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The Cognitive Functioning of Dementia Patients:
An Examination of the Hierarchic Dementia Scale, and the
Impact of Cognitive Functioning on Caregiver Burden and
Desire to Institutionalize

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Abstract

The Cognitive Functioning of Dementia Patients:
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Dementia is a chronic condition leading to a decline in independent

functioning. The objective of the study was to examine dementia patient

cognitive functioning by using the Hierarchic Dementia Scale (HDS), and

examine the impact of cognitive functioning on caregiver burden and desire

to institutionalize the patient. It was hypothesized that the HDS would be a

valid and reliable measure of patient cognitive functioning, would

differentiate among profiles of patients, and would be predictive of caregiver

burden and desire to institutionalize. The study examined 185 pairs of

dementia patients and caregivers. Caregivers were given standardized

interviews and patients were evaluated both directly and indirectly. Using

Pearson Correlation the HDS was found to be related to established

measures of dementia, and to have good internal consistency. Cluster

analysis followed by MANOVA produced two and three separate clusters. It

is evident that different groups of patients do not perform better or worse on

certain subsets of HDS subscales, but rather inter-individual variations are

understood in the context of illness duration. Direct multiple regression

analysis revealed caregiver health and patient behaviour problems as predicative of burden while cognitive functioning was not (F (17, 167) = 12.25, $p<.001$). Discriminant function analysis highlighted both caregiver and patient characteristics as important in predicting institutionalization; caregiver burden and health were key ($X^2 = 40.51$, $p<.001$). This study demonstrates the utility of the HDS in evaluating patient cognitive functioning and in differentiating among separate clusters of patients. Both caregiver and patient functioning are important in understanding burden and desire to institutionalize.

Acknowledgments

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<center>Review of the Literature</center>

Overview of Dementia Characteristics

Dementia is a condition which refers to a chronic and progressive loss of the ability to function independently. It includes deterioration in cognitive and communicative skills, personality changes, and eventually leads to the need for total care (Bayles & Kazniak, 1987; Cummings, 1998; Cohen-Mansfield et al., 1996; Small, 1996). Dementia, in and of itself, is not necessarily irreversible. The characteristics of dementia vary somewhat depending upon the specific etiology, however, a hallmark of dementia is significant cognitive decline (Blazer, 1995; Breitner & Welsh, 1995). Primary Degenerative Dementia (PDD) is a term which refers to progressive and irreversible cognitive deterioration, most commonly observed in elderly individuals (American Psychiatric Association, 1994). Alzheimer disease, first described in 1907 by Dr. Alois Alzheimer (Thomas &Isaac, 1987), now often referred to as Dementia of the Alzheimer Type (DAT), is the most frequent cause of PDD (Bayles &Kazniak, 1987; Jobst et al., 1994; Schneider and Small, 1996).

Although estimates of PDD can be difficult due to methodological problems such as differences in the definition of dementia across studies (Rockwood & Stadnyk, 1994), as the Canadian (and indeed world) population ages, the best estimates regarding the prevalence of dementia is that it will increase. Based on data gathered in 1991 and 1992, the

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Canadian Study of Health and Aging Working Group (1994) estimate that

8.0% of all Canadians aged 65 and over met the criteria for dementia. This

prevalence figure is essentially evenly proportioned between community-

based and institutionalized individuals, with twice as many women as men

being afflicted. If prevalence estimates remain unchanged, the Working

Group suggests that the number of cases of dementia in Canada will almost

triple by 2031, whereas the total population is expected to increase by a

factor of only 1.4. Such an increase in the numbers of individuals with PDD

suggests that the need and demand for community-based support services

and for institutional care will also increase accordingly (CSHA, 1994;

McEwan, Donelly, Robertson & Hertzman, 1991).

Changes within the brain have been well studied in persons with PDD.

Advances in neural imaging techniques have demonstrated that both

anatomical and physiological changes occur in the brain (Jagust, 1994;

Mayberg, 1994; Shear et al., 1995). Cortical atrophy, neuritic plaques

(composites of dead cell fragments which fill the intercellular space),

neurofibrillary tangles (twisted protein filaments which disrupt axonal

transmission), and disruption in neurotransmitter systems (most specifically

the cholinergic and noradrenergic systems) are the hallmarks of the demented

brain, with changes often clustering within the temporal and parietal regions

(Dournaud, Delaere, Hauw & Epelbaum, 1995; Larson et al., 1992; Peskind,

1996; Small, 1996). The behavioural and/or cognitive difficulties

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experienced by individuals is often related to the specific areas in the brain which have been most damaged in the degenerative process (Alexander et al., 1997; Kotrla, Chacko, Harper, Jhingran & Doody, 1995; Mayberg, 1994). The relation between neurological damage and functional decline is not, however, totally predictable. Snowdon (1997) provided a compelling case report of a "cognitively sharp" centenarian whose brain at autopsy revealed abundant tangles and plaques, demonstrating that there can be a wide range of clinical manifestations of DAT.

Research suggests a strong genetic causal factor, particularly for DAT (Bergen, Engedel & Kringlen, 1997; Li et al., 1995; Silverman et al., 1994; Simpson & Burns, 1996; Small, 1998). When age of onset is earlier in life (for example, in an individual's 40s or 50s as opposed to 70s or 80s), there are more likely to be several family members with the disease (Li et al., 1995; Silverman et al., 1994). In addition to complex genetic influences, several environmental and psychosocial risk factors appear to play a role in disease development (Scott, 1998; Small, 1998).

There are no cures or preventative treatments for PDD. With regard to DAT in particular, the focus of drug therapy has been mainly palliative in nature, with a focus on symptom management (e.g., cognitive deterioration, behavioural regression) and slowing disease progression (Breitner & Welsh, 1995; Flint & Reekum, 1998; Schneider, 1996). New antidementia drugs are being researched (Grossberg & Lake, 1998; Schneider, 1998). There are,

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however, nonpharmacologic interventions to assist a dementia patient's ability to cope, and support of the care provider is an extremely important part of overall dementia management (Kumar, Zucker Goldstein & Doraiswamy, 1996). All types of intervention are important as they may prevent or delay institutionalization of a dementia patient (Grossberg & Lake, 1998).

Impact of Dementia on Cognitive Skills

Some decline in many cognitive skills is generally an experience which occurs for "normal" older adults (Bayles & Kazniak, 1987; Blass, 1996; Hanninen et al., 1995; Linn et al., 1995; Reisberg, Borenstein, Franssen, Shulman, Steinberg & Ferris, 1986), and advanced age has been consistently shown to be a risk factor for decline on cognitive test scores (Prince, Lewis, Bird, Blizard & Mann, 1996). PDD, although once considered an unavoidable phase in normal senescence, is now generally considered to be an aberration of the normal aging process (Bayles & Kazniak, 1987; Nebes & Madden, 1988; Larson et al., 1992; Reisches, Schaub & Schlattman, 1996), or perhaps representative of the extreme and pathological end of aging, particularly in relation to vascular disease and cognitive decline (Prince, 1995). The onset of PDD is insidious and subtle, and a diagnosis of probable PDD is generally made once the disease has begun to advance (Breitner & Welsh, 1995).

A person with dementia will generally experience a deterioration in performance of skills measured by both neuropsychological tests and on many functional tasks (Baum, Edwards, Yonan & Storandt, 1995). Perhaps the best known and most extensively explored aspect of cognitive decline in PDD is memory failure, which has been found to be a relatively strong predictor of DAT (Geerlings, Jonker, Bouter, Ader & Schmand, 1999). Much research has specifically examined the effect of PDD on the episodic (the autobiographical record of personal experiences) and the semantic (the "thesaurus" of organized knowledge and rules regarding words and concepts) aspects of memory (Nebes, Martin &Horn, 1984). Many researchers have found impairment in both episodic and semantic memory in dementia sufferers (e.g., Bayles & Kazniak, 1987; Nebes, Boller & Holland, 1986). Nebes et al. (1984) suggest more specifically that the semantic structure of memory may be grossly intact, although the access to that structure, particularly in demand situations, is impaired. Hodges, Salmon and Butters (1992) report evidence that there is a semantic breakdown caused by storage degradation rather than simply a disorder of semantic access. It has also been determined that the retrieval of long established memories (secondary memory) is quite different from the ability to establish and recall new information (primary memory) for dementia patients. Especially when the disease is in its early stages, patients are able to more easily recall "old" memories, but have much more difficulty encoding and recalling newer

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material. As the disease progresses, primary memory also becomes more affected (Davis & Mumford, 1984; LaRue, D'Elia & O'Clark, 1986; Locascio, Growdon & Corkin, 1995; Storandt, Botwinick & Danziger, 1986; Wilson, Kramer, Fox & Kazniak, 1983; Wilson, Kazniak & Fox, 1981). Jeste, Wragg, Salmon, Harris and Thal (1992) found a greater disruption in the organization of semantic memory in patients with Alzheimer disease who also had delusions contrasted to those without delusions. Attempts to teach patients with PDD to improve their memory generally have not yielded positive results (e.g., Heun, Bierbrauer & Benkert, 1995; Weingartner, Kaye, Smallberg, Ebert, Gilin & Sitaram, 1981). Sahgal et al. (1992) report that visual spatial memory processes, in particular, are impaired in the early stages of Alzheimer disease and continue to decline as the disease progresses.

Decline in language skills is also an area which has long been investigated in the study of dementia. Persons with PDD gradually lose their ability to communicate meaningfully. Similar to memory impairment, some language skills may be relatively preserved in early stages of the disease, but are more affected in later stages. Difficulties such as word finding problems, and the semantic and pragmatic use of language generally become worse as the disease progresses (Bayles & Kazniak, 1987; Butters & Delis, 1995; Chobor & Brown, 1990; Emery & Bresleau, 1988; Harrold, 1998). Price, Gurrit, Weintraub, Geula, Leimkuhler and Mesulam (1993) specifically noted that when language deficits were present, the deficit usually took the form of

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a fluent aphasia, where speech was well articulated and grammatically correct, but lacking in logical content. Researchers continue to examine what aspects of language may be hallmarks of dementia onset (e.g., Chan, Salmon, Butters & Johnson, 1995; Flicker, Ferris & Reisberg, 1993), as well as what aspects of language might be preserved for a period of time (e.g., Kertesz, Appell & Fisman, 1986; Lawlor, Ryan, Schmeidler, Mohs & Davis, 1994).

Although memory and language deficits are generally viewed as the major characteristics of the cognitive decline of someone with PDD, other aspects have also been observed. Some cognitive skills are considered to slow more disproportionately in persons with dementia compared to normal older adults (Nebes & Madden, 1988). Processing speed is one such skill which has been examined. Response time is a skill which is generally regarded as slowing down with normal aging (Blass, 1996), and tends to slow more significantly for dementia sufferers (e.g., Bayles & Kazniak, 1987; Myerson et al., 1989; Riege, Lanio, Harker & Kuhl, 1988). Visual perceptual abilities decline in normal aging, and decline still more significantly in persons with PDD (Bayles & Kazniak, 1987; Eslinger & Benton, 1983; Mentis et al., 1996). Visual abilities have received more research attention lately as researchers such as Cronin-Golomb, Corkin and Growdon (1995) and Furey-Kurkjian et al (1996) have demonstrated that visual dysfunction may be a predictor of cognitive decline in persons with DAT. Conceptual skills are

disrupted as well, as evidenced by difficulties with tasks such as reading comprehension, judgement, recognizing and producing pantomime, and effective problem solving by dementia patients (Bayles & Kazniak, 1987; Chan et al., 1995; Teri, Borson, Kiyak & Yamagishi, 1989). An extension of the disruption of the conceptual network by the dementing illness, overall cognitive flexibility (reflected in the capacity for success in new learning or generating solutions to problems) becomes impaired (Breitner & Welsh, 1995; Rebok & Brandt, 1989). As PDD advances, it is also not uncommon to witness the return of primitive reflexes (Koller, Glatt, Wilson & Fox, 1982). Patients with DAT are also likely to experience anosognosia, the impaired ability to recognize or appreciate their own experiences of skill deficit, a condition which may thus interfere with attempts at the development of compensatory strategies (Kotler-Cope & Camp, 1995; Ott, Lafleche, Whelian, Buongiorno, Albert & Fogel, 1996).

Behaviour and Psychiatric Manifestations

Although cognitive deficits are generally considered the main feature of PDD, many patients will also experience a concomitant behavioural or psychiatric difficulty as well (Kumar et al., 1996; Lloyd, Jafner & Holme, 1995; Reichman, Coyne, Amirneni, Molino & Egan, 1996). The presence of verbal or physical aggression by patients can threaten the physical and emotional well-being of individuals close to them (Arsland, 1995; Arsland, Cummings, Yenner & Miller, 1996; Hamel et al., 1990; Mohs, Kim, Johns,

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Dunn & Davis, 1986; Reisberg, Borenstein, et al., 1986; Tsai, Hwang, Yang & Liu, 1996). Sleep disturbance (often a diurnal rhythm reversal or fragmented sleep), is also a common behavioural difficulty which is very disruptive in the lives of care providers (Cohen-Mansfield, 1986; Mohs et al., 1986; Reichman et al., 1996; Reisberg, Borenstein, et al., 1986; Satlin, 1994). Agitation or restlessness is another phenomenon which can be experienced by an individual with PDD (Mohs et al., 1986; Reichman et al., 1996; Reisberg, Borenstein, et al., 1986). Dementia is also likely to have a significant impact on sexual behaviour. Derouesne, Guigot, Chermat, Winchester and Lacombley (1996) noted that 75% of dementia patients experienced sexual changes ranging from decreased interest to displays of inappropriate sexual behaviour. Psychiatric symptoms such as psychosis (the presence of delusions or hallucinations), mood disturbance, and anxiety are further problems faced by patients and those who care for them (Aarsland et al., 1996; Reichman et al., 1996; Reisberg, Borenstein, et al., 1986). Personality changes in dementia sufferers are also likely, possibly related to degree of cognitive impairment (Jacomb & Jorm, 1996; Welleford, Harkins & Taylor, 1995), and may actually be an early marker for the onset of a dementing illness (Welleford et al., 1995). Pearson, Teri, Reifler and Raskind (1989) report that depression among individuals with DAT is a possible comorbid condition and is more likely to occur in patients at early stages with mild to moderate levels of impairment. Jacomb and Jorm (1996)

suggest that there is a decrease in 'positive' aspects of personality traits, such as dependability and punctuality, which are dependent upon a cognitive infrastructure.

