Inventory (BDI) - Not depressed<10; mildly depressed 10-17; moderately depressed 17-25; severely depressed>25
Zarit Burden Inventory (ZBI) -total scores range from 0-88
Zarit Anger Subscale (ZAN) - total scores range from 0-16
Desire to Institutionalize (DI) -total scores range from 0-3

for both spouse and daughter caregivers to determine whether the data for caregiver groups could be combined into one group. As shown in Table 4, the direction of the inter-relations do not differ substantially for the two subject groups. The magnitude of the correlations, although they may differ significantly from zero for one group and not the other (e.g. patient index), the difference between these correlations, assessed by Fisher's z test, was not significant. Thus, while daughter and spouses differed in the mean value on the dependent variable the relationships among the variables of interest were the same. For all subsequent analyses the data for daughter and spouses were combined.

Comparision of scores with norms for formal caregivers (i.e. nurses and doctors) on the MBI subscales (Maslach, & Jackson, 1986) indicated that caregivers were within the moderate range on emotional exhaustion; on the depersonalization subscale the caregiver scores fell within the low range; and the average score on the personal accomplishment subscale was within the high range. Comparisions of MBI scores must be made with caution because the MBI used in the present study was revised in order to be applicable to informal caregivers.

The data on depression for the present sample indicate that this sample was similar to other studies on levels of depression (e.g. Gallagher et al., 1989a). The distribution of BDI scores was: 49 caregivers scoring were not depressed (BDI<10), 13 were mildly depressed (BDI = 10-16), 9 were moderately depressed (BDI = 17-25) and 4 were severely depressed (BDI>25). With a BDI cutoff score of 10, as suggested by Gallagher and colleagues (1989a), 28% of the sample were experiencing clinically significant depression. Gallagher et al. (1989a) reported that 47% of their sample fell within this depressed range. The average burden

Table 4: Pearson correlation coefficients between the desire to institutionalize and predictor variables for daughters and wives.

	PT	ST	MBI				BDI	ZBI	
Subscales:				EE	DEP	LPA			ZAN
Daughters	.20	.20	.38*	.20	.25	.36	.33	.37*	.17
Wives	.57**	.24	.42**	.48**	-.08	.31	.24	.33*	.19

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

Patient Index (PT)

Stage (ST)

Maslach Burnout Inventory (MBI)
    Emotional Exhaustion (EE)
    Depersonalization (DEP)
    Lack of Personal Accomplishment (LPA)
Beck Depression Inventory (BDI)
Zarit Burden Inventory (ZBI)
    Zarit Anger Subscale (ZAN)

scale score ($M = 32.4$) was lower in comparison to levels of burden reported in previous studies of caregivers recruited through counselling or support groups (e.g. Hassinger, 1985; Zarit et al., 1986).

3.2 Preliminary treatment of the data

Data were first screened for accuracy of entry, missing cases, fit of the distribution of the data with the assumptions underlying multivariate analysis and outliers. All values fell within plausible minimum and maximum ranges and no missing cases were found in the data.

The assumptions underlying multivariate regression analysis are that; 1) each variable and all linear combinations of variables are distributed normally; 2) there is linearity with the predicted scores, and 3) variability in scores is homogeneous for all values of the other variable (Tabachnick, & Fidell, 1989).

The regression equation computed for a set of variables is the line which maximizes the correlation between the observed score and the predicted score while minimizing the squared deviation of each observed score from the predicted score. When the assumption of normality is met, for each of the predicted values the standardized residuals are normally distributed around a mean of zero. The examination of the distribution of the individual variables through histograms is one way to screen for normality. It is also possible to determine normality statistically by determining whether the kurtosis and skewness of the distribution deviate significantly from normality. Multivariate normality may be determined from the examination of the residuals scatterplot where the residual values are plotted against the predicted values. When the assumption of normality has not been violated values on the scatterplot will be concentrated along the zero line and will trail off symmetrically above and below the zero line. In addition, normality may be assessed by examining a normal probability plot which plots the actual normal values of the residuals with the expected normal values which are estimated from the z score a residual would have if the distribution were normal. When the assumption of normality has not been violated the actual values will line up with the main diagonal, when it has been violated the actual line will deviate above or below the main diagonal (Tabachnick, & Fidell, 1989).

The individual predictor variables were assessed for departures from normality. Examination of the histograms for the distributions of the MBI and the ZBI indicated that these variables were normally distributed. Likewise, statistical analyses of the kurtosis and skewness of the distributions of the MBI, and the ZBI indicated that these distributions were not significantly different from the normal distribution. However, examination of the histogram for the BDI distribution revealed a negatively skewed distribution and statistical analysis of the skewness and kurtosis indicated a significant departure from normality. To adjust for this violation of normality, the BDI was logarithmically transformed. The transformation improved the shape of the distribution, however the results of the subsequent analyses were not changed significantly. Therefore, for ease of interpretation all analyses of the BDI are with the untransformed data.

The criterion variable was also examined for violations of normality. A histogram of the Desire to Institutionalize revealed a truncated and negatively skewed distribution. In a attempt to adjust for this violation of normality, desire to institutionalize was logarithmically transformed. However, due to the truncated nature of the distribution the transformed distribution did not improve the shape of the distribution or significantly change the results of the subsequent analyses. As a result, all analysis reported is with the untransformed data. Due to the restricted range of variability of the criterion variable correlations between the variables may be attenuated resulting in a degraded solution and therefore, conservative estimates of the predictability of the variables of interest (Tabachnick, & Fidell, 1989).

The assumptions of linearity and homoscedasticity were also assessed by examination of the residual scatterplot. If a relationship exists between a predictor and criterion variable which is nonlinear the linear portion of the relationship will be used to produce a regression equation and the remaining variance in the predictor will be considered residual. When the assumption of linearity is violated examination of the residual plot will reveal a curvilinear pattern. When the linearity assumption is met the residual plot will appear rectangular. Similarly when the assumption of homoscedasticity is violated examination of the residuals is diagnostic, since it is assumed that the variability of errors of prediction are similar for the predicted values. When homoscedasticity is violated the spread of residuals is uneven with the spread becoming larger at certain values, when met the spread of residuals is approximately the same for all values (Tabachnick, & Fidell, 1989).

An examination of the residual plots of the linear combinations of predictor variables did not demonstrate any serious violations of the assumptions of normality, linearity, and homoscedasticity. Also examination of the normal probability plots ruled out the possibility of serious departures from normality.

The multivariate outliers were assessed by Mahalanobis distance. This statistic computes the distance of a case from the means of all the variables, or the centroid, of the remaining cases. If the case is significantly different, with $p < .001$, based on a combination of values the case is identified as an outlier (Tabachnick, & Fidell, 1989). In the present data no cases were identified by Mahalanobis distance as outliers.

3.3 *Regression analyses*

The order of variable entry was based on a transactional model of stress, in which the demand of the caregiving situation is determined by the appraisals made by the caregiver. The importance of psychological variables can only be assessed adequately within the context of caregiving demands, in other words, psychological variables such as burnout and burden can only be deemed to be of theoretical and applied significance if they can be shown to predict variance over and above the variance accounted for by patient disability variance.

3.3.1 The role of burnout in the prediction of the desire to institutionalize

A hierarchical regression analysis was performed to examine the degree to which the subscales of the MBI predicted the desire to institutionalize. Patient index was entered at step one of the regression equation. In the second step of the regression equation the subscales of the MBI were entered. This order of variable entry allows the level of patient disability to be controlled for statistically and the subscales of the MBI to be assessed with the effects of patient disability removed. Table 5 displays the total R^2, the change in R^2, the F associated with the change in R^2, and the zero order correlations between the predictor variables and the criterion. Severity of patients' disability accounted for 23% of the variability in caregiver rating of the desire to institutionalize,(F_{inc} $(4,70) = 21.60$, $p < .001$). The burnout subscale resulted in a significant increase in

R^2, accounting for an additional 9% of the variance in caregivers' ratings of the desire to institutionalize, (F_{inc} (4,70) = 2.89, p <.01).

Beta weights for the regression equation are presented in Table 5. Standardized beta weights range from negative one to positive one and reflects the contribution of individual variables to the regression equation. As shown in Table 5, only the emotional exhaustion subscale contributed significantly to the prediction of the desire to institutionalize (t(74) = .25, p < .05). Neither the depersonalization nor the personal accomplishment subscales added significantly to the prediction of the desire to institutionalize.

3.3.2 The role of burden in the prediction of the desire to institutionalize

In previous studies, burden has been shown to be a significant predictor of the desire to institutionalize (e.g. Morycz, 1985; Zarit et al. 1986). In order to determine whether burden would account for variance in the desire to institutionalize over and above the patient disability measure a second hierarchical regression analysis was performed in which the order of entry was: patient index and ZBI. As previously mentioned, this order of variable entry allows the level of patient disability to be controlled for statistically and in this equation allows the ZBI to be assessed with the effects of patient disability removed. Table 6 displays the total R^2, the change in R^2, the F associated with the change in R^2, and the zero order correlations between the predictor and criterion variables in the second equation. The addition of the ZBI in the second step did not increase R^2 significantly. The burden measure did not account for a significant amount of variance in the criterion variable over and above patient disability.

Table 5: Hierarchical regression analysis of the MBI subscales in the prediction of the desire to institutionalize.

Predictor Variables		β	Total R^2	Change in R^2	F for Change	r
Step 1						
Patient Index		.48**	.23	.23	21.6***	.48
Step 2						
Burnout			.31	.09	2.90**	
	EE	.25*				.40**
	DEP	-.17				-.02
	LPA	.14				.29*

Burnout
  Emotional Exhaustion (EE)
  Depersonalization (DEP)
  Lack of Personal Accomplishment (LPA)

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

Table 6: Hierarchical regression analysis of ZBI in the prediction of the desire to institutionalize

Predictor Variables	β	Total R^2	Change in R^2	F for Change	r
Step 1					
Patient Index	.48**	.23	.23	21.6***	.48
Step 2					
ZBI	.20	.26	.03	3.20	.38**

Zarit Burden Inventory (ZBI)

*** $p < .001$
** $p < .01$

3.3.3 The role of depression and anger in the prediction of the desire to institutionalize

A third hierarchical regression analysis was performed to determine whether depression and anger would account for a significant amount of variance in caregivers' desire to institutionalize over and above the variance accounted for by patient disability. Again patient index was entered at step one of the regression equation. In the second step of the regression equation the anger subscale of the burden measure and the BDI were entered. This order of variable entry again allows the level of patient disability to be controlled for statistically and in this equation anger and depression to be assessed with the effects of patient disability removed. Table 7 displays the total R^2, the change in R^2, the F associated with the change in R^2, and the zero order correlations between the predictor and criterion variables in the second equation. The addition of depression and anger in the second step did not increase R^2 significantly. The BDI and the ZAN did not account for a significant amount of variance in the criterion variable over and above patient disability.

3.3.4 Social Desirability

It is possible that individuals' motivation to respond in a socially desirable manner attenuated the magnitude of the observed relations in the prediction of the desire to institutionalize. It was thought that social desirability would act as a suppressor variable, attenuating the relationship of the predictor variables with the criterion variable. Social desirability was entered at step one of the regression equation. In the second step of the regression equation patient index was entered. In the third step of the regression equation the subscales of the MBI were entered. This order of variable entry allows the level of social desirability to

Table 7: Hierarchical regression analysis of ZAN and BDI in the prediction of the desire to institutionalize

Predictor Variables	β	Total R^2	Change in R^2	F for Change	r
Step 1					
Patient Index	.48**	.23	.23	21.60***	.48
Step 2		.26	.03	1.39	
BDI	.18				.23*
ZAN	-.06				.19

Beck Depression Inventory (BDI)
Zarit Anger Subscale (ZAN)

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

be controlled for statistically and allows the variable of interest to be assessed with the effects of social desirability removed. Table 8 displays the total R^2, the change in R^2, the F associated with the change in R^2, and the zero order correlations between the predictor variables and the criterion. Social desirability was not a significant predictor of caregivers' desire to institutionalize. After removing social desirability patients' disability accounted for 26% of the variability in caregiver rating of the desire to institutionalize,(F_{inc} (4,70) = 22.14 , $p < .001$). The addition of the burnout subscales in the third step did not increase R^2 significantly. Similar analyses were run for the BDI and ZBI, ZAN. Contrary to predictions, social desirability did not act as a suppressor variable. Instead, due to degree of overlap of shared variance with the other predictor variables it weakened the relationship between predictor and criterion variables.

3.4 Correlational analyses of the MBI

Several investigators have questioned whether burnout can be distinguished in a meaningful manner from depression. For example, Enzman and Kleiber (1990) reported that emotional exhaustion and depression were significantly correlated ($r = .40$). In the current study the emotional exhaustion subscale of the MBI was also significantly correlated ($r = .60, p < .01$) with the BDI. The results are displayed in Table 9.

Evans and Fischer (1989) used a principal components analysis to address the relation between depression and burnout. Their results indicated that the subscales of burnout were distinct from depression. To further examine the relationship among depression and burnout a principal components analysis was conducted. Principal components analysis produces linear combinations of variables that provide a mathematical summary of the interrelation of variables

Table 8: Hierarchical regression analysis of social desirability, patient index and burnout subscales in the prediction of the desire to institutionalize.

Predictor Variables	β	Total R^2	Change in R^2	F for Change	r
Step 1					
Social Desirability	-.16	.02	.02	1.77	-.16
Step 2					
Patient Index	.48**	.26	.23	22.14***	.48**
Step 3					
Burnout		.32	.07	2.28	
EE	.21				.40**
DEP	-.18				-.02
LPA	.14				.29*

Burnout
  Emotional Exhaustion (EE)
  Depersonalization (DEP)
  Lack of Personal Accomplishment (LPA)

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

Table 9: Pearson correlation coefficients among main variables.

	EE	DEP	LPA
EE			
DEP	.36**		
LPA	.32**	.08	
BDI	.60**	.35**	.22

Burnout
- Emotional Exhaustion (EE)
- Depersonalization (DEP)
- Lack of Personal Accomplishment (LPA)

Beck Depression Inventory (BDI)

** $p < .01$

in the data set. Principal components analysis is frequently used as a method of examining the underlying structure or dimensionality of the variance within a data set. In interpreting the results of a principal components analysis, it is customary to consider components with eigenvalues of greater than one. Eigenvalues reflect the degree of variance accounted for by specific components, and values less than one indicate that the factor accounts for less variance than individual variables included in the analysis. In the present analysis only one component emerged with an eigenvalue greater than one. The component accounted for 50.5% of the variance in caregiver responses and showed the strongest association with measures of emotional exhaustion and depression. The results are displayed in Table 10.

Correlational analyses were conducted on the subscales of the MBI to address the process model of burnout proposed by Leiter and Maslach (1988). They found in support of their process theory of burnout, that emotional exhaustion was positively correlated with depersonalization, which was negatively correlated with lack of personal accomplishment. Emotional exhaustion was not correlated with personal accomplishment. In contrast to the pattern of previous findings, emotional exhaustion was positively correlated with both depersonalization ($r = .36$, $p < .01$) and lack of personal accomplishment ($r = .32$, $p < .01$). Depersonalization was not significantly correlated with personal accomplishment. Table 11 compares the present pattern of correlations with the pattern presented by Leiter and Maslach (1988).

Table 10: Principal components analysis of depression and burnout subscales.

Component measures	Factor loadings
EE	.85
BDI	.82
DEP	.62
LPA	.49

Emotional Exhaustion (EE)
Depersonalization (DEP)
Lack of Personal Accomplishment (LPA)
Beck Depression Inventory (BDI)

Table 11. A comparison of Pearson correlation coefficients among the subscales of the MBI in the present study and in the Leiter and Maslach (1988) study.

	Present study		Leiter and Maslach	
	EE	DEP	EE	DEP
DEP	.36**		.49*	
LPA	.32**	.08	.15	.30*

Emotional Exhaustion (EE)
Depersonalization (DEP)
Lack of Personal Accomplishment (LPA)

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

Chapter 4
Discussion

The main goal of the present study was to determine whether burnout would predict the desire to institutionalize in caregivers to dementia patients. It was hypothesized that burnout would predict desire to institutionalize over and above patient disability. It was also hypothesized that burden, depression and anger would be correlated with desire to institutionalize but would not predict desire to institutionalize over and above patient disability variables. Secondary goals of the present study were to examine the relationship between burnout and depression and to compare the process of burnout in informal caregivers with past studies on formal caregivers.

