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Disability Assessment in Dementia of the Alzheimer's Type

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March, 1995

A Thesis Submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree
of Ph.D. in Rehabilitation Science

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ABSTRACT

Functional disability assessments are recognized as being important for the diagnosis of Dementia of the Alzheimer's type (DAT) as well as for monitoring the impact of intervention and determining the need for home assistance or institutionalization. Existing instruments designed for the assessment of functional disability with this population are generally unsatisfactory with regards to their content or psychometric properties. The objective of this research project was to develop a more appropriate French and English assessment of functional disability for use with proxy-respondents of community-dwelling individuals who have DAT. The Disability Assessment for Dementia (DAD) was developed in several stages using three panels composed of health care professionals and caregivers of individuals with DAT. Forward-backward translation procedures were performed at each stage to ensure that the French and English versions of the scale were comparable. Content validity was verified by a fourth panel of experts. The DAD was then administered to 59 community-dwelling DAT subjects and their caregivers to determine internal consistency and the need to eliminate items. The instrument developed, which consisted of 46 items, was reduced to 40 items, 17 related to basic self-care and 23 to instrumental activities of daily living, as a result of this process. The content validity of the final version was established by a majority of members from the panel of experts. It also demonstrated a high degree of internal consistency (Cronbach's alpha=0.96) and excellent interrater (N=31) and test-retest (N=45) reliability (Intraclass correlation coefficients of 0.95 and 0.96 respectively). In addition, it was found not to have gender bias. Estimates of its validity were determined in another study. The DAD represents a valid and reliable instrument which is short and easy to administer. This instrument should have a positive impact on geriatric rehabilitation, and on clinical and research activities with the DAT population. It will be one of the only functional disability instruments available in French and English.

RESUME

Les mesures de l'incapacité fonctionnelle sont maintenant reconnues comme étant essentielles comme aide diagnostic pour les démences de Type Alzheimer (DTA). Elles sont aussi nécessaires pour la planification d'interventions appropriées et le suivi avec cette population ainsi que pour la détermination des besoins au niveau des soins à domicile ou de la nécessité d'institutionaliser. Les mesures de l'incapacité fonctionnelle utilisées avec cette population sont souvent peu satisfaisantes quant à leur contenu ou leurs propriétés métrologiques. L'objectif de ce projet de recherche était donc de développer un instrument de mesure de l'incapacité fonctionnelle (français et anglais) plus adéquat et pouvant être utilisé avec les soignants de personnes atteintes d'une DTA vivant à domicile. L'Évaluation de l'Incapacité Fonctionnelle dans la Démence (IFD) a été développé en plusieurs étapes avec la participation de trois groupes composés de professionnels de la santé et de soignants d'individus atteints d'une DTA. L'instrument a été traduit à chacune des étapes afin de s'assurer que les versions française et anglaise étaient comparables. La validité de contenu a été vérifiée par un quatrième groupe d'experts. Le IFD fut par la suite administré à 59 sujets atteints d'une DTA vivant dans la communauté et leur soignant afin de déterminer la consistence interne et le besoin d'éliminer des éléments. Suite à ce processus, l'instrument, composé de 46 éléments, fut réduit à 40 éléments, 17 étant reliés aux activités de base et 23 aux activités instrumentales. La validité de contenu de cette nouvelle version fut établie par une majorité de membres du groupe d'experts. Le IFD démontra aussi un haut niveau de consistence interne (Cronbach's alpha=0.96) et une excellente fiabilité inter-observateurs (N=31) et test-retest (N=45) (coefficients de corrélation intra-classe de 0.95 et 0.96 respectivement). De plus, l'instrument n'a pas démontré de biais quant au genre. Sa validité a été vérifiée lors d'une étude parallèle. Le IFD est un instrument valide et fiable qui est court et facile à administrer. Il devrait avoir un impact positif sur la réadaptation gériatrique lors d' activités cliniques ou de recherche avec la population DTA. Il sera une des seules mesures de l'incapacité fonctionnelle disponible en français et en anglais.

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ABBREVIATIONS

ADL	Activities of Daily Living
BADL	Basic Activities of Daily Living
BDR	Blessed Dementia Rating Scale
DAD	Disability Assessment in Dementia
DAT	Dementia of the Alzheimer's Type
DAFS	Direct Assessment of Functional Status
DRS	Dementia Rating Scale
DSM-III-R	Diagnostic and Statistical Manual of Mental Disorders, revised
e	English
f	French
FAST	Functional Assessment Staging of Alzheimer's Disease
FAQ	Functional Activities Questionnaire
GDS	Global Deterioration Scale
IADL	Instrumental Activities of Daily Living
ICC	Intraclass Correlation Coefficient
IFD	Évaluation de l'Incapacité Fonctionnelle dans la Démence
MMSE	Mini-Mental State Examination
NINCDS-ADRDA	The National Institute of Neurological and Communicative Disorders and Stroke - Alzheimer's Disease and Related Disorders Association
OARS	Older Americans Resources Survey
SAILS	Structured Assessment of Independent Living Skills
SMMSE	Standardized Mini-Mental State Examination
WHO	World Health Organization

STATEMENT OF ORIGINALITY

This research project has made an original contribution to knowledge by developing a reliable and content-valid, French and English instrument to assess functional disability in community-dwelling individuals with dementia of the Alzheimer's type (DAT) through the use of a proxy respondent. The uniqueness of the instrument rests on the fact that this will be one of the only functional instrument for DAT available in French and English, thus facilitating multi-centered and international studies. It is also one of the few instruments with the DAT population assessing not only the problematic activities of daily living but also the impairments affecting performance.

The student's contribution consisted in the elaboration of an original methodology for instrument development and its implementation, which led to the development of this novel functional disability scale for persons with DAT.

CHAPTER 1

INTRODUCTION

The elderly population has grown exponentially since the year 1900 (Government of Canada, 1988). Canadian citizens over the age of 65 currently represent 10.7% of the population and this segment is expected to experience a 62% rise by the year 2006 (Health and Welfare Canada, 1991). In this group of individuals, the proportion of seniors with mental health problems, such as the dementias, has also demonstrated a major increase (Health and Welfare Canada, 1991).

In a recent nation wide Canadian study on health and aging (Canadian Study of Health and Aging Working Group, 1994) the prevalence of dementia was estimated at 8% for individuals aged 65 and older. Findings from this study show a drastic increase in prevalence with age, from an estimated 2.4 % for the 65 to 74 age group to 34.5% in the 85 and over age group . It is estimated that approximately half of the individuals with dementia are currently living in the community and that the ratio of women to men is about 2:1 (Canadian Study of Health and Aging Working Group, 1994; Health and Welfare Canada, 1991).

Dementia of the Alzheimer's type (DAT) represents about 64% of all cases of dementia in Canada (Canadian Study of Health and Aging Working Group, 1994). Comparable figures for the United States are reported by Katzman and Jackson (1991). In Canada, the overall prevalence of DAT was estimated at 5.1% for individuals aged 65 and older. A drastic increase in prevalence with age was also demonstrated for this group from 1% for the 65 to 74 age group to 26 % in the 85 and above age group. Results, comparable to the ones presented for all cases of dementias, are also found with regards to the distribution of cases across gender and type of residence (Canadian Study of Health and Aging Working Group, 1994). Although there is very little variation across Canada in the prevalence of dementia, a higher proportion of DAT cases is found in the Atlantic provinces and Quebec. It is estimated that the prevalence of dementia in Canada, and specifically of DAT, will triple by the year 2031 while the normal elderly population will have increased by only 40% (Canadian Study of Health and Aging Working Group, 1994). These figures provide warning of the health care challenges that await us in future years. At least we have the information to plan services so that the needs of seniors in our country, especially those with disabling conditions such as a dementia of the Alzheimer's type, can be met.

Disruption in functional independence, which impacts negatively on the quality of life, usually occurs as a result of DAT (Ferm, 1974; Lévesque et al., 1990; Teunisse et al., 1991). Although there is no cure for this disease, it may be possible to assist individuals with DAT and their caregivers in their daily lives. Because the decline in functional performance is such a predominant feature in DAT, measures of functional disability are now considered important elements of comprehensive assessments for this population (Hershey et al., 1987; Katzman, 1986; McKhann et al., 1984; Reed et al., 1989; Teunisse et al., 1991). Such instruments are crucial for monitoring disease progression, for making decisions regarding care and for planning medical and rehabilitative intervention strategies. They are also essential for evaluating interventions, conducting research and making decisions on legal issues like curatorship, so that the needs of individuals with DAT and their family can be better met. It is, therefore, essential to have appropriate tools to measure functional performance in DAT.

This study describes the development and testing of a new French and English functional measure, the Disability Assessment for Dementia (DAD) Scale, designed to meet the specific needs of community-dwelling DAT subjects. Evidence of content validity, internal consistency, and interrater and test-retest reliability are also provided. When fully tested, this instrument will be very valuable for clinical and research activities with Alzheimer's patients.

Before describing the different phases involved in the elaboration of the DAD Scale, pertinent literature on DAT and functional assessment with this population is discussed in

Chapter 2. The etiology, pathophysiology and clinical presentation of the disease are first presented since it is important to have a good understanding of the disease to be able to design an appropriate assessment. The concept of functional disability is then defined and the usual components and desirable properties of functional assessment measures are reviewed. Next, the need for functional disability assessments for DAT and specific properties of such instruments are discussed. Finally, existing functional assessments used with Alzheimer's patients are reviewed.

In Chapter 3, the rationale and objectives of the study are presented. Chapter 4 outlines the methodology used in the development of the Disability Assessment for Dementia Scale. Specifically it describes the translation process utilized, the panels of experts and study subjects recruited, the procedures followed for content development and psychometric testing, and the analysis performed.

Results from the panels of experts used in the development and content validation of the instrument and the tests of internal and external reliability conducted with Alzheimer and caregiver subjects are presented in Chapter 5. These findings, their theoretical and clinical implications and the limitations of the study are discussed in Chapter 6. Finally, the conclusions are presented in Chapter 7, along with contributions of the study. Future directions are also proposed.

CHAPTER 2

LITERATURE REVIEW

2.1 DEMENTIA OF THE ALZHEIMER'S TYPE

Dementia is a syndrome characterized by intellectual decline severe enough to interfere with occupational or social activities. It involves significant alterations in memory with deterioration in at least one other area of cognitive performance such as language, abstract thinking or judgment (American Psychiatric Association, 1987; Consensus Conference, 1987; Habib et al, 1989; Katzman, 1986). The onset and progression of dementia are variable depending on the underlying pathology (American Psychiatric Association, 1987; Consensus Conference, 1987). More than 60 pathological states such as DAT or vascular disease have been found to cause dementia (Katzman, 1986).

Dementia of the Alzheimer's type (DAT) is the most frequent cause of dementia (Consensus Conference, 1987; Katzman, 1986). According to Katzman and Jackson (1991), DAT represents approximately two thirds of dementia cases occurring in the elderly population. Usually appearing in middle or late life, it is a progressive deteriorating disease of insidious onset that affects higher mental functions.

Definite diagnosis of DAT can only be made histologically through biopsy or autopsy because there are no peripheral biochemical markers for the disease. Therefore, diagnosis of patients relies on clinical differentiation. Uniform criteria for the clinical diagnosis of probable and possible DAT have been established by the NINCDS-ADRDA workgroup (McKhann et al., 1984; Tierney et al., 1988). The criteria are compatible with the DSM-III-R (American Psychiatric Association, 1987) and the International Classification of Disease (Wood & Badley, 1978).

Using these criteria, a diagnosis of probable Alzheimer's disease is made in cases presenting a typical insidious onset of dementia with progressive deterioration, in the absence of other diseases which could be at the origin of the cognitive deficits. A diagnosis of possible DAT is given when the origin and course of the disease are atypical, or when there are other conditions present which could produce dementia but are not believed to be the cause. A clinical diagnosis is established following a complete medical examination which usually includes a medical history, mental status testing, and a physical and neurological examination. Neuropsychological and functional testing, as well as laboratory tests, are also found to be useful diagnostic aids (Consensus Conference, 1987; Katzman & Jackson, 1991; McKhann et al., 1984).

Sensitivity and specificity of the criteria for the diagnosis of probable DAT have been determined in a clinicopathological study (Tierney et al., 1988). Values ranged from 64% to 86% for sensitivity and from 89% to 91% for specificity. The variations seen in these results are believed to be due to variability in the neuropathologic and clinical criteria used in the diagnostic process (Tierney et al., 1988).

2.1.1 Etiology and Pathophysiology

The etiology of the changes observed in DAT is unknown (Katzman, 1986). Genetic, metabolic and environmental factors have been proposed and are being currently investigated (Amaducci et al., 1986; Boerrirgter et al., 1992; Davies, 1986; Farlow et al., 1994; Katzman, 1986; Rocca et al., 1986).

The role of heredity as a causal factor in DAT is being intensively investigated and although much progress has been made, the picture is far from clear. The majority of cases of DAT seem to occur sporadically. However, it seems that 5 to 10% of the cases would be inherited forms of the disease termed Familial Alzheimer Disease (FAD) (Boerrigter et al., 1992; Katzman & Jackson, 1991). This hereditary form of the disease is often divided in two categories, the early onset which is said to occur before the age of 65 and the late onset. Some of the factors that have been proposed as a possible cause of early onset FAD are mutations on chromosome 21 in a small portion of the cases (Farlow et al., 1994; Goate et al., 1991; St. George-Hyslop et al., 1989) and DAT susceptibility genes on chromosome 14 in most other early onset FAD (Mullan et al., 1992; Schellenberg et al., 1992; Nechiporuk et al., 1993). However, for several cases who do not present these mutations the cause remains unknown.

Evidence for an association between a gene on chromosome 19 and late onset FAD was recently reported (Pericak-Vance et al., 1991; Roses et al., 1990; Strittmatter et al., 1993; Yu et al., 1994). This relationship has also been found for sporadic cases of the disease (Brousseau et al., 1994). Although it is probable that some DAT cases originate from a genetic defect, it is hypothesized that other factors may play a determinant role in the manifestation of the disease. Therefore it is likely that the cause of DAT is multifactorial (Boerrigter et al., 1992; Cummings, 1993).

Age is a major risk factor for DAT. The incidence of the disease seems to increase exponentially with age (Breteler et al., 1992; Evans et al., 1991; Health & Welfare Canada, 1991; Katzman & Jackson, 1991; Rocca et al., 1986) It increases from 1% at 60 years to 35% at 85 years (Breteler et al., 1992; Cummings, 1993). In addition, the incidence seems to be slightly higher in women regardless of age (Rocca et al., 1986).

Down's Syndrome is also considered a risk factor by several researchers since individuals who present this condition have 3 copies of chromosome 21 and all develop DAT if they live to 50 years (Breteler et al., 1992; Katzman & Jackson, 1991; Rocca et al., 1986). Other factors which are proposed as being related to an increased risk of developing the disease are previous history of head trauma (Breteler et al., 1992; Graves et al., 1990) and lack of education (Hill et al., 1993). However, the association of these factors with DAT remains highly controversial.

The disease is characterized by morphologic changes at the microscopic and macroscopic level. Macroscopic changes such as progressive brain and ventricular atrophy and microscopic changes such as neuritic plaques, neurofibrillary tangles and granuovacuolar bodies have been reported (Katzman, 1986; Katzman & Jackson, 1991; Kemper, 1984; Reisberg, 1983; Van Hoesen & Damasio, 1987). The loss of neurons and synapses contribute to the clinical syndrome of DAT. More and more evidence seems to suggest that amyloid is one of the key intermediaries that leads to these changes (Cummings, 1993; Katzman & Jackson, 1991). Amyloid is an abnormal protein which has been found in the core of neuritic plaques. It is believed to be among the first changes occurring in the disease in the form of diffuse plaques which are thought to be immature neuritic plaques (Cummings, 1993). The level of amyloid deposits is found to reach toxic levels in the brains of DAT patients and this is believed to cause the pathologic changes noted at the cellular level. Neuritic plaques, which are present in normal aging, are more "abundant" in DAT. An abnormal protein, tau, present in neurofibrillary tangles has also been associated with disruption of cellular function (Cummings, 1993; Katzman & Jackson, 1991).

These changes are not globally distributed in the brain but present in a regional pattern. Many cerebral areas such as the limbic lobe and the association cortices (primary specific association areas and multimodal area) of the temporal, frontal, parietal, and occipital lobes are affected by the disease but these areas are not affected uniformly (Consensus Conference, 1987; Cummings, 1993; Katzman & Jackson, 1991; Van Hoesen & Damasio, 1987). It appears that the temporal and parietal lobe are the most severely involved structures, while the frontal lobe is moderately affected. The occipital lobe is found to be the least severely involved area in most cases. In addition, the degree of involvement of the different structures varies from one individual to another. The primary motor, somatosensory and visual cortices are usually preserved while the multimodal association areas, responsible for the integration of perception, thoughts and purposeful activities, are mostly affected (Consensus Conference, 1987; Katzman & Jackson, 1991; Van Hoesen & Damasio, 1987).