Some studies have investigated the relation between the severity of cognitive decline and behavioural (i.e., non-cognitive) disturbances. Rasmussan, Carson, Brookmeyer, Kawas and Brandt (1996) and Taft and Cronin-Stubbs (1995) note that the general trend in research suggests a relation between behavioural symptoms and a greater degree of cognitive and functional decline. Cooper, Mungas and Weiler (1990) reported that agitation/anger, personality change, wandering, psychosis, and insomnia were all associated with a decline in cognitive functioning, although they noted that the correlations are small. Kurita, Blass, Nolan, Black and Thaler (1993) found cognitive and behavioural difficulties in individuals with DAT progress simultaneously, however, a similar relation could not be documented between cognitive status and behavioural impairments for individuals with vascular dementia. Jeste et al. (1992) reported a 35% prevalence of delusions and a 17% prevalence of hallucinations in individuals with Alzheimer disease. They noted that the presence of psychotic symptoms was associated with greater severity of dementia (although psychosis per se was less frequent in patients with severe dementia). They also highlighted a possible association between the occurrence of psychotic symptoms and a more rapidly deteriorating course of dementia. Mortimer,

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Ebbitt, Jun and Finch (1992), however, did not find the presence of hallucinations to be related to cognitive severity, but noted a relation of hallucinations to functional decline. Reisberg, Borenstein, et al. (1986) speculate that behavioural difficulties arose from the two interacting processes of brain changes and the psychological impact of the experience of cognitive loss. Researchers are not in complete agreement regarding this relation. For example, Lloyd et al. (1995) and Teri et al. (1989) did not find behaviour problems, either individually or collectively, correlated with cognitive impairment, although they acknowledged the possibility that they may have sampled a group which was overly homogeneous within the level of cognitive impairment experienced. There generally is more consensus among researchers regarding the great physical and emotional toll which behavioural and psychiatric disturbances exact on the caregivers of dementia patients (Satlin, 1994; Tariot, 1996), often leading to a desire to discontinue home maintenance of the patient (e.g., Knopman, Kitto, Deinard & Heiring, 1988).

Course and Nature of Decline in Functioning

It is known that dementia patients decline at different rates and at present it is not possible to predict confidently the course of the disease (Stern & Jacobs, 1995). Doraiswamy et al. (1998) highlighted the fact that early onset DAT is distinguished by the rapidity of symptom progression (i.e., progression over three to five years). There are also forms in which the

disease course is protracted, progressing over 15 or 20 years. Dastoor and

Cole (1983) and Jacobs et al. (1994) also have found age of onset of

dementia prior to age 65 years to be associated with more rapid disease

progression. Other researchers, however, have found conflicting results of

no effect of age on disease course (e.g., Bracco et al., 1994; Burns, Jacoby

& Levy, 1991; Drachman, O'Donnell, Lew & Swearer, 1990; Katzman et al.,

1988). These conflicting results must be considered in the context of the

stage of the disease when the patient was first examined as well as whether

age was treated as a discrete or continuous variable. Dastoor (1998) has

proposed the development of a model of decline in DAT in which the age of

symptom onset is the most significant risk factor and significantly predicts

the rate of decline on language and praxic functions.

Some researchers (e.g., Alexander et al., 1997; Dastoor, 1998;

Rasmusson et al., 1996; Rosen, Mohs & Davis, 1986; Small, LaRue, Komo,

Kaplan & Madelkern, 1995) have speculated as to whether the variability in

the rate of decline may be related to the degree of premorbid intellectual

competence and level of education. Alexander et al. (1997), in particular,

have recently suggested a "cognitive reserve hypothesis" as a way explaining

variability in decline in dementia sufferers. Their results demonstrated that,

after controlling for clinical and demographic characteristics, there were

greater cerebral metabolic deficits in the brains of some patients with

Alzheimer disease. Alexander et al. noted that the greater degree of cerebral

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deficit was associated with greater premorbid intellectual function, and suggested that premorbid ability may somehow delay or diminish the clinical features of dementia, although the disease continues to progress. Both Alexander et al. and Taylor et al. (1996) suggest that reading performance in particular may be the singularly most useful measure of premorbid intellectual ability in persons with Alzheimer disease. Other researchers (e.g., Drachman et al., 1990; Bracco et al., 1994) did not find education level (as an indicator of intellectual ability) to be related to patient cognitive decline.

The presence of language and memory deficits have also been examined in attempting to predict the rate of further cognitive decline in dementia patients. Decline in memory skills has been found to be predictive of decline overall (Small et al., 1995). Self-reported memory complaints have been associated with further decline in memory and cognitive skills in older adults who already have some level of cognitive impairment, but have not been found to be predictive of further decline in those older adults who are cognitively normal at the point of memory complaint (Schofield, Marder, Gooneief, Jacobs, Sano & Stern, 1997). Studies of language dysfunction have yielded promising predictive value in studies of the rate of cognitive decline. Both Bracco et al. (1994) and Faber-Langendoen, LaBarge, Miller and Berg (1988) suggest that the presence of aphasia may signal more rapid progression in dementia. Dysfunction particularly within the semantic

network has been found to be predictive of subsequent rate of cognitive decline in patients with probable DAT (Chan et al., 1995).

In addition to the rate of decline, the nature of the decline in cognitive skills has received research attention in recent years (Teri, McCurry, Edland, Kukull & Larson, 1995). It is well accepted that persons with PDD will experience a progressive decline in cognitive skills, however, the pattern of that decline is not uniform amongst all patients (Bayles & Kazniak, 1987; Dastoor & Cole, 1985-1986; Doraiswamy et al., 1998; Teri et al., 1995). In fact, considerable individual variation occurs not just in terms of disease duration, but in the emergence of specific symptoms of the disease.

Some researchers have suggested a subgroup approach to understanding variability in dementia progression. For example, Furey-Kurkjian et al. (1996) suggested that a subgroup of patients with probable Alzheimer disease experienced visual disturbances as their primary difficulty and, compared to Alzheimer patients without this primary visual difficulty, performed significantly better on memory tests and worse on tests of visuospatial skills. Price et al. (1993) found that persons with DAT divided into groups based upon their most significant impairment. The largest group experienced significant changes in attention or recent memory, one group experienced language disturbance as the primary area of difficulty, and a third group experienced visuospatial deficits as the area of greatest impairment. In general, it was the initial salient deficit which remained the

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aspect of greatest concern during much of the disease course, while similarly the preservation of a particular cognitive domain early in the course of the disease suggested relative preservation with the advancement of the disease. At terminal stages of the disease, severe deficits generally emerged in all faculties. Stern and Jacobs (1995) also note that age of onset of the disease prompted a differential pattern of impaired and preserved cognitive skills. Valdois, Joanette, Poissant, Ska and Dehaut (1990) have determined that there is also heterogeneity in the cognitive profiles of normal elderly and caution against over-interpretation regarding the identification of neuropsychologically based subgroups in DAT.

Assumptions made regarding the nature of the functional decline in dementia have an impact upon the methods used to measure deterioration in skills. Staging systems refer to dementia measurement tools which attempt to assess and monitor the progressive decline in skills (Cohen-Mansfield et al., 1996). Reisberg and his colleagues (e.g., Reisberg, Ferris, et al., 1986; Reisberg, Ferris, de Leon & Crook, 1982) have long been proponents of a stage approach to the classification of individuals with Alzheimer dementia, seeing the age-associated cognitive decline of normal aging and progressive Alzheimer disease on a single clinical continuum ranging from forgetfulness to confusional phases to late stage dementia. Their development of the Global Deterioration Scale has been used for many years in dementia classification.

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Such staging systems, however, have implied an accurate understanding of the disease course, both past and future (Cohen-Mansfield et al., 1996). Historically much research has tended to assume a homogeneous progression of cognitive decline, however Dastoor and Cole (1985-1986) and Dastoor (1998) have noted that there is considerable inter-individual variation within the pattern of decline and suggest that the notion that dementia (specifically DAT) is a homogeneous condition following a uniform course of progression be reconsidered. At this time, the heterogeneity of the clinical, anatomical, and physiological characteristics of DAT is being more regularly acknowledged and the disease features are not generally considered to be uniform in their expression, with variability expressed in terms of the emergence of symptoms and in terms of duration of the disease.

Burns, Jacoby and Levy (1991), Folstein (1989), Haxby (1988), Haxby, Raffaele, Gillette, Schapiro and Rapoport (1992) have all worked to more thoroughly understand the heterogeneity of Alzheimer disease, noting how there is considerable intersubject and intrasubject variability in patients who have been studied, even when similar degrees of overall dementia severity or disease duration are present. Heterogeneity has also been a term used to describe the uneven anatomic distribution of the disease evidenced in the brain of Alzheimer disease patients, heterogeneity which may reflect variability in disease expression based on the location of the neural damage

(Haxby, 1988). Haxby et al. (1992) noted that while the overall population of patients with Alzheimer disease is generally heterogeneous, intra-individual functioning did not reveal a great deal of variability, and the rate of decline for individual patients could be well predicted within a linear model following two evaluations. These researchers suggested that the rate at which dementia worsens is a trait that varied significantly among individual patients. Mortimer et al. (1992) also suggested that both cognitive and functional skills can predict later cognitive and functional progression rates in individual patients.

Burns et al. (1991) found that the cognitive function of dementia patients aligned within three clusters, representing mild, moderate, and severe dementia. Folstein (1989) and Haxby (1988) believe these heterogenous characteristics are suggestive of the presence of subtypes of Alzheimer disease. Folstein, in particular, suggested that the phenotypic features of the cognitive syndrome, age of onset, and the severity of the neuropathology suggested specific subtypes of Alzheimer disease. It may also be possible to observe clustering of the characteristics of dementia within a heterogenous population. Overall, Scott, Rhoades and Lesser (1990) reported that scores of the clinical manifestations of dementia cluster into relatively discrete groups which suggest naturally occurring stages or phases in progressive cognitive decline. These stages are considered to encompass behaviours such as anxiety, depression, and sleep disturbance in

a nonspecific phase, adding clinical manifestations such as personality changes, difficulties with memory and other cognitive abilities, and loss of independence in other stages leading to late dementia. It is further suggested by Overall et al. (1990) that the cluster analysis reveals the presence of distinct thresholds for occurrence of new impairments along the cognitive decline continuum. Mortimer et al. (1992) raise the possibility as well that there may exist parallel, yet distinct processes of progression in Alzheimer disease in the examination of cognitive and functional decline which differ significantly with regard to clinical predictors. These researchers have speculated that these two potential parallel progressions may reflect neural hemispheric characteristics, hypothesizing that greater cognitive decline may be observed in individuals with a greater degree of left hemisphere damage, while individuals with greater difficulty in functional skills may present with a disease process primarily affecting the right hemisphere. The work of Bouchard and Rosser (1996) also highlighted various subgroups within PDD, and as well noting the hierarchic nature of decline within specific skill areas.

Jorm (1985) cautioned against the use of establishing qualitatively different subtypes, noting apparently distinguishable groups to be better explained by a quantitative rather than by a qualitative variability. Clearly, the nature of heterogeneity in dementia, and the concepts of subtypes and clusters require further examination (Cohen-Mansfield et al. 1996).

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Review of the Hierarchic Dementia Scale

There has been more effort recently to develop rating scales designed for use with dementia patients. A good dementia assessment tool should sample a variety of cognitive functions, be of appropriate difficulty yet sensitive to the deficits characteristic of the condition, have a relatively short administration time, and have good reliability (Ferris, Crook, Flicker, Reisberg & Bartus, 1986). It remains a challenge in the measurement of cognitive decline to have tasks that include different degrees of difficulty and are thus more sensitive to change over time as skills deteriorate (Locaiscio et al., 1995; Mohs et al., 1986). It is also important to consider a variety of information together (e.g., neurophysiological, psychometric, clinical information) at the time of diagnosis and in further tracking of disease progression (Flicker, Ferris & Reisberg, 1991, 1993; Shapiro & Tate, 1988; Zappoli et al., 1995).

Noting that existing measures did not adequately deal with the heterogeneous aspect of cognitive skill decline, Dastoor and Cole developed the Hierarchic Dementia Scale (HDS) (Cole & Dastoor, 1980; Cole, Dastoor & Koszycki, 1983; Dastoor & Cole, 1985-86, 1988). Based on a reverse-Piagetian theory, the HDS was designed to determine optimal levels of performance with regard to many different mental functions in an accurate and sensitive manner. Jean Piaget is well known for his hierarchy of cognitive development in children (Clarke-Stewart, Friedman & Koch, 1985;

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Ginsburg & Opper, 1969). He postulated that as a child grows older, he or she gradually acquires greater cognitive ability, passing through the sensory-motor stage, followed by the preoperational stage, concrete operational stage, and then finally the formal operational stage. A child who successfully accomplishes tasks appropriate to his or her age level can be expected to complete successfully tasks at lower levels of the hierarchy, but not necessarily those at higher levels. Similarly with dementia, Dastoor and Cole (1985-86, 1988) suggest that there appears to be a fairly consistent hierarchy at work, similar to that of Piaget, except that the functional decline in dementia patients approximates Piaget's developmental stages in reverse. The HDS attempts to measure cognitive functioning and monitor decline based on this apparent hierarchic organization of mental functions. The HDS has also proven to be sensitive to changes in cognitive performance when used in longitudinal research (e.g., Bickel, 1996; Cooper, Bickel & Schaufele, 1996; Dastoor, 1998; Pushkar Gold, Dastoor & Zieren, 1996).

Caregiver Experience of Burden

Characteristics of care providers for dementia patients have also received a good deal of research attention in the past decade, particularly in relation to how the experience of caregiving impacts on care providers' well-being, sense of burden, and decision to institutionalize the patient. Quality-of-life issues of all persons affected by dementia must be addressed (Duncan & Seigal, 1998). There are many challenges as well in dealing with social

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services as a caregiver. Although receiving a diagnosis of PDD for a close or loved relative is profoundly stressful, getting the diagnosis can also be a beneficial experience in the sense of giving a name to the problem and allowing the care provider (and perhaps patient) to start dealing with the information (Connel & Gallant, 1996). Although there are currently a number of community services to assist individuals who care for a dementia patient, not all identified needs are being met (Delany & Rosenvinge, 1995). It remains important to provide good information regarding the diagnosis and support to initially deal with that information, as well as for services to try to meet the needs of caregivers in their greatest areas of stress and burden (Connel & Gallant, 1996; Nygaard, 1991).