4.1 Sample Description

Similar to past research, a high level of distress was found in the caregiver sample. Cappeliez (1993) in a review of depression in the elderly estimated that 20 to 25 percent of the elderly experienced dysphoria, 10 to 15 percent presented with moderate to severe depressive symptoms and approximately five to eight percent were clinically depressed. In the general elderly population the prevalence of clinical depression has been estimated at 9.7% (Blazer, & Williams, 1980) but estimates of rates of dysthymia, dysphoria, and depressive symptoms in the general elderly population are as high as 26% (Blazer, Hughes and George, 1987). Examination of depressive symptoms in the general elderly population have yielded average BDI scores ranging from 5.5 to 6.84 (Bourque, Blanchard, & Vézina, 1990; Vézina, Landreville, Bourque, & Blanchard, 1991).

In samples of caregivers to relatives with dementia, studies which have measured depressive symptomatology using the BDI have found that approximately 30 to 49 percent of caregivers met the cut off for depression (e.g., Dura et al., 1990; Fiore et al., 1983; Gallagher et al., 1989a; Gallagher et al., 1989b). Studies that have used the long form of the BDI have reported sample means in the range of 9.39 to 11.2 (Fiore et al., 1983; Gallagher et al., 1989b; Haley et al. 1987). Gallagher and colleagues' (1989a) found, with a sample of caregivers, a BDI cut off of 10, instead of the traditional cut off of 17 for moderate depression maximized the sensitivity and specificity of the measure.

In this study, using a cut off of 10 on the BDI, 28% of the sample scored in the depressed range with 72% reporting no depressive symptoms. Twenty four percent of caregivers scored within the moderate range and 4% of the sample was within the severely depressed range on the BDI. The mean BDI score in the present sample was 9.28. Compared to norms for the general population and for the elderly it appears that caregivers in this study were more likely to exhibit depressive symptoms (i.e. 28% reported depressive symptoms). In comparison to studies with caregivers of dementia relatives estimates of the prevalence of depressive symptoms and BDI means are slightly below the low end of the range.

Similarly average levels of burden in the present sample were lower than those reported in previous studies in which the samples had been self selected (e.g. Hassinger, 1985; Zarit et al. 1986). As previously mentioned, burden is a specific measure applicable only to caregivers and therefore, it is not possible to compare noncaregiving groups on level of burden. Thus, the burden measure has limited comparability with noncaregiving groups and with normative data.

In interpreting the findings it is necessary to consider differences in the characteristics and selection of the present sample from previous studies. Schultz et al. (1990) suggested, based on an extensive review of the caregiving literature, that the more representative the population of caregivers the lower the rates of depression. Studies selecting caregivers from support groups or the media have higher rates of depressive symptomatology than those recruiting all individuals from a geographic location. It is likely that rates of depression are inflated in studies that have relied on caregivers from support groups, counselling centres or media volunteers since distress is often the factor which motivates individuals to seek help. It is not surprising, for studies with such self-selected samples in which individuals are actively seeking help often to alleviate their distress, that caregiver distress is high. Unlike many prior studies examining affective states in caregivers, subjects in this study were drawn from the population of dementing patients who were referred, within the last two years, to geriatrics at a local general hospital. While subjects in the present study may also be classified as help seekers they were seeking help for the purposes of patient diagnosis rather than for management of their own distress. It is likely that the lower rates of depression in the present study may be more applicable to the general population of caregivers and not just those seeking help to relieve distress.

Differences in sample characteristics do not appear to be responsible for differences in rates of depression. A number of studies using the BDI have found that patient disability is positively correlated with level of depressive symptomatology (for a review see, Schultz et al. (1990). In the present study, mental status scores indicated that the sample was moderately to severely impaired. Similarly, based on the possible range of scores, mean scores on IADL, ADL and the derived Reisberg stages indicated that patients were moderately to severely impaired. In other words the degree of patient disability in this sample is comparable to other studies reporting higher levels of caregiver distress.

The assumption in the literature has been that elevated rates of depression in caregivers are the result of the increased stress or burden experienced by these individuals. In other words, it has been suggested that as a function of increased stress, caregivers are more likely to experience depressive signs and symptoms than the general elderly population. In the present study this assumption was supported. The significant correlation between burden and depression suggests that caregivers who reported higher levels of burden also reported higher levels of depression ($r = .55, p < .01$). Past studies have also found that burden is positively correlated with depression (e.g., Jenkins, Parham, & Jenkins, 1985; Lawton, et al., 1991; Pruchno, & Resch, 1989).

4.2 Predictability of patient disability on the desire to institutionalize

Patient disability has been examined by a number of past studies as a major stressor facing caregivers. Studies have shown that patient disability is predictive of caregiver's level of distress and is also predictive of institutionalization (e.g., Chenoweth, & Spencer, 1986; Deimling, & Poulshock, 1985; Hammel et al., 1990; Nygaard, 1991; Pruchno et al., 1990). In our study patient disability was the most powerful predictor accounting for 23% of the variance in caregivers' ratings of the desire to institutionalize. A number of other studies have found patient disability to be a much less powerful predictor of institutionalization than in the present study. Past research has shown significant but modest relationships between patient disability and desire to institutionalize (Gonyea, 1987; Morycz, 1985) while others report no relationship (e.g. Colerick, & George, 1986; Zarit et al., 1986).

This discrepancy in findings, is likely is due to the comprehensive nature of the disability index constructed for the present study. Patient disability was conceptualized as a multidimensional construct comprised of cognitive impairments, functional disabilities (both instrumental and basic ADL) and behavioural disturbances. In many studies patient disability has not been addressed using this comprehensive model. Often only one or two of these areas of impairment have been assessed (e.g. Colerick, & George, 1986; Gonyea, 1987; Morycz, 1985; Zarit et al., 1986).

The current findings point to the importance of using a comprehensive measure of patient disability. If comprehensive patient disability measures are not used it may lead to an inaccurate focus on the characteristics of the caregiver rather than characteristics of the caregiving situation. In particular, when appraisal constructs such as burden are measured the data may imply that some caregivers exaggerate the stressfulness of their situation. For example, in a study by Zarit et al. (1986) disability was measured by two scales that assessed cognitive impairments and behavioural disturbance. Zarit et al, found that burden, but not patient disability was a significant predictor of institutionalization. It is possible that a more comprehensive measure of patient disability may have revealed a significant relationship with institutionalization.

4.3 Predictability of caregiver burden on the desire to institutionalize

It was hypothesized that burden would be correlated with desire to institutionalize but would not predict desire to institutionalize over and above patient disability variables. As previously mentioned burden has been conceptualized as the appraisal of caregiving stress, involving both primary and secondary appraisal processes. Burden has been viewed as a mediator between the primary objective stressor and negative emotional outcomes (Lawton et al., 1989). Previous research has found that burden is correlated with desire to institutionalize as well as actual institutionalization (e.g. Brown et al., 1990; Gonyea, 1987; Hassinger, 1985; McFall, & Miller, 1992; Pruchno, et al., 1990; Zarit et al., 1986). In this study burden accounted for 14% of the variance in caregivers' desire to institutionalize. However, burden did not predict desire to institutionalize over and above patient disability. Similar findings were reported by Pruchno, et al. (1990). They found that caregiver burden was significantly correlated with the desire to institutionalize but did not predict desire to institutionalize over and above patient disability measures.

As noted earlier, one reason for the inability of the burden construct to predict institutionalization may be related to the heterogeneity or lack of precision of the construct. As conceptualized by Zarit and others, caregiver burden may vary both as a function of an inadequate skill repertoire or the lack of coping resources. Therefore, caregiving situations may be experienced as stressful when they call for skills not within the individual's repertoire or when they exceed available coping resources. However, the examination of burden subscales, derived from the factor structure reported by Hassinger (1985), indicated that more specific constructs such as anger or guilt did not provide greater predictive power. Conclusions based on these data must be made with caution given that currently there is no evidence to support the construct validity of the burden subscales reported by Hassinger.

4.4 Predictability of caregiver burnout on the desire to institutionalize

The main goal of the present study was to determine whether burnout would predict the desire to institutionalize in caregivers to dementia patients. It was hypothesized that burnout would predict desire to institutionalize over and above patient disability. Consistent with predictions, the modified burnout measure was the only psychological variable that added significantly to the prediction of the desire to institutionalize above and beyond that accounted for by patient disability. After controlling for patient disability burnout accounted for an additional 9% of the variance in the desire to institutionalize.

There are a number of possible reasons why burnout may be a more powerful predictor of desire to institutionalize than burden. As previously mentioned, burden, has been conceptualized as the caregiver's assessment of stressfulness of potential objective stressors and as the appraisal of the effects that caregiving demands have had on their lives. Those experiencing high levels of burden may still find ways to cope with their situation. Burnout, on the other hand, has been conceptualized as the negative emotional outcome of the stress process and is considered to reflect the failure to cope successfully with stress (Maslach, 1978; Brill, 1984). Caregivers who report high levels of burnout are thought to have depleted their resources and therefore, the only option left is to institutionalize their relative.

The difference between the predictive power of burnout and burden also may be due to differential precision of the two constructs. Burden taps both the skill repertoire and/or the lack of coping resources of the caregiver. Burnout reflects specifically the caregiver's resource depletion. It is possible that the homogeneity and precision of the burnout construct may produce better prediction of institutionalization than burden. Although burnout may have multiple determinants the variable remains homogeneous in that it can be considered the final common pathway of a variety of stress and coping outcomes.

It was also hypothesized that depression would be correlated with desire to institutionalize but would not predict desire to institutionalize over and above patient disability variables. Depressive symptoms, similar to burden, have been found to correlate with institutionalization and with the desire to institutionalize (Pruchno, et al., 1990). In this study depression accounted for 5% of the variance in caregivers' desire to institutionalize. However, depression did not predict desire to institutionalize over and above patient disability. Again, the present findings are similar to those reported by Pruchno, et al. (1990) who found a univariate relation between depression and desire to institutionalize, however depression did not predict desire to institutionalize over and above patient disability measures.

The conceptual basis of burnout and depression may account for differences in their predictive power. It was suggested that burnout differs from depression in terms of underlying attributional processes. Measures of burnout require subjects to causally link the caregiving situation to their current distress. Measures of depression require subjects to report on generalized symptoms of current distress, but do not require any causal attributions concerning the source of their distress. It is likely that caregivers reporting high levels of depression may be more likely to make internal attributions for the cause of their distress (Abramson, et al., 1978) whereas, those reporting high levels of burnout have attributed the cause of their distress to the caregiving situation. Having made a situational attribution, e.g. I am burned out because of caregiving, it is more likely that caregivers will act to alleviate their distress by reducing their caregiving demands.

The present study made predictions based on a number of models. The stress and coping framework proposed by Lazarus and Folkman (1984) proposes that individuals are engaged in a dynamic interchange with the environment. Zarit's model is also a transactional model and is primarily distinguished from Lazarus' model in that he specifically addresses the caregiving relationship. Hobfoll's resource conservation model of stress (Hobfoll, 1989) proposes that stress occurs when resources are threatened, lost or not gained through the investment of resources. Romeis (1989) has emphasized the importance of resource depletion in caregiver's decision to institutionalize. Romeis' model predicts that as the gap widens between care receiver demands and caregiver resources and strain increases, so does the probability of the caregiver deciding to institutionalize. The model predicts that institutionalization will occur when care receiver demands are excessive and resources are depleted.

In all of the above mentioned models the process of becoming stressed or of institutionalization is emphasized. Terminology used by stress researchers implies a dynamic interactional process between the stressors and responses. However much of the research to date has been cross sectional in nature, and therefore the interactional, dynamic or temporal relations between stressors and responses have generally been neglected. In addition, these models have presented a stress process which is mostly unidirectional. In the resource models stressors are viewed as impinging on resources which dwindle over time. However, little attention has been paid to the possibility that individuals may draw on new resources or renew existing resources.

4.5 The discriminant validity of caregiver burnout

A secondary goal of the study was to examine the relationship between burnout and depression. The discriminant validity of these two constructs was evaluated using three procedures 1) examination of zero order correlations; 2) examination of the factor structure of the constructs; and 3) examination of the predictive power of the constructs. Research findings based on correlational data have suggested that a moderate relationship exists between burnout and depression (typically in the .4 to .6 range). Enzman and Kleiber (1990) reported that emotional exhaustion and depression were significantly correlated ($r = .40$). The current study also found a significant zero order correlation between the emotional exhaustion subscale and depressive symptoms ($r = .60, p < .01$). A significant zero order correlation was also found between the depersonalization subscale and the BDI ($r = .35$ $p < .01$) but not between the personal accomplishment subscale and the BDI ($r = .22, p > .05$). Based on this pattern of correlations it may be concluded that depressive symptomatology and aspects of burnout overlap. However, it is important to note that the lack of correlation between personal accomplishment subscale and the BDI would suggest that components of the burnout scale are distinguishable from depression.

On the basis of high correlations between burnout subscales and measures of depression, Meier (1984) has argued against the discriminant validity of the burnout construct. However, it has been argued by Haaga (1991) that the presence of a significant correlation does not support a position that two constructs are indistinguishable. He suggests discriminant validity should be viewed as a continuous rather than dichotomous concept and that discriminant validity should be assessed using multiple methods.

A principle components analysis was used by Evans and Fischer (1989) to address the relationship between depression and burnout. Their results indicated that the subscales of burnout were distinct from depression. In the present study the same analysis resulted in only one factor which accounted for 54.3% of the variance in caregiver responses. The discrepancy between these findings is possibly due to differences in measurement instruments. Evans and Fischer (1989) used a six-item scale that assessed only subjects' affective symptoms of depression. Consequently, the evidence their study provides for the discriminant validity of these two constructs must be questioned since the findings are based on an incomplete measure of depressive symptomatology. In this study a comprehensive, well established, theoretically based measure of the cognitive, somatic and affective depressive symptoms was implemented, and therefore the findings may be viewed with more confidence.

Another method of assessing the discriminant validity was to examine the predictability of the constructs. It was argued that evidence of the discriminant validity would be provided if one construct was a significantly more powerful predictor of the desire to institutionalize. The results of the regression analysis suggest that burnout is distinguishable from depression since the burnout measure was predictive of caregivers' desire to institutionalize while depression was not.

Thus, the correlational analyses and the factor analysis suggest that burnout and depression share considerable variance. The results of the regression analysis however reflect a differential relation between burnout and depression concerning the prediction of desire to institutionalize. In addition, burnout and depression may also differ with respect to underlying attributional processes. However, in the present study attributions were not measured directly and therefore, while the findings are suggestive of an attributional distinction they are not conclusive. Future studies which employ direct measures of attributions would allow for more conclusive statements.

4.6 The process of caregiver burnout

Correlational analyses were conducted on the subscales of the MBI to address the process model of burnout proposed by Leiter and Maslach (1988). Leiter and Maslach (1988) theorized that the sequence of the burnout process (based on a sample of formal caregivers, i.e. nurses) was: stressful interaction leading to emotional exhaustion; high levels of emotional exhaustion leading to depersonalization and depersonalization leading to diminishing feelings of personal accomplishment. Leiter and Maslach (1988) found, in support of their process theory of burnout, that emotional exhaustion was positively correlated with depersonalization, which was negatively correlated with lack of personal accomplishment. Emotional exhaustion was not correlated with personal accomplishment.

In contrast to the pattern of previous findings, in the present study emotional exhaustion was positively correlated with both depersonalization and lack of personal accomplishment. Depersonalization was not significantly correlated with personal accomplishment. Consistent with Leiter and Maslach's (1988) position, it is possible that emotional exhaustion may lead to increased depersonalization. However, in the present sample, there were no indications that depersonalization led to decreases in personal accomplishment. Rather, emotional exhaustion was associated with reports of lack of personal accomplishment.