Changes occurring at the cellular level have an impact on the chemical functioning of the brain. The cholinergic system is severely affected by the disease. The nucleus basalis of Meynert which is an important structure for the production of the brain's acethylcholine, undergoes cellular loss very early in the disease process. Other systems such as the noradrenergic and serotonergic systems are also affected by the disease (Katzman & Jackson, 1991).

The impact of alterations at the cellular and chemical levels can be observed in the cognitive abilities and behaviour of DAT patients and underlie the clinical manifestations of the disease.

2.1.2 Clinical Presentation

The clinical presentation of the disease varies according to the cortical areas involved (Van Hoesen & Damasio, 1987). Impairments in cognition and behaviour which lead to functional disabilities can be observed (Bouchard, 1990; Katzman, 1986; Reisberg, 1983). The symptoms usually appear insidiously and patients slowly deteriorate over a period of several years. The clinical manifestations usually become more complex as the disease progresses.

Reisberg et al. (1982) described the clinical presentation and course of the disease according to seven stages. In the first stage, there is no evidence of cognitive decline, while in stage two, very mild cognitive deficits characterized by subjective complaints of cognitive loss without clinically observable deficits are present. This stage appears to be benign for many individuals (Reisberg et al., 1986). The third stage is characterized by mild cognitive decrements and clinical evidence of decline in social and occupational functioning. This stage appears to be a borderline condition between normal aging and DAT (Reisberg et al., 1986). The early stages of DAT really begin in the fourth stage when moderate cognitive deficits, which impair memory and ability to deal with instrumental daily tasks, can be clearly observed through clinical workups. From stages five to seven, cognitive losses become progressively more severe. There is a decline in the ability to function in daily and social activities which leads eventually to institutionalization. According to Reisberg (1983), every individual correctly diagnosed with DAT should go through all of these stages although the duration of each stage may vary from several months to years. These stages form the basis of the Global Deterioration Scale (GDS) which is used to classify the severity levels of the symptoms. Reisberg (1983) also described simultaneous deterioration in five other areas of function: concentration, recent memory, past memory, orientation and functional activities.

The enormous variability reported in the rate of decline of subjects who present with DAT has lead some investigators to consider progression of the disease according to a sub-group model instead of a stage model as characterized by Reisberg et al. (cited in Galasko et al., 1991). A sub-group model implies heterogeneity in the progression of the disease. Some of the factors which have been investigated as predictors of deterioration in the disease are age at onset (Huff et al., 1987; Jacobs et al., 1994; Seltzer & Sherwin, 1983), aphasia (Faber-Langendoen et al., 1988; Seltzer & Sherwin, 1983), extrapyramidal symptoms (Chui et al., 1985; Mayeux et al., 1985; Stern et al., 1987), behavioural and psychotic symptoms as well as depression (Lopez et al., 1990; Stern et al., 1987). Unfortunately, the validity of subtypes in DAT has not yet been determined and the cause of variability in both symptoms and rate of decline is still unknown (Galasko et al., 1991).

2.1.2.1 Cognitive Changes

Profiles of changes in both cognition and behaviour can be delineated in DAT although the symptoms and the evolution of the disease vary from one individual to another. The initial symptoms are usually cortical, such as cognitive deficits in memory (Consensus Conference, 1987; Flicker et al., 1986; Martin, 1987; Reisberg, 1983; Van Hoesen & Damasio, 1987), language (Branconnier & DeVitt, 1983; Chui et al., 1985; Reisberg, 1983; Van Hoesen & Damasio, 1987), orientation (Liu et al., 1991; Reisberg, 1983), praxis (Bouchard, 1990; Van Hoesen & Damasio, 1987), gnosis, attention and executive functions (Bouchard, 1990; Reisberg, 1983; Van Hoesen & Damasio, 1987). Sub-cortical symptoms such as behavioural and motor deficits seem to manifest themselves in the later stages of the disease (Bouchard, 1990; Corkin, 1984).

Amongst the cognitive impairments seen in DAT, disturbances in memory, language and spatial orientation are considered (Branconnier & DeVitt, 1983) to be key factors for an early determination of DAT. These deficits as well as impaired executive functions are reported by Van Hoesen and Damasio (1987) to be important clinical manifestations of the disease.

Memory deficits are always present. They are often the initial clinical manifestations of the disease and the most prominent symptoms (Consensus Conference, 1987; Flicker et al., 1986; Martin, 1987; Reisberg, 1983; Van Hoesen & Damasio, 1987). It seems that most types of memory are involved; primary or working memory, secondary memory, remote memory and semantic memory (Chertkow & Bub, 1990; Flicker et al., 1986; Morris & Kopelman, 1986). Deficits of retrieval and storage mechanisms are evident (Branconnier & DeVitt, 1983) and deficits in primary or working memory have been described by several authors (Baddeley et al., 1991, Morris & Baddeley, 1988; Morris & Kopelman, 1986). On the other hand, not all aspects of secondary or long term memory have been found to be affected in the early stages of the disease. While procedural memory, that represents memory for skills appears quite preserved, the memory for facts and episodes seems to be very impaired especially with regards to retaining information on personal experience or events which have recently occurred (Knopman & Nissen, 1987; Morris & Baddeley, 1988). The clinical presentation of memory deficits progress as follows: in the early stages of the disease, individuals usually experience periods of forgetfulness; and they may have difficulty remembering minor details. As the disease evolves, memory of current events deteriorates and eventually memory for past experiences is progressively involved (Reisberg, 1983).

Disturbances in language are rarely initial signs of the disease (Van Hoesen & Damasio, 1987). According to Chui et al. (1985), they usually follow memory loss although there is a great amount of variability from one individual to another. Nonetheless, language deficits are important manifestations of the disease. The most prominent deficits in the early stage of the disease are related to lexical and semantic abilities rather than syntactical or phonemic processing (Flicker et al, 1986; Van Hoesen & Damasio, 1987). DAT subjects have been found to be impaired in word naming and word concepts as well as auditory comprehension, repetition, reading and writing (Bayles & Tomoeda, 1991; Faber-Langendoem et al., 1988). The changes in language progress from experiencing word finding difficulties, to impairments in naming, to confrontation and paraphasia, and to losses in all verbal abilities during later stages (Branconnier & DeVitt, 1983; Reisberg, 1983; Van Hoesen & Damasio, 1987).

Deficits in spatial orientation are generally present in DAT (Reisberg, 1983). They frequently occur in the early stages of the disease (Branconnier & DeVitt, 1983; Cummings & Benson, 1986). Whether these abilities are lost according to hierarchical or multi-dimensional patterns needs to be further investigated (Liu, 1993). In her study of individuals with early stage of Alzheimer's disease, Liu (1993) found that all aspects of spatial orientation were impaired. Deficits in visual perception, visuo-spatial constructional abilities, personal orientation on examiner's body, extrapersonal orientation, planning and immediate memory were found (Liu, 1993; Liu et al., 1991). Functional spatial orientation skills were also found to be deficient early on in the disease (Liu, 1993, Reisberg, 1983). Indeed, individuals experienced progressive difficulties in functional tasks such as driving and travelling to new places or even moving in familiar environments (Freidland et al., 1988; Reisberg, 1983). Wandering, on the other hand, is a behaviour associated with later stages of DAT (American Psychiatric Association, 1987). Functional deficits seem to be related to impairments in decision-making abilities, memory, attention and visuo-spatial abilities. Environmental factors also seem to have an impact on functional spatial skills (Liu, 1993).

Impairments in executive functions are also found in conjunction with other cognitive deficits in persons with DAT (Bozzola et al., 1992; Gauthier, 1988; Litvan et al., 1991; Van Hoesen & Damasio, 1987; Villardita, 1993). Executive functions are responsible for the control and regulation of organized behaviours. They are responsible for "how " or "whether" a person is going to engage in an activity. They, therefore, coordinate the execution of cognitive functions, such as memory or attention, so they can be applied to daily life situations. Executive functions are distinct from other cognitive functions and personality characteristics (Lezak, 1983; Winegarner, 1993). Lezak (1983, 1987) described several components of executive functions. These consisted of the ability to formulate goals, to plan and organize an intended behaviour, to initiate and to carry out the intended behaviour effectively and completely, and to monitor the behaviour.

Literature on impairments in executive functions with the DAT population is scarce. Mildly to moderately demented Alzheimer subjects have been found to be significantly more impaired than normal control groups matched for age and education when compared on neuropsychological measures of executive functions (Litvan et al., 1991; Villardita, 1993).

Van Hoesen and Damasio (1987) described impairments in the ability to monitor ongoing activities, to make judgments, to plan for the future and to problem-solve. They also noted decreased insight in DAT. These investigators mentioned that the relationship between these deficits and the mechanisms of cognitive disruption was still unclear. It seems that the abilities to initiate, plan, problem-solve and monitor action are affected if learning and memory are impaired. However, it is clear that other systems are also involved in disruptions of the executive functions. According to these authors, problems in executive functions and problem-solving are present in early stages of the disease and become completely disrupted in the advances stages. Bozzola et al. (1992) found diminished initiative to be prevalent (61.3%) in their sample of community dwellers with DAT.

Deterioration in executive functions has also been observed by investigators assessing functional abilities in DAT. These functions are known to be important control and organizational mechanisms for the performance of daily activities. Deterioration in executive functions have manifested themselves as an inability to initiate, organize and complete basic activities such as dressing, bathing, personal hygiene and eating as well as higher level tasks like using the telephone or purchasing (De Ajuriaguerra et al., 1967; Laberge, 1990; Laberge & Gauthier, 1994). Skurla et al. (1988), in a study comparing severity of dementia with performance in daily activities in DAT and normal control subjects, observed difficulty in performing activities related to proper sequencing of the activity. Moreover, they observed volitional problems such as prolonged staring, refusal to complete a task or lack of initiation. Finally, in a multi-center trial using intra-cerebroventricular infusions of a muscarinic receptor agonist, Gauthier (1988) observed three progressive stages of executive function impairment: 1) loss of initiation; 2) loss of problem solving and planning; and 3) loss of familiar automatic gestures.

2.1.2.2 Functional Changes in Activities of Daily Living

Changes in functional abilities are important manifestations of DAT. They are included as criteria to assist in the diagnosis of probable DAT as determined by the NINCDS-ADRDA work group (McKhann et al., 1984; Tierney et al., 1988).

The changes in functional abilities observed in DAT have been discussed by several authors. Reisberg et al. (1984) described the progressive changes according to seven stages in his Functional Assessment Staging of Alzheimer's Disease (FAST). These stages correspond to the seven stages of cognitive changes that he had described earlier in the Global Deterioration Scale (GDS) (Reisberg et al., 1982). Functional deficits start to occur at the stage when cognitive deficits are mild and first become apparent in complex occupational tasks such as work or hobbies and in social activities. For example, individuals may forget appointments or have difficulty finding their way in unfamiliar environments. When the deficits in cognition become moderate, individuals with DAT have more difficulty in performing complex instrumental activities like dealing with finances or shopping. At this point, living alone will become problematic but they can still adequately perform basic tasks such as dressing or moving around their community. When the cognitive deficits become moderately severe, the individuals starts to experience difficulties with basic activities of daily living. This usually begins with problems in choosing appropriate clothing. They are no longer able to live alone and should not drive or use public transportation by themselves. As the disease progresses, the individuals lose the ability to dress, bathe and toilet. Urinary and faecal incontinence may also occur. Eventually speech, as well as locomotion abilities, are lost. The individuals are severely cognitively impaired and need ongoing care. The observed characteristic pattern of progressive deterioration described in the FAST was empirically tested by Sclan and Reisberg (1992) in a recent study with 56 individuals diagnosed with DAT. Their findings supported their assumption that functional decline follows a characteristic pattern and that functions are lost in a hierarchical fashion.

The progressive loss of functional ability in a hierarchical pattern has been substantiated by several longitudinal studies (Carswell & Eastwood, 1993; Green et al., 1993; Stern et al., 1990). Stern et al. (1990) followed 67 individuals with DAT from six months to six and a half years. They found that the ability to perform higher level tasks like doing chores, handling money, or remembering short lists changed early in the course of the disease and continued to decline as the disease progressed. On the other hand, changes in basic self-care abilities appeared later in the course of the disease (four or five years after onset) and continued to deteriorate over time.

In addition, Green et al. (1993) monitored 104 DAT subjects for 31 months using well established ADL and IADL scales. They observed greater deterioration in instrumental activities of daily living over a broad range of severity levels, as measured by the Blessed Test (Blessed et al., 1968), than in basic ADL where decline was very slight in the mild cases and only marked in the moderate to severe dementias. Once basic ADL started to change, subjects deteriorated quite quickly. These authors also found that on an individual basis, the rate of deterioration in daily activities over one period in time did not provide any indication of the rate of change in subsequent periods.

Baum et al. (1993) arrived at similar conclusions based on data from a cross-sectional study of 106 community residing individuals with DAT at various stages of the disease. Comparisons across stages led the authors to conclude that complex activities and problem solving skills were behaviours lost early in the disease, while no significant deterioration in single overlearned tasks was found until moderate stages of the disease. From the results of this study, it was implied that DAT subject could benefit from task simplification in the initial stages of the disease to complete more complex tasks.

Several authors have not only attempted to describe the functional changes observed in DAT, but have also discussed the origin of these difficulties. De Ajuriaguerra et al. (1967) observed the dressing and undressing behaviours of approximately 100 demented subjects. They described difficulties in initiating dressing or undressing, using a piece of clothing or part of a piece of clothing, doing the activity in the right sequence, positioning clothing appropriately with regards to the body or with regards to another piece of clothing, recognizing certain clothes, and completing the task. Problems with dressing started to appear in the early stages of the disease prior to difficulties with undressing and were mostly related to deficits in cognition and perception. Impairments in executive functions also had a major impact on the ability to perform these tasks. It has been suggested that a wide range of deficits in cognition (memory, attention), perception and executive functions (initiation, judgment) can affect the performance in dressing/undressing (Beck, 1988). Similar impairments have also been related to disability in eating and in grocery shopping (Gray, 1989), meal preparation (Gray, 1989; Baum & Edwards, 1993) and driving (Donnelly & Karlinsky, 1990)

In general, the functional impairments observed in DAT seem due to cognitive deficits such as memory, concentration, praxis and gnosia (Lévesque et al., 1990). More recently, several authors have emphasized the impact of behaviour alteration and deficits in executive functions such as spontaneity, planning and organization, completion of the task, judgment, sequencing and volition on functional changes in activities of daily living (ADL) (Gauthier, 1988; Laberge, 1990; Skurla et al., 1988; Weintraub, 1986). Indeed, results from a study by Reed et al. (1989) with 59 demented individuals assessed on established measures of cognition and function in ADL suggested that the cognitive measure explained only about one third of the variance in activities of daily living.

The functional deficits observed in DAT appear to be of multiple origins. The impact of cognitive deficits on functional status has been extensively reported in the literature. In recent years, several authors have put more emphasis on the importance that executive functions exert on the performance of functional activities. Functional disability assessment will now be addressed.

2.2 ASSESSMENT OF FUNCTIONAL DISABILITY

Measures of functional disability are important tools for decision making with regard to diagnosis, prognosis and planning of care. They are also necessary outcome measures for research.

2.2.1 Definition of Functional Disability

Functional disability is a concept. Although independence in function is considered by health professionals to be one of the main goals of rehabilitation, there is no universal definition of it. The problem is partly related to the lack of uniform terminology. Different terms such as impairments, functional limitations, deficits or disabilities are commonly used. In order to adequately assess functional disability, it is imperative to define it in measurable terms.

The concept of functional disability is often viewed within a model of health (Granger, 1984; Jette, 1984; Leering, 1979; Rubenstein et al., 1988). Conceptual definitions of health have changed considerably over the years with the emergence of new health problems, the chronic illnesses (Hébert, 1982; Granger, 1984). As the classical model of health, centered solely on the characteristics of disease, was very limited for use with chronic conditions, the functional perspective has been included in more recent models (Granger, 1984; Hébert, 1982; Wood & Badley, 1978). Clearly, knowledge of the etiology, the pathology and the manifestations of a disease are not sufficient to care for chronically disabled individuals since the condition is not curable. It is, however, important to consider the impact of the disease on the individual's life, how it affects functioning in activities and roles on a day to day basis (Hébert, 1982).

In 1980, the World Health Organization (WHO) presented the International Classification of Impairments, Disabilities and Handicaps based on a new model of health. This internationally accepted model and classification is more appropriate than the limited medical model and provides a common terminology for different health care professionals. This model is composed of three levels; the organ, the person and the society. The organ level is concerned mainly with psychological, physiological and anatomical structures or functions of body parts. Impairments are the manifestations of deficits in these structures or functions. As a consequence of these impairments, a disability may occur. A disability is situated at the level of the person and represents a disturbance in behaviours or performance in activities of daily living like communication, personal care, locomotor and body disposition (instrumental ADL). At the societal level, the ability to fulfil social roles as determined by social norms and social policies can be influenced by impairments and disabilities. A disabled individual who cannot adapt to meet the demands of society will be handicapped.