There are many risk factors related to feelings of burden, and overall mental and physical health difficulties. Various correlates of caregiver feelings and well-being have been explored. Many researchers have found a relation between caregiver functioning and various care receiver oriented variables such as cognitive decline or behaviour problems. For example, Horowitz (1985) and Pearlin, Mullan, Semple and Skaff (1990) have both found that the extent of impairment of the dementia sufferer predicts the type and amount of help families provide, which in turn impacts upon the experience of stress. Brodaty, Griffin and Hadzi-Pavlovic (1990) indicated that the difficulties with communication, the need for constant supervision, and the disruption of personal life were all related to caregiver distress.

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Gallagher-Thompson, Brooks, Bliwise, Leader and Yesavage (1992) have reported that care-receiver night time sleep disturbance and wandering, as well as rate of cognitive decline, are related to caregiver perceived stress. Perceived stress, however, generally tended to decrease over time despite continuing decline in patient cognitive functioning, perhaps suggesting that caregivers may adapt to stress over time (Gallagher-Thompson et al, 1992).

Morris, Morris and Britton (1988) reported that caregiver factors, excluding care receiver factors, correlated best with feelings of caregiver burden. O'Rourke, Haverkamp, Rae, Tuokko, Hayden and Beattie (1996) have further suggested that there is also a relationship between expressed burden and a systemic response bias, which may reflect the degree to which burden among spousal caregivers may be confounded by social desirability, and caution that the measurement of expressed burden rather than perceived burden may be important. Draper, Poulos, Poulos and Ehrlich (1995) focused on the multifactorial nature of caregiver stress, noting factors such as a worsening in the quality of the relationship between the caregiver and patient, being a spouse, poor caregiver self-rated health, and behaviour/mood disturbance in the patient to be risk factors for burden. Many researchers have acknowledged the intensely stressful experience of caregiving and suggest that further research is required in this area. Gwyther and Strulowitz (1998) in particular emphasized the need for more consistent definitions of caregiver stress and improvements in design, sampling, and measures.

Caregiver Desire to Institutionalize

As an individual ages, the presence of physical disability, incontinence, or dementia, as well as a lack of social ties (e.g., a spouse or children) are situations which are associated with the reception of institutional care (Brock, Foley & Salive, 1996). Many dementia patients are cared for in their own homes or in the home of a relative, with institutional care often used as a reluctant and difficult last option when there is no available caregiver, or when the caregiver no longer feels able to continue coping within the care situation (Brock et al., 1996; Brodaty, McGilchrist, Harris & Peters, 1993; Cohen et al., 1993; Haupt & Kurz, 1993). There is no easy method to determine which caregivers will be more likely to make the decision to institutionalize; there is a complex interaction between characteristics of the caregiver and of the dementia sufferer (Colerick & George, 1986; Mittelman et al., 1993).

The literature notes many factors relevant to institutionalization. There is conflicting evidence regarding what is the most important singular predictor or collective group of predictors in a caregiver's decision to institutionalize a dementia patient who had been maintained at home. This lack of clarity can be linked to the use of different measures, follow-up intervals, statistical analysis methods, and divergent population samples (Severson et al., 1994). Both patient and caregiver characteristics have been

used often in efforts to predict the key facets in a caregiver's decision to institutionalize a dementia patient.

Caregiver Characteristics in Predicting Institutionalization

Many researchers have provided evidence for the key role the characteristics of caregivers play in the decision to institutionalize someone they care for with PDD (e.g., Colerick & George, 1986; Gilhooly, 1986; Pushkar Gold, Feldman Reis, Markiewicz & Andres, 1995; Liberman & Kramer, 1991; Morris et al., 1988; Newans, Forster & Kay, 1995; Zarit, Todd & Zarit, 1986). Haupt and Kurz (1993) reported that relatively more women than men became institutionalized and that caregivers caring for spouses were over-represented in the group of patients being cared for at home. Colerick and George (1986) found that caregivers who are relatively younger, female, employed outside the home and earning above-average incomes, experiencing high levels of stress, dissatisfied with their leisure activities, and self-medicating with psychotropic medication were more likely to admit their spouse or parent to institutional care. When dementia sufferers played a central role for the caregiver (particularly in a spousal relationship), when the caregiver had been functioning longer in the caregiving role, had greater satisfaction in the caregiving role, and needed relatively little outside assistance to continue caregiving, the likelihood of the continuance of home maintenance was increased (Colerick & George, 1986; Pruchno, Michaels and Potashnik, 1990). Not all researchers have found

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predictive value in the caregiver relationship with the patient (e.g., O'Donnell, Drachman, Barnes, Peterson, Swearer and Lew, 1992). Gilhooly (1986) and Morycz (1985) found that caregivers who had fewer supports and also had to deal with many other demands in their lives were more likely to opt for institutionalization. Caregivers who have higher levels of burden initially and were more involved in the daily tasks of the care receiver were also more likely to choose to institutionalize (Brown, Potter and Foster, 1990; Morycz, 1985).

The relation of service use and caregiver burden has been examined by Brown et al. (1990), who found that caregiver burden predicted both the use of community services and institutionalization. The impact of service use on pre-empting the need to institutionalize is unclear, with some studies having demonstrated that service use is helpful in maintaining community placement (e.g., Rabins, 1996), while some studies have noted a greater likelihood of institutionalization when many community services are involved (e.g., Haley, 1989). Mittleman et al. (1993) found that there is no effect of service use on future institutionalization. Caregivers' desire to institutionalize is also strongly related to a final decision to institutionalize (Haupt & Kurz, 1993; Morycz, 1985; Pruchno et al., 1990). Caregiver reports of strain and stress appear to be related not only to the desire to institutionalize (Morycz, 1985) but to actual placement as well (Colerick &George, 1986).

<u>Patient Characteristics in Institutionalization</u>

Researchers have also highlighted patient characteristics (as measured by mental status performance, neuropsychological performance, or competence in activities of daily living) as crucial in understanding the institutionalization process in persons with dementia (e.g., Cohen, Tell & Wallack, 1986; Drachman et al., 1990; Heyman et al., 1987; Knopman et al., 1988; Mittleman et al., 1993; Nygaard, 1991; O'Donnell et al., 1992; Severson et al., 1994).

Some researchers have reported that the severity of cognitive decline is an important predictor variable in the caregiver's decision to institutionalize a care receiver (Green and Ondrich, 1990; Heyman et al., 1987; Knopman et al., 1988). Among factors associated with nursing home admissions Green and Ondrich (1990) reported that individuals with greater cognitive impairment had 1.6 times the odds of admission than did other individuals admitted to nursing homes, while those with impairment in functional skills demonstrated a 1.7 times higher risk factor. Heyman et al. (1987) noted that language disability, memory loss, and other cognitive difficulties at entry into their study predicted subsequent admission to nursing homes or other chronic care institutions. Knopman et al. (1988) also found that patient functional status (including cognitive skills, functional skills, and presence of behavioural problems) at the initial visit were predictive of subsequent institutionalization and of death. Pushkar Gold et al. (1996) determined in a

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longitudinal study that initial scores on the HDS significantly predicted patient institutionalization or death. Further, although some studies have reported that patient status does not play an important role in predicting institutionalization (e.g., Colerick & George, 1986; Zarit et al., 1986), these studies restrict the range of severity of dementia. It is possible as well that the link between patient functioning and institutionalization could be affected by an overly diagnostically heterogeneous sample (Knopman et al., 1988). Severson et al. (1994) found cognitive and functional status of a dementia patient to be related to risk for institutionalization. Although specific caregiver variables other than the number of other caregivers actively involved (such as caregiver burden or well-being) were not evaluated, the authors argued that the key role of patient cognitive and functional status remains prominent, and that caregiver variables may only serve to mediate the relationship between patient variables and institutionalization.

Other studies have highlighted the importance of behaviour problems such as incontinence, impaired communication, poor hygiene, aggression, and irritability in understanding the decision to institutionalize (Chenowith, 1986; Hutton, Dippel, Loewenson, Mortimer & Christians, 1985; Zimmer, Watson & Treat, 1984). Mittleman et al. (1993) have proposed incontinence as being a key component in the decision of the caregiver to institutionalize the patient although behavioural challenges as wandering, hallucinations, and delusions did not. O'Donnell et al. (1992) reported that incontinence (as

part of overall functional impairment) combined with behavioural challenges

is predictive of institutionalization. Specific behaviour disorders which

predicted institutionalization included incontinence, paranoia, aggressive

behaviour, irritability, hallucinations and delusions, loss of regard for the

feelings of others, and inappropriate sexual behaviour (O'Donnell et al.,

1992). Steele, Rovner, Chase and Folstein (1990) suggest that behaviour

problems in daily living such as agitation, restlessness, delusions, or

depression are key in understanding placement. Magni, Binetti, Bianchetti

and Trabucchi (1996) note that behaviour problems, and specifically

delusions, are related to nursing home placement. Heyman et al. (1987)

found that gender and age were significance predictors of institutionalization,

however, these findings have not been supported by several other

investigators (Drachman et al., 1990; Knopman et al., 1988; O'Donnell et

al., 1992; Steele et al., 1990).

Caregiver and Patient Variables Interact in Desire to Institutionalize

Both patient and caregiver variables are important in understanding the

process of institutionalization of dementia patients (Brodaty et al., 1993).

Haupt and Kurz (1993) indicated that a compilation of care receiver variables

(specifically older age, more severe global cognitive decline, incontinence,

depression, angry outbursts, and aggression) as well as the caregivers' desire

to end the caregiving role differentiated among Alzheimer patients living at

home and those recently admitted to a nursing home, as well as predicted

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nursing home placement. Pruchno et al. (1990) highlighted that the impact on actual institutionalization is a result of a combination of caregivers' desire to institutionalize, length of time spent as a caregiver, religion, uplifts, and forgetful behaviours of the patient. The work of Stuckey et al. (1996) also highlighted that although an understanding of burden and well-being is important in understanding the experience of caregiving, once the relationship to the care receiver and severity of care receiver dementia was controlled for, no burden measures and only one well-being measure were significant predictors of likelihood to institutionalize. They suggest that although burden and well-being may both be affected by the caregiving experience, they do not contribute independently to the maintenance of the caregiving role.

The decision to institutionalize may only partly be predictable on the basis of caregiver, patient, and situational variables. Hamel et al. (1990) found that unpredictable aspects regarding the decision to institutionalize were important, in that unpredictable extraneous circumstances such as illness of another relative or physical illness of the patient sometimes precipitated institutionalization. Cohen et al. (1993) have also broadened understanding of the factors which determine the decision of caregivers to institutionalize a care receiver with dementia. These researchers specifically attempted to predict which caregiver-care receiver dyads would choose to maintain community care rather than seek institutional placement. Cohen et

al. (1993) were more successful in predicting which dyads would choose community care (93%) versus placement (49%) at the point of initial assessment. A significant portion of those caregivers who had originally chosen community care, however, had opted for placement at an 18 month follow-up. A subgroup of these "changers" provoked specific concern as some care providers assumed that they could continue the care arrangement under any circumstances and did not have solid future plans; these caregivers were likely to seek placement in a crisis situation. Cohen et al. (1993) report that a combination of caregiver, care receiver, and situational variables are important in determining both the decision to institutionalize and actual institutionalization.

Implications of Institutionalization

The decision to institutionalize someone with dementia can be viewed as a process which occurs over time and often family members require a good deal of support to make the final move towards institutional care (Chenowith, 1986). Researchers have also found that the caregiving role does not necessarily end at the point of institutional placement, but rather the caregiving role undergoes a change (Pushkar Gold et al., 1995; Zarit & Whitlatch, 1992, 1993). Caregivers generally do not give up their role, but rather shift the responsibility for caregiving. Both Brown et al. (1990) and Haley (1989) reported that caregivers experienced a reduced level of burden or stress following placement, although Zarit and Whitlatch (1992, 1993)

note that many caregivers continue to experience significant stress once their role changes.

Survival of dementia patients is shorter than that of patients institutionalized for other debilitating conditions (Herbert, Parlato, Lese, Dabaj, Forette & Boller, 1995). Once a person with PDD enters an institutional setting, it is not unusual for their death to occur relatively soon, with rate of decline being a significant factor (Brodaty et al., 1993). Herbert et al. (1995) found that although the severity of dementia did not predict length of survival, the combination of dementia and loss of functional capacities was important in predicting survival, although similar results were not obtained by Magni et al. (1996). Zubenko, Mulsant, Sweet, Pasternak and Tu (1997) report that in their study population, 56.6% of patients with Alzheimer disease were alive at two-year follow-up, compared to only 45.5% of patients with multi-infarct dementia. Patients with dementias of mixed or uncertain etiologies also had a poor survival rate; only 50% were alive at the end of the surveillance period.

Purpose of Study and Hypotheses

Better understanding of the nature of dementia is important in providing patients, families, and service providers with more complete knowledge regarding the disease. The skills of dementia patients are known to decline, and it is becoming increasingly evident that each dementia patient does not deteriorate following a common prescribed path. Evaluating

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dementia with an assessment tool validated against currently accepted and utilized measures, and which considers current issues related to the nature of disease progression, provides a valid and thorough indication of the skills and deficits presented by the patient. It is also important to evaluate the variability among dementia patients in understanding the differences in patient and caregiving needs. Understanding the impact of PDD on the lives of persons who care for family members with dementia within their home environment has significant implications in determining the best method of supporting such caregivers and patients. Specifically, enhancing the understanding of the impact of a care provider's sense of burden and their desire to institutionalize the dementia sufferer may assist service providers and policy makers in understanding the crucial points of intervention to assist in averting costly institutionalization while preserving an acceptable level of quality of life for the care provider.

The overall objective of this study is to assess the utility of the HDS in comparison with other measures of cognitive functioning in dementia patients and to determine the ability of the HDS to differentiate among profiles of patient cognitive functioning. The HDS will also be evaluated regarding its utility as a predictor of caregiver burden and the desire of the caregiver to end home care.

Hypothesis #1

The HDS will be a valid and reliable measure of the cognitive functioning of dementia patients in comparison with other commonly used and established measures of dementia patient cognitive functioning.

The original work of Cole and Dastoor (1980) and Cole et al. (1983) well established concurrent validity with the Blessed Scale and the Chricton Scale. Based on established validity with these scales, it is expected that the HDS will also demonstrate concurrent validity with the Global Deterioration Scale (Reisberg, Ferris, de Leon & Crook, 1982), the Mini Mental State Exam (Folstein, Folstein & McHugh, 1975), and the Clifton Assessment Procedures for the Elderly, revised (Pattie & Gilleard, 1975), measures which are currently more commonly used to evaluate dementia patient functioning in the Montreal area.