Proceeding from Leiter and Maslach's view that emotional exhaustion initiates the process of burnout, the present results suggest that in family caregivers, emotional exhaustion may give rise simultaneously to depersonalization and feelings of lack of accomplishment. The direct relation between emotional exhaustion and personal accomplishment may reflect attachment characteristics that are not present been formal caregivers and their recipients of care. Although data collected in the present study do not permit examination of the temporal relation between the subcomponents of burnout, it is possible that in family caregivers personal accomplishment may play a mediational role in the process of burnout, rather than being the final stage of the burnout process. It is possible that the personal accomplishment in family caregivers may be related to caregiver attachment or gratification in caregiving. This may act to slow or even circumvent emotional exhaustion or depersonalization. However, since caregiver attachment or gratification was not measured in the current study it is only possible to speculate on the importance of these variables. Longitudinal data will be necessary in order to make strong claims concerning the process of burnout. In longitudinal studies it will be possible to examine the interrelation among the subcomponents of burnout over time.

4.7 Clinical Implications

To address practical issues, the results of the present study indicate that patient disability was the most important predictor of caregivers' desire to institutionalize. The importance of this variable on deciding to institutionalize would suggest that reducing the objective demands of the caregiving situation would facilitate the caregiver in maintaining this role. The objective demands of caregiving may be reduced though the provision of a number of formal services (Kraus & Armstrong, 1977). Behaviour management techniques may be taught to caregivers in order to reduce the disruptive behaviours of the relative with dementia. Respite in the form of home care, day care or hospital stays may reduce the load of caregiving demands.

The findings of the present study indicate that not only is burnout a good predictor of the desire to institutionalize but it is a better predictor than burden, depression and anger. The modified caregiver burnout measure may be used in medical assessments in order to better identify those who are more at risk for institutionalization. Concerning issues of practicality, this tool requires minimal time to administer and score and therefore, may be easily included in medical evaluations in primary care.

The development and evaluation of therapeutic techniques to reduce level of burnout is also necessary. Due to the lack of empirical evidence, it is difficult to determine what would help caregivers to experience less burnout or reverse the process of burnout once begun. To date, insufficient information is available on the process of burnout and interventions for reversing burnout. Studies on burnout in formal caregivers have highlighted the importance of a number of variables which are associated with lower levels of burnout. Of particular relevance to the present population are the findings of Leiter and Maslach (1988). They found that supportive interpersonal contact acted as a buffer against burnout. A number of studies in the caregiving literature have reported lowered distress in individuals attending support groups (for a review see Toseland, & Rossiter, 1989). In addition strategic management of the stressor has been shown to be associated with lower levels of burnout (Pines, & Maslach, 1978). Maslach and Pines (1977) reported that workers who were able to take work breaks during the day were less likely to burnout. It is therefore likely that respite which would allow the caregiver to have short daily breaks would reduce burnout.

4.8 Limitations of the Current Study and Recommendations for Future Research

Due to the limitations inherent in the present study a number of questions were elicited. Therefore, several suggestions may be made for possible directions in future research. The present work is limited by the cross sectional nature of the design which makes it impossible to chart changes in affect and/or the impact of disability as caregivers make the transition from caring to yielding their role. As Pearlin (1992) has pointed out, the career of caregivers is often comprised of 3 stages: residential care, institutional placement and bereavement. Within these stages the demands and stresses of caregiving change. It is possible that during the course of caregiving changes occur in the relative importance of objective vs. subjective variables in predicting institutionalization. It is also possible that early in caregiving the objective indicators of disability may be the best predictors of institutionalization but as caregivers become worn down by the demands of caregiving subjective indicators may become more important predictors of the desire to institutionalize. For example, Zarit and Whitlach (1992) in a longitudinal study examined well-being in caregivers to dementia patients as they made the transition to institutionalization. A more detailed examination of the dimensions of the stress process revealed both change over time and continuity in various aspects of caregiver well-being.

The cross sectional nature of the design also limits the degree to which process variables can be examined. Since the temporal relations are obscured by the design it is not possible to make confident statements about the process of burnout. It should also be pointed out the Leiter and Maslach's (1988) study suffers from the same limited design. Therefore, in order to examine possible changes in the importance of variables over the stages of caregiving or examine the temporal aspects in process variables it will be necessary to conduct longitudinal research.

Another potential concern in this study was the accuracy with which caregivers assessed the disability of their relatives and their own levels of distress. The concern of inaccurate positive self-presentation was addressed through inclusion of a social desirability questionnaire as a control measure. Contrary to expectations social desirability did not act as a suppressor variable. Instead, due to the degree of overlap of shared variance with the other predictor variables, social desirability weakened the relationship between predictor and criterion variables. Recently much debate has occurred in the literature about the utility of considering social desirability as a suppressor variable since many studies have reported the contrary (Block, 1990; Edwards, 1990; Nicholson, & Hogan, 1990; Walsh, 1990). It is also been argued that the popularity of social desirability has waned with accumulation of behavioural evidence (Block, 1990). Thus, in the present study the need for such a measure of response bias is debatable since the criterion measure is behaviourally based.

A word of caution is necessary in interpreting the findings of the regression analyses. As previously mentioned, the truncated distribution of the criterion variable may have resulted in a degraded solution with conservative estimates of the predictability of the variables of interest (Tabachnick, & Fidell, 1989). It is therefore possible that other affect variables may have reached significance if the criterion variable was normally distributed. It is unlikely that this violation of the assumption of normality reduced the generalizability of the findings since transformations were performed on the criterion and the results of the regression analyses were similar.

Finally, the present study examined processes related to caregiving in a sample of female caregivers. It is possible that the relation between burnout and the desire to institutionalize may not be generalizable to male caregivers. However, the results of Miller and Cafasso (1992) indicate that there is little evidence that men and women differ in their patterns of caregiving or the outcome of their caregiving efforts. They suggested that future efforts in this area will need to specify more clearly the theoretical relations that link gender to caregiving outcomes. The authors note that while gender may be an enduring attribute the meaning of gender differences is often less than clear.

However, there may be phenomenological differences in the experience of caregiving in wives and daughters. Change in residence may lead to abrupt restructuring of the family unit for daughters, while wives do not experience this restructuring. This change may be compensated for by the number of individuals in the daughter's immediate family that may be available to assist with caregiving demands. In addition, daughters may experience interference with work roles, while wives are likely to be retired. The decision to institutionalize may be associated with different consequences for daughters than wives. For daughters institutionalization may allow the resumption of previous family and work functions. For wives institutionalization may lead to an increase in isolation.

4.9 Conclusions

In summary, the findings of the current study indicate that patient disability is the most powerful predictor of caregivers' desire to institutionalize. The modified burnout measure was the only psychological predictor that added significantly to the prediction of the desire to institutionalize over and above that accounted for by patient disability. Burden, depression and anger were correlated with desire to institutionalize but did not predict desire to institutionalize over and above patient disability variables. Examination of the relationship among burnout and depression, indicates that these constructs should be viewed as having some overlap, but also as distinguishable as evidenced by their discriminability in the prediction of the desire to institutionalize. The pattern of correlations in the present study suggest that the progression of burnout may be experienced differently for informal caregivers than formal caregivers. However conclusive statements concerning process can not be made due to the cross-sectional nature of this study.

The current zeitgeist in the caregiver literature is to focus on the characteristics of the caregiver, however, the current findings suggest that it is important to consider the patient characteristics. It may be worthwhile to develop measures based on sub-types or specific profiles combining the cognitive, behavioral and functional impairments of dementia patients in order to increase predictability. Longitudinal studies would allow for the development of such subtypes or profiles and would facilitate the identification of those at greatest risk for institutionalization.

Appendices

Appendix A: Patient and Caregiver Demographics

Patient and Caregiver Demographics

Caregiver Interview

Subject ID _____

Date of Interview ____/_____/___
Day/Month/Year

Visit Time: Start ___:___ Interview Time: Start ___:___

Study Subject:

Name: ______________________________________
Surname Given Names

Age: ________ Sex: ________

When was your relative diagnosed with dementia?____________

Caregiver:

Name: ______________________________________
Surname Given Names

Address:____________________________________
No. Street Apt.#

____
City Province Postal Code

Telephone: ________________

Age: ________ Date of Birth: ____/_____/___
Day/Month/Year

Sex: ________ Relationship: ___________________

Marital Status:__________________

Years of Education:________________

Are you the main person caring for your mother/father/husband?___________

How long have you been a caregiver to your mother/father/husband?________

How long have you lived together? ________

Does anyone else live with you?_____________
Husband______ Children______ Other _____

For your age would you say, in general, your health is:

1. excellent 2. good 3. fair 4. poor or 5. bad?

Compared to your own health 5 years ago would you say your health is:

1. excellent 2. good 3. fair 4. poor or 5. bad?

Have you ever been diagnosed with a psychiatric condition?___________________

Condition?____

Are you currently employed? _____ If no: When did you last work?_________

Why did you stop working?____

How many hours per week do you work? ___________

On average how many hours do you spend caring or helping your

mother/father/husband with various tasks during the day?____________________

Have you obtained any of the following services within the past year?

Homemaker Service

1 Yes 2 No

Number of times per year ____

Help with Personal Care of Mother/Father/Husband

1 Yes 2 No

Number of times per year ____

In-Home Nursing Care

1 Yes 2 No

Number of times per year ____

Day Center or Day Hospital

1 Yes 2 No

Number of times per year ____

Temporary Hospital or Nursing Care

1 Yes 2 No

Number of times per year ____

Self-help or Support Groups

1 Yes 2 No

Number of times per month ____

Counseling Services for support in caring for your Mother/Father/Husband

1 Yes 2 No

Number of times per month ____

Appendix B: Cognitive Measure

Cognitive Measure

		Score	Maximum Points
Orientation			
1. What is the	Year?	____	1
	Season?	____	1
	Date?	____	1
	Day?	____	1
	Month?	____	1
2. Where are we?	Province?	____	1
	Country?	____	1
	Town/City?	____	1
	House?	____	1
	Address?	____	1
Registration			
3. Name three objects (ball, flag, tree), taking one second to say each. Then ask the patient all three after you have said them. Give one point for each correct answer. Repeat the answers until the patient learns all three.		____	3
Attention and calculation			
4. Serial sevens. Give one point for each correct answer. Stop after five answers. Alternate: Spell WORLD backwards.		____	5
Recall			
5. Ask for the names of three objects learned in question three. Give one point for each correct answer.		____	3
Language			
6. Point to a pencil and a watch. Have the patient name them as you point.		____	2
7. Have the patient repeat "No ifs, ands, or buts."		____	1

	Score	Maximum Points
8. Have the patient follow a three stage command. "Take the paper in your right hand. Fold the paper in half. Put the paper on the floor."	____	3
9. Have the patient read and obey the following: "CLOSE YOUR EYES". (Write it in large letters.)	____	1
10. Have the patient write a sentence of his/her choice. (The sentence should contain a subject and an object and should make sense. Ignore spelling errors when scoring.) ____	1	
11. Enlarge the design printed below to 1-5 cm per side and have the patient copy it. (Give one point if all sides and angles are preserved and if the intersecting sides form a quadrangle.)	____	1

New England Medical Center

Department of Psychiatry

Marshal F. Folstein, M.D.
Chairman and Professor
Department of Psychiatry
Tufts University School of Medicine

Psychiatrist-in-Chief
New England Medical Center

NEMC #1007
750 Washington Street
Boston, Massachusetts 02111

Tel: (617) 636-5772
Fax: (617) 636-8442

E-Mail:
MFOLSTEI@OPAL.TUFTS.EDU.

December 9, 1994

April D'Aloisio
Department of Psychology
Dalhousie University
Halifax, Nova Scotia
CANADA B3H 4J1

Dear Ms. D'Aloisio:

I am pleased to grant you permission to use the Mini-Mental State Exam (MMSE) in your research on the "Emotional Correlates of the Desire to Institutionalize in Caregivers to Relatives with Dementia." Use of the Mini-Mental State Examination (MMSE) for the purpose of research or treatment of patients is given without charge. However, if you would like to defray the costs incurred in reproduction and the processing of your request, please send a check payable in the amount of $10.00 to the Mini-Mental State Examination Fund and mail it to the address below.

New England Medical Center
Department of Psychiatry
750 Washington Street
NEMC #1007
Boston, MA
Attention: Ann Lawlor

Please insure that the MMSE is appropriately cited ("Mini-Mental State: A Practical Method for Grading the Cognitive State of Patients for the Clinician". *Journal of Psychiatric Research*, 12(3):189-198, 1975) in any written materials that may result from this research.

Sincerely yours,

Marshal Folstein MD

Marshal F. Folstein, M.D.
Chairman, Department of Psychiatry

MFF/cdc

The principal teaching hospital for
Tufts University School of Medicine

Appendix C: Activities of Daily Living Measure

Activities of Daily Living Measure

The following questions are concerning how your mother/father/husband manages (his/her) daily life. Please indicate by filling in the number which best describes your relative's current ability (within the past two weeks) to perform these activities of daily living (without help, level of help required or not at all).

A. TOILET	
1.	Cares for self at toilet completely, no incontinence
2.	Needs to be reminded, or needs help in cleaning self, or has rare (weekly at most) accidents
3.	Soiling or wetting while asleep more than once a week
4.	Soiling or wetting while awake more than once a week
5.	No control of bowels or bladder

B. FEEDING	
1.	Eats without assistance
2.	Eats with minor assistance at meal time and/or with special preparation of food, or help in cleaning up after meals
3.	Feeds self with moderate assistance and is untidy
4.	Requires extensive assistance for all meals
5.	Does not feed self at all and resists efforts of others to feed him

C. DRESSING	
1.	Dresses, undresses and selects clothes from own wardrobe
2.	Dresses and undresses self, with minor assistance
3.	Needs moderate assistance in dressing or selection of clothes
4.	Needs major assistance in dressing, but cooperates with the efforts of others to help
5.	Completely unable to dress self and resists efforts of others to help

D. GROOMING (neatness, hair, etc.)	
1.	Always neatly dressed, well-groomed, without assistance
2.	Grooms self adequately with occasional minor assistance, e.g., shaving
3.	Needs moderate and regular assistance or supervision in grooming
4.	Needs total grooming care, but can remain well-groomed after help from others
5.	Actively negates all efforts of others to maintain grooming

E. PHYSICAL AMBULATION	
1.	Goes about grounds or city
2.	Ambulates within residence or about one block distant
3.	Ambulates with assistance of cane walker wheelchair and 1. gets in and out without help 2. needs help with getting in and out
4.	Sits unsupported in chair or wheelchair, but cannot propel self without help
5.	Bedridden more than half the time

F. BATHING	
1.	Bathes self (tub, shower, sponge bath) without help
2.	Bathes self with help in getting in and out of tub
3.	Washes face and hands only, but cannot bathe rest of body
4.	Does not wash self, but is cooperative with those who bathe him
5.	Does not wash self and resists efforts to keep him clean

Appendix D: Instrumental Activities of Daily Living Measure

Instrumental Activities of Daily Living Measure

The following questions are concerning how your mother/father/husband manages (his/her) daily life. Please indicate by filling in the number which best describes your relative's current ability (within the past two weeks) to perform these activities of daily living (without help, level of help required or not at all).