Therefore, it is at the disability level that functional limitations occur (Hébert, 1982) as a result of impairments in organ systems and/or other factors such as the individual's social or physical environment (Granger, 1984; Rubenstein et al, 1988).

This new view of health has important implications for all aspects of intervention including the ability to accurately assess an individual's capacities. Tools used for the assessment of people with chronic diseases and physical limitations should move away from being diagnostic-based and should focus instead on the disability.

2.2.2 Components of Functional Disability Measures

According to Granger (1984), comprehensive measures of functional disability should include different groups of tasks; basic ADL, instrumental ADL, leisure activities, occupational pursuits, travelling and transportation, as well as social interactions. Several authors (Lawton, 1972; Leering, 1979; Reuben & Solomon, 1989) have categorized these tasks in levels organized according to a hierarchy of complexity. Reuben and Solomon (1989) divided functional tasks in 3 levels: basic activities (self-care activities); intermediate activities (instrumental activities); and advanced activities (activities that are beyond the means of self-maintenance like recreational or occupational activities).

The most common way to measure functional disability is through the assessment of basic (BADL) and instrumental (IADL) activities of daily living (Kempen & Suurmeijer, 1990). Mobility is sometimes added to these measures. These tasks, as opposed to advanced activities, are of major concern to health professionals working with the demented elderly population. They are key factors for determining an individual's ability to live alone. Also if the individual needs care, they are important for decisions regarding the amount of care required.

Basic activities of daily living are activities that are important for self-care like bathing, dressing, eating and continence (Kempen & Suurmeijer, 1990; Katz, 1983; Lawton, 1972). Katz (1983) has reported a hierarchy in the ability to perform these activities which was empirically validated. Instrumental activities of daily living are more complex. They are activities that are important for maintenance in a specific environment and include such areas as meal preparation, housekeeping, banking and transportation (Kempen & Suurmeijer, 1990; Katz, 1983; Lawton, 1972). Mobility is the ability to move in an environment to be able to accomplish BADL and IADL. The number and the kind of activities assessed in each of these areas vary from author to author.

Several authors (Fitzgerald et al., 1993; Kempen & Suurmeijer, 1990; Norstrom & Thorslund, 1991; Spector et al., 1987) have attempted to verify if the commonly used basic and instrumental activities constitute one dimension or if they really represent two distinct dimensions of functional disabilities that should form separate scales. These authors have also investigated if a hierarchical relationship existed among the items.

Findings from individual studies differ on these questions. Spector et al. (1987) and Kempen and Suurmeijer (1990) using factor analysis, Guttman Scaling Procedure and Mokken's Stochastic Cumulative Scale Analysis showed that basic and instrumental activities constitute one dimension which can be organized hierarchically. They proposed, however, that BADL and instrumental ADL could be used as separate scales.

More recent studies have suggested otherwise. Norstrom and Thorslund (1991) assessed the validity of the division commonly made in daily activities into basic and instrumental components through factor analysis of items with a random sample of 421 community residents aged 75 year and over. The analysis revealed two distinct dimensions: basic and instrumental activities. After submitting the items loading on the IADL factor to a Guttman analysis, the authors could not conclude that a hierarchy existed among these items. They advocated that in order to have an overall assessment of disability in the elderly, both basic and instrumental activities should be assessed.

Fitzgerald et al. (1993) also looked at the dimensionality of activities of daily living using items from the Older Americans Resources and Services questionnaire (OARS) (1978). Using principle component analysis, the researchers found four dimensional factors. These were: 1) advanced ADL which consisted of items such as using the telephone, managing money, eating and taking medications; 2) basic ADL which included dressing, transferring, walking, bathing; 3) household ADL which involved preparing meals, shopping, housework and traveling; and 4) incontinence which was a weak fourth dimension. It was hypothesized that the reason incontinence did not factor with the basic ADL was due to the response format and rating which was not comparable to the other ADL items. In addition, they found that advanced ADL was the only dimension which was significantly associated with scores on a measure of cognitive functions. These results lead the authors to conclude that basic, household and advanced ADL were three independent and unidimensional scales.

Although there is no consensus whether basic or instrumental activities represent one or two dimensions, all authors agree that in order to adequately assess functional disability, a scale should examine all these dimensions of disability.

2.2.3 Desirable Properties of Functional Disability Measures

As functional assessment is important for health care planning, there is a need for measures that are rigorously developed and tested. Criteria which should be considered when developing a functional disability measure will now be discussed. These include the conceptual approach used, the purpose, the reliability, the validity, the reponsiveness, the method of administration and the practicality of the measure.

2.2.3.1 Conceptual Approach and Purpose

According to McDowell and Newell (1987), functional measures should be based on a specific conceptual approach. This is important as it provides a rationale for developing the measure and choosing the dimensions covered by the instrument.

It is also essential to specify the clientele targeted and the purpose of the instrument as it will influence instrument development. The instrument may be descriptive/discriminative, predictive or evaluative (Kirshner & Guyatt, 1985; Law & Letts, 1989). It may also fulfil more than one purpose.

A descriptive scale provides a portrait of the individual's status at one point in time and allows comparison between individuals or groups. Such instruments should include items which are important constituents of the dimensions assessed and which are relatively stable over a short period of time. Reliability and validity should be determined while responsiveness is not crucial for these types of scales (Kirshner & Guyatt, 1985; Law & Letts, 1989).

A predictive scale compares the individual's status against a set of predefined criteria. These scales are most often used as screening measures. They should include items which are related to the criterion to which they are being compared and these items should be scaled so that correlations with that criterion are maximized. Reliability and criterion-related validity would be necessary while responsiveness would not be relevant (Kirshner & Guyatt, 1985; Law & Letts, 1989)

An evaluative scale measures change in a person's or a group' s status over time. Such scales are useful to monitor progress of therapy or to measure the benefit of specific treatment in intervention studies or clinical trials. It should include items which would reflect clinically important changes over time. The scaling should offer a response choice with enough gradations to detect change. Test-retest reliability, longitudinal construct validity and responsiveness are very important properties for such a scale (Guyatt et al., 1987; Guyatt et al., 1989; Kirshner & Guyatt, 1985; Law & Letts, 1989; Kane & Kane, 1981; McDowell & Newell, 1987).

2.2.3.2 Reliability, Validity and Responsiveness

Sound functional assessments should, according to several authors, fulfil at least two criteria: they must be reliable and valid (Law & Letts, 1989; Kane & Kane, 1981; McDowell & Newell, 1987). More recently, researchers have advocated that responsiveness be added to this list (Deyo et al., 1991; Guyatt et al., 1987; Guyatt et al., 1989; Law & Letts, 1989; Kane & Kane, 1981; McDowell & Newell, 1987).

2.2.3.2a **Reliability**

Reliability is the degree to which an instrument is reproducible and stable under different testing conditions (Jette, 1984; Kerlinger, 1986; Streiner & Norman, 1989). Different types of reliability can be obtained according to the purpose of the instrument and the type of data collected. Interrater, intrarater and test-retest reliability assess external or observer variability while internal or inter-item variability is determined by internal consistency. These are two different components of reliability (Feinstein, 1987).

Interrater reliability assesses if scores obtained from different raters are similar, assuming that the construct under study has not changed. When testing is redone by the same rater, intrarater reliability is determined. Test-retest reliability looks at the stability of the measure at different points in time with the same rater (Streiner & Norman, 1989) and is a useful concept when scales are self-administered.

Whenever reliability is determined by testing on two separate occasions, it is important to choose an appropriate time interval. It should not be so short as to permit subjects remembering the answers from the first testing session. However, the interval should not be too long in order to avoid changes in the property under study. The time interval will vary depending on the population studied and the construct under investigation. Streiner and Norman (1989) mention that an interval of 2 to 14 days is generally used.

Different statistical tests may be used to assess external reliability. The choice of an appropriate statistical analysis will depend on the type of data collected and the purpose of the test (Streiner & Norman, 1989). For continuous data, the intraclass correlation coefficient is often recommended as it considers both the variance attributable to raters and to subjects (Bartko, 1966; Fleiss, 1986; Kramer & Feinstein, 1981). In comparison, the Pearson's product-moment correlation, another commonly used reliability coefficient, is less appropriate and more liberal as it ignores systematic bias. This statistic measures trend but does not indicate the extent to which the instruments yield the same results (Kramer & Feinstein, 1981; Streiner & Norman, 1989). Acceptable reliability coefficients for an instrument vary from author to author. A coefficient of .80 or higher is often recommended for group reliability but values greater than .95 are suggested for individual decision making (Carmines & Zeller, 1979; Kramer & Feinstein, 1981). The test statistics of choice for nominal or ordinal data are Cohen's kappa and Weighted kappa (Fleiss, 1981; Kramer & Feinstein, 1981). Kappa type statistics measure concordance between data while correcting for chance expected agreement and have been shown to be equivalent to the Intraclass Correlation Coefficient under certain circumstances (Kramer & Feinstein, 1981; Streiner & Norman, 1989).

Internal consistency or homogeneity determines the extent to which the different elements in a measure are assessing the same construct (Feinstein, 1987; Streiner &

Norman, 1989). Testing this property, therefore, involves making sure that the items included in the scale represent different components of the construct under study as opposed to being aspects of different constructs. This implies that the items should correlate well with the total score. However, items should only correlate moderately (ranging from .40 to .80) with each other; otherwise high correlations would mean redundancy of the items and low correlations denote little relationship. Internal consistency is therefore not appropriate for multidimensional measures unless each dimension is assessed as an individual scale (Streiner & Norman, 1989).

The most common test statistic to determine internal consistency is Cronbach's alpha (Cronbach, 1951). In testingt alpha, it can be determined which items decrease the homogeneity of the scale. This is therefore very helpful for the identification of items which should be removed during scale development. Feinstein (1987) suggested a value of .80 or above as representing good internal consistency. Item-total correlations which provide information about the relationship of the individual items to the total (excluding that item) are also used. Streiner and Norman (1989) noted that items with item-total correlations lower than .20 should be discarded. An alternative method which can also be employed is the split-half reliability (Nunnally, 1978). In this approach, the scale is randomly divided into two parts which are then correlated with each other. For an internally consistent scale the two halves should be highly correlated. The Spearman Brown prophesy formula is usually the statistic of choice. It should be noted that this method may not be appropriate if there is a specific order in which the items are presented (Streiner & Norman, 1989).

2.2.3.2b **Validity**

Validity is the degree to which an instrument measures what it is supposed to measure (Jette, 1984; Kerlinger, 1986; Streiner & Norman, 1989). Therefore, having a valid scale will imply that inferences can be made from the scores obtained with a high degree of confidence. This is assessed mainly through face, content, criterion and construct validation.

Face validity is usually a subjective judgment on whether the instrument appears to measure what it is suppose to measure. It is a minimal standard for validity. Having face validity may be important to increase acceptance of the scale by respondents or users. In some instances, it is preferable to conceal the true nature of the questions to avoid false responses (Streiner & Norman, 1989). However, face validity is a highly desirable property for functional measures.

Content validation assesses if the instrument includes all the important dimensions of the construct under study, and the adequacy with which the dimensions have been covered in the form of items (Streiner & Norman, 1989; Thorn & Deitz, 1989). This is an important step in the initial stages of instrument development. Content validity is ascertained through a review of the literature on theories and research pertaining to the construct under study, and the use of expert judgments. Employing a panel of experts to determine content validity is a qualitative method. Procedures are usually left to the ingenuity of the test developer (Thorn & Deitz, 1989). Spitzer et al. (1981) designed a three-phased approach to determine the content validity of an index of quality of life. Phase one consisted of identifying the domains encompassing quality of life and developing items reflective of this domain. Three advisory panels composed of experts in the field, patients and relatives were used for this purpose. Phase two consisted of pretesting drafts of the measure developed in the previous phase on subjects to eliminate unnecessary items and to determine the practicality of the scale. In the last phase two panels were used to verify content validity of the final version of the scale. Content validity was accepted if a majority (51%) of members in each panel agreed on questions pertaining to appropriateness and importance of each item, adequacy of the number of items and ability of the scale to discriminate among individuals and groups. Content validity, however, should not be the only criterion to determine if a measure is valid; it should be followed by other forms of validation.

Criterion validation involves comparing the instrument with another well-established measure of the same construct (gold standard) which is not used because it is too costly or impractical. There should be strong correlations between the two measures. The criterion to which the instrument is compared can be a future event or behaviour (predictive validity) or a behaviour occurring at the same point in time (concurrent validity) (Feinstein, 1987; Streiner & Norman, 1989). Unfortunately, there is no real gold standard to assess functional disability. New measures are usually compared to existing instruments which have demonstrated strong psychometric properties and/or are commonly used. Because of the lack of a gold standard for functional measures, construct validity is usually determined.

Construct validation is carried out to determine whether the items of a measure adequately represents a construct or variable that cannot be directly observed or measured. An example of such a construct is functional disability. The choice of items identified as being representative of the construct stems from theory and clinical observation. For instance, activities of daily living are usually used to assess functional disability. Construct validation requires the testing of a hypothetical relationship between the construct of interest and another construct to which it is thought to be related. The instrument being studied is tested against a measure of the other construct to see if the obtained relationship is as hypothesized. These relationships can be positive (convergent) or negative (divergent) (Feinstein, 1987; Streiner & Norman, 1989). For example, in DAT it is hypothesized that the construct of functional disability is related to the construct of cognitive deterioration. Consequently, functional measures are often validated against cognitive measures.

2.2.3.2c **Responsiveness**

Responsiveness is the ability of a measure to detect clinically significant changes in a patient's status over time, even if they are minimal (Deyo et al., 1991; Guyatt et al., 1987). This is especially important when one wants to monitor change in a treatment program or assess the impact of an intervention over time. Unfortunately there exist no standards, at the present time, to determine if an instrument is responsive and there is no agreement between authors on how it should be assessed. The most common method for the assessment of responsiveness is to compare scores from the instrument before an after a treatment of "known efficacy". However, this method does not take into account the variability in score that may be observed among stable subjects or that could result from receiving treatment and learning. Some authors have therefore suggested to also measure change in a similar comparison group composed of stable subjects or of subjects receiving a placebo treatment (Deyo et al., 1991; Guyatt et al., 1987). Many statistical tests have been proposed to quantify responsiveness (Deyo et al., 1991; Guyatt et al., 1987; Kazis et al., 1989; Liang et al., 1985). There is, however, no consensus as to which of these tests represent the best index of responsiveness.

2.2.3.3 Method of Administration and Practicality

Another issue which can have an impact on the validity and reliability of the results obtained from a measure is the method of administration.

Performance based measures (direct observation) are often considered superior to evaluation by a questionnaire or checklist. Using a community dwelling elderly population, Myers et al. (1993) investigated whether functional performance measures were superior to self-assessment on questionnaires. They found that, although each method can provide different types of information, performance measures were not superior to questionnaires with respect to their psychometric properties, acceptability to respondents, ease of administration or scoring. Moreover, the authors pointed out that no one tool, questionnaire or performance-based assessment should be used for all purposes or populations and that there may be value in using both methods of evaluation.

Since the conditions observed in the elderly may be complex, especially when cognitive and affective impairments are present, an informant's report must often be used rather than self-report or direct observation. Even if the use of a proxy may introduce a bias in the result (Rubenstein et al., 1984), self-report may be unreliable in dementia because of patients' lack of insight regarding their abilities (Kiyak et al., 1994; McGlynn & Kaszniak, 1991). Direct observation may also be impractical as the presence of an examiner during activities can disturb patients thus influencing their performance. It is also difficult with this method to assess a wide range of activities.

Only a few studies have addressed these issues with regard to functional assessment of the elderly population. Moreover, within these investigations, there is little information on the cognitively impaired population.

Studies have investigated the comparability of measurement of BADL and IADL through direct observation, self and informant reports on elderly individuals admitted to psychiatric wards (Kuriansky et al., 1976) and to homes for the elderly (Little et al., 1986). Both have shown that informant reports were more closely related to direct observation than self-reports. However, agreement between direct observation and informant's report were low to moderate in each study. Kuriansky et al. (1976) found that cognitively impaired individuals tend to overestimate their abilities while those with affective disorders tend to underestimate. Conversely, Little et al. (1986) did not find any significant difference for accuracy of report between affectively and cognitively disabled populations. Kivela (1984) assessed the comparability of measurement of functional status through direct observation compared to informant's report for the chronically ill and well elderly residing in the community. Results showed that agreement between these two methods was better for basic activities of daily living (94-97%) than for instrumental activities of daily living (64-77%). Kaufert et al. (1979) obtained similar results in a study comparing questionnaire-based ratings to clinical ratings of elderly primary care patients. They found an agreement between 79 and 98 % for mobility and self-care functions while the agreement was between 57 and 68% for more complex activities. In general, studies investigating patient-proxy comparability on measures of functional status have reported that elderly subjects tended to perceive themselves as functioning at a higher level than informant reports (Magaziner et al., 1988; Rubenstein et al., 1984).