Hypothesis #2

The HDS will differentiate among profiles of dementia patient cognitive functioning.

Previous findings of Dastoor and Cole (1985-86) has established the presence of interindividual variability in the pattern of functional decline of dementia patients when measured with the HDS. It is hypothesized that the HDS scores will highlight this interindividual variability in a way which indicates distinct profiles based upon cognitive functioning.

Hypothesis #3

The HDS will be predictive of caregiver burden and desire to end home care of the dementia patient.

Empirical findings (Gallagher-Thompson et al., 1992; Horowitz, 1985; Pearlin et al., 1990) reported that the cognitive functioning of dementia patients is an important variable in understanding the experience of caregiver burden. The findings of Green and Ondrich (1990), Heyman et al. (1987), and Knopman et al. (1988) all indicate that dementia patient cognitive functioning are important in predicting caregivers' desire to institutionalize the persons for whom they care. The findings of Pushkar Gold et al. (1996) further indicated that initial scores on the HDS significantly predicted patient institutionalization or death. It is therefore hypothesized that HDS scores will be significant predictors of both caregiver burden and desire to institutionalize.

Method

One hundred and eighty-five pairs of dementia patients and their primary caregivers were evaluated in this study. Patients involved in the study had received, at least one year previously, a medical diagnosis of progressive dementia, had no additional life-threatening or immobilizing illnesses, and were being maintained in the community with varying degrees of success by relatives who were the primary caregiver. A total of 152 of the patients had diagnoses of Alzheimer disease, 10 had a diagnosis of multi-infarct dementia, and 23 were diagnosed with dementia of unknown etiology. Participant referrals were from many agencies in the Montreal area, including hospitals, daycare centres, community health clinics, and the Alzheimer's Society of Montreal. All dementia patients and their caregivers who fulfilled the study requirements (i.e., where the patient had a diagnosis of Primary Degenerative Dementia and was cared for within their home environment) and who agreed to participate in a study on caregiving of dementia patients were accepted as study participants.

Most primary caregivers were spouses of the patient, a total of 113, however, 52 were children of the patient, and 20 were another relative of the patient (e.g., siblings or relatives by marriage). The mean age of the caregivers was 63.81 years, and they had been functioning in the caregiving role for an average of 3.29 years, ranging from one month to 16 years. The

mean age of the patients was 75.35 years. The sample consisted of participants in both of Canada's official languages, with 112 English speaking caregivers and patients, and 73 French speaking caregivers and patients. Most caregivers, 126, were female, and 59 of the caregivers were male. There were 114 female patients within the sample, and 71 male patients.

Measures

A. Direct Patient Measures

1. The Hierarchic Dementia Scale

The Hierarchic Dementia Scale (HDS) (Cole & Dastoor, 1980; Cole et al., 1983) provided measures of patient functioning in various areas of cognitive functioning such as orientation, memory, praxic and gnostic abilities, language, and motor abilities. This scale facilitates the evaluation of patients with differing levels of cognitive decline ranging from minimal dysfunction to severe dementia. The scale consisted of twenty subscales arranged in a hierarchic fashion from easy to difficult. The maximum score for each subscale was ten and the maximum score for the entire scale was two hundred. The HDS has an inter-rater reliability coefficient of .84, and an alpha coefficient of internal consistency of .97. The scale has a concurrent validity of .72 and .74 with two other established measures of dementia cognitive functioning.

2.   The Mini Mental State Exam

The Mini Mental State Exam (MMSE) (Folstein, Folstein & McHugh, 1975) is a widely applied and easily administered instrument used to assess dementia patient functioning. A total score of thirty is possible. Questions regarding orientation to space and time, short term memory, language, and praxic abilities are considered. The scale has a concurrent validity of .80 with an activities checklist (Ashford, Hse, Becker, Kuman & Bekian, 1986).

B.   Indirect Patient Measures

1.   The Global Deterioration Scale

The Global Deterioration Scale (GDS) (Reisberg, Ferris, de Leon & Crook, 1982) provided a concise estimate of the level at which a dementia patient is currently functioning. The seven stage scale ranges from no cognitive decline, to moderate, and to very severe cognitive decline; dementia begins at the fourth stage. Each level is accompanied by a description of specific cognitive and physical characteristics that the patient would be expected to display. A level of functioning is chosen by matching the description of a level of functioning to the patient's level of functioning via patient and caregiver interviews. The GDS has been validated with behavioural, neuroanatomic, and neurophysiologic measures of patients with primary degenerative dementia.

2.   The Clifton Assessment Procedures for the Elderly

The Clifton Assessment Procedures for the Elderly, revised (Pattie &

Gilleard, 1975) is a well established scale which is extensively used in

Britain. It briefly and easily assesses basic patient physical, cognitive, and

social functioning according to the caregiver. It has been successfully

validated against psychiatric diagnoses and discharge from hospital.

3.   The Memory and Behavior Problem Checklist

The Memory and Behavior Problem Checklist (Zarit, Reever & Bach-

Peterson, 1980; Zarit, 1983; Zarit, Zarit & Reever, 1982; Zarit, Orr & Zarit,

1985) provided an evaluation of the caregiver's subjective impression of the

frequency of the patient's behavioural and memory problems. Caregivers

also indicated whether any particular behaviour had been a problem before

the onset of dementia. The scale is comprised of 28 items that caregivers

are likely to encounter on a daily basis. Caregivers were asked to indicate

how frequently each problem had occurred in the past week. The scale has

been found to correlate with duration of illness and patient impairment in

daily functioning.

4.   Demographic Information

In addition to measures of cognitive functioning, basic demographic

information was gathered for each patient in the form of a standardized

interview given to each caregiver. This information included age, gender,

ethnicity, education, socioeconomic status, marital status, and personal and family history.

C. Caregiver Measures

1. Demographic Information

Caregivers were given a standardized interview obtaining similar basic demographic information to that of the patient. Included in this was a statement on the part of the caregiver as to whether they would consider institutionalizing their patient if a hypothetical "ideal" situation existed (i.e., financially inexpensive, close in proximity, liked and accepted by both patient and caregiver), or if the caregiver would still prefer to continue home maintenance.

2. The General Health Questionnaire

The General Health Questionnaire (Goldberg, 1978, 1979) provided an assessment of the state of caregiver physical and mental health of a very recent nature. The caregiver was additionally asked to indicate whether the presence of a particular complaint was usual or unusual for them. It has a test-retest reliability of .75 and has been found to correlate significantly with clinical assessment of health and feelings of burden.

3. The Burden Interview

The Burden Interview (Zarit, Reever & Bach-Peterson, 1980; Zarit, 1983; Zarit, Zarit & Reever, 1982; Zarit, Eiler & Hassinger, 1985 Zarit, Orr & Zarit, 1985) assessed the extent of burden experienced by the caregiver by

examining the extent to which caring for the patient had a negative effect on the caregiver's public and private life. This scale has been found to correlate with social support indices, the quality of the prior relationship between patient and caregiver, and behavioural problems exhibited by the patient.

<u>Procedure</u>

A pilot study was conducted in order to assess the clarity and comprehensibility of the caregiver interview. Five primary caregivers of mentally or physically impaired patients were administered the complete caregiver package.

Volunteers for the actual study were approached once consent to contact them had been established by the referring agency. Each caregiver and patient was given the option of having the session take place in his or her home or at the University. Interviewers visited in pairs whenever possible to facilitate the speed of the visit and to aid in continued activity with the dementia patient in order to enable the caregiver to respond freely regarding the care situation.

Caregivers were given the option of completing the majority of the questionnaires themselves or replying verbally to the interviewer. The interview is intended to be completed in one session of approximately two hours. However, subsequent sessions were necessary for some participants. Referrals to social service agencies were provided to the caregiver upon request.

The patient assessment package was also intended to be completed in one session. In some cases the caregiver was present during the assessment to offer translation when the preferred language of the patient was neither English nor French, or to offer reassurance. Caregivers were instructed beforehand to avoid cueing the patient as to the appropriate responses. A second visit was occasionally necessary to complete the assessment in the case of a fatigued or uncooperative patient.

A short telephone follow-up interview was conducted six to twelve weeks following the interview. Changes in the caregiving situation (i.e., more or less available help, changes in patient or caregiver health, or patient institutionalization) were evaluated.

Results

Plan of Analysis

The analysis of results is based on 185 pairs of subjects (a person with dementia and the primary caregiver) who each completed an assessment. Dementia patients were directly and indirectly evaluated regarding their cognitive functioning and behaviour problems, while caregivers also completed questionnaires regarding themselves and their relationship with the patient.

A variety of techniques were used in analysing the data:

(1)   Pearson product moment correlations to establish strength of association between the variables. Associations were also specifically examined between indicators of patient function, (i.e., measures of cognitive function and of behaviour problems), as well as between total and subscale scores of the HDS.

(2)   A reliability analysis using Chronbach's alpha on HDS scores in order to examine the internal consistency of the HDS.

(3)   Factor and cluster analyses to examine the patterns of the HDS subscale scores.

(4)   A multivariate analysis of variance (MANOVA) following cluster analysis to examine if the patterns of HDS subscale scores yield identifiable groups based on pattern of decline.

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(5)   Multiple regression analyses (direct and hierarchical) to determine the

impact of patient characteristics on caregiver burden.

(6)   Discriminant function analyses (DFA) to assess caregiver desire to

institutionalize the patient or to continue home maintenance.

Preliminary Analysis

Raw data inspection began with a check for univariate outliers in the

sample. Data entry accuracy and the distribution of all variables were

investigated using SPSS list wise frequency analysis for valid observations.

The minimum and maximum value of the variables were inspected for

plausibility. No cases were rejected for out-of-range factor values.

Examination of the data of the 185 pairs of caregivers and care receivers

with regard to the assumptions of linearity, normality, multicollinearity, and

homogeneity suggested a normally distributed sample which revealed no

threat to the multivariate analyses.

Assumptions of General Linear Model Regression

Regression analyses require a case to variable ration of 4:1

(Tabachnick & Fidel, 1983). In the regressions presented in this study, the

ratio is approximately 11:1 (185 pairs of respondents to 17 independent

variables), which is well above the minimum requirements for regression.

Tests for significance of regression coefficients were computed with 95%

confidence intervals.

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Assumptions of MANOVA

Cochrane's C and Bartlett-Box F were found to be non-significant for univariate homogeneity of variables. Inspection of the Mahalanobis' distance measures for the MANOVA failed to reveal multivariate outliers. Box's M test for all dependent variables was found to be nonsignificant, indicating homogeneity of the variance-covariance matrices.

Assumptions of Discriminant Function Analysis

Box's m test was found to be nonsignificant indicating the existence of homogeneity of the variance-covariance matrices. All cases passed the tolerance test showing that the data set was not adversely affected by multicollinearity and singularity.

Characteristics of the Population Sample

Table 1 provides means and standard deviations for the characteristics of the sample of 185 pairs of persons with Dementia and their primary caregivers. Although there is variation in the demographic and socioeconomic features of the caregivers and care receivers, it is possible to build a general profile. The majority of dementia patients (82.2%) have Alzheimer Disease and are 75 years of age. More than half of these dementia patients are women, have approximately nine years of formal education, and are suffering some cognitive impairment as a result of their condition. These individuals are most often cared for by a spouse, but are often cared for by one of their children or another relative. The typical

Table 1

Characteristics of Population Sample

N = 185

CAREGIVING VARIABLES	Mean	Standard Deviation
Age	63.81	(14.04)
Annual Income	$27 862.73	($22 364.81)
Years of Education	11.21	(4.27)
Years of Caregiving	3.29	(2.61)

Relationship to Patient	Spouse: 113 (61%)	Child: 52 (28%)	Other Relative:20(11%)
Language	English Speaking: 112 (60.5%)		French Speaking: 73 (39.5%)
Gender	Female: 126 (68%)		Male: 59 (32%)
Decision at Interview	Home Maintenance: 139 (75%)		Institutionalize: 46 (25%)
Decision at Follow-up	Home Maintenance: 98 (79%)		Institutionalize: 26 (21%)

CARE RECEIVER VARIABLES	Mean	Standard Deviation
Age	75.35	(8.15)
Years of Education	9.36	(4.29)
HDS Scores	134.57	(49.58)
MMSE Scores	13.79	(8.93)
GDS Scores	3.70	(3.69)

Gender	Female: 114 (62%)	Male: 71 (38%)
Diagnosis	Alzheimer Dementia: 152 (82.2%)	
	Vascular Dementia: 10 (5.4%)	
	Etiology Unknown: 23 (12.4%)	

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caregiver is a woman between the ages of 49 and 77 years, with about 11 years of formal education, and an annual income ranging from well below the poverty line to about $48 000. These individuals have generally been in a caregiving role for about three years and three-quarters of these caregivers wished to institutionalize the person they are caring for.

Psychometric Properties of the HDS

Using the multistage Bonferroni procedure to guard against inflated significance levels, a Pearson correlation matrix among the HDS total score and the HDS subscale scores yielded generally high coefficients (see Table 2), indicating that to a large degree, the HDS is a homogeneous measure and the individual subscale scores are reflective of the patient's overall performance. All subscales correlated significantly with the HDS total score, $p < .001$. Specifically the subscales of Gnosis (the ability to recognize, for example, words, images, and left and right orientation), Concentration, and Drawing are the most correlated with the total HDS score (with correlational values of 0.898, 0.883, and 0.866 respectively), while Recent Memory, although still significant, is the least correlated, with a value of 0.543.

A reliability analysis using Cronbach's alpha was performed in order to examine the internal consistency of the HDS. The Cronbach alpha for the total HDS score is .9714, with individual subscale correlational averages ranging from .7533 to .9532 ($p < .001$) (see Table 3). These high alpha

Table 2

Correlations of HDS Total Score With Subscale Scores

	Correlation[*]
Orienting Reflexes	.71
Prefrontal	.65
Ideomotor	.81
Looking	.74
Ideational	.90
Denomination	.81
Verbal Comprehension	.76
Written Comprehension	.84
Writing	.84
Registration	.85
Gnosis	.90
Reading	.81
Orientation	.77
Construction	.87
Concentration	.88
Calculation	.84
Drawing	.87
Motor	.68
Remote Memory	.77
Similarities	.76
Recent Memory	.54

[*] All correlation coefficients $p < .001$

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Table 3

Alpha Reliabilities of HDS Subscales

	Standardized Item Alpha[*]
Orienting Reflexes	.76
Prefrontal	.83
Ideomotor	.92
Looking	.87
Ideational	.92
Denomination	.94
Verbal Comprehension	.92
Written Comprehension	.95
Registration	.83
Gnosis	.93
Reading	.93
Orientation	.75
Construction	.89
Concentration	.92
Calculation	.95
Drawing	.92
Motor	.91
Remote Memory	.81
Form of Writing	.90
Content of Writing	.94
Similarities	.93
Recent Memory	.88

[*] All correlation coefficients $p < .001$

values indicate that the HDS is a measure with great internal consistency, and that individual subscales are also consistently constructed.