A. ABILITY TO USE TELEPHONE	
1.	Operates telephone on own initiative - looks up and dials numbers, etc.
2.	Dials a few well-known numbers
3.	Answers telephone, but does not dial
4.	Does not use telephone at all

B. SHOPPING	
1.	Takes care of all shopping needs independently
2.	Shops independently for small purchases
3.	Needs to be accompanied on any shopping trip
4.	Completely unable to shop

C. FOOD PREPARATION	
1.	Plans, prepares and serves adequate meals independently
2.	Prepares adequate meals if supplied with ingredients
3.	Heats, serves and prepares meals or prepares meals but does not maintain adequate diet
4.	Needs to have meals prepared and served

D. HOUSEKEEPING	
1.	Maintains house alone or with occasional assistance
2.	Performs light daily tasks such as dish washing, bed making
3.	Performs light daily tasks, but cannot maintain acceptable level of cleanliness
4.	Needs help with all home maintenance tasks
5.	Does not participate in any housekeeping tasks

E. LAUNDRY	
1.	Does personal laundry completely
2.	Launders small items, rinses stockings, etc.
3.	All laundry must be done by others

F. MODE OF TRANSPORTATION	
1.	Travels independently on public transportation or drives own car
2.	Arranges own travel via taxi, but does not otherwise use public transportation
3.	Travels on public transportation when accompanied by another
4.	Travel limited to taxi or automobile-with assistance of another
5.	Does not travel at all

G. RESPONSIBILITY FOR OWN MEDICATIONS	
1.	Is responsible for taking own medications in correct dosages at correct time
2.	Takes responsibility if medication is prepared in advance in separate dosage
3.	Is not capable of dispensing own medication

H. ABILITY TO HANDLE FINANCES	
1.	Manages financial matters independently (budgets, writes checks, pays rent, etc.), collects and keeps track of income
2.	Manages day-to-day purchases, but needs help with banking, major purchases, etc.
3.	Incapable of handling money

Philadelphia Geriatric Center

My rainbow token of the covenant between Me and you for perpetual generations

5301 Old York Road • Philadelphia, Pennsylvania 19141 • (215) 456-2900 • FAX: (215) 456-2940
Direct Dial:
(215)456-2000 FAX(215)456-2017

Chairman of the Board
Richard B Pearl
President
Bernard Liebowitz
Executive Vice President
Frank Podietz
Vice Chairmen
Arnold S Hoffman
Arnold H Kramer
Martin Kreiman
Shirley R Shils
Robert H Silver
Harry Stern
Treasurer
Martin Brat
Associate Treasurer
Leonard Cantor
Secretary
Marvin Levin
Associate Secretary
Madlyn Abramson
Past Chairmen
Harry A Robinson*
David H Soms
Les Vizan*
Charles Hoffman
William Schwartz
William Perlstein
*(deceased)
Honorary Vice Chairmen
Joseph Abramson
Harry Levin
Edward N Polsner
Honorary Secretary
Mrs Benjamin Prager, Jr
Vice President for
Medical Affairs
William N Kavesh MD

September 22, 1992

April D'Aloisio
Dalhousie University
Department of Psychology
Halifax, Nova Scotia
CANADA B3H 4J1

Dear Ms. D'Aloisio,

I'm glad to have you use the PSMS and IADL scales in any way you wish. I'm enclosing a couple of recent papers on these skills - you'll see that there are a few new data among them but some of the discussion may be useful.

We have a separate Clinical Psychology Department whose director is Deborah Frazer. I've sent your letter on to her and she will respond directly to you.

Sincerely,

Powell Lawton

M. Powell Lawton, Ph.D.
Director, Polisher Research Institute

MPL/ba
encl.

cc: Deborah Frazer, Ph.D.

Board of Directors: Madlyn Abramson, Evelyn Berger, J. Robert Benhas, Martin Brat, Howard Brown, Charles H. Byer, Leonard Cantor, Alan E. Casnoff Esq., Joseph J. Fenkel, Bernard Fishman, Robert Ford, William Frankel, Louis W. Fryman Esq., Morris Gocial, Lewis H. Gold Esq., Bennett Goldstein, Norris S. Harzenstein, Arnold S. Hoffman, Charles Hoffman, Ned J. Kaplin, William N. Kavesh MD, Barbara S. Klegar, Joseph C. Kohn Esq., Arnold H. Kramer, Martin Kreiman Esq., Michael H. Krekstein Esq., Seth J. Lehr, Marvin Levin, Bernard Liebowitz, Frederick D. Lipman Esq., Belle R. Loschultz, Joseph M. Manko Esq., Jerome B. Mucinick, Jack Parnetch, Richard B. Pearl Esq., William Perlstein, Frank Podietz, Bernard Roth, William Schwartz, Shirley R. Shils, Arthur Shoyer, Steven J. Sidewater, Robert H. Silver, David H. Soms, Harry Stern, Carol Summers, Edward Tann, Stanley C. Tuttleman, Gussie Vizan, Don Waldman, Leonard Wasserman, Harry Weiss, Sandra Weiss, David S. Zeitch

Appendix E: Behavioural Disturbance Measure

Behavioural Disturbance Measure

The following questions are concerning behaviours which your mother/father/husband may have demonstrated. Please indicate how often this problem has occurred during the past week by filling in a number from 0-4. Please respond to all statements.

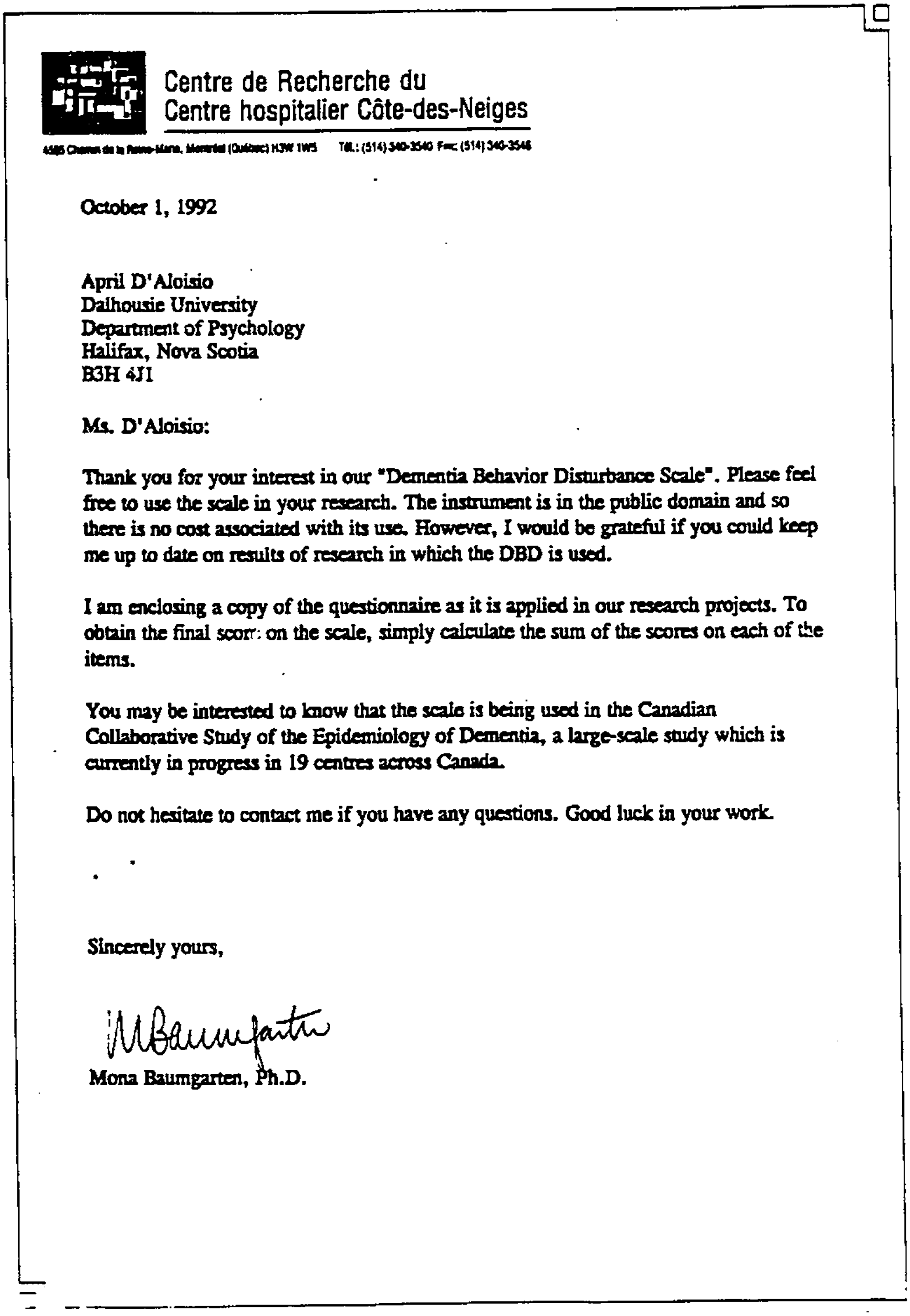
How often:

0	1	2	3	4
Never	Rarely	Sometimes	Frequently	All of the time

How often
0-4

1. ____ Mother/father/husband shows lack of interest in daily activities.
2. ____ Mother/father/husband makes unwarranted accusations.
3. ____ Mother/father/husband is verbally abusive, curses.
4. ____ Mother/father/husband empties drawers or closets.
5. ____ Mother/father/husband dresses inappropriately.
6. ____ Mother/father/husband exposes herself/himself indecently.
7. ____ Mother/father/husband screams for no reason.
8. ____ Mother/father/husband makes physical attacks (hits, bites, scratches, kicks).
9. ____ Mother/father/husband makes inappropriate sexual advances.
10. ____ Mother/father/husband paces up and down.
11. ____ Mother/father/husband moves arms and legs in a restless or agitated way.
12. ____ Mother/father/husband gets lost outside.
13. ____ Mother/father/husband is incontinent of urine (wets herself/himself).
14. ____ Mother/father/husband is incontinent of stool (soils herself/himself).
15. ____ Mother/father/husband wakes up at night for no obvious reason.
16. ____ Mother/father/husband wanders in the house at night.
17. ____ Mother/father/husband sleeps excessively during the day.
18. ____ Mother/father/husband overeats.
19. ____ Mother/father/husband refuses to eat.
20. ____ Mother/father/husband cries or laughs inappropriately.
21. ____ Mother/father/husband refuses to be helped with personal care tasks such as bathing, brushing teeth.
22. ____ Mother/father/husband throws food.

23.____ Mother/father/husband wanders aimlessly outside or in the house during the day.
24.____ Mother/father/husband hoards things for no obvious reason.
25.____ Mother/father/husband destroys property or clothing, breaks things.
26.____ Mother/father/husband loses, misplaces, or hides things.
27.____ Mother/father/husband asks the same question over and over again.
28.____ Mother/father/husband repeats the same action, (e.g., wiping table)over and over again.



Centre de Recherche du
Centre hospitalier Côte-des-Neiges

4565 Chemin de la Reine-Marie, Montréal (Québec) H3W 1W5 Tél.: (514) 340-3540 Fax: (514) 340-3546

October 1, 1992

April D'Aloisio
Dalhousie University
Department of Psychology
Halifax, Nova Scotia
B3H 4J1

Ms. D'Aloisio:

Thank you for your interest in our "Dementia Behavior Disturbance Scale". Please feel free to use the scale in your research. The instrument is in the public domain and so there is no cost associated with its use. However, I would be grateful if you could keep me up to date on results of research in which the DBD is used.

I am enclosing a copy of the questionnaire as it is applied in our research projects. To obtain the final score on the scale, simply calculate the sum of the scores on each of the items.

You may be interested to know that the scale is being used in the Canadian Collaborative Study of the Epidemiology of Dementia, a large-scale study which is currently in progress in 19 centres across Canada.

Do not hesitate to contact me if you have any questions. Good luck in your work.

Sincerely yours,

MBaumgarten

Mona Baumgarten, Ph.D.

Appendix F: Burden Measure

Burden Measure

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. Please read each statement and indicate how often you feel that way: Never, Rarely, Sometimes, Frequently, or Nearly Always. There are no right or wrong answers.

How often:

0	1	2	3	4
Never	Rarely	Sometimes	Frequently	Nearly always

How often
0-4

1. ____ Do you feel that your relative asks for more help than she/he needs?

2. ____ Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

3. ____ Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

4. ____ Do you feel embarrassed over your relative's behaviour?

5. ____ Do you feel angry when you are around your relative?

6. ____ Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

7. ____ Are you afraid of what the future holds for your relative?

8. ____ Do you feel your relative is dependent on you?

9. ____ Do you feel strained when you are around your relative?

10. ____ Do you feel your health has suffered because of your involvement with your relative?

11. ____ Do you feel that you don't have as much privacy as you would like, because of your relative?

12. ____ Do you feel that your social life has suffered because you are caring for your relative?

13. ____ Do you feel uncomfortable about having friends over because of your relative?

14.____ Do you feel that your relative seems to expect you to take care of her/him as if you were the only one she/he could depend on?

15.____ Do you feel that you don't have enough money to care for your relative in addition to the rest of your expenses?

16.____ Do you feel that you will be unable to take care of your relative much longer?

17.____ Do you feel you have lost control of your life since your relative's condition?

18.____ Do you wish you could just leave the care of your relative to someone else?

19.____ Do you feel uncertain about what to do about your relative?

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

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

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

0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely

PENNSTATE

(814) 865-1710

Gerontology Center
College of Health and Human Development

The Pennsylvania State University
210 Henderson Building South
University Park, PA 16802-6505

October 7, 1992

April D'Aloisio
Department of Psychology
Dalhousie University
Halifax, Nova Scotia
Canada B3H 4J1

Dear Ms. D'Aloisio:

You have permission to use the Burden Interview in your research. (The correct title of the instrument is "Burden Interview", not Zarit Burden Interview).

I have enclosed some recent papers for your interest. The book you inquired about, Caregiving Systems: Informal and Formal Helpers, is an edited volume of papers presented at a conference on caregiving held here a year ago. It will be published early next year by Erlbaum. You might also look for a paper on the consequences of institutionalization which should be appearing in the October Gerontologist. I do not have copies available to include right now.

As for your request about internship possibilities, there is not currently a clinical training program at Penn State with an emphasis on aging. There are still very few programs of that kind, and I am not sure what I could recommend to you.

Good luck with your research.

Sincerely,

Steven H Zarit

Steven H. Zarit, Ph.D.
Professor of Human Development

Appendix G: Anger Subscale of the Burden Measure

Anger Subscale of the Burden Measure

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. Please read each statement and indicate how often you feel that way: Never, Rarely, Sometimes, Frequently, or Nearly Always. There are no right or wrong answers.

How often:

0	1	2	3	4
Never	Rarely	Sometimes	Frequently	Nearly always

How often
0-4

1. ____ Do you feel that your relative asks for more help than she/he needs?

5. ____ Do you feel angry when you are around your relative?

6. ____ Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

9. ____ Do you feel strained when you are around your relative?

16.____ Do you feel that you will be unable to take care of your relative much longer?

18.____ Do you wish you could just leave the care of your relative to someone else?

19.____ Do you feel uncertain about what to do about your relative?

Appendix H: Global Physical/Emotional Stress Subscale of the Burden Measure

Global Physical/Emotional Stress Subscale of the Burden Measure

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. Please read each statement and indicate how often you feel that way: Never, Rarely, Sometimes, Frequently, or Nearly Always. There are no right or wrong answers.

How often:

0	1	2	3	4
Never	Rarely	Sometimes	Frequently	Nearly always

How often
0-4

3. ____ Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

7. ____ Are you afraid of what the future holds for your relative?

10.____ Do you feel your health has suffered because of your involvement with your relative?

15.____ Do you feel that you don't have enough money to care for your relative in addition to the rest of your expenses?

17.____ Do you feel you have lost control of your life since your relative's condition?

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

0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely

Appendix I: Patient Dependency Subscale of the Burden Measure

Patient Dependency Subscale of the Burden Measure

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. Please read each statement and indicate how often you feel that way: Never, Rarely, Sometimes, Frequently, or Nearly Always. There are no right or wrong answers.

How often:

0	1	2	3	4
Never	Rarely	Sometimes	Frequently	Nearly always

How often
0-4

8. ____ Do you feel your relative is dependent on you?

12.____ Do you feel that your social life has suffered because you are caring for your relative?

14.____ Do you feel that your relative seems to expect you to take care of her/him as if you were the only one she/he could depend on?

Appendix J: Social Discomfort Subscale of the Burden Measure

Social Discomfort Subscale of the Burden Measure

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. Please read each statement and indicate how often you feel that way: Never, Rarely, Sometimes, Frequently, or Nearly Always. There are no right or wrong answers.

How often:

0	1	2	3	4
Never	Rarely	Sometimes	Frequently	Nearly always

How often
0-4

4. ____ Do you feel embarrassed over your relative's behaviour?

13.____ Do you feel uncomfortable about having friends over because of your relative?