Studies on patient-proxy comparability are difficult to interpret since factors, other than the use of a proxy, seem to have an impact on the concordance obtained between responses. Important factors are the type and specificity of questions asked. Agreement between self and informants on questionnaire or interviews are found to be closer when fewer choices for responses are offered, and when the items assessed are more concrete and less complex (Magaziner et al., 1988; Sprangers & Aaronson, 1992). This may explain why concordance was found to be lower on the IADL items compared to the basic ADL items for several of the studies reviewed. The questions on most scales pertaining to IADL are often more global or ambiguous thus leaving more margin for variability in the interpretation of the questions.

Another factor which may also have influence concordance in ratings is in the choice of the proxy. Closer relationships between subjects and proxies are found to increase the agreement on functional measures (Klein-Paris et al., 1986; Magaziner et al., 1988; Sprangers & Aaronson, 1992).

Unfortunately, it is unclear from a review of the literature which method of administration is superior for the functional assessment of the cognitively impaired population. Nonetheless, the literature supports the use of a proxy respondent for the measurement of functional status. Whenever using such a method care should be taken in the selection of a precise tool and in the choice of a proxy respondent.

Practicality of the instrument is another factor which should also be considered. In particular, the clarity of the instructions and the scoring system, the amount of material and the expertise needed to administer the assessment, the costs involved and the time required to administer and score the instrument are of concern (Law & Letts, 1989). These may be sources of burden on the evaluator and consequently affect the quality of the data gathered. The inconvenience that the instrument may cause to the respondent should also be considered. A tool that is not too long to administer nor complicated with clear response choices presents definite advantages.

2.2.4 Existing Measures of Functional Disability

The literature reports several scales for the assessment of BADL and IADL in the elderly (Kane & Kane, 1981; McDowell & Newell, 1987). Most of the available scales however do not provide a conceptual approach on which their development was based and in light of which results of assessment can be interpreted (McDowell & Newell, 1987). Scales vary according to the target population. Most of these measures have been developed for physically disabled populations such as individuals suffering strokes or rheumatoid arthritis. As a result, current assessments of functional status have mostly addressed the area of physical performance (Jette, 1984) and are not appropriate for cognitively impaired populations. Scales also differ according to their purpose (screening, assessment, maintenance), the domains assessed (multidimensional vs unidimensional), the methods of administration (direct observation, self or informant reports), the length of the assessment and the scoring method (Kane & Kane, 1981). The majority of the functional evaluations are task/outcome oriented (Carswell et al., 1992) and are scored using an ordinal or rank-ordered scale (Law & Letts, 1989) reflecting the level of functional independence or the type of help needed to successfully perform the activities. Most of the ADL scales are found to be quick and easy to administer and score (Law & Letts, 1989).

McDowell and Newell (1987) reported that the lack of psychometric information is the major weakness of the existing scales. Linn and Linn (1982) also mentioned that several scales do not provide definitions for the items used and lack information about rating procedures. For example, subjects may be scored either on real performance or on what they say they are able to do. While options exist, instructions should be clearly stated.

2.3 ASSESSMENT OF FUNCTIONAL DISABILITY IN DEMENTIA OF THE ALZHEIMER'S TYPE

2.3.1 Need for Functional Disabilities Measures Designed for the DAT Population

The importance of determining ability to perform functional activities in dementia is now recognized. It is not only important for the diagnosis of DAT (American Psychiatric Association, 1987; McKhann et al., 1984), but also to monitor the impact of interventions, to determine the need for home assistance and even institutionalization (Green et al., 1993; Mahurin et al., 1991). Indeed, deterioration in functional activities has been found to be a critical predictor of institutionalization for the cognitively impaired (Riter & Fries, 1992).

Several researchers have studied the empirical relationship between the cognitive and functional disabilities observed in DAT. The goal being to determine whether cognitive assessments, currently used for diagnosis, can also be used to estimate the functional status of demented populations. Some of these studies will now be presented.

The changes in functional abilities and in cognition observed in DAT have been compared in longitudinal studies. There is a controversy in the literature as to whether these changes follow a parallel course. Increasing evidence seems to point to the fact that this may not be the case. Gauthier and Gauthier (1990) reported results of a study of 38 intermediate stage DAT subjects who were followed over a period of nine months. During that time, the subjects were periodically assessed with a functional measure and a mental status exam. The results indicated that the magnitude of change between functional and cognitive loss differed. In addition, Reisberg (1986) reported that, unlike cognitive deterioration, functional deficits in ADL do not follow a reversal of the pattern observed in human development.

Several cross-sectional studies of dementia have also indicated a low to moderate association between cognitive skills and functional abilities in ADL (Hershey et al., 1987; Reed et al., 1989; Teri et al., 1989). Using well established measures, Teri et al. (1989) investigated the relationship between cognitive functioning, behavioural problems and functional abilities in 56 DAT subjects with moderate cognitive impairments. They found a low but significant correlation (r=.38) between the cognitive scores and the instrumental ADL scores, while no significant association was found between the cognitive scores and basic self-care skills scores.

Reed et al. (1989), who also investigated the relationship between these variables to assess the adequacy of using mental status tests to estimate functional abilities, suggested that the MMSE score explained only a small portion of the variance in physical and instrumental ADL. Moreover, the association between scores on the two tests was found to be significant only for the severely demented subjects (r=.68 for basic ADL and r=.51 for instrumental ADL), while non-significant relationships were obtained for the less demented group. The mental status measure seemed to be a better predictor of functional status for severely demented individuals and less sensitive for individuals with fewer symptoms. These results led the authors to conclude that cognitive and functional assessments may measure different concepts. Hershey et al. (1987), in a study comparing a cognitive screening test and a measure of function in ADL with vascular dementia patients, also concluded that both measures assess different concepts. They advocated that both types of tools should be used to determine severity of dementia.

In a recent study, Teunisse et al.(1991) also emphasized the need to use measures of both cognitive and functional abilities for the assessment of dementia even though they had found a stronger relationship between these two variables than previously reported studies (r=-.77) with mildly to moderately demented subjects. Their results should, however, be interpreted with caution since some of the instruments used had not been carefully tested and the psychometric information was sparse. The authors emphasized that cognitive assessment alone cannot determine overall severity of dementia. Other aspects such as social support and functional abilities in ADL need to be investigated as well.

Most of the reported studies suggested that cognitive function and ADL abilities are not strongly related. In consequence, these studies support the need to test functional abilities in ADL separately from mental status when assessing severity of dementia. Baum et al. (1993) caution against the tendency to rely only on results of cognitive tests for assessment and management of demented patients as they assess different functions. According to these authors, performance in activities of daily living reflects the ability to integrate different cognitive functions in the production of common behaviours. It would seem that functional assessments provide a more concrete and meaningful way to show families that this integration is successful. This is fundamental in order to develop adequate interventions (Carswell & Eastwood, 1993).

Authors also agree that scales developed for the elderly in general are not appropriate for use with the DAT population and that specific scales should be developed for this group (Carswell et al., 1992; Sclan & Reisberg, 1992; Weintraub, 1986).

2.3.2 Specific Properties of Functional Disability Measures Designed for the DAT Population

Functional scales designed for the DAT population should have a conceptual basis and be designed with specific purposes in mind. They should also be practical and have adequate psychometric properties.

In addition to these general properties, the content of disability scales designed for the DAT population should be relevant to that population. The items should not only be representative of the activities of elderly in general, but they should also be items that can be affected by the disease process and show progressive disability in DAT if it occurs. The type of scaling should also allow changes in performance to be documented. Since this study focuses on the assessment of disability in community- dwelling individuals with DAT, only studies which have addressed the need for assessment with this particular clientele will be reported.

It is generally accepted that basic ADL should be a part of disability assessment in dementia however there are questions concerning whether instrumental activities should be included as these are lost early in the progression of the disease. Several recent studies have demonstrated the importance of including these instrumental activities for the assessment of the cognitively impaired elderly (Barberger-Gateau et al., 1992; Green et al., 1993; Hill et al., 1993).

Barberger-Gateau et al. (1992) assessed cognitively impaired elderly individuals with the Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969) and a cognitive measure to identify which items on the functional measure were related to cognitive impairments independent of age, sex and education. They then determined the ability of the IADL items to screen for cognitive impairment and dementia in community residing elderly. Telephoning, using transportation, taking medication and handling finances were strongly correlated with the cognitive score. When combined, these activities were found to have a sensitivity of 94% and a specificity of 71% for the diagnosis of dementia. Hill et al. (1993) also found, in their study, that instrumental activities of daily living scales used in conjunction with history questionnaire were good predictors of the diagnosis of dementia with both a sensitivity and a specificity of 89%.

Green et al. (1993), in their longitudinal study of community residing individuals with DAT, found that while their measure of functioning in basic ADL was more sensitive to changes in severely demented subjects, the IADL measure responded to changes in mild and moderately demented subjects. They concluded that measures of IADL were useful to detect changes in the early phases of the disease.

It has also been suggested by some authors that a suitable measure for assessing functional disability in the DAT population should not only measure whether the individual is able to perform the activities but should also describe how a task is performed. Such a scale would have a great clinical usefulness for guiding interventions (Baum & Edwards, 1993; Carswell et al., 1992).

2.3.3 Functional Disability Measures in DAT

Several studies in the literature have addressed the measurement of functional status with the demented elderly. Some assessments have focused on one area of functioning such as feeding (Athlin et al., 1989; Rogers & Snow, 1982); dressing (Beck, 1988); meal preparation (Baum & Edwards, 1993) or driving (Lucas-Blaustein et al., 1988). Others have assessed a combination of activities. This review will focus on the latter.

Instruments designed for use with the general elderly population, such as Lawton and Brody's Physical Self-Maintenance and Instrumental Activities of Daily Living Scales (1969) are often used to assess DAT patients. Such scales, targeting the area of physical performance, are not appropriate to use with cognitively impaired populations whose functional disabilities are related to deficits in mental functions. A few instruments have been developed to meet the specific needs of the demented population (Blessed et al., 1968; Laberge, 1990; Loewenstein et al., 1989; Mahurin et al., 1991; Moore et al., 1983; Reisberg et al., 1984; Skurla et al., 1988; Weintraub, 1986). A description of selected instruments is presented in appendix A. These instruments will now be compared in terms of conceptual basis, purpose, content, scoring system, method of administration and psychometric properties.

2.3.3.1 Conceptual Basis

Only a few of the instruments reviewed have been found to be based on a theoretical model. The FAST from Reisberg et al. (1984) is based on the Global Deterioration Scale (Reisberg et al., 1982) which describes the evolution of DAT in seven stages. The Psychogeriatric Basic ADL Scale (Laberge, 1990; Laberge & Gauthier, 1994) presents activities which are organized in a hierarchy according to the findings of Katz (1983). The Direct Assessment of Functional Status (DAFS)(Loewenstein et al., 1989) also has tasks organized according to a hierarchy based on a functional model proposed by Reisberg et al. (1984, 1985).

Most of the other assessments lack a theoretical framework. However for some scales, the authors have reported that the content has been developed from reviews of the literature and consultation with experts (Loewenstein et al., 1989; Mahurin et al., 1991; Moore et al., 1983; Skurla et al., 1988).

2.3.3.2 Purpose

All of the instruments reviewed can be classified as being descriptive/discriminative (Blessed et al., 1968; Laberge, 1990; Loewenstein et al., 1989; Moore et al., 1983; Reisberg et al., 1984; Skurla et al, 1988; Weintraub, 1986). They aim at identifying or quantifying the functional impairments in cognitively impaired populations. Only one instrument, the FAST (Reisberg et al., 1984) has been developed as a predictive tool to be used for diagnostic purposes. None of the instruments qualify as evaluative measures as they have not been assessed with regard to their ability to detect change. Despite that fact, the Dementia Scale (Blessed et al., 1968) has been used in many studies to measure change in subjects' status over time (Corey-Bloom et al., 1993; Huff et al., 1987; Jacobs et al., 1994; Mayeux et al., 1985)

2.3.3.3 Content

All of the scales reviewed contain items which are relevant to the assessment of functional disability in a cognitively impaired population. Still, none of the instruments meet all of the requirements stated in the previous section with regard to content.

Several instruments assess functional disability in conjunction with other aspects (Blessed et al., 1968; Loewenstein et al., 1989; Mahurin et al., 1991; Moore et al, 1993). The Functional Dementia Scale (Moore et al., 1983) presents overall information on cognitive and affective impairments as well as on some aspects of functional disabilities in ADL. It is a measure of global functioning. The total score does not provide a true reflection of ability to perform functional tasks as it is influenced by results in the other areas. Also, specific information on the ability to perform different activities of daily living, such as bathing or dressing, are lacking as ADL are assessed as a whole. The Direct Assessment of

Functional Status (Loewenstein et al., 1989) also includes domains of cognitive and functional abilities that were found by experts to be problematic with the DAT clientele. Each domain is assessed more extensively with this instrument, however, than in the previous scale.

A number of assessments incorporate only self-care or instrumental activities and are therefore missing important components for the evaluation of functional disability in community-dwelling individuals. Sometimes, both dimensions are present but the range of activities is very limited in certain areas. The Psychogeriatric Basic ADL Scale (Laberge, 1990) covers only one dimension as it was developed for the assessment of basic ADL. The Direct Assessment of Functional Status (Loewenstein et al., 1989) primarily assesses instrumental tasks and only two out of the seven domains cover basic activities. Most of these domains are evaluated through the assessment of isolated skills which may not adequately measure real capacity in the performance of daily activities where the integration of many skills is required.

The Activities of Daily Living Situational Test (Skurla et al., 1988) evaluates performance in four tasks (dressing, meal preparation, telephoning and purchasing) that have been identified by experts as being problematic for cognitively impaired elderly. As with the instrument previously described, it focuses mainly on the instrumental ADL functions as only one task pertains to basic ADL. This scale may not detect deficits in functional abilities when used with severely impaired patients who can no longer perform complex activities. Since validation of content has not been reported for these scales, except for the Psychogeriatric Basic ADL Scale (Laberge, 1990; Laberge & Gauthier, 1994) and the FAST (Reisberg et al., 1984), we may question the validity of their content.

With the exception of the instruments from Laberge (1990) and Skurla et al. (1988), none of the measures reviewed provide an indication on the manner that the activities are performed. It is therefore difficult to determine the nature of the deficits or impairments that affect performance. Most of the scales simply document whether a person can perform the activity or the type of assistance, physical or verbal, needed to do the activities. In the Psychogeriatric Basic ADL Scale (Laberge, 1990; Laberge & Gauthier, 1994) five basic activities of daily living (bathing, dressing, personal hygiene, continence and feeding) are assessed according to the executive functions that are required for adequate performance. This instrument specifically assesses aspects of ADL related to mental functioning and provides information on the origin of the observed disabilities. Skurla et al. (1988) do not clearly indicate which impairments are at the origin of the difficulties observed in performing daily tasks. However, each activity is broken down into subtasks which are indicative of certain cognitive deficits. For example, dressing, the only basic ADL activity, includes as a subtask "Attempts to select clothing". This points out problems in initiation although this is not clearly stated in the instrument. The problem with this measure is that for some of the subtasks it is not always clear if difficulty in performing is due to cognitive or physical deficits (Guralnik & Branch, 1989). In their critique of the instrument, these authors noted that while both physical and mental performance are evaluated, a clear differentiation between behaviours related to each of these domains is not always apparent. They emphasized that physical and mental performance in ADL should be assessed separately in dementia. In fact, clinicians need tools that can distinctly identify areas of deficit in order to facilitate treatment planning and researchers require this information to assess the specific impacts of intervention.

2.3.3.4 Scoring System

Most scales require a categorical judgment from the rater. Items are scored either on a nominal or dichotomous scale (Loewenstein et al., 1989) reflective of the person's ability to correctly or incorrectly perform the task, or on an ordinal scale (Blessed et al., 1968; Laberge, 1990; Mahurin et al., 1991; Moore et al., 1983; Skurla et al., 1988; Weintraub, 1986) indicative of the degree of impairment or the type of assistance required. Only two of the performance based scales take time into account (Mahurin et al., 1991; Skurla et al., 1988). This is scored independently from the ability to perform the tasks. Skurla and collaborators (1988), however, question the value of using time as an indicator of disability with this population.

The FAST (Reisberg et al., 1984) is scored on an ordinal scale ranging from 1 to 7f which correspond to 16 functional stages organized in a hierarchy. The final score represents the highest ordinal value attributed to the subject. It should be noted that this scale may not apply when an individual does not show a typical evolution as described by the authors.