Correlations Among Study Variables

Again using the Bonferroni procedure a second Pearson correlation matrix of the cognitive measures, patient and caregiver demographic variables, and measures of caregiver functioning yielded moderate correlations. Table 4 indicates that the four measures of cognitive function of the dementia patients (HDS, MMSE, GDS, and Clifton) are correlated with each other, with scores reflecting more or less impairment relating to each other in a corresponding manner and ranging from .54 to .86 (p <.05). Specifically the HDS is correlated with the MMSE (.86, p < .05), the GDS (-.74, p < .05), and the Clifton (-.62, p < .05). The HDS is not significantly correlated with caregiver report of patient behaviour problems. The HDS is thus significantly related to scores on other established measures of assessment of dementia patient cognitive abilities, but not to patient behaviour problems.

Factor and Cluster Analyses

An exploratory factor analysis was performed to examine whether the subscales of the HDS would produce relatively independent and coherent patterns. An oblique rotation was used as it was already known that the subscales are correlated with one another. The results of the factor analysis suggest that two factors together explain 70.5% of the variance in HDS

Table 4

<u>Pearson Correlation Coefficients for the Sample</u>

Variable	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. HDS	.86*	-.74*	-.62*	-.12	.05	.09	.09	.01	-.20*	.21*	.07	-.04	-.17*	.01
2. MMSE		-.77*	-.54*	-.25*	-.03	.04	.03	-.04	-.20*	.14*	.04	-.15*	-.16*	.01
3. GDS			.55*	.20*	.02	-.03	-.04	.06	.10	-.13*	-.02	.16*	.23*	-.05
4. Clifton				.05	-.03	-.07	-.03	.08	.25*	-.15*	-.07	.12	.06	.03
5. Behaviour Problems					.73*	.53*	.35*	.11	-.09	.15*	.09	-.05	-.05	-.05
6. Caregiver Reaction						.61*	.51*	.17*	-.09	.22*	.14*	-.10	-.22*	.02
7. Caregiver Burden							.61*	.17*	-.16*	.32*	.18*	-.00	-.23*	.13*
8. Caregiver Health								.06	-.09	.25*	.00	-.03	-.27*	.08
9. Caregiver Income									-.28*	.17*	.44*	.06	.18*	.27*
10. Caregiver Age										-.42*	-.16*	.25*	-.14*	.25*
11. Caregiver Gender											.20˙	.12	-.49˙	-.03
12. Caregiver Education												.19*	.19*	.28*
13. Care Receiver Age													.13*	-.05
14. Care Receiver Gender														-.18*
15. Care Receiver Education														

˙p < .05

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scores, with the HDS subscales are correlated with one another. The results of the factor analysis suggest that two factors first factor accounting for 63.2% of the variance on its own, with the second accounting for an additional 7.3% of the variance. As seen in Table 5, factor loadings range from -.27 to .32 on the first factor, and -.28 to .33 on the second factor. A multivariate analysis of variance (MANOVA) following a cluster analysis examined whether the HDS subscale scores of individual dementia patients would yield separate and identifiable groups of patients in terms of pattern of decline. Specifically, it was examined whether dementia patients could be divided into qualitatively different groups based on cognitive test performance. The cluster analysis was able to produce unique clusters for two and three separate groups. With the use of Wilkes' criterion there was a significant multivariate main effect for cluster membership at the 2-cluster level, F (22,161) = 40.65, p < .001. Follow-up univariate F-tests revealed significant effects for each of the separate subscales (see Table 6). As can be seen from Figure 1, the first group in the 2-cluster level represents 70 low functioning dementia patients while the second group portrays 114 patients who perform at a significantly higher cognitive level. It is evident from the generally parallel structure of the graph that different groups of patients do not perform better or worse on certain subsets of HDS subscales (e.g., language versus praxic abilities). The results suggest instead that dementia patients generally perform consistently well or poorly across the various

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Table 5

Factor Loadings for First and Second Factors

Variable	First Factor Score	Second Factor Score
Orienting Reflexes	-.27	.33
Prefrontal	-.24	.29
Ideomotor	-.19	.26
Looking	-.27	.33
Ideational	.05	.02
Denomination	-.06	.12
Verbal Comprehension	-.11	.18
Written Comprehension	.11	-.04
Registration	.23	-.16
Gnosis	-.02	.09
Reading	-.14	.20
Orientation	.25	-.19
Construction	.07	.00
Concentration	.23	-.16
Calculation	.27	-.20
Drawing	.03	.04
Motor	-.27	.33
Remote Memory	.24	-.18
Form of Writing	-.01	.08
Content of Writing	.15	-.09
Similarities	.32	-.27
Recent Memory	.32	-.28

Table 6

Univariate F-tests Following MANOVA of 2-Cluster Level Groupings

Variable	F[+][*]
Orienting Reflexes	48.97
Prefrontal	44.39
Ideomotor	94.84
Looking	66.48
Ideational	313.46
Denomination	131.50
Verbal Comprehension	108.93
Written Comprehension	437.89
Registration	266.75
Gnosis	233.00
Reading	139.83
Orientation	151.65
Construction	225.21
Concentration	306.06
Calculation	334.27
Drawing	168.13
Motor	51.75
Remote Memory	184.09
Form of Writing	149.56
Content of Writing	206.54
Similarities	210.49
Recent Memory	43.35

[+] all univariate F-tests with (1,182) df

[*] all F-test significant at $p < .001$

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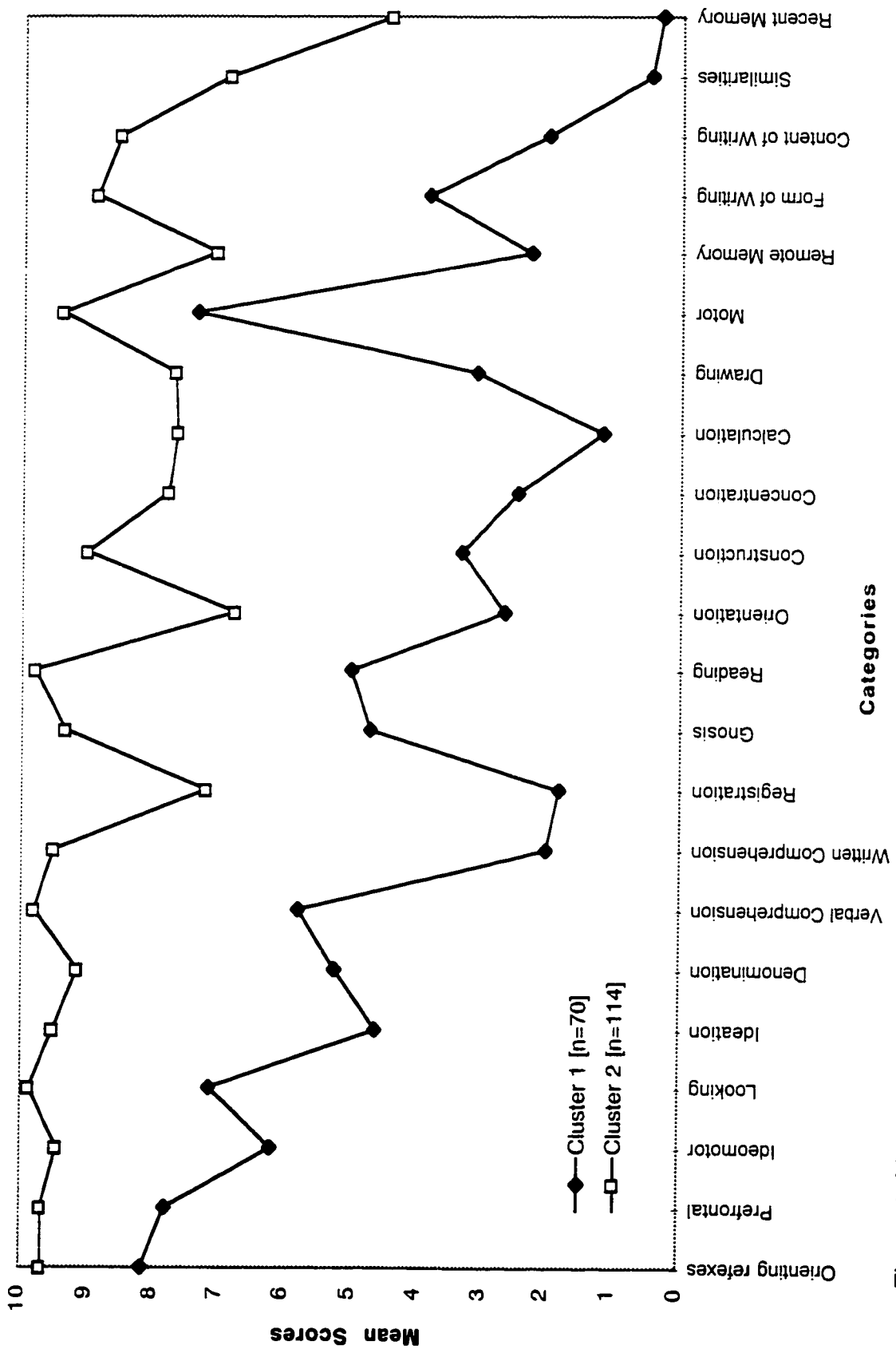
Figure 1: Mean values for HDS subscales for two-cluster groupings following MANOVA.

subscales. MANOVA following the first cluster analysis did not yield significant results in examining the effect of patient age or duration of illness. This finding suggests that the difference between the two cluster groupings are not simply due to age or different stages of the illness. It is unclear, however, what is responsible for the significant effect in forming two cluster groupings; perhaps this effect is explained by individual differences.

At the 3-cluster level, using Wilkes' criterion, there is also a significant multivariate main effect, F (44,320) = 38.44, p < .001, revealing significant effects for each HDS subscale (see Table 7). At the 3-cluster level, a "High" functioning group consisting of 40 patients exists (see Figure 2). The largest group with a membership of 114 patients represents a moderately impaired group, and a "Low" functioning group of 30 patients is also evident. Again, it is evident that the different groups generally perform consistently well or poorly across the subscales as a whole and do not form groups on the basis of better or worse performance on certain groups of subscales, indicating that the differences between groups is in terms of the general degree of impairment and not necessarily based on differential patterns of impairment.

In the three-cluster group there is an effect of the duration of the illness (but not of age), as indicated by MANOVA following the cluster analysis F(4,360) = 4.17, p < .01. When compared to the "high" and "middle" functioning groups, the "low" group had suffered from dementia for

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Table 7
Univariate F-tests Following MANOVA of 3-Cluster Level Groupings

Variable	F^{+*}
Orienting Reflexes	45.59
Prefrontal	40.09
Ideomotor	139.69
Looking	195.48
Ideational	217.57
Denomination	169.02
Verbal Comprehension	112.42
Written Comprehension	252.66
Registration	150.40
Gnosis	241.34
Reading	330.88
Orientation	84.42
Construction	165.67
Concentration	173.37
Calculation	172.80
Drawing	164.25
Motor	44.38
Remote Memory	100.08
Form of Writing	121.96
Content of Writing	113.80
Similarities	104.91
Recent Memory	21.65

[+] all univariate F-tests with (2,181) df

[*] all F-test significant at $p < .001$

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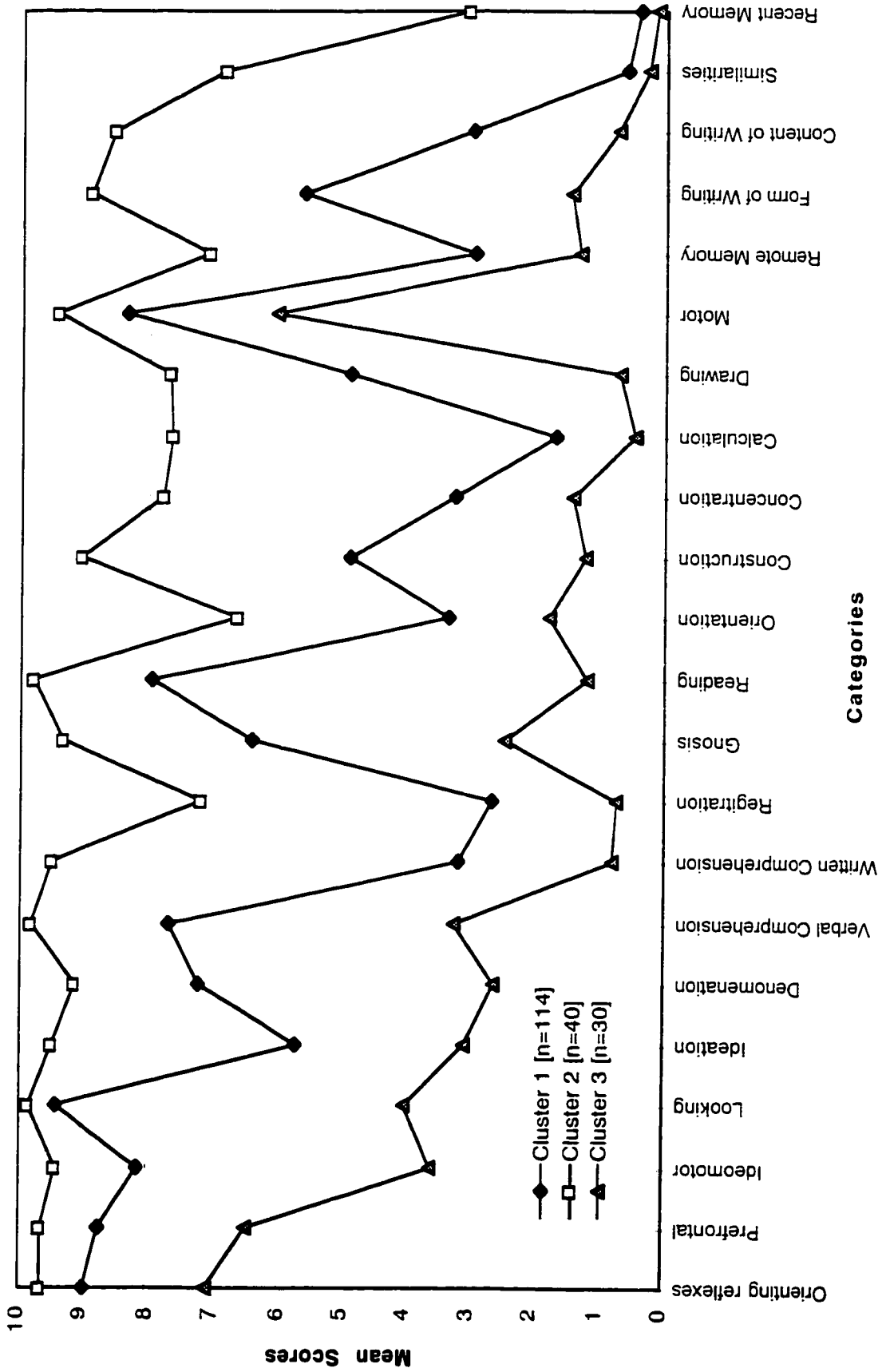
Figure 2: Mean values for HDS subscales for three-cluster groupings following MANOVA.

a significantly longer period of time. It is noteworthy that Recent and Remote Memory, Similarities, Registration, and Orientation subscales are consistent lower points for all groups at both the 2 and 3 cluster levels, indicating that these cognitive abilities are likely to be the most impaired among various patterns of decline.