Appendix K: Lack of Privacy Subscale of the Burden Measure

Lack of Privacy Subscale of the Burden Measure

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. Please read each statement and indicate how often you feel that way: Never, Rarely, Sometimes, Frequently, or Nearly Always. There are no right or wrong answers.

How often:

0	1	2	3	4
Never	Rarely	Sometimes	Frequently	Nearly always

How often
0-4

2. ____ Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

11.____ Do you feel that you don't have as much privacy as you would like, because of your relative?

Appendix L: Guilt Subscale of the Burden Measure

Guilt Subscale of the Burden Measure

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. Please read each statement and indicate how often you feel that way: Never, Rarely, Sometimes, Frequently, or Nearly Always. There are no right or wrong answers.

How often:

0	1	2	3	4
Never	Rarely	Sometimes	Frequently	Nearly always

How often
0-4

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

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

Appendix M: Burnout Measure

Burnout Measure

The purpose of this questionnaire is to discover how various persons feel about their demands as caregivers. There are 22 statements of thoughts and feelings about caregiving. Please read each statement carefully and decide if you ever feel this way about caregiving. If you have never had this feeling, fill in 0 (zero). If you have had this feeling, indicate how often you feel it by filling in the number (from 1 to 6) that best describes how frequently you feel that way.

How Often:

0	1	2	3	4	5	6
Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Everyday

How Often
0 - 6 Statements:

1. ______ I feel emotionally drained from being a caregiver.
2. ______ I feel used up after a day of taking care of my mother/father/husband.
3. ______ I feel fatigued when I get up in the morning and have to face another day taking care of mother/father/husband.
4. ______ I can easily understand how my mother/father/husband feels about things.
5. ______ I feel I treat my mother/father/husband as if she/he were an impersonal object.
6. ______ Being with my mother/father/husband all day is really a strain for me.
7. ______ I deal very effectively with the problems of my mother/father/husband.
8. ______ I feel burned out from being a caregiver.
9. ______ I feel I'm positively influencing my mother/father/husband's life through my work as a caregiver.
10. ______ I've become more callous towards people since I became a caregiver.
11. ______ I worry that being a caregiver is hardening me emotionally.
12. ______ I feel very energetic .
13. ______ I feel frustrated by taking care of my mother/father/husband.
14. ______ I feel I'm working too hard at caregiving.
15. ______ I don't really care what happens to my mother/father/husband.
16. ______ Being with my mother/father/husband puts too much stress on me.
17. ______ I can easily create a relaxed atmosphere with my mother/father/husband.

18. ______ I feel exhilarated after spending quality time with my mother/father/husband.
19. ______ I have accomplished many worthwhile things as a caregiver.
20. ______ I feel like I'm at the end of my rope.
21. ______ As a caregiver, I deal with emotional problems very calmly.
22. ______ I feel my mother/father/husband blames me for some of her/his problems.

Psychometrics Canada Ltd.
Room 103, Students' Union Building
University of Alberta
Edmonton, Alberta T6G 2J7

Tel: (403) 433-6467
1-800-661-5158
Fax: (403) 432-1209

Please quote this invoice number on your remittance

Invoice No.: 009205
Customer No.: 803776

Bill To:
Dalhousie University

Psychology Department
Halifax, NS B3H 1S4

Ship To:
Dalhousie University
Attn: April Daloisio
Psychology Department
Halifax, NS B3H 1S4

Date	GST Registration Number	Terms
09/22/92	104341714	Net 15 days

P.O Number	Sales Person	Ship Via
164905	KIM	Ground Mail

Ordered	Shipped	B.O	Item Number	Description	Unit Price	Extended Price
1	1	0	3450	Maslach Specimen Set	27.00	$27.00

COMMENTS:

Order Total	$27.00
Misc.Charges	$.00
Freight	$3.00
GST	$2.10
Amount Due	$32.10
Amount Paid	$.00
Balance Due	$32.10

Terms: net 15days, 2% per month on outstanding balance

Appendix N: Depression Measure

Depression Measure

On this questionnaire are groups of statements. Please read each group of statements carefully.
Then pick out the one statement in each group which best describes the way you have been feeling the **past week, including today**! Circle the number beside the statement you picked.
If several statements in the group seem to apply equally well, circle each one. Be sure to read all the statements in each group before making your choice.

1.
0 I do not feel sad.
1 I feel sad.
2 I am sad all the time and I can't snap out of it.
3 I am so sad or unhappy that I can't stand it.

2.
0 I am not particularly discouraged about the future.
1 I feel discouraged about the future.
2 I feel I have nothing to look forward to.
3 I feel that the future is hopeless and that things cannot improve.

3.
0 I do not feel like a failure.
1 I feel I have failed more than the average person.
2 As I look back on my life, all I see is a lot of failures.
3 I feel I am a complete failure as a person.

4.
0 I get as much satisfaction out of things as I used to.
1 I don't enjoy things the way I used to.
2 I don't get real satisfaction out of anything anymore.
3 I am dissatisfied or bored with everything.

5.
0 I don't feel particularly guilty.
1 I feel guilty a good part of the time.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.

6.
0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.

7.
0 I don't feel disappointed in myself.

1 I am disappointed in myself.
2 I am disgusted with myself.
3 I hate myself.

8.
0 I don't feel I am any worse than anybody else.
1 I am critical of myself for my weaknesses or mistakes.
2 I blame myself all the time for my faults.
3 I blame myself for everything bad that happens.

9.
0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

10.
0 I don't cry any more than usual.
1 I cry more now than I used to.
2 I cry all the time now.
3 I used to be able to cry, but now I can't cry even though I want to.

11.
0 I am no more irritated now than I ever am.
1 I get annoyed or irritated more easily than I used to.
2 I feel irritated all the time now.
3 I don't get irritated at all by the things that used to irritate me.

12.
0 I have not lost interest in other people.
1 I am less interested in other people than I used to be.
2 I have lost most of my interest in other people.
3 I have lost all of my interest in other people.

13.
0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty in making decisions than before.
3 I can't make decisions at all anymore.

14.
0 I don't feel I look any worse than I used to.
1 I am worried that I am looking old or unattractive.
2 I feel that there are permanent changes in my appearance that make me look unattractive.
3 I believe that I look ugly.

15\.
0 I can work about as well as before.
1 It takes extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all.

16\.
0 I can sleep as well as usual.
1 I don't sleep as well as I used to.
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
3 I wake up several hours earlier than I used to and cannot get back to sleep.

17\.
0 I don't get more tired than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.
3 I am too tired to do anything.

18\.
0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now.
3 I have no appetite at all anymore.

19\.
0 I haven't lost much weight, if any, lately.
1 I have lost more than 5 pounds.
2 I have lost more than 10 pounds.
3 I have lost more than 15 pounds.

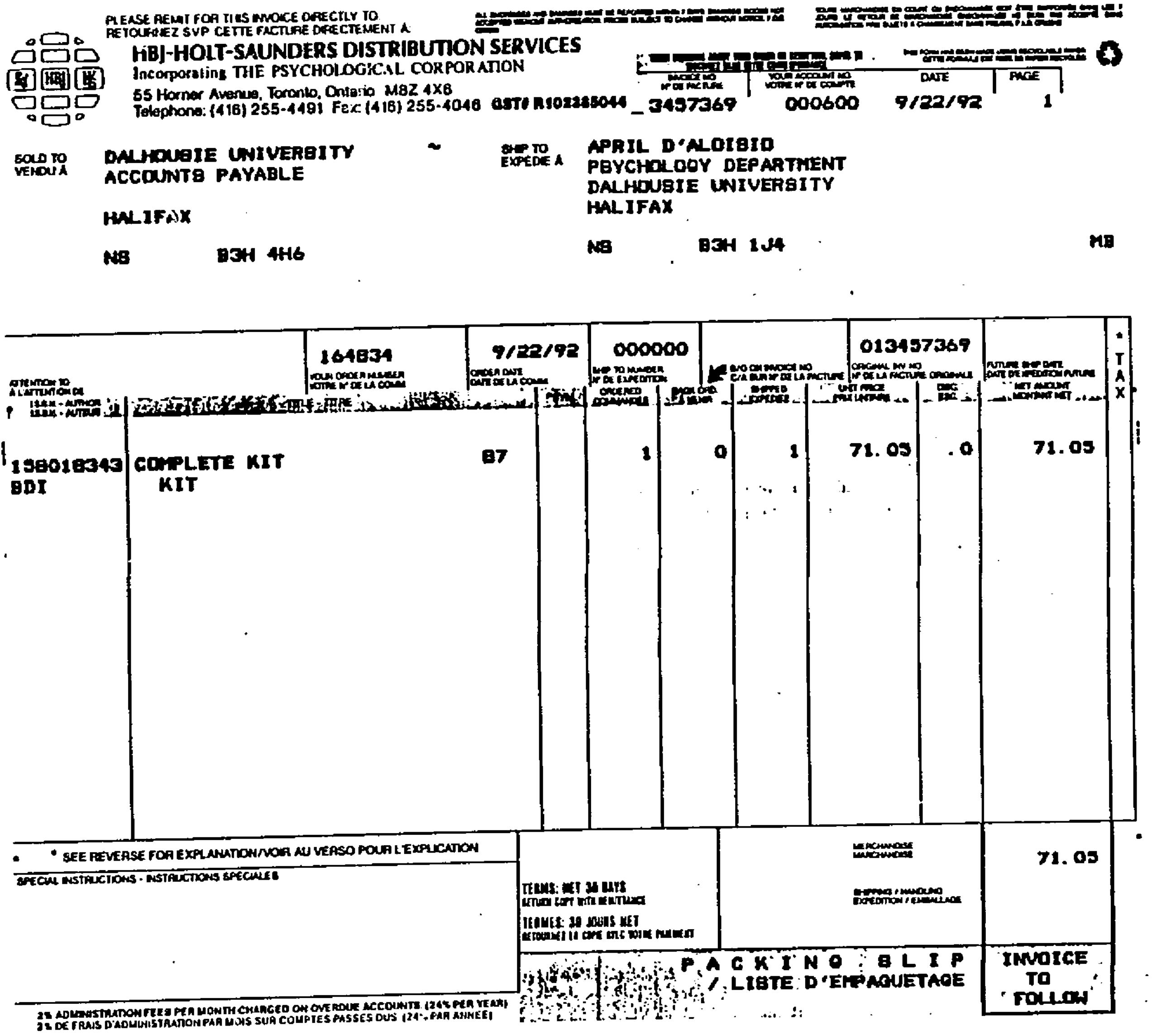
I am purposely trying to lose weight by eating less.
Yes____ No____

20.

0 I am no more worried about my health than usual.
1 I am worried about physical problems such as aches and pains; or upset stomach or constipation.
2 I am very worried about physical problems and it's hard to think of much else.
3 I am so worried about my physical problems that I cannot think about anything else.

21.

0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.



PLEASE REMIT FOR THIS INVOICE DIRECTLY TO
RETOURNEZ SVP CETTE FACTURE DIRECTEMENT A

HBJ-HOLT-SAUNDERS DISTRIBUTION SERVICES
Incorporating THE PSYCHOLOGICAL CORPORATION
55 Horner Avenue, Toronto, Ontario M8Z 4X6
Telephone: (416) 255-4491 Fax (416) 255-4046 GST# R102285044

INVOICE NO Nº DE FACTURE	YOUR ACCOUNT NO. VOTRE Nº DE COMPTE	DATE	PAGE
3437369	000600	9/22/92	1

SOLD TO
VENDU A

DALHOUSIE UNIVERSITY
ACCOUNTS PAYABLE

HALIFAX

NS B3H 4H6

SHIP TO
EXPEDIE A

APRIL D'ALOISIO
PSYCHOLOGY DEPARTMENT
DALHOUSIE UNIVERSITY
HALIFAX

NS B3H 1J4

MB

YOUR ORDER NUMBER VOTRE Nº DE LA COMM	ORDER DATE DATE DE LA COMM	SHIP TO NUMBER Nº DE EXPEDITION	B/O ON INVOICE NO C/A SUR Nº DE LA FACTURE	ORIGINAL INV NO Nº DE LA FACTURE ORIGINALE	FUTURE SHIP DATE DATE DE EXPEDITION FUTURE
164834	9/22/92	000000		013457369	

ATTENTION TO / A L'ATTENTION DE ISBN - AUTHOR ISBN - AUTEUR	TITLE - TITRE			ORDERED COMMANDES	BACK ORD.	SHIPPED EXPEDIES	UNIT PRICE PRIX UNITAIRE	DISC ESC	NET AMOUNT MONTANT NET	* TAX
158018343 BDI	COMPLETE KIT KIT	87		1	0	1	71.05	.0	71.05	

* SEE REVERSE FOR EXPLANATION/VOIR AU VERSO POUR L'EXPLICATION

SPECIAL INSTRUCTIONS - INSTRUCTIONS SPECIALES

TERMS: NET 30 DAYS
RETURN COPY WITH REMITTANCE
TERMES: 30 JOURS NET
RETOURNEZ LA COPIE AVEC VOTRE PAIEMENT

MERCHANDISE MARCHANDISE	71.05
SHIPPING / HANDLING EXPEDITION / EMBALLAGE	

PACKING SLIP / LISTE D'EMPAQUETAGE

INVOICE TO FOLLOW

2% ADMINISTRATION FEES PER MONTH CHARGED ON OVERDUE ACCOUNTS (24% PER YEAR)
2% DE FRAIS D'ADMINISTRATION PAR MOIS SUR COMPTES PASSES DUS (24% PAR ANNEE)

Appendix O: Desire to Institutionalize Measure

Desire to Institutionalize Measure

These next questions are about placement in institutions for long-term care.

1. In the last year have you ever thought about placing your mother/father/husband in a nursing home or other institution? Have you thought about it:
    1 very seriously
    2 somewhat seriously
    3 haven't thought seriously about it
    4 haven't thought about this at all

2. In the last year, have you discussed it with anyone? Yes No

3. Have you called a nursing home or institution? Yes No

4. Have you visited a nursing home or institution? Yes No

5. Have you taken your mother/father/husband to visit a nursing home or institution? Yes No

6. Have you applied for placement? Yes No

Dalhousie University

Department of Psychology
Halifax, Nova Scotia
Canada B3H 4J1

(902) 494-3417
FAX: (902) 494-6585

September 14,1992.

Dr. Gonyea
Boston University School of Social Work,
264 Bay State Rd. Boston, MA
02215.

Dear Dr. Gonyea,

I am writing to request permission to use your questionnaire on the Stages of Institutional Decision-making in my research on the "Emotional Correlates of the Desire to Institutionalize in Caregivers to Dementia Patients". It is necessary for me to obtain written permission in order to include this measure in my Ph.D. thesis. I would also be interested in hearing about and/or receiving reprints of your latest work. I look forward to your reply. Thank-you.

Sincerely,

April D'Aloisio

Permission granted
Best wishes
Judith G Gonyea
9-29-92

Appendix P: Social Desirability Measure

Social Desirability Measure

Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is true or false as it pertains to you personally.

1. Before voting I thoroughly investigate the qualifications of all the candidates. T F
2. I never hesitate to go out of my way to help someone in trouble. T F
3. It is sometimes hard for me to go on with my work if I am not encouraged. T F
4. I have never intensely disliked anyone. T F
5. On occasion I have had doubts about my ability to succeed in life. T F
6. I sometimes feel resentful when I don't get my way. T F
7. I am always careful about my manner of dress. T F
8. My table manners at home are as good as when I eat out in a restaurant. T F
9. If I could get into a movie without paying and be sure I was not seen, I would probably do it. T F
10. On a few occasions, I have given up doing something because I thought too little of my ability. T F
11. I like gossip at times. T F
12. There have been times when I felt like rebelling against people in authority even though I knew they were right. T F
13. No matter who I'm talking to, I'm always a good listener. T F
14. I can remember "playing sick" to get out of something. T F
15. There have been occasions when I took advantage of someone. T F
16. I'm always willing to admit it when I make a mistake. T F
17. I always try to practice what I preach. T F
18. I don't find it particularly difficult to get along with loud mouthed, obnoxious people. T F

19. I sometimes try to get even, rather than forgive and forget. T F

20. When I don't know something I don't at all mind admitting it. T F

21. I am always courteous, even to people who are disagreeable. T F

22. At times I have really insisted on having things my own way. T F

23. There have been occasions when I felt like smashing things. T F

24. I would never think of letting someone else be punished for my wrongdoings. T F

25. I never resent being asked to return a favour. T F

26. I have never been irked when people expressed ideas very different from my own. T F

27. I never make a long trip without checking the safety of my car. T F

28. There have been times when I was quite jealous of the good fortune of others. T F

29. I have almost never felt the urge to tell someone off. T F

30. I am sometimes irritated by people who ask favours of me. T F

31. I have never felt that I was punished without cause. T F

32. I sometimes think when people have a misfortune they only got what they deserved. T F

33. I have never deliberately said something that hurt someone's feelings. T F

Appendix Q: Letter of Introduction

Letter of Introduction

Dear :

Recently I saw your ___*(father, mother, husband)*___ in my clinic. As you know, I made a diagnosis of ____________ and we discussed some aspects of this disease. As we discussed at that time, an important part of our care for your *(father, mother, husband)*___ is to make sure that you too remain healthy. We discussed briefly your experience in giving care.