2.3.3.5 Method of Administration

Most instruments are questionnaires that are administered to a significant informant through an interview (Laberge, 1990; Moore et al., 1983; Reisberg et al., 1984; Weintraub, 1986). Three evaluations use direct observation with a trained rater (Loewenstein et al., 1989; Mahurin et al., 1991; Skurla et al., 1988). As mentioned previously, there are advantages and disadvantages in each method when used with the cognitively impaired population. Authors who have developed the performance-based instruments feel that an observational assessment represents a more valid instrument than self- or informant reports because of possible reporter bias. However, these instruments are more time-consuming and less practical to use. In addition, the fact that they require an artificial simulation of activities in the clinical setting, which is an unfamiliar situation, may have an impact on the cognitively impaired person and may thus not provide a true reflection of their abilities. On the other hand, ratings by the use of proxies is problematic. As discussed earlier, caregivers, generally, tend to underestimate subjects' performance. In addition, the accuracy of ratings is found to vary according to the complexity and concreteness of the questions. It is also affected by the amount of contact with the subject (Klein-Paris et al., 1986; Magaziner et al., 1988; Spranger & Aaronson, 1992). All of the questionnaire-based instruments presented in this review are quick and easy to administer.

2.3.3.6 **Psychometric Properties**

As detailed in appendix A, the instruments presented have been tested to different degrees with regard to their validity and reliability. To the best of our knowledge, none have been tested for responsiveness.

Reliability was established for all scales reviewed with the exception of the Activities of Daily Living Situational Test (Skurla et al., 1988). Most instruments have been tested for interrater reliability and have demonstrated good (Pearson's correlation coefficient ranging from .86 to 1.00) agreement between raters (Loewenstein et al., 1989; Mahurin et al., 1991; Moore et al., 1983; Reisberg et al., 1984) . The Blessed Dementia Scale (Blessed et al., 1968) was the only one in which reliability was found to be low (ICC =.30) (Cole, 1990). Test-retest reliability was cited for five of the scales: the Direct Assessment of Functional Status (Loewenstein et al., 1989), the Functional Dementia Scale (Moore et al.,1983), the Psychogeriatric Basic ADL Scale (Laberge, 1990; Laberge & Gauthier, 1994), the Record of Independent Living (Weintraub, 1986) and the Structured Assessment of Independent Living Skills (Mahurin et al., 1991). These instruments demonstrated moderate to high stability over time with correlation coefficients ranging from .54 to 1.00. Internal consistency was reported only for the Functional Dementia Scale (Moore et al., 1983) and the Structured Assessment of Independent Living Skills (Mahurin et al., 1991). Alpha coefficients were found to be high (alpha=.90) for both measures.

All instruments have been validated. For the most part validation consisted of comparing the scales to established cognitive measures in an attempt to establish construct validity (Loewenstein et al., 1989; Mahurin et al., 1991; Moore et al., 1983; Reisberg et al., 1984; Skurla et al., 1988; Weintraub, 1986) or senile plaques counts for the Blessed Dementia Scale (Blessed et al., 1968). For two instruments, criterion related validity was determined using other recognized functional measures (Laberge, 1990; Reisberg et al., 1984). Few scales have, unfortunately, been assessed on more than just one type of validity.

2.4. CONCLUSION

Functional independence is important for well-being and quality of life of the elderly person. Individuals with DAT experience important progressive deterioration in their ability to perform daily activities. Because it is an important manifestation of the disease, changes in functional abilities are included as criteria to assist with diagnosis.

There is a need for assessments of functional disability designed specifically for the DAT population. Mental status tests or functional assessments intended for the general elderly population are not appropriate instruments to use with these individuals.

Existing instruments designed for the assessment of functional disability in DAT have been reviewed with regard to their conceptual basis, their purpose, the appropriateness of their content, their practicality and their psychometric properties. Based on the review of the literature, none of the instruments met all of the criteria set forth by the investigators. In particular, several scales failed to incorporate all dimensions that should be included in a functional disability measure for community residing individuals with DAT. If they did, there was no indication as to which impairments affect performance. Additional concerns pertain to the weakness of some of the instruments reviewed in term of their psychometric properties.

CHAPTER 3

RATIONALE AND OBJECTIVES OF THE STUDY

3.1 RATIONALE FOR THE STUDY

Dementia of the Alzheimer's type is a seriously disabling disease. Measures of functional performance are recognized as being important constituents of comprehensive assessments to detect and to determine the severity of this condition (Hershey et al., 1987; Katzman, 1986; McKhann et al., 1984; Reed et al., 1989; Teunisse et al., 1991). These measures are also essential for planning and monitoring adequate interventions with these individuals (Green et al., 1993; Mahurin et al., 1991). A review of the literature revealed the importance of designing instruments specifically for the DAT population. Existing general functional assessments for the elderly are not appropriate for use with this group because the content of most measures pertains largely to physical dysfunction. A critical analysis of the instruments that have been specifically developed for use with the DAT population has revealed weaknesses related to their content or their performance in assessing community dwellers.

The literature as well as consultations with health care professionals and caregivers have clearly indicated the need for the development of a more appropriate tool, specifically designed for community residing individuals with DAT, that would be useful in both clinical and research settings.

According to these sources, such an instrument should have a strong conceptual foundation. It should include a combination of basic and instrumental activities of daily living which can be affected by the disease. This would permit detection of disability across different severity levels. It was also recommended to design assessments which would not only indicate which activities are problematic but also which aspects of performance are disabled. This would greatly increase the clinical usefulness of the instrument. It implies looking at impairments known to have an impact on activities of daily living with the Alzheimer's population.

The scale should demonstrate good psychometric properties including the ability to respond to change in the patient's status. Practicality of the tool for use in a community setting should also be considered. The use of information from a significant informant, which has been found to be of value with this population, would seem to be more reliable than an interview with the patient because of the lack of insight characteristic of Alzheimer's patients. It would also be most practical as it could be easily administered in the community, would be less time consuming than direct observation and would allow the assessment of tasks that may be difficult to observe in the clinic (ex. transportation). Issues such as the use of concrete and precise statements and observable behaviours, the restriction of response choices and the selection of a suitable proxy should also be considered in the development of the instrument to increase its accuracy.

3.2 OBJECTIVES OF THE STUDY

The global objective of this research project was to develop an appropriate assessment of functional disability designed for caregivers of community-dwelling patients who have a dementia of the Alzheimer's type (DAT).

Functional disability refers in this study to any restriction in the ability to perform an activity, a task or a behaviour of every day life such as basic self-care or instrumental activities, as defined by the World Health Organization (WHO) (1980) in its Classification of Impairments, Disability and Handicaps.

The four objectives of the study were to: 1) identify the domains encompassing functional disability in DAT and develop items reflective of the domains, 2) verify content validity of the instrument developed to assess functional disability in DAT, 3) conduct tests of internal reliability and eliminate poor items, and 4) validate content and perform tests of external reliability with the final version of the instrument.

Besides developing an appropriate and psychometrically sound instrument, another important goal was to produce an assessment that would be practical for use in the clinical setting and for research activities. This involved creating a French and English assessment. In the province of Quebec, it is particularly important to be able to meet the needs of both the French and English population. It is also necessary for research. The availability of a suitable bilingual outcome measure would greatly facilitate multi-centered and even international studies. The study also looked at the influence of variables, such as age, gender, education or severity of disease, on the performance of functional activities by DAT subjects as measured by the new instrument .

CHAPTER 4

METHODOLOGY

The four stated objectives of the study were met through six consecutive stages as shown in Table 1. The methodology for each stage is presented in this chapter. It includes a description of the four Advisory panels that were asked to participate in the different phases of the development and content validation of the DAD as well as the DAT subjects and primary caregivers who volunteered for the pre-test or participated in testing the internal and external reliability of the scale. The procedures followed and the statistical analyses used at each stages are also described. The methodology employed is partly based on the process proposed by Spitzer and collaborators (1981). The project has been approved by the ethic committee of the School of Physical and Occupational Therapy.

4.1 TRANSLATION PROCEDURE

Since one of the objectives was to obtain a French and English instrument, the development and content validation were carried out simultaneously in both languages. Throughout the different stages, whenever new content was added or modifications were made to the instrument, it went through a translation procedure to ensure that both versions were comparable. The process, which was initiated at the beginning of stage 1 and repeated in subsequent stages, is described in this section.

4.1.1 Translators

Two occupational therapists and two neurologists, who were fluent in French and English, had knowledge of the objectives and the scope of the study as well as the intent of the measure, were asked to participate in the translation or in evaluation of translations of the measure. These expertises have been suggested by Del Greco et al., (1987) and Streiner and Norman (1989).

Table 1.

Objectives and Stages of the Study

OBJECTIVES	STAGES	DAD[a] VERSIONS OBTAINED
1. Identification of the domains and item generation	I. PANEL 1: Mail questionnaire on DAD 1 PANEL 2: Meeting on functional disabilities PANEL 3: Meeting on cognitive impairments	**DAD 2**
	II. Pre-test	
2. Content validation of DAD	III. PANEL 4: Mail questionnaire and meeting on content agreement	**DAD 3**
3. Tests of internal consistency and item reduction	IV. Administration of DAD 3 to 59 caregivers of individuals with DAT[b].	
4. Psychometric tests of the final version of the DAD	V. Final validation of content through the mail with PANEL 4	**DAD 4**
	VI. Verification of interrater and test-retest reliability with DAD 4	

[a] Disability Assessment for Dementia
[b] Dementia of the Alzheimer's Type

One of the occupational therapists acted as the French translator while the other one performed the English translations. The two neurologists served as evaluators of the translations. Therefore one acted as the French evaluator and one as the English evaluator. Each of these individuals undertook the same tasks throughout all translation procedures performed during the study.

Occupational therapists were chosen as translators since they are considered to be experts in assessing functional performance with Alzheimer's patients and are therefore well versed in the domain of functional disability with this population. They also understand the intent of such a measure. Neurologists were chosen as evaluators because of their knowledge of Alzheimer's disease and functional disability with this clientele. Translators and evaluators were remunerated for their time.

4.1.2 Procedure

The scale was translated according to methods proposed by Del Greco et al., (1987) and Streiner and Norman (1989) (figure 1).

The occupational therapists and neurologists who fulfilled the criteria previously outlined were recruited from the Douglas Hospital, Hôpital Hôtel-Dieu de Montréal, Hôpital Notre-Dame and the School of Physical and Occupational Therapy at McGill. They were first contacted by phone and then mailed an introductory letter explaining the objectives of the study as well as an operational definition of functional disability. Versions to be either translated or evaluated were sent by mail to the respective translators and evaluators.

Whenever translation was needed with a new version of the DAD, the items were first translated into French by the French translator recruited for the study. This translation was then assessed by the French evaluator to determine its adequacy. The results from this process were monitored by the investigators and discrepancies were analyzed. The French version was then translated back into English by the English translator who was blind

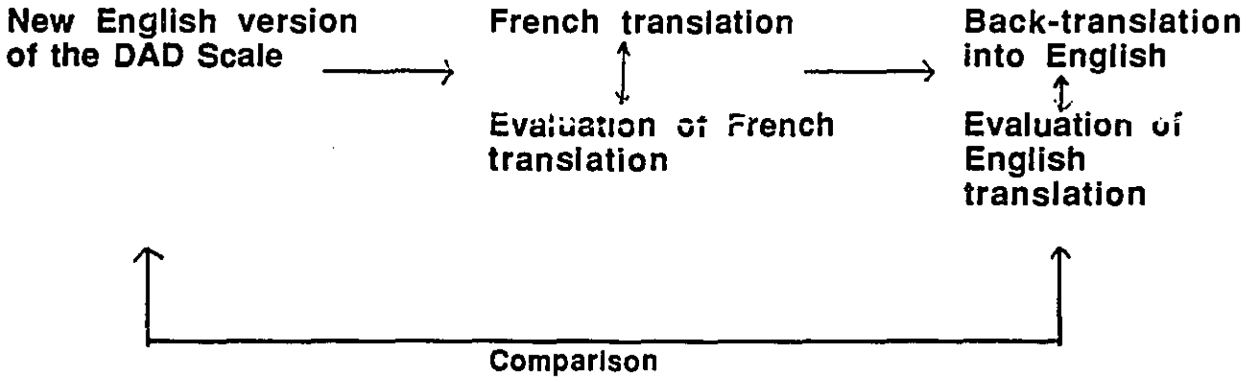

Figure 1. Translation Process

to the initial version. The translation was assessed by the English evaluator who was also blind to the initial version. The back-translation was then compared to the initial version by the researchers and differences were examined. If incongruities were found between the two versions, items were redrafted and went through the procedure until a comparable version was obtained.

4.2 STAGE I

Panels composed of experts and caregivers were formed to identify domains of functional disability in DAT and items reflective of these domains. They were also consulted on weighting of items and scaling format. Panels were composed of a maximum of 11 individuals. This number of participants was chosen as it had been found to be suitable for good group productivity by Streiner and Norman (1989) and Fink et al. (1984). Panel members were consulted by mail or during a meeting. All meetings were tape recorded and transcribed.

4.2.1 Panel Members

4.2.1.1 Health Care Professionals

Twenty-three bilingual health care professionals from various fields (table 2) were asked to participate in one of three panels. Allocation to the panels was done according to the topic and the expertise required to discuss it. The geographical location of members and costs were also considered in the assignment of members to a panel.

To be eligible for inclusion participants had to be considered experts in their field and thus had worked extensively with the population of interest in a clinic or a research setting. Experts were recruited from different disciplines to obtain a wider range of information on functional disability. Whenever feasible, professionals were recruited from different areas in

Table 2.

Composition of the Panels Recruited for Stage I

PANEL	GOALS	HEALTH CARE PROFESSIONALS	CAREGIVERS (GDS[a] stage)
1	Comments on DAD[b] 1	2 Occupational Therapists (1f,1e) 2 Neurologists (1f,1e) 2 Neuropsychologists (1f,1e) 3 Nurses (1f,2e)	1 stage 3 (e) 1 stage 4 (f)
2*	Opinions on Disability	3 Occupational Therapists (b) 2 Nurse (b) 2 Geriatricians (b)	2 stage 3 (b) 1 stage 4 (b)
3*	Opinions on Impairments	3 Occupational Therapists (b) 1 Neurologist (b) 3 Neuropsychologists (b)	

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*Two investigators were present for the meetings of panel 2 & 3
[a] Global Deterioration Scale
[b] Disability Assessment for Dementia
b = Bilingual
e = English
f = French

the province as well as from other provinces. Panel members received an honorarium for their time.

4.2.1.2 Caregivers

Five bilingual caregivers of community residing persons who had been diagnosed as having probable DAT were asked to participate in one of two panels (table 2). Caregivers were defined as individuals providing daily care to a community residing individual who had been diagnosed with "probable" DAT according to DSM-III-R (American Psychiatric Association, 1987) and the NINCDS-ADRDA criteria (McKahnn et al., 1984; Tierney et al., 1988). Individuals who met these criteria were recruited from a list of participants in a previous study or through referral from the McGill Center for Studies in Aging. An attempt was made to include caregivers of individuals who were at different stages of the GDS (Reisberg et al., 1982) and who could therefore provide information on functional disabilities for different levels of severity.

4.2.1.3 Investigators

Two of the investigators served as coordinators for the panels. They were responsible for selecting panel members and allocating them to appropriate panels. This implied consulting different sources to obtain the best experts available. They were also responsible for contacting panel members, sending out information and questionnaires, making sure that all questionnaires were returned and complete, running the meetings and, finally, interpreting results. These investigators were present during the meetings. Their role was to act as moderators of the discussion, and to ensure that the meeting ran smoothly and was tape recorded. This included timing the discussion and making sure that consensus on all questions was reached. They had to remain objective and thus did not participate in content generation or direct panel members toward conclusions.

4.2.2 Procedure

4.2.2.1 Panel 1

A preliminary version of a disability measure for DAT, the Disability Assessment for Dementia 1 (DAD 1) (Appendix B), which had been developed from the work of Gauthier and collaborators (Gauthier, 1990; Gauthier & Gauthier, 1990; Gauthier et al., 1990A, B, 1991A, B) and the results of a pilot study (Laberge, 1990) were used as a basis for obtaining information on suitable items. DAD 1 was a dichotomous scale composed of 30 questions which assessed disability in self-care and instrumental activities according to impairments of executive functions. It yielded a total score of 30. Higher scores indicated less disability while lower scores denoted more difficulties.

Two caregivers and nine health care professionals (table 2) from different Provinces in Canada were contacted by telephone and asked if they would participate on the panel. All agreed to participate. Each panel member was sent the English or French version (Appendix B) of DAD 1, the objectives of the study, the operational definition of functional disability used in this study, and a structured questionnaire (Appendix C).

They were asked whether they strongly agreed, agreed, disagreed, or strongly disagreed, that the total group of items included in DAD 1 reflected the domains of functional disability in dementia. They were asked about other domains that they felt might be missing. They were also questioned on the appropriateness of the proposed DAD 1 items, the need to add or delete items and the terminology used. They were required to determine the importance and the frequency of occurrence of each item on a three point-scale ranging from "very important" to "not important at all". Finally, panel members were consulted about the use of executive functions to assess disability and on the potential ability of the scale to discriminate between Alzheimer patients and healthy subjects, as well as among Alzheimer individuals at different stages of the disease. Suggestions were also solicited on scaling format. Obtaining expert opinions through the mail allowed the recruitment of experts from different regions outside of the Montreal area at a feasible cost.

4.2.2.2 Panel 2

Experts were asked, during a three hour meeting, for their spontaneous opinions about appropriate items to assess functional disability in DAT. They had not seen the DAD 1 or the structured questionnaire.