Regression Analyses Predicting Caregiver Burden

Multiple regression analyses were performed in order to determine the impact of patient characteristics on caregiver experience of burden. Care receiver diagnosis; cognitive status measures (HDS, MMSE, GDS, and Clifton) and behaviour problems; care receiver age, gender, and education; caregiver age, gender, education, and relationship to patient; and self-perceived health were used as variables in predicting caregiver burden. As shown in Table 8, the results of a direct regression indicates that both caregiver self-reported health and caregiver reported patient behaviour problems are significant determinants of caregiver burden; there is no significant effect of patient cognitive measures, including the HDS, in predicting burden. A total of 55.5% of the variance in burden scores was explained by the variables in the equation, $F(17,167) = 12.25$, $p < .001$. Although the level of patient education, the length of time the caregiver had been providing care to the patient, and the extent of caregiver reaction to patient behaviour problems were not significant predictors, they did approach significance as trends in the data ($p < .08$). The results indicate that

Table 8

Direct Regression Analysis Predicting Caregiver Burden

Variables	Beta	r	sr²	t
Relationship to Care Receiver	.07	-.06	.03	.62
Caregiver Health	.39	.59	.32	6.24*
GDS Score	-.01	-.03	-.01	-.14
Diagnosis	-.07	-.01	-.06	-1.23
Years of Caregiving	.10	-.00	.10	1.87**
Care Receiver Education	.11	.13	.09	1.73**
Care Receiver Age	.05	-.00	.03	.62
Behaviour Problems	.29	.52	.19	3.65*
Caregiver Income	-.01	.16	-.01	-.10
Caregiver Gender	.13	.32	.07	1.42
Caregiver Education	.08	.18	.07	1.30
Clifton Score	-.02	-.06	-.02	-.30
MMSE Score	.09	.04	.04	.87
Care Receiver Reaction	.15	.59	.09	1.78**
Caregiver Gender	-.00	-.23	-.00	-.05
Care Receiver Age	-.11	-.16	-.06	-1.16
HDS Score	-.05	.09	.02	-.43

$R^2 = 55.5\%$ $F(17,167) = 12.25$

* $p < .001$

** $p < .10$

caregivers who care for patients that they perceive as having more behavioural symptoms of dementia (but not necessarily those patients who score lower on objective measures of cognitive functioning) experience a greater sense of burden from the caregiving situation.

A hierarchical regression analysis using the same variables as in the direct regression was performed in order to allow the non-patient-based measures and demographic variables to serve as covariates for the four cognitive status measures and caregiver reported patient behaviour problems. As can be seen in Table 9, the variables which are controlled by being entered in step 1 of the regression equation account for 51.89% of the variance in burden scores $\underline{F}(12,172) = 15.46$, $\underline{p} < .001$. Caregiver self-reported health and caregiver reaction to the extent of reported patient behaviour problems were significant in predicting self-reported burden; caregiver gender and caregiver level of education were revealed as trends in the data ($\underline{p} < .11$). When the second block of the patient-based variables was allowed to enter, a total of 55.49% of the variance was accounted for $F(17,167) = 2.70$, $p < .001$, with the R^2 change of 4%. Caregiver health continues to be a strong predictor of burden, and actual reported behaviour problems replaces reaction as a predictor of burden. Years of caregiving, patient education, and reaction to behaviour problems remain as trends in predicting caregiver burden ($\underline{p} < .08$). These results indicate that caregivers who report they are in poorer health and care for patients they perceive as

Table 9

Hierarchical Regression Analysis Predicting
Caregiver Burden Controlling for Demographic Variables

STEP 1

Variables	Beta	r	sr²	t
Relationship to Care Receiver	.07	-.06	.03	.66
Caregiver Health	.38	.59	.32	6.09*
Diagnosis	-.06	-.01	-.06	-1.05
Years of Caregiving	.08	-.00	.07	1.38
Care Receiver Education	.10	.13	.08	1.57
Care Receiver Age	.04	-.00	.02	.48
Caregiver Income	-.02	.16	-.02	-.37
Caregiver Gender	.15	.32	.09	1.69**
Reaction to Behaviour Problems	.36	.59	.30	5.59*
Caregiver Education	.09	.17	.07	1.36
Care Receiver Gender	.04	-.23	.02	.40
Caregiver Age	-.12	-.16	-.06	-1.18

$R^2 = 51.89\%$ $F(12,172) = 15.46$

STEP 2

Variables	Beta	r	sr²	t
Relationship to Care Receiver	.06	-.06	.03	.62
Caregiver Health	.38	.59	.32	6.24*
Diagnosis	-.07	-.01	-.06	-1.23
Years of Caregiving	.10	-.00	.10	1.87**
Care Receiver Education	.11	.13	.09	1.73**
Care Receiver Age	.04	-.00	.03	.62
Caregiver Income	-.01	.16	-.06	-.10
Caregiver Gender	.13	.32	.07	1.42
Reaction to Behaviour Problems	.15	.58	.09	1.78**
Caregiver Education	.08	.18	.07	1.30
Care Receiver Gender	-.00	-.23	-.00	-.05
Caregiver Age	-.11	-.16	-.06	-1.16
GDS Score	-.01	-.03	-.01	-.14
Clifton Score	-.02	-.06	-.02	-.30
Behaviour Problems	.29	.52	.19	3.65*
MMSE Score	.09	.04	.04	.87
HDS Score	-.05	.09	-.02	-.43

$R^2 = 55.49\%$ $F(17,167) = 7.70$ R^2 Change = 4%

* $p < .001$ ** $p < .10$

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more difficult experience a greater sense of burden, and that the actual level of cognitive deficit present in the patient is less important.

Discriminant Function Analyses Predicting Desire to Institutionalize

A direct discriminant function analysis was performed using caregiver and care receiver variables as predictors of membership within two groups. Predictor variables were caregiver and care receiver demographic variables, care receiver cognitive status measures, behaviour problems, caregiver health, and caregiver burden. The two groups were caregivers who desired to institutionalize the dementia patient for whom they cared or who desired to continue home maintenance at the time of the original interview.

One discriminant function was calculated which correctly classified groups in 71.4% of cases (X^2 = 40.51, $p < .001$). As can be seen from Figure 3, the discriminant function maximally separates caregivers desiring to continue home maintenance and those who wish to institutionalize the dementia patient.

A loading matrix of correlations between predictor values, as seen in Table 10, suggests that the important variables in distinguishing between caregivers desiring institutionalization over home maintenance are self-rated burden and health, reported behaviour problems for the dementia patient, caregiver education, and income ($p < .01$). Relationship of caregiver to care receiver and caregiver age emerged as trends ($p < .10$) in predicting group membership. Caregivers who are feeling more burdened and in poorer

Group 1 - Continue Home Maintenance: -.30

Group 2 - Institutionalize: .90

Figure 3. Plot of two group centroids on one discriminant function derived from 16 caregiver and care receiver variables at time of original interview.

Table 10

Discriminant Function Analysis of Caregiver Desire to Institutionalize or Continue Home Maintenance at Time of Original Interview

Predictor Variables	Correlations of Predictor Variables with Discriminant Functions	Univariate $F_{(1,183)}$
Years of Caregiving	-.13	.78
Relationship to Care Receiver	-.25	3.18**
Diagnosis	.17	1.37
Caregiver Gender	.09	.37
Caregiver Education	.46	10.27*
Caregiver Age	-.24	2.88**
Care Receiver Gender	.09	0.33
Care Receiver Education	.10	.47
Care Receiver Age	-.04	.71
Caregiver Health	.51	13.07*
Behaviour Problems	.44	9.68*
Caregiver Burden	.70	24.56*
Income	.36	6.52*
HDS Score	-.02	0.26
MMSE Score	-.16	1.29
GDS Score	.19	1.86
Clifton Score	.09	.42
Canonical R	.46	
Eigenvalue	.270	

$*$ $p < .01$
$**$ $p < .10$

health, who perceive their care receiver to have more behaviour problems, who are younger, who have more formal education and more financial resources are more likely to desire institutionalization of the dementia patient for whom they care. The strongest predictive contribution is caregiver self-rated burden.

A second discriminant function analysis was performed using the same variables and groups as before, but including the predictor variable of Care Receiver Change. This analysis examines group membership of home maintenance versus institutionalization for those caregivers whose care receivers still lived at home at the time of a six week follow-up. The Care Receiver Change variable represents those caregivers who changed their minds regarding their desire to institutionalize or to continue home maintenance.

Of the original 185 cases, 64 were excluded from the analysis due to missing data, which in some cases represented caregivers who could not be reached for follow-up, or when care receivers no longer lived at home due to institutionalization or death. The remaining missing data were scattered over cases and variables, with no evident patterning on the basis of grouping or demographic variables.

One discriminant function was calculated from the remaining 121 cases which correctly classified groups in 78.51% of cases (X^2 = 33.70, p<.01). As shown in Figure 4, the discriminant function separates

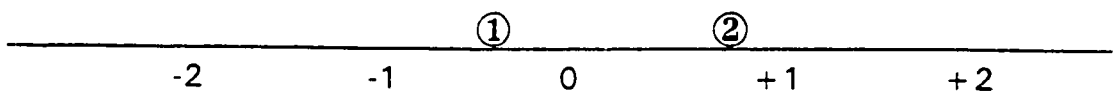Group 1 - Continue Home Maintenance: -.30

Group 2 - Institutionalize: 1.19
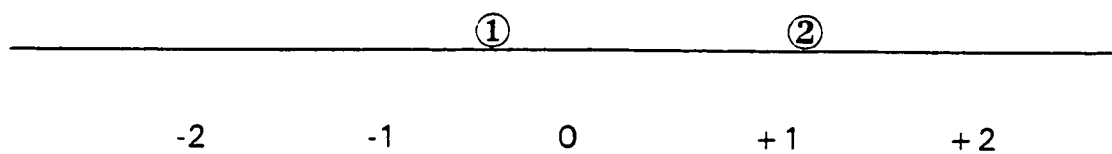
Figure 4. Plot of two group centroids on one discriminant function derived from 17 caregiver and care receiver variables at time of follow-up.

caregivers desiring to continue home maintenance and those who wish to institutionalize at the time of the follow-up survey.

A loading matrix of correlations between predictor values, as seen in Table 11, indicates that the variables of caregiver burden, caregiver health, and behaviour problems are important in distinguishing between caregivers who desire institutionalization or home maintenance at the time of follow-up. Caregivers health and burden are especially key in distinguishing between the two groups ($p<.001$), as well as care receiver behaviour problems, although to a lesser extent ($p<.05$). Years of caregiving, caregiver education, and income emerge as trends ($p<.10$) in predicting group membership. At the time of follow-up, caregivers who were feeling more burdened and in poorer health, and whose care receiver experiences more behaviour problems were more likely to desire to institutionalize the dementia patient for whom they cared.

Table 11
Discriminant Function Analysis of Caregiver Desire to Institutionalize or Continue Home Maintenance at Time of Follow-Up

Predictor Variables	Correlations of Predictor Variables with Discriminant Functions	Univariate $F_{(1,119)}$
Years of Caregiving	-.26	2.89***
Relationship to Care Receiver	.07	.20
Diagnosis	-.10	.40
Caregiver Gender	.20	.78
Caregiver Education	.25	2.68***
Caregiver Age	.03	.43
Care Receiver Gender	-.20	1.77
Care Receiver Education	.11	.58
Care Receiver Age	-.02	.19
Caregiver Health	.52	11.55*
Behaviour Problems	.30	3.89**
Caregiver Burden	.74	23.35*
Income	.26	3.07***
HDS Score	-.01	.23
MMSE Score	.02	.10
GDS Score	.04	.54
Clifton Score	.21	1.92
Care Receiver Change	.07	.20
Canonical R	.46	
Eigenvalue	.270	

*$p < .001$
**$p < .05$
***$p < .10$

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Discussion

Hypothesis 1 - <u>The HDS will be a reliable and valid measure of the cognitive</u>

<u>functioning of dementia patients in comparison with other established</u>

<u>measures of dementia patient cognitive functioning</u>

The results of the study provide evidence indicating that the HDS is

indeed a reliable and valid measure of the cognitive functioning of dementia

patients. When compared with other popular measures of dementia patient

functioning (namely the MMSE, GDS, and Clifton rating scales), the HDS is

correlated in a manner which indicates that better functioning on the HDS

also reflects better functioning on each of the other measures. This

significant correlational finding indicates that the HDS is a valid measure as

HDS scores are consistent with the outcome scores of other standard

measures. The finding offers validation as well for the concept of viewing

dementia in a reverse-Piagetian fashion. Measures of dementia patient

cognitive functioning generally correlate as well with behaviour problems

exhibited by the patient (e.g., Rasmussan et al, 1996; Taft & Cronin-Stubbs,

1995). Although, within this particular sample the HDS was not significantly

correlated with the caregiver rating of patient behaviour problems, a trend

regarding a negative relationship between these measures (i.e., higher patient

functioning related to fewer behaviour problems) is evident.