The matter of caregiving for patients with these diseases is currently an active area of research across North America and is also being investigated at Dalhousie University. A Ph.D. student in clinical psychology, April D'Aloisio, is in fact doing her Ph.D. thesis on the experience of caregiving. She has worked with many of our patients in the past, in particular the elderly and caregivers to the elderly, as part of her training in clinical psychology. I am writing to ask if you would consider participating in her study.

If you agree, you may contact me at 496-2687. April will then contact you and, at a time convenient to you, come to your home, or meet in some other convenient locale, to discuss your experience with caregiving. This will be in the form of a structured interview which takes approximately 1 1/2 hours to complete.

We support April's work and look forward to the results. You are, however, under no obligation to participate, and of course if you choose not to participate, this will in no way affect the sort of care which you can expect to receive. If you do choose to participate, then you can be assured that the results will be strictly confidential and indeed the results of your participation will be known only to April. We are hoping that 100 people will choose to take part in this project. The information from this survey will be reported for the group and will not be reported in any way that can allow identification of an individual.

I am grateful to you for your consideration of this request.

Yours sincerely,

Kenneth Rockwood, MD, FRCPC
Division of Geriatric Medicine

Appendix R: Informed Consent Form

Informed Consent Form

/Subject's Name:______________________ Id.#_____

Investigators: April D'Aloisio and Dr. Mick Sullivan.

Project title: The Emotional Consequences of Caregiving

Introduction: You are invited to take part in a research study at Camp Hill Medical Centre. It is important that you read and understand several general principles that apply to all who take part in our studies:

(1) Taking part in the study is entirely voluntary. Your decision on participation in this study will not affect the quality of care provided to you or your relative for whom you provide care.

(2) Personal benefit may not result from taking part in the study, but knowledge may be gained that may benefit others.

(3) You may withdraw from the study at any time without penalty or loss of any benefits to which you are otherwise entitled.

The nature, risks, inconveniences, discomforts, and other relevant information about the study are discussed below. You are urged to discuss any questions you may have about this study with the investigators.

Purpose of Study:

Caregiving may put many demands on the caregivers. There is a need to know how these demands affect caregivers emotionally. Additionally, it is also important to understand whether the emotional experience of caregivers influences their decision to place their elderly relative in a nursing home. The purpose of this study is to assess your caregiving demands, your feelings and your thoughts and actions about placing your relative.

Conditions of involvement and Procedures

April D'Aloisio will be meeting you in your home or other convenient locale for one session, lasting approximately 1 1/2 hours. At this time you will be asked to fill out a number of questionnaires which pertain to a variety of issues related to caregiving. You will be asked questions about your relative's health and behaviour, how you have dealt with and reacted to your caregiving situation and your thoughts and feelings about institutionalization.

Risks and Discomforts:

We do not expect there to be any risks associated with this study, however, some participants may find the issues addressed in the questionnaires distressing.

You may not derive any benefit by participating in this study. However, the knowledge uncovered by the study may help others.

The Emotional Consequences of Caregiving

Other Relevant Information:

(1) Confidentiality: When the results of a study such as this are reported in medical and psychological journals at meetings, the identification of those taking part is withheld. All questionnaires will be kept in a locked file in the Clinical Psychology Department at Dalhousie University.

(2) Problems and Questions: Should any problems or questions arise in regards to the study and your rights as a participant in clinical research, you may contact April D'Aloisio (494-5178) or Dr. Mick Sullivan (494-5177), Clinical Psychology Department, Dalhousie University.

(3) Stopping the Study: You can decide to end your participation in the study at anytime, without influencing your care or your relative's care at the Camp Hill Medical Centre.

Complete Item Below

I have read and understand the explanation about this study and have been given the opportunity to discuss it and ask questions. I hereby freely and voluntarily consent to take part in this research study. I will be given a copy of the consent form.

Signature of Participant Date

Signature of Investigator Date

Appendix S: Correlation Coefficents

Appendix S: Pearson correlation coefficients among main variables and subscales.

Subscales	ZBI	ZAN	ZSTR	ZPRI	ZDEP	ZSOC	ZGUI
ZBI		.80**	.91**	.77**	.67**	.52**	.52**
ZAN			.64**	.52**	.43**	.47**	.39**
ZSTR				.69**	.55**	.42	.48**
ZPRI					.56**	.21	.23*
ZDEP						.16	.22
ZSOC							.15
EE	.77**	.63**	.69**	.68**	.44**	.36**	.20
DEP	.46**	.62**	.37**	.24*	.20	.46**	.13
LPA	.33**	.34**	.29*	.18	.06	.25*	.08
BDI	.55**	.44**	.57**	.25*	.26*	.37**	.23*
DI	.38**	.19	.28*	.32*	.28*	.16	.07

Zarit Burden Inventory (ZBI)
- Zarit Anger Subscale (ZAN)
- Zarit Physical/Emotional Stress (ZSTR)
- Zarit Lack of Privacy (ZPRI)
- Zarit Patient Dependency (ZDEP)
- Zarit Social Discomfort (ZSOC)
- Zarit Guilt (ZGUI)

Burnout
- Emotional Exhaustion (EE)
- Depersonalization (DEP)
- Lack of Personal Accomplishment (LPA)

Beck Depression Inventory (BDI)

Desire to Institutionalize (DI)

References

Abramson, L. Y., Seligman, M. E. P., & Teasdale, J. D. (1978). Learned helplessness in humans: Critique and reformulation. *Journal of Abnormal Psychology, 87*, 49-74.

Adams, R. C., Fisher, C. M., Hakim, S., Ojemann, R. G., & Sweet, W. H. (1965). Symptomatic accult hydrocephalus with "normal" cerebrospinal-fluid pressure. *New England Journal of Medicine, 273*, 117-126.

Abel, E. K. (1986). Adult daughters and care for the elderly. *Feminist Studies, 12*, 479-497.

Ajzen, I., & Fishbein, M. (1980). *Understanding Attitudes and Predicting Social Behaviour.* New Jersey: Englewood Cliffs.

Allen, S. M. (1994). Gender differences in spousal caregiving and unmet need for care. *Journal of Gerontology, 49*, 187-195.

American Psychiatric Association. (1987). *Diognostic and statistical manual of mental disorders (Third Edition, Revised).* Washington, D.C.: Author

Anthony, J. C., LeResche, L., Niaz, U., VonKorff, M. R., & Folstein, M.F. (1982). Limits of the 'Mini-Mental State' as a screening test for dementia and delirium among hospital patients. *Psychological Medicine, 12*, 397-408.

Argyle, N., Jestice, S., & Brook, C. R. B. (1985). Psychogeriatric patients: Their supporter's problems. *Age and Ageing, 14*, 355.

Barney, J. L. (1977). The prerogative of choice in long-term care. *The Gerontologist, 17*, 309-314.

Bartus, R. T., Dean, R. L., & Beer, B. (1982). The cholinergic hypothesis of geriatric memory dysfunction. *Science, 217*, 408.

Baumgarten, M., Becker, R., & Gauthier, S. (1990). Validity and reliability of the Dementia Behaviour Disturbance Scale. *Journal of the American Geriatric Society*, 38, 221-236.

Beck, A. T., Rush, A. J., Shaw, B. F., & Emery, G. (1979). *Cognitive therapy of depression*. New York: Guilford Press.

Beck, A. T., Steer, R. A., & Garbin, M. G. (1988). Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation. *Clinical Psychology Review, 8*, 77-100.

Beck, A. T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry, 4*, 561-571.

Belcastro, P. A. (1982). Burnout and its relationships to teachers' somatic complaints and illness. *Psychological Reports, 50,* 1045-1046.

Belcastro, P. A., & Gold, R. S. (1983). Teacher stress and burnout: Implications for school health personnel. *Journal of School Health, 53,* 404-407.

Belcastro, P. A., & Hays, L. C. (1984). Ergophilla...ergophobia...ergo...burnout? *Professional Psychology: Research and Practice, 15,* 260-270.

Bergmann, K., Foster, E. M., Justice, A. W., & Matthews, V. (1978). Management of the demented elderly patient in the community. *British Journal of Psychiatry, 132,* 44-49.

Bland, R. C., Newman, S.C., & Orn, H. (1988). Prevalence of psychiatric disorder in the elderly in Edmonton. *Acta Psychiatrica Scandinavica, 338,* 57-63.

Blazer, D., Hughes, D. C., & George, L. K. (1987). The epidemiology of depression in an elderly community population. *The Gerontologist, 27,* 281-287.

Blazer, D., & Williams, C. D. (1980). Epidemiology of dysphoria and depression in an elderly population. *American Journal of Psychiatry, 137,* 439-444.

Block, A. S. (1990). More remarks on social desirability. *American Psychologist, 45, 1076-1077.*

Boller, F., Mizutani, T., Roessmann, U., & Gambetti, P. (1980). Parkinson Disease, and Alzheimer Disease: Clinicopathological Correlations. *Annals of Neurology, 7,* 329-335.

Bourque, P., Blanchard, L., & Vézina, J. (1990). Étude psychométrique de l'Échelle de dépression gériatrique. *Revue Canadienne de Vieillissement, 9,* 348-355.

Boyd, J. H., & Weissman, M. M. (1981). Epidemiology of affective disorders: A reexamination and future directions. *Archives of General Psychiatry, 38,* 1039-1046.

Bradley, H. B. (1969). Community-based treatment for young adult offenders. *Crime and Delinquency, 15,* 359-370.

Branch, G., & Jette, A. M. (1982). A prospective study of long-term care institutionalization among the aged. *American Journal of Public Health, 12,* 1373-1379.

Brill, P. L. (1984). The need for an operational definition of burnout. *Family and Community Health, 6,* 12-24

Brody, E. (1966). The aging family. *The Gerontologist, 6,* 201-206.

Brody, S. J., Poulshock, S. W., & Masciocchi, C. F. (1978). The family caregiving unit: A major consideration in the long-term support system. *The Gerontologist, 18,* 556-561.

Brown, B. S., Potter, J. F., & Foster, B. G. (1990). Caregiver burden should be evaluated during geriatric assessment. *Journal of the American Geriatrics Society, 38,* 455-460.

Burke, R. J., Shearer, J., & Deszca, G. (1984). Burnout among men and women in police work: An examination of the Cherniss model. *Journal of Health and Human Resources Administration, 7,* 162-188.

Burns, A., Jacoby, R., Luthert, P., & Levy, R. (1990). Cause of death in Alzheimer's disease. *Age and Ageing, 19,* 341 -344.

Caird, W. K., & Inglis, J. (1961). The short-term storage of auditory and visual two-channel digits by elderly patients with memory disorder. *Journal of Mental Science, 107,* 1062-1069.

Canadian Medical Association. (1987). *Health care for the elderly: Today's challenges, tomorrow's options.* Ottawa: Canadian Medical Association.

Canadian Study of Health and Aging. (1994). Study methods and prevelance of dementia. *Canadian Medical Association Journal, 150,* 899-913.

Cantor, M. H. (1983). Strain among caregivers: A study of experience in the United States. *The Gerontologist, 23, 597-604.*

Cappeliez, P. (1989). Social desirability response set and self-report depression inventories in the elderly. *Clinical Gerontologist, 9,* 45-52.

Cappeliez, P. (1993). Depression in elderly persons: Prevalence, predictors, and psychological intervention. In P. Cappeliez & R. J. Flynn (Eds.), *Depression and the Social Enviroment.* Montreal & Kingston: McGill-Queen's University Press.

Chappell, N. (1989). *Formal programs for informal caregivers of the elderly or supporting elder care.* Prepared for the Policy, Communications and Information Branch, Health and Welfare Canada, Ottawa.

Chappell, N. (1991). Living arrangement and sources of caregiving. *Journal of Gerontology, 46,* 1-8.

Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. *The Gerontologist, 26,* 267-272.

Cherniss, C. (1980). *Staff Burnout. Job Stress in the Human Service Organizations.* New York: Praeger.

Chui, C. H., Teng, E. L., Henderson, V. W., & Moy, A. C. (1985). Clinical subtypes of dementia of the Alzheimer type. *Neurology, 35,* 1544-1550.

Cicirelli, V. G. (1989). Helping relationships in later life: A reexamination. In J. A. Mancini (Ed.), *Aging Parents and Adult Children.* Lexington, MA: Lexington Books.

Cohen, D., & Eisdorfer, C. (1988). Depression in family members caring for a relative with Alzheimer's disease. *Journal of the American Geriatrics Society, 36,* 885-889.

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences. 2nd ed.* Hillsdale, NJ: Lawrence Erlbaum Associates.

Cohen, M. A., Tell, E. J., & Wallack, S. S. (1986). Client related risk factors of nursing home entry among elderly adults. *Journal of Gerontology, 41,* 785-792.

Cohen, M. A., Tell, E. J., & Wallack, S. S. (1988). The risk factors of nursing home entry among residents of six continuing care retirement communities. *Journal of Gerontology, 43,* 15-21.

Colerick, E. J., & George, L. K. (1986). Predictors of institutionalization among caregivers of patients with Alzheimer's disease. *Journal of the American Geriatrics Society, 34,* 493-498.

Copple, D. B., Burton, C., Becker, J., & Fiore, J. (1985). The relationship of cognitions associated with coping reactions to depression in spousal caregivers of Alzheimer's disease patients. *Cognitive Therapy and Research, 9,* 253-266.

Coyne, J. C., & Fiske, V. (1992). Couples coping with chronic and catastrophic illness. In T. J. Akamatsu, M. A. P. Stevens, S. E. Hobfoll, & J. H. Crowther (Eds.), *Family Health Psychology.* Ohio: Hemisphere Publishing.

Crowne, D., & Marlowe, D. (1960). A new scale of social desirability independent of psychopathology. *Journal of Consulting Psychology, 24,* 349-354.

Cummings, J. L., & Benson, D. F., (1992). *Dementia A Clinical Approach (2nd Ed.).* Boston: Butterworth-Heinemann.

Deimling, G. T., & Poulshock, S. W. (1985). The transition from family in-home care to institutional care: Focus on health and attitudinal issues as predisposing factors. *Research on Aging, 7,* 563-576.

Delongis, A., & O'Brien, T. (1990). An interpersonal framework for stress and coping: An application to the families of Alzheimer's patients. In M. A. P. Stevens, J. H. Crowther, S. E. Hobfoll, & D. L. Tennenbaum (Eds.), *Stress and Coping in Later-life Families* (pp. 267-285). New York: Hemisphere Publishing.

Dohrenwend, B. S., Dohrenwend, B. P., Dodson, M., & Shrout, P. E. (1984). Symptoms, hassels, social support, and life events: Problem of confounded measures. *Journal of Abnormal Psychology, 93,* 222-230.

Dolinsky, A. L., & Rosenwaike I. (1988). The role of demographic factors in the institutionalization of the elderly. *Research on Aging, 10,* 235-257.

Doty, P., Liu, K., & Weiner, Y. (1985). An overview of long term care. *Health Care Financing Review, 6,* 69-78.