Three bilingual caregivers, and seven local, bilingual, health care professionals (table 2) were contacted by phone to solicit their participation in a meeting. When an expert was not able to participate, another expert from the same field, who met the previously listed criteria was asked to participate. This was to ensure that the panel was composed of different relevant disciplines. Those who agreed to participate were sent a letter of invitation stating the main objective of the study as well as an operational definition of disability.

During the meeting, participants were asked to determine necessary domains of a measure of functional disabilities in DAT and items that would be representative of these domains. They had to grade the items in terms of their importance in assessing functional disability and detecting change, and on their frequency of occurrence. A three point-scale ranging from "very important "(or frequent) to "not important "(or not frequent) was used for the gradings. In addition, they were consulted about the type of assistance needed in functional activities, the observed fluctuation in day-to-day performance, the insight of patients about their difficulties, the impact of age on functional abilities and their preference in terms of method of administration and scaling format.

4.2.2.3 Panel 3

Panel 3, composed of seven local, bilingual, health care professionals (table 2), was asked during a three hour meeting to define the impairments in cognitive functions which may influence the daily performance of DAT persons (WHO, 1980). The same procedures, as described for panel 2, were used to recruit the panel members and conduct the meeting.

This panel was asked to determine appropriate domains, and to evaluate their importance and frequency of occurrence on three point-scales as described previously.

Enquiries were also made about preferences in terms of method of administration and scaling format. As for panel 2, the investigators acted as moderators for the discussion.

4.2.3 Data Analysis

Information obtained from the three panels was gathered through the use of a structured questionnaire for panel 1, and through notes taken by the investigators during the meetings as well as tape recordings for panels 2 and 3. The tapes were transcribed following the meeting. This information was tabulated across panels by the investigative team. Information obtained from a review of the literature was also taken into consideration. All items rated important and frequent by the advisory panels were considered for DAD, version 2. The scaling format was based on the suggestions of the panels and the personal experience of the investigators.

DAD 2 was produced in French and English (Appendix D) using the translation procedure previously described.

4.3 STAGE II

In this stage DAD 2 was pre-tested with DAT subjects and their caregivers to determine the clarity, completeness and the practicality of the rating scale.

4.3.1 Sample

Four caregivers (two English speaking and two French speaking) of individuals with DAT were recruited from the McGill Center for Studies in Aging. Since the objective of this stage was to determine practicality and clarity of DAD 2, only a small number of subjects were recruited. It was deemed important to administer the scale to both French and English subjects to pretest each version.

To be selected, the DAT subjects had to be diagnosed with "probable" dementia of the Alzheimer's type according to the DSM-III-R (American Psychiatric Association, 1987) and the NINCDS-ADRDA criteria (McKahnn et al., 1984; Tierney et al., 1988). These criteria are commonly used for the diagnosis of DAT in clinical practice and research. Their specificity and sensitivity have been determined and are presented in chapter 2.

Subjects had to be residing in the community as the scale is designed specifically for this population. They had to live in the Montreal area or within 100 km on the North or South shores. The DAT subjects had to be in stages 3, 4, 5 or 6 of the Global Deterioration Scale (Reisberg et al, 1982). These are the stages commonly found in the community residing population. The Global Deterioration Scale (GDS) is frequently used in practice to describe the course of deterioration of the disease. The severity of symptoms is classified according to seven stages (Reisberg et al., 1982). These have been presented in chapter 2. The GDS is used once a clinical diagnosis of primary degenerative dementia has been made. It has been validated with memory, behavioural and clinical assessments (Reisberg et al., 1982; Reisberg et al., 1988), as well as neuroradiologic (De Leon et al., 1979; Reisberg et al., 1988) and neurometabolic (Ferris et al., 1980; Reisberg et al., 1982) indices for age-related and Alzheimer's related deficits. Wide variations in the correlation coefficients were obtained with the majority being between .54 - .89. Good interrater reliability (r = .82) has been reported by Gottlieb et al. (1988) for DAT subjects.

Another inclusion criterion was that the DAT subjects had to be free of physical impairments that could interfere with the performance of ADL and IADL. Since the aim was to create a scale that would assess disability associated with cognitive deficits, the presence of physical impairments could have confounded results.

As the scale was intended to be administered to a proxy, subjects had to have a primary caregiver available to answer questions on performance in ADL and IADL. Caregivers had to meet the criteria mentioned in section 4.2.1.2. To increase the accuracy of responses, several studies (Klein-Paris et al., 1986; Magaziner et al., 1988) have indicated the importance of choosing a proxy who is in close relation to the subject.

Both DAT subjects and caregivers had to be able and willing to sign a consent form (Appendix E).

4.3.2 Procedure

Each caregiver was interviewed at home by a trained rater using DAD 2. Two bilingual trained raters (an occupational therapist and a neurologist), who had experience in assessing functional disabilities with DAT subjects, participated in this stage of the study. Characteristics of the caregivers and the DAT subjects were recorded (Appendix F). Caregivers and raters were asked to comment and make suggestions on the appropriateness, clarity, completeness and practicality of the questionnaire. Duration of interviews was also noted.

4.3.3 Data Analysis

Comments and suggestions resulting from the pre-test were scrutinized by the investigators. Items that were unclear or incomplete were either changed or corrected.

4.4 STAGE III

The main objective of this stage was to validate the content of DAD 2. This was accomplished by using a fourth panel of experts and caregivers.

4.4.1 Panel

A fourth panel of experts composed of two bilingual caregivers of DAT subjects and nine bilingual health care professionals (two occupational therapists, two nurses, two neurologists, two neuropsychologists and one geriatrician), who fulfilled the same criteria as in stage II, was asked to participate. Of these experts, five were residing in the Montreal metropolitan area, one was from Ottawa, one was from Nova Scotia and one from New-Brunswick. As for the panels in stage I, the same two investigators were present during the meeting. Their role was the same as described earlier. Members of this panel also received an honorarium for their time.

4.4.2 Procedure

Potential members were phoned by one of the investigators to invite them to participate. If they agreed, DAD 2 was mailed to them along with an introductory letter, a description of the objectives of the study, an operational definition of functional disability and a structured content validation questionnaire (Appendix G).

Panel members were questioned on the adequacy of the domains included in the assessment, the relevance of assessing functional disability according to executive functions, and the appropriateness, clarity, completeness and weighting of each item. They were also consulted on the method of administration, the scaling format and the ability of the measure to discriminate between healthy and Alzheimer subjects. This was followed by a three hour meeting where these points were discussed. Panel members were asked to reach an agreement on all items. The meeting was tape recorded and transcribed.

4.4.3 Data Analysis

The information gathered from the individual questionnaires and from notes and the tape recording from the meeting were tabulated and compared by the investigators. Decisions as to whether items were kept, modified or rejected were determined by whether or not the a priori criterion (51%) was met. The same criterion was used regarding scaling format. A new version, DAD 3 (Appendix H) resulted from this stage and was translated using the procedure previously described.

4.5 STAGE IV

In stage IV data were collected on functional performance of Alzheimer subjects, using DAD 3, from a caregiver sample to obtain information on item performance. This provided information about the need for modification. Since the data used for analyses at this stage were also collected as part of the test-retest and interrater reliability studies, the data collection procedure described in this section also applies to other stages of the study. The entire procedure was described here for ease of understanding and clarity, and therefore, will not be repeated in later stages.

4.5.1 Study Sample

Fifty-nine (35 English, 24 French) caregivers of individuals with DAT were recruited from the McGill Center for Studies in Aging and the Alzheimer Society of Montreal. The number of subjects was based on recommendations of Streiner and Norman (1989) who advocated a minimum of 50 individuals to determine frequency of endorsement. Sample size was also determined by the feasibility of recruiting subjects within a 12 month period. The inclusion criteria for the DAT and caregiver subjects were the same as the ones used in stage II (table 3).

4.5.2 Procedure

4.5.2.1 Recruitment of Subjects

Advertisements for volunteers for the study were sent to the Alzheimer Society of Montreal and local newspapers. These announcements were also sent to practicing occupational therapists and neurologists from the MCGill Center for Studies in Aging to distribute to their patients.

Caregivers who called to participate in the study were screened through a telephone questionnaire by a research assistant to make sure that they met the inclusion criteria. They were also asked if they were willing to answer questions on the burden of caring for an individual with Alzheimer's Disease as a validity study was being conducted in parallel. They were informed that Alzheimer subjects would be tested on mental abilities through a brief questionnaire, the Mini-Mental State Examination. Enquiries were made regarding willingness to be revisited on one or two other occasion for test-retest and interrater studies. In addition, they were informed that, during the interview, permission to contact the Alzheimer subject's physician to confirm diagnosis would be sought and they would be asked to sign a consent form (Appendix J).

Table 3.

Inclusion Criteria for DAT[a] and Caregiver Subjects

DAT subjects:

.Diagnosed with probable DAT according to DSM-III-R[b] and NINCDS-ADRDA[c] criteria.

.Stages 3, 4, 5 or 6 of the Global Deterioration Scale.

.Residing in the community.

.No physical impairments that could interfere with the performance of self-care and instrumental activities of daily living.

.Primary caregiver available.

.Able and willing to sign a consent form.

Caregiver subjects:

.Providing daily care to a DAT subject.

.Residing in the Montreal area or within 100 km on the North or South shores.

.Able to answer questions on performance in self-care and activities of daily living.

.Able and willing to sign a consent form.

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[a] Dementia of the Alzheimer's Type
[b] Diagnostic and Statistical Manual of Mental Disorder-III-Revised
[c] National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association.

4.5.2.2 Recruitment and Training of Raters

Six raters who were French or English speaking occupational therapists or occupational therapy students participated in the data collection. They were recruited and underwent three training sessions to ensure that data collection was standardized.

Experienced occupational therapists and students were chosen as they have had training on how to use functional measures and are the ones most likely to use the scale. Besides group training sessions, each rater also performed one interview with a caregiver and a subject under the supervision of one of the investigators.

To ensure that data collection was consistent throughout the study, a meeting was scheduled when half of the data had been gathered to discuss any problems that might have arisen. In addition, the investigators were available at any time for questions that might come up during an interview.

Interviewers were asked to comment on the clarity, completeness and practicality as well as the time taken to complete the questionnaire.

4.5.2.3 Data Collection

The caregivers and Alzheimer subjects who met the inclusion criteria and who agreed to participate in the study were interviewed at home in the language of their choice by a trained French or English speaking rater. Appointments were set up by the research assistant. The initial interview lasted about one hour.

A consent form (Appendix J) which included permission to confirm the diagnosis with the physician had to be signed by both caregivers and Alzheimer subjects before the interview. Sociodemographic and clinical information such as age, sex, educational level, stage, duration of disease and medication use were collected about the individual with Alzheimer's Disease (Appendix F). Similar sociodemographic data were obtained about the caregiver. The Alzheimer subject then completed Folstein et al.'s (1975) Mini-Mental State Examination (MMSE) (Appendix I) to provide information on cognitive abilities. The caregiver was interviewed about the subject's functional disabilities using DAD 3

(Appendix H). The decision regarding the presence of the Alzheimer subject during the interview was left to the caregiver. The impact of this was later considered when determining administrative guidelines. The Rapid Disability Rating Scale-2 (Linn & Linn, 1982) and the Burden of Care Scale (Zarit et al., 1980), which were used in a parallel validation study, were administered at the same time.

Following the initial interview, the Alzheimer subject's physician was contacted by mail (Appendix K) to confirm the medical diagnosis. Information on the GDS stage of the disease, the date of first diagnosis and presence of neurological or psychiatric conditions was also obtained. A copy of the subjects' consent form was attached to the request.

All caregivers who agreed to a second and/or third interview were reassessed with DAD 3 by the same rater for the test-retest study and by a second rater for the interrater study. Both interviews were performed within one week after the initial interview. This time interval was believed to be appropriate because performance is assessed over a two week period in the DAD. Therefore, retesting after a longer time interval might have biased the results if changes in functional performance occurred as a result of observing over a different time period then in the initial interview. These interviews lasted a maximum of 1/2 hour as they only involved completing DAD 3.

Files were verified after each interview to ensure that the information was complete. If data were missing, the interviewer was contacted to provide it or asked to contact the caregiver to obtain it. Information was then entered on coding sheets (Appendix L) and into the SYSTAT data file. Data were also converted for use with SAS statistical package.

4.5.3 Instruments

4.5.3.1 The Disability Assessment for Dementia 3

The third version of the DAD (Appendix H) was administered to caregivers. The scale assessed functional abilities in activities of daily living in individuals with cognitive deficits such as DAT. Performance in self-care and instrumental activities of daily living observed over a two week period was evaluated according to abilities in initiation, planning and organization, and effective performance. The instrument examined what the individual was doing without any assistance or reminder, as opposed to what he or she might be capable of doing.

At this point the scale contained 46 items (19 related to self-care and 27 to instrumental activities) scored on a dichotomous scale. A total score was obtained by adding the rating for each question and converting the total score for applicable items into a percentage. Therefore non-applicable items were not incorporated in the total score. Higher scores represented less disability while lower scores indicated higher levels of dysfunction. A user guide and a video for administration and scoring of DAD were also developed. The DAD took approximately 15 minutes to administer.

4.5.3.2 The Mini-Mental State Examination

The Mini-Mental State Examination (MMSE) (Folstein et al., 1975) (Appendix I) is a screening test which assesses cognitive abilities. The test evaluates orientation to time and place, instantaneous recall, short-term memory, language and arithmetic abilities. It includes 11 questions and yield a maximum score of 30. It is a practical test which is easy and short to use (5-10 minutes). The test was administered in the study according to the standardized method described by Molloy et al. (1991). Folstein (1983) reported good test-retest reliability (r>.89) and interrater reliability (r>.82). Anthony et al. (1982) also reported adequate test-retest reliability for normal (r=.85) and demented (r=.90) subjects. These authors found the MMSE to be 87% sensitive in detecting dementia or delirium and 82% specific in determining the absence of disease at a cut-off point of 23/24. The MMSE has been found to be influenced by age, education and socio-economic status (Brayne & Calloway, 1990; Jagger et al., 1992; Kittner et al., 1986; Ylikoski et al., 1992). Age-specific norms for healthy men and women have been developed and validated by Bleecker et al. (1988). Performance of the MMSE as a screening tool for DAT outpatients (Uhlmann & Larson, 1991) was found to be optimal when education-specific norms were used. The cut-off scores and their respective sensitivity and specificity were 21 (82%-94%) for middle school, 23 (79%-97%) for high school, and 24 (83%-100%) for college/graduate school.

4.5.4 Data Analysis

Characteristics of Alzheimer and caregiver subjects were examined via descriptive statistics. As French and English versions of the DAD were used for data collection, French and English Alzheimer subjects were compared on their characteristics and on DAD 3 scores to determine if results from the scale could be pooled for further analysis. The performance of individual items was then assessed. Items were retained or discarded based on the results of the statistical tests and face validity.

The descriptive and comparative analyses and the presence of gender specific questions were analyzed using SYSTAT version 5.2.1 (SYSTAT, Inc., 1989). SAS statistical packages version 6.08 (SAS Institute, InC.,1993) was utilized for the tests of internal consistencies, reliability estimates for individual items and the frequencies of endorsement. Analyses were done in consultation with a statistician.

4.5.4.1 Descriptive and Comparative Analyses of the Study Sample

Descriptive statistics were obtained on the clinical characteristics of Alzheimer and caregiver subjects, the MMSE and DAD 3 for the total study populations and for the Alzheimer subjects divided into groups according to language. The descriptive summaries included means, standard deviations, medians and ranges for the continuous variables. Frequencies and percentages or proportions were obtained for the nominal and ordinal variables. Distributions were also produced and analyzed to determine normality and determine choice of appropriate statistical analysis.

Comparative analyses between French and English Alzheimer's subjects were done using the two-tailed Student t-test for independent samples and 95% confidence intervals (CI) for continuous variables. Chi-square analysis and trends in frequency distributions were considered for nominal and ordinal variables. Comparability of groups on a variable was established if the t-test or Chi-square analysis had P-values above .05.

The range of plausible differences in means for each continuous variable from the CIs and trends in frequency distributions for nominal or ordinal variables were also examined to determine if they represented clinically important differences between the French and English groups.

4.5.4.2 Items Reduction

The performance of individual items was assessed by a panel of experts during a meeting. All participants had to agree for an item to be removed or modified. Decisions regarding item reduction were based on results from three types of analyses. These were frequencies of endorsement, tests of internal consistency (Cronbach's coefficient alpha, item-total and inter-item correlation coefficients), and reliability estimates of individual items using the unweighted kappa. Individual items were also examined using multi-way tables to identify which ones may be gender specific. Face validity was an important criterion considered in the decision whether an item would be retained or removed. The statistical tests and the criteria set out to discard poor items are summarized in table 4. When a modified version of the scale was produced as a result of these analyses, it was assessed again with Cronbach alpha and item-total correlations to determine if the changes improved the scale's homogeneity. Version four of the DAD Scale resulted from this stage.