The internal consistency of the HDS has also been established. An

examination of the relation between HDS total score and the HDS subscales

reflects positive correlations. This outcome indicates that each subscale is significantly related to the total score. Internal consistency is also demonstrated through the outcome of an internal reliability analysis showing high correlations with each other item. High alpha values suggest that individual subscales are consistently constructed. Consequently, as indicated by the correlational coefficients among the HDS and its subscales, performance on separate subscales is indicative of the total HDS score. Strong internal consistency of this nature suggests also that a short form of the HDS may be an appropriate and valid alternative to the complete HDS, as suggested by Pushkar Gold et al. (1996).

Hypothesis 2 - The HDS will differentiate among profiles of dementia

patient cognitive functioning

The results of both the factor and cluster analyses suggest that the HDS reflects up to three distinct groupings regarding the functioning of dementia patients. It is evident that in the less affected group orientation, memory (both recent and remote), confrontational naming, and abstract thinking, are more impaired, with the relative preservation of functions such as comprehension, motor, ideational, and construction skills. The moderately and severely affected groups see a correspondingly drastic decline in what was already most impaired within the first cluster, but still relative sparing of the less affected skills (i.e., the cluster profiles are generally parallel to each other).

The findings of the cluster analyses are consistent with the previous work of Dastoor and Cole (1985-86) who found considerable inter-individual variability in patterns of decline using the HDS, and are also generally consistent with the work of Burns et al. (1991) who suggest that cognitive functioning becomes aligned within the three clusters of mild, moderate, and severe. There is no support for subgroup divisions among the clusters (i.e., differential patterns of impairment around groups of skills, such as Price et al, (1993)), but rather inter-individual variations are best understood in the context of duration of illness, similar to the findings of Jorm (1985) who also stressed qualitative rather than quantitative differences among patient functioning.

Hypothesis 3 - The HDS will predict caregiver burden and desire to

end home care of the dementia patient

Caregiver related health and patient behaviour problems were predictive of caregiver burden, while the cognitive status of the patient (including the HDS score) was not predictive of burden. It was expected that the results of this study would indicate a predictive relation between cognitive decline and caregiver burden, as in the work of Horowitz (1985) and Pearlin et al (1990). The findings of this study, however, indicate that in understanding the caregiver experience of burden, the caregiver's perception of the extent of the care receiver's behaviour problems is more important than the care receiver's actual objective deterioration.

The finding that the behaviour problems displayed by the dementia patient was predictive of caregiver burden while the objective cognitive measures were not raises the interesting question of the relation between behaviour problems and cognitive deterioration. The literature is mixed in regard to this relation with researchers such as Cooper et al. (1990) and Kurita et al. (1993) indicating a positive relation between cognitive deterioration and behaviour problems, while Lloyd et al. (1995) and Teri et al. (1989) did not support such a relation. An examination of cognitive deterioration and behaviour problems within this study unfortunately does not serve to illuminate their relation. Although correlational in nature, behaviour problems are significantly related to some measures of cognitive functioning, but not all. Reported behaviour problems are correlated at a lower level with the MMSE and the GDS, but not the Clifton. Although not significant, there is however a trend for a positive relation between the HDS and reported behaviour problems.

It is clear that caregiver variables are not solely responsible for understanding caregiving burden, as claimed by Morris et al (1988). It is important to consider both caregiver and care receiver characteristics, such as in the work of Draper et al (1995) who highlight the multifactorial nature of caregiver burden as including aspects such as patient behaviour problems as well as caregiver health. Obviously this is an area which would benefit from continued research.

The results of this study also suggest that both caregiver and care receiver variables are important in understanding a care receiver's decision to seek to institutionalize the person for whom they care, although, as a group, caregiver variables play a more significant role. The level of burden which the caregiver perceived was the most relevant feature in understanding the desire to institutionalize, followed by caregiver health, caregiver level of education, patient behaviour problems, and level of income (at the time of the original interview; only burden, health, and behaviour problems predict at six-week follow-up). Unlike the findings of many previous researchers (e.g., Green & Ondrich, 1990; Heyman et al, 1987; and Knopman et al, 1987), cognitive decline was not an important predictor in caregiver decision to institutionalize the care receiver. The HDS is not predictive of caregiver desire to institutionalize and does not aid our understanding of this decision process.

The importance of the role of behaviour problems in determining institutionalization has been well documented (e.g., Hutton et al, 1985; Magni et al, 1996; Mittleman et al, 1993; O'Donnell et al, 1992; Steele et al, 1990). The results of the current study indicate that those caregivers who are feeling more burdened and in poorer health, are more highly educated and have greater financial resources, and whose care receiver displays greater behaviour problems are more likely to have indicated their desire to institutionalize. These findings support previous findings of Colerick &

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George (1986) and Mittelman et al (1993) who have highlighted the complex

interaction between caregiver and dementia sufferer in determining which

caregivers will seek institutionalization for the person for whom they care.

Final Conclusions and Summary

The evaluation of the psychometric properties of the HDS reveal this

measure to be a valid and reliable measure of cognitive functioning in

dementia sufferers. This measure also serves to introduce a reverse

Piagetian framework to our understanding of the cognitive loss in the

dementing process. The results of the factor analyses indicate that there

may in fact be two separate factors and may then warrant the use of a

shorter form of the test, particularly at times when it is difficult to assess a

patient. The cluster analyses suggests that three distinct different groups

are represented in the functioning of dementia patients. Rather than different

subtests representing various clusters however, the clusters appear to run

parallel to each other, and appear to reflect mildly, moderately, and severely

affected groups, reflecting the duration of the patient illness. The inter-

individual variability of persons with dementia is evident and more

longitudinal research with the HDS will further elucidate the issues of

homogeneous versus heterogeneous patterns of decline. Although caregiver

perceived behaviour problems on the part of the care receiver are significant

in understanding the experience of caregiver burden and desire to

institutionalize, the variables representing actual cognitive decline do not

contribute greatly to our understanding of these processes. Our enhanced understanding of the caregiver experience of burden and desire to institutionalize is key in designing services and supports to assist caregivers avoid burnout and live fulfilling lives with the person for whom they care.

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APPENDIX A

THE HIERARCHIC DEMENTIA SCALE

HIERARCHIC DEMENTIA SCALE

(Cole and Dastoor)

Identification _____

Examiner: _____

Date of Exam: _____

Score: _____

Minimal [   ]   Mild [   ]   Moderate [   ]   Severe [▓▓]
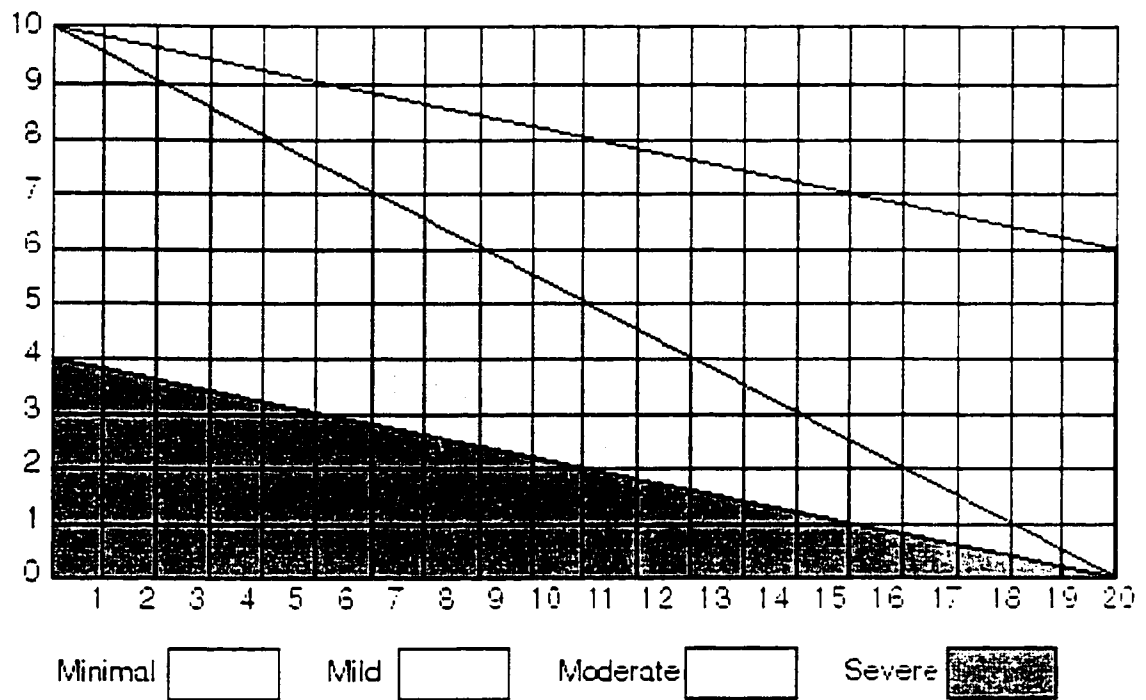
1. Orienting
10. No Impairment
8. Shakes Examiner's Hand
6. Reacts to Auditory Threat
4. Reacts to Visual Threat
2. Reacts to Tactile Threat

2. Prefrontal
10. None
8. Tactile Prehension
6. Cephalobuccal Reflex
4. Orovisual Reflex
2. Oral Tactile Reflex

3. Ideomotor
10. Reversed Hands
9. Double Rings
8. Double Fingers
7. Opposed Hands
6. Single Ring
5. Single Finger
4. Clap Hands
3. Wave
2. Raise Hands
1. Open Mouth

4. Looking
10. Finds Images
8. Searches for Images
6. Grasps content of Picture
4. Scans Picture
2. Looks at Picture

5. Ideational
10. Imaginary Match and Candle
9. Imaginary Nail and Hammer
8. Imaginary Scissors
7. Imaginary Comb
6. Match and Candle
5. Nail and Hammer
4. Scissors
3. Comb
2. Put on Shoes
1. Open Door

6. Denomination
10. No Errors
9. Nominal Aphasia – Parts of Objects
8. Nominal Aphasia – Objects
7. Use of Parts
6. Use of Objects
5. Conceptual Field – Parts
4. Conceptual Field – Objects
3. Sound Alike – Parts
2. Sound Alike — Objects
1. Deformed Words

7. Comprehension
Verbal:
5. Close eyes and touch left ear
4. Clap hands three times
3. Touch your right eye
2. Touch your nose
1. Open mouth
Written:
5. Close eyes and touch left ear
4. Clap hands three times
3. Touch your right eye
2. Touch your nose
1. Open mouth

8. Registration
10. Spoon, candle, scissors, button, whistle
8. Spoon, candle, scissors, button
6. Spoon, candle, scissors
4. Spoon, candle
2. Spoon

9. Gnosis
10. Superimposed Words
9. Superimposed Images
8. Digital Gnosis
7. Right-Left — Examiner
6. Right-Left — Self
5. Body Parts — Examiner
4. Body Parts — Self
3. Touch (pinch) 5 cm
2. Touch (pinch) 5 - 15 cm
1. Response to Touch (pinch)

10. Reading
10. Paragraph
8. Paragraph with error(s)
6. The cat drinks milk
4. Receive
2. Mouth

11. Orientation:

10. Date
8. Month
6. Year of birth
4. Morning or Afternoon
2. First Name

12. Construction

10. Four Blocks Diagonal
8. Four Blocks Square
6. Two Blocks Diagonal
4. Two Blocks Square
2. Form Board Circle

13. Concentration

10. Serial 7's (100, 93, ...)
9. Serial 3's (30, 27, ...)
8. Months of Year Backwards
7. Days of Week Backwards
6. 93 — 85
5. 10 — 1
4. Months of Year Forwards
3. Days of Week Forwards
2. 1 – 10
1. Actual Counting

14. Calculation

10. 43–17
9. 56+19
8. 39–14
7. 21+11
6. 15–6
5. 18+9
4. 9—4
3. 8+7
2. 2—1
1. 3+1

15. Drawing

10. Cube
9. Cube (difficulty with perspective)
8. Two Rectangles
7. Circle and Square
6. Rectangle
5. Square
4. Circle Inside Circle
3. Circle
2. Line
1. Scribble

16. Motor

10. No impairment
9. Increased Muscle Tone – Repeated
8. increased Muscle Tone — Initial
7. Loss of Rhythm
6. Loss of Associated Movements
5. Contractures of Legs
4. Kyphosis
3. Vertical Restriction of Eye Movement
2. Non-ambulatory
1. Lateral Restriction of Eye Movement

17. Remote Memory

10. Amount of pension
8. Number of grandchildren
6. Year of marriage or of first job
4. Father's Occupation
2. Place of Birth

18. Writing

Form:
5. Flowing Style
4. Loss of Flow
3. Letters Misshapen
2. Repetition or Substitution of Letters
1. Scribble

Content
5. No Error
4. Word Substitution
3. Missing Preposition
2. Missing Verb or Noun
V Missing 3 or 4 Words

19. Similarities

10. Airplane — Bicycle
8. Gun — Knife
6. Cat — Pig
4. Pants — Dress
2. Orange — Banana

20. Recent Memory

10. All Five
8. Any Four
6. Any Three
4. Any Two
2. Any One

APPENDIX B

THE MINI MENTAL STATE EXAM

THE MINI MENTAL STATE EXAM

Maximum Score	Score	
		Orientation
5		What is the (year)(season)(day)(month)?
5		Where are we: (state)(country)(town)(hospital)(floor)?
		Registration
5		Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he learns all 3. Count trials and record. Trials:
		Attention and Calculation
5		Serial 7s backward from 100. 1 point for each correct. Stop after 5 answers. Alternatively spell "world" backwards.
		Recall
3		Ask for the 3 objects repeated above. Give 1 point for each correct
		Language
9		Name a pencil, and watch (2 points)
		Repeat the following: "No ifs, ands or buts." (1 point)
		Follow a 3-stage command: "Take this paper in your right hand, fold it in half and put it on the floor." (3 points)
		Read and obey the following "Close your eyes" (1 point)
		Write a sentence (1 point)
		Copy design (1 point)
_____		TOTAL SCORE

APPENDIX C

THE GLOBAL DETERIORATION SCALE

THE GLOBAL DETERIORATION SCALE

1. No cognitive decline – Normal
    No subjective complaints of memory deficit. No memory deficit evident on clinical interview.

2. Very mild cognitive decline – Forgetfulness – Normal for age
    Subjective complaints of memory deficit, most frequently in following areas: Forgetting where one has placed familiar objects, forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficit in employment or social situations.