Drinka, T. J., Smith, J., & Drinka, P. J. (1987). Correlates of depression and burden for informal caregivers of patients in a geriatric referral clinic. *Journal of the American Geriatrics Society, 35,* 522-525.

Dura, J. R., Haywood-Niler, E., & Kiecolt-Glaser, J. K. (1990). Spousal caregivers of persons with Alzheimer's and Parkinson's disease dementia: A preliminary comparison. *The Gerontologist, 30,* 332-339.

Dura, J. R., Stukenberg, K. W., & Kiecolt-Glaser, J. K. (1990). Chronic stress and depressive disorders in older adults. *Journal of Abnormal Psychology, 99,* 284-90.

Edwards, A. (1990). Construct validity and social desirability. *American Psychologist, 45,* 287-289.

Eisdorfer, C., Cohen, D., Paveza, G. J., Ashford , J. W., Luchins, D. J., Gorelick, P. B., Hirschman, R. S., Freels, S. A., Levy, P. S., Semla, T. P., & Shaw, H. A. (1992). An empirical evaluation of the Global Deterioration Scale for staging Alzheimer's Disease. *American Journal of Psychiatry, 149,* 190-194.

Emery, V. O. B., & Oxman, T. E. (Eds.) (1994). *Dementia Presentations, Differential Diagnosis, and Nosology*. London: John Hopkins Press.

Endicott, J., & Spitzer, R.L. (1978). A diagnostic interview: The Schedule for Affective Disorders and Schizophrenia. *Archives of General Psychiatry, 35,* 837-844.

Enzmann, D., & Kleiber, D. (1990). Construct validity and work related factors in burnout. Paper presented at the E.N.O.P. conference 'Professsional burnout: Developments in theory and research'. Sept. 24-27, Krakow, Poland.

Erkinjuntti, T., Hachinski, V. C., & Sulkava, R. (1994). Alzheimer disease and vascular dementia Differential diagnosis. In V. O. B., Emery, & Oxman, T. E. (Eds.), *Dementia Presentations, Differential Diagnosis, and Nosology* (pp. 108-122). London: John Hopkins Press.

Evans, B. K., & Fischer, D. (1989). The dimensionality and discriminant validity of the Maslach Burnout Inventory. Paper presented at Canadian Psychology Conference, Halifax.

Farthingham, J., Skelton, M., & Hoddinott, B. (1972). The effects on the families of the presence of a mentally retarded child. *Canadian Psychiatric Association Journal, 17,* 283-289.

Ferris, C., Crook, T., Sathananthan, G., & Gershon, S. (1986). Reaction time as a diagnostic measure of cognitive impairment in senility. *Journal of the American Geriatrics Society, 24,* 529-533.

Fiore, J., Becker, J., & Copple, D. B. (1983). Social network interactions: A buffer or a stress? *American Journal of Community Psychology, 11,* 423-439.

Firth, H., McKeown, P., McIntee, J., & Britton, P. (1987). Professional depression, 'burnout', and personality in longstay nurses. *International Journal of Nursing Studies, 24,* 227-237.

Fishbein, M., & Ajzen, I. (1975). *Belief, Attitude, Intention, and Behaviour: An Introduction to Theory and Research.* Reading, Mass.: Addison- Wesley.

Flicker, C., Ferris, S. H., & Reisberg, B. (1993). A two year longitudinal study of cognitive function in normal aging and Alzheimer's disease. *Journal of Geriatric Psychiatry and Neurology, 6,* 84-96.

Folstein, M. F., Folstein, S., & McHugh, P. (1975). Mini-Mental State. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12,* 189-198.

Forbes, W. F., Jackson, J. A., & Kraus, A. S. (1987). *Institutionalization of the Elderly in Canada.* Toronto, Canada: Butterworths.

Ford, A. B., Roy, A. W., Haug, M. R., Folmar, S. J., & Jones, P. K. (1991). Impaired and disabled elderly in the community. *American Journal of Public Health, 81.* 1207-1209.

Förstl, H., Burns, A., Luthert, P., Cairns, N., & Levy, R. (1993). The Lewy-Body variant of Alzheimer's disease. *British Journal of Psychiatry, 162,* 385-392.

Freudenberger, H. J. (1974). Staff burn-out. *Journal of Social Issues, 30,* 159-165.

Gallagher, D., Rose, J., Rivera, P., Lovett, S., & Thompson, L. W. (1989a). Prevalence of depression in family caregivers. *The Gerontologist, 29,* 449-56.

Gallagher, D., Wrabetz, A., Lovett, S., Del Maestro, S., & Rose, J. (1989b). Depression and other negative affects in family caregivers. In E. Light, & B.D. Lebowitz, *Alzheimer's disease treatment and family stress: Directions for research* (pp.458-486). Rockville, MD: National Institute of Mental Health.

George, L. K., & Gwyther, L. P. (1986). Care-giver well being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, *26*, 253-259.

Gilford, D. M. (Ed.). (1988). *The aging population in the twenty-first century*. Washington, DC: National Academy Press.

Glazebrook, K., Rockwood, K., Stolee, P., Fisk, J., & Gray, J. M. (1994). A case control study of the risks for institutionalization of elderly people in Nova Scotia. *Canadian Journal on Aging, 13*, 104-117.

Golembiewski, R. T., & Scicchitano, M. (1983). Testing for demographic demographic covariants: Three sources of data rejecting robust and regular association. *International Journal of Public Administration, 6*, 290-323.

Gonyea, J. G. (1987). The family and dependency: Factors associated with institutional decision-making. *Journal of Gerontological Social Work*, 10, 61-77.

Green, V. L., & Monaghan, D. J. (1987). The effect of a professionally guided caregiver support and education group on institutionalization of care receivers. *The Gerontologist*, *27*, 716-721.

Greenberg, J. N., & Ginn A. (1979). A multivariate analysis of the predictors of long-term care placement. *Home Health Care Services Quarterly, 64*, 34-75.

Greene, J. G., Smith, R., Gardiner, M., & Timbury, G. C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: A factor analytic study. *Age and Ageing, 11*, 121-126.

Greene, V. L., & Ondrich, J. I. (1990). Risk factors for nursing home admissions and exits: A discrete-time hazard function approach. *Journal of Gerontology, 45*, 250-258.

Haack, M. R. (1988). Stress and impairment among nursing students. *Research in Nursing and Health*, *11*, 125-134.

Haaga, D. A. F. (1992). Catastrophizing, confounds, and depression: A comment on Sullivan and D'Eon. *Journal of Abnormal Psychology, 101*, 206-207.

Hachinski, V. C. (1983). Differential diagnosis of Alzheimer's dementia: Multi-infarct dementia. In B. Reisberg (Ed.), *Alzheimer's disease: The standard reference* (pp. 188-192), New York: Free Press/Macmillan.

Hachinski, V. C., Lassen, N. A., & Marshall, J. (1974). Multi-infarct dementia: A cause of mental deterioration in the elderly. *Lancet, ii*, 207-209.

Haley, W.E., Levine, E.G., Brown, S.L., & Bartolucci, A.A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2*, 323-330.

Haley, W. E., Levine, E. G., Brown, S. L., Berry, J. W., & Hughes, G. H. (1987). Psychological, social, and health consequences of caring for a relative with senile dementia. *Journal of the American Geriatrics Society, 35*, 405-411.

Haley, W. E., & Pardo, K. M. (1989). Relationship of severity of dementia to caregiving stressors. *Psychology and Aging, 4*, 389-393.

Hamel, M., Gold, D. P., Andres, D., Reis, M. Dastoor, D., Grauer, H., & Bergman, H. (1990). Predictors and consequences of aggressive behaviour by community-based dementia patients. *The Gerontologist, 30*, 206-211.

Hanley, R. J., Alecxih, L. M. B., Wiener, J. M., & Kennell (1990). Predicting elderly nursing home admissions. Results from the 1982-84 National Long-Term Care Survey. *Research on Aging, 12*, 199-228.

Hassinger, M. J. (1985). *Community-dwelling dementia patients whose relatives sought counseling services regarding patient care: Predictors of institutionalization over a one-year follow-up.* Doctoral dissertation, University of Southern California, Los Angeles.

Hayes, C. L., Soniat, B., & Burr, H. (1986). Value conflict and resolution in forcing services on "at risk" community-based older adults. *Clinical Gerontologist, 4*, 41-45.

Health and Welfare Canada. (1991). *Mental health problems among Canada's seniors: Demographic and epidemiological considerations*. Ottawa: Minister of Supply and Services Canada.

Heyman, A., Wilkinson, W. E., Hurwitz, B. J. Helms, M. J. Hayes, C. S., Utley, C. M., & Gwyther, L. P. (1987). Early-onset Alzheimer's disease: Clinical predictors of institutionalization and death. *Neurology, 37*, 980-984.

Hing, E., Sekscenski, E., & Strahan, G. (1989). *National nursing home survey* (DHHS Publication No. PHS 89-1758). Washington, DC: U.S. Government Printing Office.

Hinrichsen, G. A., & Neiderehe, G. (1994). Dementia management strategies and adjustment of family members of older patients. *The Gerontologist, 34*, 95-102.

Hobfoll, S. E. (1989). Conservation of resources. A new attempt at conceptualizing stress. *American Psychologist, 44*, 513-524.

Hornykiewicz, O., & Kish, S. J. (1984). Neurochemical basis of dementia in Parkinson's disease. *The Canadian Journal of Neurological Sciences, 11*, 185-190.

Horowitz, A. (1985). Family caregiving to the frail elderly: In C. Eisdorfer (Ed.), *Annual Review of Gerontology and Geriatrics* (Vol. 5) (pp. 194-246). New York: Springer.

Hutton, J. T., Dippel, R. L., Loewenson, R. B., Mortimer, J. A., & Christians B.L. (1985). Predictors of nursing home placement of patients with Alzheimer's disease. *Texas Medicine, 81*, 40-43.

Ingram, D. K., & Barry, J. R. (1977). National statistics on deaths in nursing homes: Interpretations and implications. *The Gerontologist, 17*, 303-308.

Jackson, D. N., & Messick, E. (1958). Content and style in personality assessment. *Psychological Bulletin*, 3, 321-338.

Jeans, E.R., Helmes, E., Mersey, H., Robertson, J. McD., & Rand,K. A. (1987). Some calculations on the prevalence of dementia in Canada. *Canadian Journal of Psychiatry, 32*, 81-85.

Jenkins, T., Parham, I., & Jenkins, L. (1985). Alzheimer's Disease: Caregiver's perceptions of burden. *Journal of Applied Gerontology, 4, 40-57.*

Joanette, Y., Ska, B., Poissant, A., & Béland, R. (1992). Neuropsychological aspects of Alzheimer's disease: Evidence for inter-and intra-function heterogeneity. In F. Boller, F. Forette, Z. Khachaturian, M. Roncet, & Y. Christen (Eds.), *Heterogeneity of Alzheimers's Disease* (pp.33-42). Germany: Springer-Verlag.

Johnson, C. (1983). Dyadic family relations and social support. *The Gerontologist, 23*, 377-383.

Jorm, A. F. (1985). Subtypes of Alzheimer's dementia: A conceptual analysis and critical review. *Psychiatric Medicine, 15*, 543-553.

Jorm, A. F., Korten, A. E., & Henderson, A. S. (1987). The prevalence of dementia: A qualitative intergration of the literature. *Acta Psychiatrica Scandinavica, 76*, 465-479.

Kane, R. L., & Matthias, R. (1984). From hospital to nursing home: The long term care connection. *The Gerontologist, 24*, 604-609.

Kane, R. L., & Matthias, R., & Sampson, S. (1983). The risk of placement in a nursing home after acute hospitalization. *Medical Care, 21*, 1055-1061.

Kasl, S. V. (1978). Epidemiological contributions to the study of work stress. In C. L. Cooper, & R. Payne (Eds.), Stress at work (pp. 3-48). New York: Wiley.

Katzman, R. (1976). The prevalence and malignancy of Alzheimer's disease: A major killer. *Archives of Neurology, 3,* 217-218.

Katzman, R. (1978). Normal pressure hydrocephalus. In R. Katzman, R.D. Terry, & K. L. Bick (Eds.) *Alzheimer's Disease: Senile Dementia and Related Disorders* (Aging, Vol. 7) (pp. 115-124). New York: Raven Press.

Kay, D. W. K., Beamish, P., & Roth, M. (1964). Old age and mental disorders in the Newcastle upon Tyne: Part I. A study of prevalence. *British Journal of Psychiatry, 10,* 146-158.

Kastenbaum, R., & Candy, S. E. (1973). The four percent fallacy: A methodological and empirical critique of extended care facility population statistics. *International Journal of Aging and Human Development, 4,* 15-21.

Khachaturian, Z. (1992). An overview of scientific issues associated with the heterogeneity of Alzheimer's Disease. In F. Boller, F. Forette, Z. Khachaturian, M. Roncet, & Y. Christen (Eds.), *Heterogeneity of Alzheimers's Disease* (pp.4-11). Germany: Springer-Verlag.

Kiecolt-Glaser J. K., Glaser, R., Shuttleworth, E. E., Dyer, C. S., Ogrocki, P., & Speicher, C. E. (1987). Chronic stress and immunity in family caregivers to Alzheimer's disease patients, *Psychosomatic Medicine, 49,* 523-535.

Knopman, D. S., Kitto, J. Deinard, S., & Heiring, J. (1988). Longitudinal study of death and institutionalization in patients with primary degenerative dementia. *The Journal of the American Geriatrics Society, 36,* 108-112.

Kramer, M., Taube, A., & Redick, R. W. (1973). Patterns of use of psychiatric facilities by the aged: Past, present and future. In C. Eisdorfer, & M.P. Lawton (Eds.), *The psychology of adult development and aging.* Washington, DC: American Psychological Association.

Kraus, A. S. (1984). The burden of care for families of elderly persons with dementia. *Canadian Journal on Aging, 3,* 45-51.

Kraus, A S., & Armstrong, M. I. (1977). Effect of chronic home care on admission to institutions providing long-term care. *Canadian Medical Association Journal, 117,* 747-749.

Kraus, A, S., & McGeer, C. P. (1982). The effect of dementia on mortality in the elderly institutionalized population. *Canadian Journal on Aging, 31,* 40-47.

Kraus, A. S., Spasoff, R. A., Beattie, E. J., Holden, E. W., Lawson, J. S., Rodenburg, M., & Woodcock, G. M. (1976). Elderly applicants to long-term care institutions. I. Their characteristics, health problems and state of mind. *Journal of the American Geriatrics Society, 24,* 117-125.

Lamont, C. T., Sampson, S., Matthias, R., & Kane, R. (1983). The outcome of hospitalization for acute illness in the elderly. *Journal of the American Geriatrics Society, 31,* 282-288.

Lawton, P. W. (1982). Competence, environmental press, and the adaptation of older people. In M.P. Lawton, P. G. Windley, & T.O. Byerts (Eds.). *Aging and the Environment: Theoretical Approaches.* New York: Springer.

Lawton, P. W., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist, 9,* 179-186.

Lawton, M. P., Kleban, M.H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology, 44,* 61-71.

Lawton, M. P., Moss, M., Kleban, M. H., Glicksman, A., & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. *Journal of Gerontology, 46,* 181-189.

Lazarus, S. R., & Folkman, S. (1984). *Stress, Appraisal and Coping.* New York: Springer.

Lee, G. R. (1980). Kinship in the seventies: A decade review of research and theory. *Journal of Marriage and the Family, 42,* 923-934.

Lee, G. R. (1992). Gender differences in caregiving: A fact in search of a theory. In J. W. Dywer and R. T. Coward (Eds.), *Gender, Families, and Elder Care.* Newbury Park, CA: Sage.

Lee, G. R. (1993). Gender differences in parent care: Demographic factors and same-gender preferences. *Journal of Gerontology, 48,* 9-16.

Lee, G. R., Dwyer, J. W., & Coward R. T. (1993). Gender differences in parent care: Demographic factors and same-gender preferences. *Journal of Gerontology, 48,* 9-16.

Leiter, M. P., & Maslach, C. (1988). The impact of interpersonal environment on burnout and organizational commitment. *Journal of Organizational Behavior, 9,* 297-308.