4.5.4.2a Frequencies of Endorsement

Frequency of endorsement or the proportion of persons who chose each alternative from an item were determined for the DAD 3. Items where one alternative showed very low (rate lower than .20) or very high endorsement (rate higher than .90-.95) or those frequently rated as non-applicable were (Streiner & Norman, 1989) considered for removal since they provided very little information and lengthened the scale.

4.5.4.2b Tests of Internal Consistency

The scale was assessed for internal consistency using three statistical measures: Cronbach's alpha, item-total correlations, and inter-items correlations.

Table 4

Criteria for Item Elimination

Statistical Tests	Elimination Criteria
.Frequency of endorsement	$f < .20$ or $f > .90$
.Cronbach's alpha	$\alpha < .80$
.Item-total correlations	$r < .40$ or $r > .80$
.Inter-item correlations	$r< .20$ or $r > .80$
.Unweighted kappa	$k < .40$

Note: Face validity and gender specificity of items were also considered for item selection.

Cronbach's alpha (α) (Cronbach, 1951) was computed with the SAS statistical software. This statistic provides an average of all possible split-half reliabilities of a scale and indicates which items may contribute to low reliability.

The formula for α is:

$$\alpha = \frac{n}{n-1}\left(1 - \frac{\Sigma\sigma_i^2}{\sigma_T^2}\right)$$

where n is the number of items, σ_i is the standard deviation for each item and σ_T is the standard deviation of the total score.

Cronbach's alpha when computed for dichotomous items gives the same as the Kuder-Richardson formula which is the appropriate index for dichotomous scales. The formula is identical except for σ_i which is substituted by p_iq_i:

$$\text{KR-20} = \frac{n}{n-1}\left(1 - \frac{\Sigma p_iq_i}{\sigma_T^2}\right)$$

where p_i represents the proportion answering correctly to question i and $q_i = (1 - p)$.

Alpha was determined for the overall scale as well as when individual questions were removed. Values of alpha were considered acceptable if of .80 or higher (Feinstein, 1987).

Item-total correlations, which represent the correlation of individual items with the total score of the scale omitting that item, were also produced. The following formula described by Nunally (1978) was used:

$$r_{i(t-1)} = \frac{r_{it}\sigma_t - \sigma_i}{\sqrt{(\sigma_i^2 + \sigma_t^2 - 2\sigma_i\sigma_t r_{it})}}$$

where $r_{i(t-1)}$ is the correlation of item i with the total, removing the effect of item i, r_{it} is the correlation of item i with the total score, σ_i is the standard deviation of item i, and σ_t is the standard deviation of the total score.

The coefficient used was the Pearson product-moment correlation which when computed with dichotomous items gives identical results to the point-biseral correlation usually recommended for this type of data. Items had to have a correlation higher than .40 to be retained (Streiner & Norman, 1989). This was set to make sure that the items did not assess different concepts but rather different components of the same concept.

Inter-item correlations were determined using Pearson product-moment correlation which yields the same results as the Phi-coefficient normally used for a dichotomous scale (Nunnally, 1978). Items that were highly correlated with other (>.80) or that presented very low correlation (<.20) (Streiner & Norman, 1989) were also considered for removal as they might be redundant or not related to the construct being studied.

4.5.4.2c Reliability Estimates of Individual Items

Unweighted kappa (Cohen, 1960), which is the index of choice for the assessment of observer agreement with nominal data, was computed to determine test-retest and interrater reliability for individual items (Kramer & Feinstein, 1981).

The formula for Kappa is:

$$k = \frac{p_o - p_e}{1 - p_e}$$

where is p_o the proportion of observed agreement and p_e is the proportion of chance-expected agreement.

This statistic corrects for agreement expected by chance. This process allowed identification of items that were less reliable and should be considered for deletion to improve global reliability of the scale. Although standards for the interpretation of the kappa are rather arbitrary (Kramer & Feinstein, 1981), the guidelines suggested by Landis and Koch (1977) were used. According to these authors, k below .20 represent slight to poor agreement, values ranging from .21 to .40 are considered fair, values from .41 to .60 are moderate, values from .61 to .80 indicate substantial agreement and values over .81 are considered almost perfect.

4.6 STAGE V

In this stage the content validity of DAD was reverified following the removal of items.

4.6.1 Panel

The same experts and caregivers who participated to the panel in stage IV were contacted for participation in this stage of the study.

4.6.2 Procedure

The members were consulted by mail on the content validity of the reduced version of DAD. They were sent an introductory letter, DAD 3, justifications for the proposed changes and a structured questionnaire on the modifications made to the instrument following stage IV (Appendix M). They were asked if they agreed or disagreed to each modification suggested.

4.6.3 Data Analysis

The answers from the returned questionnaires were examined by the investigators. Fifty one percent of the panel members had to support any proposed change in order to keep the modification. Otherwise, the item was retained as previously presented.

Following this stage the final version, DAD 4 (Appendix N) was produced. There was no need for translation at this stage as the modifications to the scale consisted mainly of deleting questions.

4.7 STAGE VI

This stage consisted in verifying test-retest and interrater reliability of DAD 4, the final version of the scale. The influence of explanatory variables on the DAD scale was also assessed. The data collected in stage IV with DAD 3, were employed after the deleted items were removed. The procedure has already been described in section 4.5.

4.7.1 Data Analysis

Alzheimer subjects' performances on the final version of the DAD Scale and its subsections were examined using descriptive and comparative analyses. Tests of interrater and test-retest reliability were performed and the presence of gender difference in the scale was investigated. Additional analyses were conducted to determine the influence of explanatory variables on results obtained on the final version of DAD.

The descriptive and comparative analysis were performed using SYSTAT version 5.2.1 (SYSTAT, Inc., 1989). SAS statistical packages version 6.08 (SAS Institute, InC.,1993) was utilized for the tests of reliability and the analysis of the influence of explanatory variables. Analyses were done in consultation with a statistician. Only subjects whose diagnosis was confirmed were included for data analysis.

4.7.1.1 Descriptive and Comparative Analyses of the DAD Scale

Descriptive statistic were calculated for the total DAD score, the self-care and instrumental subsections, and the executive function subsections. In addition, distributions across stages of the disease were produced for the total score and the subsections.

The associations between the ADL and IADL subsections as well as between the executive functions subsections were examined. These associations were determined using the Pearson's product-moment correlation coefficient which is used for continuous variables. This test statistic determines the strength of a linear association between the variables. While there are no concrete standards, correlation coefficients from .25 to .50 indicate a fair degree of association, coefficients from .50 to .75 denote a moderate to good relationship and values above .75 show very good to excellent relationship (Colton, 1974). Assumptions with regards to linearity of associations, normality of distributions and homoscedasticity must be met for employing this statistic (Nunnally, 1978). Whenever these assumptions were violated, Spearman's rho, the non-parametric equivalent, was used. Bonferroni-adjusted probabilities (tests of significance on the relationships) were also performed for Pearson's correlation. This criterion assesses probabilities associated with each correlation while providing protection for multiple tests. Correlations were considered significantly different from zero for P-values below .05.

The relationship between the ADL and IADL subsections was further investigated. These variables were plotted on a graph. Regression lines were fitted for the total score and at different cut-off scores for both variables to assess the extent to which changes in one variable were associated with changes in the other. Reasonable cut off scores were determined from visual inspection of the plotted graph.

The analysis was based on the following statistical model:

$$Y = \beta_0 + \beta_1 X$$

where Y represents the dependent variable, X is the independent variable, β_0 is the y-intercept of the line and β_1 is the slope or regression coefficient (Kleinbaum et al., 1988). The slope β_1 represents the amount of change in Y for one unit of change in X.

4.7.1.2 Tests of Reliability

Test-retest and interrater reliability were determined using two reproducibility indices, the intraclass correlation coefficient (ICC) and the concordance correlation coefficient . The intraclass correlation coefficient (ICC) is considered the measure of choice to assess both interrater and intrarater reliabilities (Fleiss, 1986; Kramer & Feinstein, 1981; Streiner & Norman, 1989). The ICC for interrater reliability was estimated from a two-way random effects model (Bartko, 1966):

$$R = [MSP-MSE] / [MSP + MSE(k-1) + k(MSR-MSE) / n]$$

where MSP is the variance due to subjects, MSE denotes the error variance, MSR denotes the variance due to rater effects, n is the number of subjects and K the number of raters. .

The test-retest reliability was estimated from the following one-way random effects model (Bartko,1966):

$$R = (MSP-MSE) / [MSP + (k-1)\ MSE]$$

A 95% confidence interval was also calculated for the intraclass correlation coefficients.

The concordance correlation coefficient (Lin, 1989) was calculated with its 95% confidence interval. This coefficient assesses the degree to which observations from each subjects are identical and thus fall on a 45_{o}° line. Unlike the ICC, this measure does not allow identical readings to be interchangeable, but treats them as distinct. In addition, this index is found to be robust against small samples from the uniform and Poisson distributions. The concordance correlation coefficient compares deviations from the 45_{o}° line when pairs of ratings are correlated to deviation from the 45_{o}° line when the pairs of ratings are uncorrelated:

$$p_c = \frac{2S_{12}}{S_1^2 + S_2^2 + (Y_1 - Y_2)^2}$$

where S_{12} represents variability when pairs of ratings from both interviews are correlated, S_1 and S_2 represent the variance and Y_1 and Y_2 the means for ratings from the first and second interviews respectively.

A correlation coefficient of 0.80 or higher was accepted as showing good reliability for the two indices utilized (Carmines & Zeller, 1979; Kramer & Feinstein, 1981).

4.7.1.3 Tests of Gender Differences

Analysis were performed to determined if gender differences existed in DAD. Therefore, scores obtained on the scale were compared between male and female Alzheimer subjects. Before performing such an analysis, comparability of the two groups on their characteristics was assessed. Analyses to determined comparability of groups were described in section 4.5.4.1 .

Since male and female groups were found to differ on one variable, an analysis of covariance was performed. This analysis consists of establishing whether mean DAD scores for male and female vary significantly when adjusting for the effect of possible confounders. It entails a multiple regression model in which the independent variable of interest (gender) is treated as a nominal variable while the variables being controlled or covariate can be on any scale. This nominal variable is included in the regression model as a dummy variable. This analysis should be preceded by a test of homogeneity of slopes to ensure that there are no significant interactions between the covariates and gender otherwise analysis of covariance should not be performed. The regression model used in the analysis of covariance was:

$$Y = \beta_0 + \beta_1 X + \beta_2 Z$$

where Y is the dependent variable, X is considered to be the covariate and Z is the dummy variable, gender in this particular case (Kleinbaum et al., 1988). The alpha was again set at .05 for determining significant relationships.

4.7.1.4 Influence of Explanatory Variables

The influence of explanatory variables on the DAD scores was assessed with multiple regression analysis. The analyses were performed in the form of:

$$Y = \beta_0 + \beta_1 X_1 + \beta_2 X_2 + \beta_3 X_1 X_2$$

where Y represents the dependent variable, X are explanatory variables, X_1X_2 describes the interaction between X_1 X_2 and β are the regression coefficients (Kleinbaum et al., 1988).

The influence of the following variables were considered for analysis: age, marital status, education, duration of the disease, GDS stage, mental status scores on the MMSE and interactions between these variables. This choice of explanatory variables which would possibly affect results on the DAD were based on clinical judgment and information from the literature.

Correlation matrices were produced to determine the correlation of the explanatory variables with the dependent variable, DAD, and amongst themselves. These can help in the interpretation of the regression coefficient obtained. According to Kerlinger (1986), interpretation may be difficult especially when the explanatory variables are highly correlated. It then becomes difficult to establish the relative influence of these variables on the dependent variable. The ideal situation is when the explanatory variables are highly correlated with the dependent variable and demonstrate low correlations amongst themselves.

The multiple regression was performed with SAS version 6.08 (SAS Institute Inc., 1993) using a forward selection method where single variables are analyzed for inclusion in the model.

CHAPTER 5

RESULTS

The findings of this study are presented in several sections. In the first part, information is provided on the forward-backward translation procedures used at different stages in the study. Results from the three panels of experts who participated in domain identification and the item selection process are then presented. Modifications to the scale following the pre-test are also described. Next, results relative to content validation of the scale are provided. This includes information gathered from individual responses of the panel as well as group consensus data.

This is followed by a presentation of the findings from the tests performed and the steps taken for item reduction which resulted in the final version of the Scale. Finally, content validity as well as tests of internal consistency, interrater and test-retest reliability are assessed for the final version of the scale. Variables which have an impact on scores obtained from the scale are also explored.

5.1 TRANSLATION

Versions 1, 2 and 3 of the Disability Assessment for Dementia were translated using a forward/backward translation process so that content development and validation as well as tests of reliability were done simultaneously in both French and English.

In general, French and English speaking evaluators were in agreement with the French translations and English back-translations performed. Whenever changes were recommended by the evaluators, they were reviewed by the investigators who decided which one, the translator's or evaluator's formulation, would best represent the intent of the scale and should be kept. For the versions of the scale that were translated (DAD 1, DAD 2 and DAD 3), backtranslations were comparable to the original version indicating that both French and English versions were similar. The final version of the scale, DAD 4, did not need to go through the translation procedure since no new material was added. Modifications consisted of removing items from the third version.

5.2 STAGE I

Three panels of experts were consulted about the domains of functional disability in dementia of the Alzheimer's type and asked to generate items reflective of these domains. The information provided by each of the three panels and the decision making process for selecting items are presented in this section.

5.2.1 Panel 1

Nine experts from different fields and two caregivers were consulted by mail on the appropriateness of DAD 1 (appendix B) through a structured questionnaire. Of these panel members, two, a caregiver and a neurologist, did not respond. The caregiver went through a family crisis shortly after he had agreed to participate and thus was unable to complete the questionnaire. The neurologist never returned the questionnaire even after a telephone reminder. Therefore the responses of eight health care professionals and one caregiver were considered in analyzing data from this panel.

Eight (89%) panel members found that the total group of items included in DAD 1 were reflective of and adequately covered the domains of functional disability in dementia. When questioned about each item, all of the 30 proposed items were considered appropriate and thus suitable for the assessment of disability in dementia by the majority of panel members (range between 67% to 100% for individual items) All items were also considered to be either very important or important to detect a change in disability in persons with dementia by the majority of panel members. Most items were found to occur very frequently or frequently by over 51% of panel members. Exceptions were items on telephoning, shopping, going on an outing, and handling finances. These activities, in contrast to the others assessed, do not necessarily need to be done on a daily basis. They were, however, considered to be important for inclusion in a disability assessment with this population. As mentioned by one of the panel members, these activities are essential for an individual living alone but may be less frequently done by someone who is living with a spouse or a relative.

Additional items relating to the ability to take medications, to do housework and to get involved in leisure activities were recommended by several panel members. Some panel members also mentioned that the issue of safety was very important for some activities and should be incorporated into appropriate items such as meal preparation and hygiene. Suggestions for the addition of general items assessing whether or not a person is safe at home and can be left alone for a certain period of time were made. The possibility of adding items on mobility was also proposed but not accepted since it was not strongly suggested by the panel members. Minor changes with regards to wording were also offered to improve the clarity and precision of some of the items.

Concerning the format, all but one panel member found that organizing the items according to executive function was useful. In terms of scaling, four (44%) members agreed with the dichotomous (yes/no) format while two (22%) disagreed and three (33%) were not able to respond because they lacked knowledge in that area. Concerns with this type of scaling format were related to the ability of the scale to detect change in functional ability over time.

When asked if this assessment would be able to discriminate between a group of healthy subjects and those with Alzheimer's disease on functional disability, all members agreed (33%) or strongly agreed (67%). The majority (89%) also agreed that the scale would be able to discriminate functional disability between individuals with DAT at different stages of the disease.

Overall, the proposed scale was positively accepted with some minor changes and additional items by the majority of members.

5.2.2 Panel 2

The objective of this panel was to obtain spontaneous information on the domains of functional disability for dementia of the Alzheimer's type as well as items which should be included in such a scale. The intent was to get opinions from panel members without previous guidance on the part of the investigators so that experts and caregivers would rely on their expertise and experience developed in working with or caring for Alzheimer patients. The panel was composed of six health care professionals and three caregivers as one of the nurses contacted was not able to attend the meeting described in chapter 4.

The members, even though they came from different fields, reached a consensus very easily on which items should be included in a disability assessment. The domains and items that were retained as being important by a majority of members pertained to basic self-care, instrumental, social and leisure activities (table 5).

For self-care activities, dressing and hygiene were considered important to distinguish between early and later stages of the disease as problems in these activities tend to occur at the end of stage 4 and mostly in stage 5. Both health care professionals and caregivers pointed out that in earlier stages patients can do these activities if reminded but as the disease progress, patients seem to experience more difficulties in preparing for the task and with the quality of performance. Problems with dressing included difficulty in selecting and taking out clothes, forgetting to put them on and inability to dress in the appropriate order. Some difficulty in the ability to dress appropriately for specific occasions or temperature was also reported. Cleanliness was another concern as patients would wear the same clothes day after day. The problem of personal hygiene was also reported by one caregiver; her husband failed to notice when he was not clean. The issue of safety while bathing was also raised and seemed to be of great concern.