3. Mild cognitive decline – Early Confusional – Compatible with onset of AD
    Earliest clear—cut deficits. Manifestations in more than one of the following areas: Patient may have gotten lost when travelling to an unfamiliar location, co-worker s and family aware of relatively poor performance, word and name finding deficit becomes evident to intimates, patient may read a passage or a book and retain relatively little material, decreased facility in remembering names upon introduction to new people, lost or misplaced an object of value, concentration deficit may be evident on clinical testing. Objective evidence of a memory deficit obtained only with an intensive interview.

4. Moderate cognitive decline – Late confusional – Mild AD
    Clear—cut deficit on careful clinical interview. Deficit manifest in following areas: Decreased knowledge of current and recent events, may exhibit some deficit in memory of own personal history, concentration deficit elicited on serial subtractions, decreased ability to travel, handle finances,etc.

5. Moderately severe decline – Early dementia – Moderate AD
    Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of own current life (e.g., address, names of grandchildren), frequently some disorientation to time or to place, difficulty with simply serial subtractions. Persons at this stage retain knowledge of many major facts regarding themselves and other. They invariably know their own names and generally know their spouses and children's names. They require no assistance with toileting or eating, but may have some difficulty in choosing the proper clothing to wear.

6. Severe cognitive decline – Middle dementia – Moderately Severe AD
    May occasionally forget the name of spouse, entirely dependent on others for survival, largely unaware of all recent events and experiences in own life, retain some knowledge of past lives, generally unaware of surroundings, may have difficulty counting backwards or even forwards, may become incontinent, inability to travel alone to most places (but sometimes may know way to very familiar location), diurnal rhythm likely disturbed, usually recall own name. Personality and emotional changes occur. They are often variable and include delusional behaviour (e.g., spouse is an imposter), talking to imaginary figures or own mirror reflection, obsessive symptoms, and aggression.

7. Very severe cognitive decline – Late dementia – Severe AD
    All verbal abilities are lost (frequently only grunting), incontinent of bladder and sometimes bowel, assistance required in toileting and feeding, loss of basic psychomotor skills (e.g., walking). Generalized and cortical neurologic signs and symptoms are frequently present.

APPENDIX D

THE CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY. REVISED

CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY (CAPE) -- REVISED

Behaviour Rating Scale

Please circle the appropriate number for each item:

1. With regard to walking, he/she:
   - shows no signs of weakness
   - walks slowly without aid, or uses a stick
   - is unable to walk, or if able to walk, needs frame, crutches or someone by his/her side

2. He/she keeps him/herself occupied in a constructive or useful activity (works, reads, plays games, has hobbies, etc.):
   - almost always occupied
   - sometimes occupied
   - almost: never occupied

3. He/she socialises with others:
   - does establish a good relationship wi:n others
   - has some difficulty establishing good relationships
   - has a great deal of difficulty establishing good relationships

4. He/she is willing to do things suggested or asked of him/her:
   - often goes along
   - sometimes goes along
   - almost never goes along

5. He/she understands what you communicate to him/her (you may use speaking, writing, or gesturing):
   - understands almost everything you communicate
   - understands some of what you communicate
   - understands almost nothing of what you communicate

6. He/she communicates in any manner (by speaking, writing or gesturing):
   - well enough to make him/herself easily understood at all times
   - can be understood sometimes or with some difficulty
   - can rarely or never be understood for whatever reason

7.   With regard to eyesight, he/she:

- can see (or can see with glasses)
- partially blind
- totally blind

8.   With regard to hearing, he/she:

- has no hearing difficulties, without hearing aid
- has no hearing difficulties, though requires hearing aid
- has hearing difficulties which interfere wits communication
- is very deaf

APPENDIX E

CAREGIVER INTERVIEW

INTERVIEW

1. Sex   (1) Male _____   (2) Female _____

2. Age _____
   Ethnic Origin _____   Preferred Language _____

3. Marital Status: (1) single _____   (3) divorced or separated _____
                     (2) widowed _____   (4) married _____

4. Religion: (1) Protestant _____   (4) other _____
                (2) Catholic _____   (5) None _____
                (3) Jewish _____

5. How many years of education do you have (last grade/level completed)?
   1 2 3 4 5 6 7 8   9 10 11 12   13 14 15 16   17 18 19 20 21 22 23 24 25
   Grade School   High School   College   Graduate or Professional

6. What is/was your occupation?_____
   Blishen _____

7. Are you employed? FT _____   PT _____   Retired _____   Homemaker _____

8. Caregiver's (& spouse's) total income received from all sources in the past year (nearest thousand): _____

9. Relationship to care-receiver _____

10. Care-receiver's age _____   Care-receiver's sex _____
    Care-receiver's ethnic origin _____
    Care-receiver 's Preferred Language _____

11. Care-receiver 's marital status: (1) single
                                            (2) widowed
                                            (3) divorced or separated
                                            (4) married

12. How many year's of education does care-receiver have (last grade/level completed)?
     1 2 3 4 5 6 7 8   9 10 11 12   13 14 15 16   17 18 19 20 21 22 23 24 25
     Grade School   High School   College   Graduate or Professional

13. What was his/her occupation? _____
    Blishen _____

14. How many children does care-receiver have (living)? Sons _____ Daughters _____
    What are their ages (approximate)? List:

15. Do any of them live within an hour's drive of the care-receiver? If yes, list:

16. Current living arrangement of caregiver:
    Alone _____   With other relative(s) _____
    With spouse only _____   With non-relative(s) _____
    With spouse and children _____
    With spouse and other relative(s) _____
    With child(ren) only _____

17. Do caregiver and care-receiver reside together? Yes _____ No _____
    If no, ask Questions 18, 19, and 20.

18. a) Current type of housing of care-receiver:

    Own house _____
    Apartment In housing designed for the elderly _____
    Apartment not In housing for the elderly _____
    Child's home _____
    Other (specify) _____

18 b) Current living arrangement of care-receiver:

Alone _____
With spouse only _____
With spouse and children _____
With spouse and other relative(s) ___
With child(ren) only _____
With other relative(s) With non-relative(s)

19. a) On the average, how long does it take you to get from your home to care-receiver's home
(i.e. a one-way trip)? Specify: _____

b) How many times per week do you make this trip? Specify:

c) Have you experienced any problems or difficulties in making these trips?
Yes _____   No _____
If yes, specify:

20. In an average week, how much time would you spend with the care-receiver? Specify in
hours: _____

   NOTE: include phone contact with care-receiver and with agencies on care-receiver
                affairs.

21. How long have you been acting as a caregiver for: _____
    Specify: _____

22. Are you aware (or have you been informed) of the cause of _____'s memory problem
(i.e. been diagnosed)?
    Yes _____   No _____
    If yes, specify: _____

DECISION 1

If appropriate facilities were available right now, that is if a nursing home or another place was available right now that you would be happy with, that is not too expensive, that is close, that your would like, would you try to continue to care for _____ at home, or would you change to some other alternative (i.e. placement in an institution or nursing home)?

Continue to maintain: _____   To institutionalize: _____

How sure are you about this decision?

1	2	3	4	5
Not at sure	Uncertain	Somewhat sure	Sure	Very sure

APPENDIX F

GENERAL HEALTH QUESTIONNAIRE

GENERAL HEALTH QUESTIONNAIRE

(please read carefully)
We should like to know if you have had any medical complaints, and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.
Thank you very much for your co-operation.

HAVE YOU RECENTLY:

1.	been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual
2.	been feeling in need of medicine to pep you up?	Not at all	No more than usual	Rather more than usual	Much more than usual
3.	been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
4.	felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
5.	been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
6.	been getting a feeling of tightness or pressure in you head?	Not at all	No more than usual	Rather more than usual	Much more than usual
7.	been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
8.	lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
9.	had difficulty in staying asleep once you go to sleep?	Not at all	No more than usual	Rather more than usual	Much more than usual
10.	felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
11.	been getting edgy and bad tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
12.	been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual

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13. found everything getting to be too much for you?	Not at all	No more than usual	I~Rather more than usual	Much more than usual
14. been reeling nervous and up tight all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
15. been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
16. been taking longer over the things you do?	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
17. Felt on the whole you were doing things well?	Better than usual	About the same	Less than usual	Well Much less well
18. Been satisfied with the way you've carried out your tasks?	More satisfied	About same as usual	Less Satisfied than usual	Much less satisfied
19. felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
20. felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much Less capable
21. been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
22. been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
23. felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
24. felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
25. thought of the possibility that you might do away with yourself?	Definitely not	I don't think so	Has crossed my mind	Definitely have
26. found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
27. Found yourself wishing you were dead and away from it all?	Not at all	No more than usual	Rather more than usual	Much more than usual
28. Found that the idea of taking your own life kept coming into your mind?	Definitely not	I don't think so	Has crossed my mind	Definitely have

APPENDIX G

THE MEMORY AND BEHAVIOUR QUESTIONNAIRE

INSTRUCTIONS TO CAREGIVER

Part A: "I am going to read you a list of common problems. Tell me if any of these problems have occurred during the past week. If so, how often have they occurred?"

• Hand the caregiver the sheet on which the frequency and reaction ratings are printed.

Part B: "How much does this problem bother or upset you at the time it happens?"
• When the caregiver's response to frequency is "7", you determine reaction by asking:
"How much does it bother or upset you when you have to supervise
_____ to prevent that?"

A. FREQUENCY RATINGS:
   0   = never occurred.

   1   = has occurred, but not in past week.

   2   = has occurred 1 or 2 times in past week.

   3   = has occurred 3 to 6 times in past week.

   4   = occurs daily or more often.

   7   = would occur, if not supervised by caregiver
   (e.g. wandering except when door is locked).

   8   = patient never performed this activity
   (eg. male never did housework).

B. REACTION RATINGS:
   0 = not at all

   1 = a little

   2 = moderately

   3 = very much

   4 = extremely

BEHAVIOURS	FREQUENCY	REACTION
1. Wandering or getting lost	0 1 2 3 4 7 8	0 1 2 3 4
2. Asking the same question over and over again	0 1 2 3 4 7 8	0 1 2 3 4
3. Hiding things (money, jewelry, etc.)	0 1 2 3 4 7 8	0 1 2 3 4
4. Being suspicious or accusative	0 1 2 3 4 7 8	0 1 2 3 4
5. Losing or misplacing things	0 1 2 3 4 7 8	0 1 2 3 4
6. Not recognizing familiar people	0 1 2 3 4 7 8	0 1 2 3 4
7. Forgetting what day it is	0 1 2 3 4 7 8	0 1 2 3 4
8. Starting, but not finishing things	0 1 2 3 4 7 8	0 1 2 3 4
9. Destroying property	0 1 2 3 4 7 8	0 1 2 3 4
10. Doing things that embarrass you	0 1 2 3 4 7 8	0 1 2 3 4
11. Waking you up at night	0 1 2 3 4 7 8	0 1 2 3 4
12. Being constantly restless	0 1 2 3 4 7 8	0 1 2 3 4
13. Being constantly talkative	0 1 2 3 4 7 8	0 1 2 3 4
14. Talking little or not at all	0 1 2 3 4 7 8	0 1 2 3 4
15. Engaging in behaviour that is potentially dangerous to themself	0 1 2 3 4 7 8	0 1 2 3 4
16. Reliving situations from the past	0 1 2 3 4 7 8	0 1 2 3 4
17. Seeing or hearing things that are not there (hallucinations or delusions)	0 1 2 3 4 7 8	0 1 2 3 4
18. Unable to use the phone	0 1 2 3 4 7 8	0 1 2 3 4
19. Unable to do simple tasks which he/she used to do (eg. put away groceries, simple repairs)	0 1 2 3 4 7 8	0 1 2 3 4
20. Unable to stay alone by self	0 1 2 3 4 7 8	0 1 2 3 4
21. Drinks too much (i.e. alcohol)	0 1 2 3 4 7 8	0 1 2 3 4
22. Being confused and not knowing where he/she is	0 1 2 3 4 7 8	0 1 2 3 4

BEHAVIOURS	FREQUENCY	REACTION
23. Has sudden changes of mood (i.e. gets upset, angered or cries easily)	0 1 2 3 4 7 8	0 1 2 3 4
24. Shouts, yells or moans	0 1 2 3 4 7 8	0 1 2 3 4
25. Denies or is unaware of limitations imposed by illness	0 1 2 3 4 7 8	0 1 2 3 4
26. Are there any other problems?	0 1 2 3 4 7 8	0 1 2 3 4

27. Please glance back at the list, are any of these problems similar to the behaviours he/she had before the onset of illness?

Yes _____ No _____

If yes, circle the numbers on the questionnaire.

APPENDIX H

THE BURDEN INTERVIEW

INSTRUCTIONS:

The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way.

---

1. Do you feel that your relative asks for more help than he/she needs?
   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

8. Do you feel that your relative is dependent upon you?

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

9. Do you feel strained when you are around your relative?
   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

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

   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

22.   Overall, how _often_ do you feel burdened in caring for your relative?
   0 - never   1 - rarely   2 - sometimes   3 - quite frequently   4 - nearly always

APPENDIX I

TWO-MONTH FOLLOW-UP INTERVIEW

FOLLOW-UP

Today's Date: _____

Is care-receiver still at home? Yes _____   No _____

IF "NO"

1.   a.) What happened?

    b.) What do you think could have been done, or done differently, to make it more likely that care-receiver would still be at home?

IF "YES"

2.   a) Are there any changes in the services you've been receiving (e.g., increased or decreased hours/week; changed agencies; additional agencies; more services being received from same agency .

    or (if applicable), have you started to use any new services?

b.) Are you still the primary (main) caregiver? Yes _____ No _____

If "no", what happened?

c.) You had previously listed this person(s) as being an additional caregiver for
_____ (see first interview). Have there been any changes (e.g., withdrawal of a
caregiver; increase or decrease in the amount of care provided ....)?

d.) Any additional new caregivers? Yes _____ No _____

If "yes", list:

relationship to care-receiver   area of aid

e.) Have there been any changes in (care-receiver's) _____ (e.g., medications, physical/behavioural problems)?

Yes _____ No _____

If "yes", list?

f.) Have you changed your mind regarding your decision to (see first interview)

_____ maintain at home   _____ institutionalize

Yes _____ No _____

If "yes", elaborate:

3.   How have you been feeling over the past few weeks (e.g., behavioural, emotional, physical)?