Lieberman, M. A., & Kramer, J. H. (1991). Factors affecting decisions to institutionalize demented elderly. *The Gerontologist, 31,* 371-374.

Lishman, W. A. (1978). *Organic psychiatry: The psychological consequences of cerebral disorder.* Oxford: Blackwell Scientific.

Litwak, E., & Longino, C. F.,Jr., (1987). Migration patterns among the elderly: A developmental perspective. *The Gerontologist, 27,* 266-272.

Liu, K., & Manton, K. G. (1983). The characteristics and utilization pattern of an admission cohort of nursing home patients. *The Gerontologist*, *23*, 92-98.

Liu, K., & Palesch, Y. (1981). The nursing home population: Different perspectives and implications for policy. *Health Care Financing Review*, *213*, 15-23.

Longino, C. F.,Jr., Jackson, D. J., Zimmerman R. S., & Bradsher, J. E. (1991). The second move: Health and geographic mobility. *Journal of Gerontology*, *46*, 218-224.

Lowenthal, M. F., Berkman, P., & Associates. (1967). *Aging and mental disorder in SanFrancisco.* San Francisco: Jossey-Bass.

Mace, N., & Rabins, P. (1981). *The 36-hour day: A family guide to coping for persons with Alzheimer's disease, related dementing illness, ana memory loss in later life.* Baltimore, MD: Johns Hopkins Press.

Maddox, G. L. (1975). Families as context and resource in chronic illness. In S. Sherwood (Ed.), *Long-term care: A handbook for researcher, planners, and providers.* New York: Spectrum Publishers.

Maslach, C. (1978). The client role in staff burn-out. *Journal of Social Issues*, *34*, 111-124.

Maslach, C., & Jackson, S. E. (1981). The measurement of experienced burnout. *Journal of Occupational Behavior*, *2*, 99-113.

Maslach, C., & Jackson, S. E. (1986). *Maslach Burnout Inventory. Manual (2nd edition).* Palo Alto, CA: Consulting Psychologists Press.

Maslach, C., & Pines, A. (1977). The burnout syndrome in the day care setting. *Child Care Quarterly*, *6*, 100-113.

Mayeux, R, Stern, Y., & Sano, M. (1992). A comparison of clinical outcome and survival in various forms of Alzheimer's Disease. In F. Boller, F. Forette, Z. Khachaturian, M. Roncet, & Y. Christen (Eds.), *Heterogeneity of Alzheimers's Disease* (pp.4-11). Germany: Springer-Verlag.

McCoy, J. L., & Edwards, B. E. (1981). Contextual and sociodemographic antecedents of institutionalization among aged welfare recipients. *Medical Care*, *19*, 907-921.

McFall, S., & Miller, B. H. (1992). Caregiver burden and nursing home admission of frail elderly persons. *Journal of Gerontology*, *47*, 73-79.

McPherson, B. D. (1983). *Aging as a social process*. Toronto: Butterworths.

Meier, S. T. (1984). The construct validity of burnout. *Journal of Occupational Psychology*, *57*, 211-219.

Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *The Gerontologist, 32*, 498-507.

Miller, E. (1973). Short- and long-term memory in patients with presenile dementia (Alzheimer's disease). *Psychological Medicine, 3*, 221-224.

Moen, P., Robison, J., & Fields, V. (1994). Women's work and caregiving roles: A life course approach. *Journal of Gerontology, 49*, 176-186.

Morris, J. N., & Sherwood, S. (1983). Informal support resources for vulnerable elderly persons: Can they be counted on, why do they work? *International Journal of Aging and Human Development, 18*, 81-98.

Morris, J. N., Sherwood, S.& Gutkin, C. E. (1988). Inst-risk II: An approach to forecasting relative risk of future placement. *Health Services Research, 23*, 511-536

Mortimer, J. A. (1983). Alzheimer's disease and senile dementia: Prevalence and incidence. In B. Reisberg (Ed.), *Alzheimer's disease: The standard reference* (pp. 141-148). New York: Free Press/Macmillan.

Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease. *Research on Aging, 7*, 329-361.

Moss, M. B., & Albert, M. S. (1988). Alzheimer's disease and other dementing disorders. In M. S. Albert, & M. B. Moss (Eds.), *Geriatric Neuropsychology* (pp. 145-178). New York: Guilford Press.

Narain, P., Rubenstein, L. Z., Wieland, G. D., Rosbrook, B., Strome, L. S., Pietruszka, F., & Morley J. E. (1988) Predictors of immediate and 6-month outcomes in hospitalized elderly patients. The importance of functional status. *Journal of the American Geriatrics Society, 36*, 775-783.

National Centre for Health Statistics. (1983). Sex differences in health and use of medical care, United States, 1979. *Vital and health statistics.* Washington, DC: U.S. Government Printing Office.

Nelson, A., Fogel, B.S., & Faust, D. (1986). Bedside cognitive screening instruments: A critical assessment. *Journal of Nervous and Mental Disorders, 174*, 73.

Newman, S., Struyk, R., Wright, P., & Rice, M. (1990). Overwhelming odds: Caregiving and the risk of institutionalization. *Journal of Gerontology, 45*, 173-183.

Nicholson, R. A., & Hogan, R. (1990). The construct validity of social desirability.*American Psychologist, 45*, 290-291.

Niederehe, G., & Oxman, T. E. (1994). The dementias: Construct and nosologic validity. In V. O. B., Emery, & Oxman, T. E. (Eds.), *Dementia Presentations, Differential Diagnosis, and Nosology* (pp. 19-45). London: John Hopkins Press.

Noelker, L. S., & Wallace, R. W. (1985). The organization of family care for frail elderly. *Journal of Family Issues, 6,* 23-44.

Nygaard, H. A. (1991). Who cares for the caregiver? Factors exerting influence on nursing home admissions of demented elderly. *Scandinavian Journal of Caring Sciences, 5,* 157-162.

Palmore, E. (1976). Total chance of institutionalization among the aged. *The Gerontologist, 16,* 504-507.

Pearlin, L. I. (1992). The careers of caregivers. *The Gerontologist, 5,* 647.

Peterson, C., & Seligman, M. E. P. (1984). Causal explanations as a risk factor for depression: Theory and evidence. *Psychological Review, 91,* 347-374.

Pfeiffer, E. (1977). Psychopathology and social pathology. In J. E. Birren, & K. W. Schaie (Eds.), *Handbook of psychology and aging.* New York: Van Nostrand Rinehold.

Pillemer, K., & Finkelhor, D. (1989). Causes of elder abuse: Caregiver stress versus problem relatives. *American Journal of Orthopsychiatry, 59,* 179-187.

Pines, A., Aronson, E., & Kafry, D. (1981). *Burnout.: From Tedium to Growth.* New Jersey: Free Press.

Pines, A., & Maslach, C. (1978). Characteristics of staff burnout in mental health settings. *Hospital and Community Psychiatry, 29,* 233-237.

Poulshock, S. W., & Deimling, G. T. (1984). Families caring for elders in residence: Issues in the measurement of burden. *Journal of Gerontology, 39,* 230-239.

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.

Prohauska, T. R., & McAuley, W. J. (1983). The role of family care and living arrangements in acute care discharge. *Journal of Gerontological Social Work, 5,* 67-80.

Pruchno, R. A., Michaels, J. E., & Potashnik, S. L. (1990). Predictors of institutionalization among Alzheimer disease victims with caregiving spouses. *Journal of Gerontology, 45,* 259-266.

Pruchno, R. A., & Potashnik, S. L. (1989). Caregiving spouses: Physical and mental health in perspective. *Journal of the American Geriatrics Society, 37, 697-705.*

Pruchno, R. A., & Resch, N. L. (1989). Aberrant behaviours and Alzheimer's disease: Mental health effects on spouse caregivers. *Journal of Gerontology, 44,* 177-182.

Quayhagen, M. P., & Quayhagen, M. (1988). Alzheimer's stress: Coping with the caregiver role.. *The Gerontologist, 28,* 391-396.

Rabins, P. V., Mace, N. L., & Lucas, M. J. (1982). The impact of dementia on the family. *Journal of the American Medical Association, 248,* 333-335.

Reisberg, B. (Ed.). (1983). *Alzheimer's disease: The standard reference.* New York: Free press.

Reisberg, B. (1986). Dementia: A systematic approach to identifying reversible causes. *Geriatrics, 41,* 30-46.

Reisberg, B., Ferris S. H., de Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assesment of primary degenerative dementia. *American Journal of Psychiatry, 139,* 1136-1139.

Robertson, D., Stolee, P., & Rockwood, K. (1989). The prevalence of cognitive impairment in a Canadian population. *Acta Psychiatrica Scandinavica, 80,* 303-309.

Rockwood, K., & Stadnyk, K. (1994). The prevalence of dementia in the elderly: A review. *Canadian Journal of Psychiatry, 39,* 253-257.

Romeis, J. C. (1989). Caregiver strain toward an enlarged perspective. *Journal of Aging and Health, 1,* 188-208.

Rosen, W. G., Terry, R. D., Fuld, P. A., Katzman, R., & Peck, A. (1980). Pathological verification of ischemic score in differentiation of dementias. *Annals of Neurology, 7,* 486-488.

Rossi, A. S., & Rossi, P. H. (1990). *Of Human Bonding: Parent Child Relations Across the Life Course.* New York: Aldine de Gruyter.

Schulz, R., Visintainer, P., & Williamson, G. M. (1990). Psychiatric and physical morbidity effects of caregiving. *Journal of Gerontology, 45,* 181-191.

Schwartz, M. F. (1990). Introduction to chapter five: Neuropsychology of Alzheimers Disease: The case for subgroups. In M.S. Schwartz (Ed.), *Modular Deficits in Alzheimers Type Dementia.* Cambridge: MIT Press.

Shanas, E. (1979). The family as a social support system in old age. *The Gerontologist, 19,* 169-174.

Shapiro, E., & Tate, R. (1985). Predictors of long-term care facility use among the elderly. *Canadian Journal on Aging, 4*, 11-19.

Shapiro, E., & Tate, R. (1988). "Who is really at risk of institutionalization?" *The Gerontologist, 28*, 237-245.

Shapiro, E., & Webster, L. M. (1984). Nursing home utilization patterns for all Manitoba admissions, 1974-1981. *The Gerontologist, 24*, 610-615.

Siedler, H., & Malamud, N. (1963). Creutzfeldt-Jakob's disease: Clinicopathologic report of 15 cases and review of the literature. *Journal of Neuropathology and Experimental Neurology, 22*, 381-402.

Sim, A., & Sussman, I. (1962). Alzheimer's disease: Its natural history and differential diagnosis. *Journal of Nervous and Mental Disorders, 135*, 489-499.

Smallegan, M. (1985). There was nothing else to do: Needs for care before nursing home admission. *The Gerontologist, 25*, 364-369.

Soldo, B. J., & Myllyluoma, J. (1983). Caregivers who live with dependent elderly. *The Gerontologist, 23*, 605-611.

Speare, A., Jr., Avery, R., & Lawton, L. (1991). Disability, residential mobility, and changes in living arrangements. *Journal of Gerontology, 46*, 133-142.

Statistics Canada. (1986). *Highlights: Disabled persons in Canada*. Catalogue 82-602. Ottawa: Minister of Supply and Services Canada.

Statistics Canada. (1987). *Population and dwelling characteristics: Age, sex and marital status*. Canada 1986. Catalogue 93-101. Ottawa: Minister of Supply and Services Canada.

Statistics Canada. (1989). *Population projections for Canada, Provinces and Territories 1987-2011*.Catalogue 91-520. Ottawa: Minister of Supply and Services Canada.

Statistics Canada. (1990). *Barriers confronting seniors with disabilities in Canada*. Catalogue 82-615. Ottawa: Minister of Supply and Services Canada.

Steele, C., Rovner, M. P. H., Chase, G. A., & Folstein, M. (1990). Psychiatric symptoms and nursing home placement of patients with Alzheimer's disease. *American Journal of Psychiatry, 147*, 1049-1051.

Stevens, S., & Christianson, J. (1986). *Informal Care of the Elderly*. Lexington, MA: Lexington Books.

Stone, R., Cafferata, G., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *The Gerontologist, 27*, 616-626.

Swearer, J. M., Drachman, D. A., O'Donnell, & Mitchell, A. L. (1988). Troublesome and disruptive behaviours in dementia: Relationships to diagnosis and disease severity. *Journal of the American Geriatrics Society, 36,* 784-790.

Tabachnick, B. G., & Fidell, L. S. (1989). *Using Multivariate Statistics (2nd ed.).* New York: Harper Collins.

Tennstedt, S. L., Crawford, S., & McKinlay, J. B. (1993). Determining the pattern of community care: Is coresidence more important than caregiver relationship? *Journal of Gerontology, 48,* 74-83.

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment and management of behavioural problems in dementia: The revised Memory and Behaviour Problems Checklist. *Psychology and Aging, 7,* 622-631.

Thompson, E. H., & Doll, W. (1982). The burden of families coping with the mentally ill: An invisible crisis. *Family Relations,* 31, 379-388.

Tobin, S., & Kulys, R. (1981). The family and the institutionalization of the elderly. *Journal of Social Issues, 37,* 145-157.

Tomlinson, B. E., Blessed, G., & Roth, M. (1970). Observations on the brains of demented old people. *Journal of the Neurological Sciences, 11,* 205-242.

Toseland, R. W., & Rossiter, C. M. (1989). Group interventions to support family caregivers: A review and analysis. *The Gerontologist, 29,* 438-448.

Townsend, A. (1990). Nursing home care and family caregivers' stress. In M. A. P. Stevens, J. H. Crowther, S. E. Hobfoll, & D. L. Tennenbaum (Eds.), *Stress and Coping in Later-life Families* (pp. 267-285). New York: Hemisphere Publishing.

Vézina, J., Landreville, P., Bourque, P., & Blanchard, L. (1991). Questionnaire de Depression de Beck: Étude psychométrique d'une population francophone. *Revue Canadienne de Vieillissement, 10,* 29-39.

Vicente, L., Wiley, J. A., & Carrington, R. A. (1979). The risk of institutionalization before death. *The Gerontologist, 25,* 55-61.

Walker, A. J. (1992). Conceptual perspectives on gender and family caregiving. n J. W. Dywer and R. T. Coward (Eds.), *Gender, Families, and Elder Care.* Newbury Park, CA: Sage.

Walsh, J. (1990). Comment on social desirability.*American Psychologist, 45,* 289-290.

Wan, T. T. H., & Weissert, W. G. (1981). Social support networks, patient status and institutionalization. *Research on Aging, 3,* 240-256.

Weissert, W. G., & Cready, C. M. (1989). Toward a model for improved targeting of aged at risk of institutionalization. *Health Services Research,* 24, 485-510.

Wentzel, J.W. (1984). *Clinical Handbook of Depression.* New York: Gardner Press.

Wilson, R. S., Kaszniak, A.W., & Fox, J. H. (1981). Remote memory in senile dementia. *Cortex, 17,* 41-48.

Wingard, D. L., Jones, D. W., & Kaplan, R. M. (1987). Institutional care utilization by the elderly: A critical review. *The Gerontologist, 27,* 156-163.

World Health Organization (1981). *Disability prevention and rehabilitation.* WHO Technical Reports Series 668. Geneva, SZ.

York, J. L., & Calsyn, R. J. (1977). Family involvement in nursing homes. *The Gerontologist, 17,* 500-505.

Young, R. F., & Kahana, E. (1989). Specifying caregiver outcomes: Gender and relationship aspects of caregiving strain. *The Gerontologist, 29,* 660-666.

Zarit, S. H. (1990a). Concepts and measures in family caregiving research. Paper presented at the Conference on Conceptual and Methodological Issues in Family Caregiving Research. June, Toronto.

Zarit, S. H., Anthony, C. R., & Boutselis, M. (1987). Interventions with care givers of dementia patients: Comparison of two approaches. *Psychology and Aging, 2,* 225-232.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20,* 649-655.

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist, 26,* 260-266.

Zarit, S. H., & Witlatch, C. J. (1992). Institutional placement: Phases of transition. *The Geronotologist, 32,* 665-672.