Problems in actual feeding were reported to occur in later stages of the disease but modifications in eating habits and appropriateness while eating were noted to change earlier. Continence usually became a problem only in late stages of the disease. In the middle stages, it was noted that if the person was reminded or provided with verbal help, they were able to manage adequately.

Table 5.

Items Suggested by Members of Panel 2 for Inclusion in a Disability Assessment

Self-care activities	Instrumental activities	Social and Leisure Activities
eating	cooking	social interactions
dressing	shopping	hobbies
using the toilet	mobility in environment (orientation to space)	special events
hygiene	driving	
	use of public transportation	
	finance	
	medication	
	housework	
	telephoning	

Instrumental tasks were noted to deteriorate earlier in the disease process. Panel members mentioned that individuals in the early stages lose the ability to do complete meals but could still prepare simple meals. For shopping, caregivers reported that patients usually needed to be cued about what to buy.

Activities like driving or taking public transportation were found to be lost early in the disease process and were closely related to difficulty in orienting oneself in the environment. These activities were of great concern for panel members in terms of safety. Caregivers reported that changes in the ability to orient oneself in the environment started first in unfamiliar environments and were later followed by difficulties in familiar places such as being able to go around the block. They noticed that when patients started having these difficulties, they usually showed enough insight to recognize that they were lost and to ask for help. However, these compensatory abilities eventually deteriorated until the person was no longer able to go out alone.

Panel members also reported that there was a gradual loss of ability to deal with financial matters over time but that the capacity to take care of finance autonomously was lost in early stages. Elementary skills such as counting simple amounts of money became gradually more difficult early in the disease. In terms of medication intake, patients were found to experience difficulty remembering to take their pills and thus needed to be prompted. When using the telephone, Alzheimer subjects could still answer the phone in middle stages of the disease, however, their conversation was not always adequate and they had trouble relaying messages and finding numbers in the phone book. In earlier stages they could more often relay messages or telephone someone using compensatory techniques such as writing down messages or having a list of phone numbers near the phone. Problems reported by panel members regarding housework were related to the quality of the performance, neatness and the ability to complete the tasks.

Inclusion of social and leisure activities in the scale was considered particularly important by caregivers who noted that these activities had a major impact on their lives.

According to panel members, inability to engage in leisure pursuit is an early indicator of disease progression. They noticed a lack of interest in leisure activities and reduced interactions with others. Behavioural problems were also reported but were not considered for inclusion as the scale was not intended to assess behavioural disturbances.

Panel members agreed that, as the disease progresses, Alzheimer subjects lose insight into their difficulties and the possible risks that some activities may present. They also noted that patients often do not have the incentive to ask for help. Panel members mentioned that fluctuations in day-to-day performance in functional tasks were especially noticeable in a stressful situation or if the patient was upset.

When asked about their method of assessment with this population, panel members replied that they would favor both observation of performance and a questionnaire, with the caregiver as the pivotal sources of information.

5.2.3 Panel 3

Members of this panel were questioned about the impairments in cognitive functions that influence the daily performance of patient with DAT. All of the seven health care professionals, who were contacted, participated in the meeting.

As for the previous panel, members easily reached a consensus about which impairments could influence the performance in ADL in Alzheimer's Disease. The panel members agreed that problems in perceptual, cognitive and executive skills had an important impact on performance and could help delineate change in performance level. Perceptual and cognitive problems included decreased sense of reality, judgment and insight, flexibility, adaptability, praxia, memory, capacity to learn new abilities, orientation to time and space, attention, language, sequencing and perceptual integration. The executive functions retained were planning and organization, initiative and ability to monitor performance.

When asked about preferred method of evaluation and scaling format, panel members stated that functional disability should be assessed through both observations of patients and interviews of caregivers. They believed that if precise questions were asked, proxy's responses were quite reliable. Most members were not using formal scales to assess functional disability with this population as they had not found a suitable assessment. They commented that there was a need for scales allowing identification of cause of deficit in functional performance in order to guide intervention.

5.2.4 Comparison of Information Generated in the Three Panels and Items Selection.

Information on disability gathered from panels 1 and 2 was very similar. Both panels identified self-care, instrumental and leisure activities as being important domains of functional disability. Panel 2 also identified social skills and behavioural aspects as being important. These, however, were not in line with the objective of the intended scale as they do not correspond to the operational definition of disability. Therefore, they were not included.

All information gathered from these panels was considered in developing the items. The dimensions proposed and retained are listed in table 6. Notions of safety and quality of performance, considered to be important and to change over time, were included in appropriate items. For example, in the basic self-care activities, these aspects were included in the item on bathing where emphasis was put on ability to "safely" wash "all body parts". These were also incorporated in items of dressing, where success in selecting clothes depended on taking into consideration the occasion and cleanliness of clothes; continence, where the ability to complete the task without accidents was emphasized; and eating where manners and pace were considered. For instrumental activities, safety was included as a component of the item on meal preparation.

Moreover, for instrumental tasks, the term "meal" was replaced by "light snack" as it was considered more important for functioning at home to be able to prepare a snack than a more complex meal. Particularly in this population, a light snack often replaces a more

Table 6.

Items Included in the Disability Assessment for Dementia 2 as a Result of Stage I

Disabilities

- .Self-care activities
  - .Hygiene
  - .Dressing
  - .Undressing
  - .Continence
  - .Eating
- .Instrumental activities
  - .Meal preparation
  - .Telephoning
  - .Going on an outing
  - .Finance & Correspondence
  - .Medications
  - .Housework
- .Leisure

Impairments

- .Initiation
- .Planning & Organization
- .Effective performance

elaborate meal. Items pertaining to driving and visiting were deleted as requested by panel members. Walking was retained as it is considered as a major activity. The term "banking" was replaced by "finance" as it is a more comprehensive term. Not everyone goes to the bank but they may accomplish other financial tasks. It was decided that taking medication, showing interest in activities such as hobbies and friends, and housework would be added as they were identified as being crucial by many panel members. For leisure and housework the effectiveness of participation in these activities was included. Finally, an item on the ability to stay safely at home alone was added to the scale. The concept of time of performance was also added as an additional question.

Members from all three panels identified the need to develop scales that not only indicate which activities are problematic but also which components of performance present difficulties. In consequence, the initial intent to develop an instrument assessing functional disability according to impairments was retained. Information from panels 1 and 3 was used to determine which impairments would be included in the items (table 6). Several cognitive impairments were mentioned by members of panel 3. When considering which to include, it was important to consider those that could be easily observed by caregivers since the scale is a proxy-respondent evaluation It was kept in mind that caregivers do not have the specialized training of the health care professional and may not be in a position to assess or understand the impact of cognitive abilities such as memory or perceptual integration. Executive functions which are related to cognitive performance in functional activities seemed to be most amenable for assessment by caregivers.

Decisions regarding scaling format were made after considering feedback from all panels, the investigator's expertise and information provided in the literature. The dichotomous scale was retained despite questions by members of panel 1 as to whether it would provide a sufficiently sensitive scale. It was felt that sensitivity would be adequate as the scale assessed functional performance according to two spheres organized in a hierarchical fashion. One pertained to deterioration in functional disability where instrumental activities are lost first followed by self-care activities (Gauthier & Gauthier, 1990; Sclan & Reisberg, 1992; Stern et al., 1990). Moreover, progressive deterioration in skills is even observed within these activities. For example, in self-care activities, dressing and hygiene are abilities that are lost before eating and continence (Sclan & Reisberg, 1992). The second sphere concerned executive functions where deficits have been found to deteriorate from problems in initiation in early stages, to planning and organization and finally to automatic activities (Gauthier, 1988).

At the end of this stage, retained items were included in a dichotomous scale, DAD 2, which yielded a continuous global score. As the intent of the scale was to judge actual performance, the investigators, based on their experience and time frames used in other scales, selected the last four weeks as an appropriate period within which to evaluate performance. This was later reviewed with panel 4.

5.3 PRE-TEST

5.3.1 Characteristics of the Sample

Four caregivers of individuals who had been diagnosed as "probable" dementia of the Alzheimer type participated in the pre-test. Two of these were spouses while the other two were children. The Alzheimer subjects were two French and two English females who had primary or secondary education and ranged in age from 64 to 79 years (mean=71, SD=6). One subject was in stage 3 of the Global Deterioration Scale while two were in stage 4 and one in stage 5.

5.3.2 Data Analysis

The scale was reported to be quick and easy to use, taking an average of 14 minutes. Caregivers provided extra information and comments in addition to answering the questions. The scale was found to be adequate for assessing functional disabilities by both raters and caregivers although issues were raised about the scaling format. When a person had never performed the activity before or had not had the opportunity to do it in the four weeks prior to the interview, a Yes/No response did not seem sufficient. Some caregivers would have preferred answering on a four point scale ranging from "never does the activity" to "always does the activity".

Overall the scale was deemed to be clear, practical, and complete and did not require major changes. The addition of the term "independently" in the introductory statement was suggested as it reemphasized to caregivers that they need to assess items based on independent performance. These issues were raised with panel 4.

5.4 CONTENT VALIDATION

The content validity of the scale was assessed using a fourth panel of experts. They were consulted individually using a structured questionnaire and during a meeting they were asked to reach a consensus on the content of the DAD 2 Scale.

All experts contacted participated in the panel with the exception of one neurologist. He was not replaced as the panel was large enough and made up of members with the desired expertise. The a priori criteria set for accepting items or for making modifications was of 51% of the panel members in agreement. This stage was also used to eliminate, add or change items. It led to the development of a new version of the scale (DAD 3). Results from individual questionnaires and group meeting will now be presented.

5.4.1 Individual Responses

Most panel members (67%) found that the total group of items in DAD 2 adequately covered the domains of functional disability in community residing individuals with dementia. When asked about the appropriateness and usefulness of assessing functional disability according to executive functions, 89% of members were in agreement. Experts' ratings of individual items, on importance, clarity and completeness for a scale aiming at detecting a change in disability, are reported in table 7. A majority of panel members voted in favor of these characteristics for all items. Item 11, which inquired about

Table 7.

Experts' Ratings of Individual Items on Importance, Clarity and Completeness.

Items	Important		Clear and Complete	
	YES	NO	YES	NO
Initiation section agreement range (%)	89-100	0-11	56-78	0-44*
Planning and organization section agreement range(%)	67-100	0-22	56-89	0-33
Effective performance section agreement range(%)	89-100	0-11	67-89	0-22

* 44% pertained to only one item # 11, other items ranged between 0-22%

ability to initiate housework and leisure activities, was the only one considered unclear by several experts. Although they felt positively about the content of the item, panel members requested that it be made more precise by separating leisure and housework into two items.

In addition, for items in the initiation section, they suggested, as much as possible, to use the same verb at the beginning of each sentence. It was also pointed out that the item "decide to telephone someone" would be more complete if "for a specific purpose" was added. For the planning and organization section, members suggested that the item "planning the activities at appropriate time" be removed as a general statement and added to specific items as it is an important component of most but not all activities. For the effective performance section, a suggestion was made to say "use the toilet " instead of "attending to bladder and bowel function " as it would be clearer to the caregiver. Similarly, for telephoning it was suggested to use "carry out a telephone conversation " instead of "hold and complete " as it was a more common phrase. Finally, for medication use it was felt that adding "at correct dosage " would make it clearer.

When asked if important items were missing, 56% of members answered yes. Named items were playing cards, driving, using public transportation or taxi, grooming, sleeping disturbances, communication abilities and use of specific appliances such as a washing machine. A number of these items were subsumed under larger headings. For example, playing cards was included under leisure and washing clothes was enclosed under housework. This was done intentionally as it would have been too lengthy to incorporate all possible housework or leisure activities. On the other hand, items on grooming, driving and taking public mode of transportation were considered for addition to the scale. They were part of the initial version DAD 1 but were removed after stage two. Language abilities were not incorporated in the scale as the intent was not to assess cognitive impairments or behaviour disturbances.

The majority of experts (56%) accepted the dichotomous scaling format. Concerns of dissenting members were related to the sensitivity of the scale if this scaling format was employed. Several panel members were in general agreement with the scaling format but made some suggestions to improve it. For example, assessing a subject against his or her own baseline score or using percentage to express results was also recommended. The use of a category "non applicable" was also suggested as a better estimate of performance than a "yes" if the person did not do the activity. The "yes" response tends to inflate scores.

Seventy-eight percent of the members were in agreement with the use of a significant other as a method of assessment of functional disability. Some members pointed out that the choice of a good informant, who resides or spends a lot of time with the subject and has sound cognitive and behavioural abilities, should be an important requirement for a reliable report. There was also a suggestion to assess the frequency with which the activities were performed during the four weeks period. However frequency does not necessarily reflect disability as it may vary from one individual to another and still be adequate.

The majority of members agreed that the scale could discriminate between healthy and Alzheimer's subjects on functional disabilities (67%) as well as between individuals who are at different stages of the disease (78%).

When solicited for additional comments, some experts felt that the four week time frame over which performance was assessed was too long for caregivers to remember and that it should be shortened to one or two weeks. In addition, some members noted that instead of using the word "independently", the phrase "without help or reminder" would clarify the intent of the term.

5.4.2 Group Results

As a means of reaching agreement, the validation questionnaire was reviewed with the group of experts during a meeting. The same agreement level (51%) set previously was employed. Several of the suggestions made in the individual responses to the questionnaire were raised during the meeting. These were discussed to obtain consensus. Divergences or additions to the responses presented in the last section (5.4.1) will now be emphasized.

For items in the initiation section, panel members expressed concern about the choice of "decide" at the beginning of sentences which may not capture exactly the idea of initiating the action. It may be difficult for caregivers to know if the patient has decided. The use of another term such as "attempt" was suggested as it seemed to be more observable and to better capture the intent.

In addition all agreed that the item "decide to go out for a walk" should be more comprehensive and include visit and shopping. It was therefore decided to replace this item by "go on an outing" with an example in parenthesis to explain what outing means. Panel members also pointed out that "shopping" is subsumed under outing and therefore should not be a separate item.

There was also consensus to divide leisure, housework and social activities into separate items and to add correspondence to the finance section. It was proposed to replace "housework" by the more comprehensive term "household chores" that, for example, would include yard work. The addition of "undressing" was recommended as an important activity. Panel members also suggested to add "relay" to "adequately take a telephone message" as the item did not necessarily imply that the message was transmitted to the caregiver.

The group also agreed on separating the item "returning from shopping with appropriate items and money" into two parts, one related to the ability to bring back the right items and the other concerning skills in managing pocket money. This latter item was considered essential for daily functioning and different from doing financial transactions which are at a higher and more complex level. In relation to the ability to orient oneself into space, members found that it should be assessed by two items related to navigating in familiar and unfamiliar environments. They pointed out that these abilities are lost at different stages of the disease and are manifestations of the disease progression.

Suggestions for improving the scale, such as including non-applicable, scoring the total as a percentage and reducing the number of gender specific questions, were discussed. It was agreed that in the introductory statement, the time frame of four weeks should be reduced to two weeks since panel members had observed that caregivers tend to only remember within this period. They also concurred with replacing "independently" by "without help or reminder" as it is more precise. There was also consensus that "doing the activity at appropriate times" should not be asked as one statement but that the time component should be added to appropriate questions. It was decided to include it in the initiation section instead of planning.

5.4.3 Data Analysis

A majority of members from the panel of experts agreed that the DAD 2 scale was content valid to assess functional disability in a community residing population with dementia of the Alzheimer's type. The suggestions for adding some items (grooming, undressing, correspondence and mode to transportation), and combining others (shopping and going on an outing) were retained. Separating items like leisure and housework were considered in version three of the DAD scale.

Including the time component within questions and modifying the initial statement and the scoring system were also maintained. Moreover, some of the wording changes suggested to improve the clarity of the scale were incorporated. For leisure activities, only the statement about showing interest was retained as it was considered difficult for caregiver to assess if a person is participating "effectively" in leisures. The DAD 2 scale was thus modified, and became a 46 item rather than a 36 item questionnaire (appendix H). It went then through the translation process.

5.5 TESTS OF INTERNAL CONSISTENCY AND ITEMS REDUCTION

5.5.1 Characteristics of the Study Sample

The characteristics of the 59 Alzheimer and caregiver subjects who agreed to participate in the study are presented in table 8. Diagnosis was confirmed for all patients.

The Alzheimer subjects ranged in age from 49 to 89 years. There were approximately equal numbers of males and females with slightly more English speaking subjects. Time since diagnosis ranged from one to 122 months. The sample was moderately cognitively impaired and mostly in Stages 4 and 5. It was thus representative of the population we would expect to find in the community.

The distribution for age was unimodal and normally distributed. The distribution of MMSE was negatively skewed (median= 17, skewness= -.4)while the distribution for duration of the disease in months showed positive skewness (median=16, skewness= 2.0)

The caregivers ranged in age from 34 to 84 years and were predominantly female. The majority (78%) were spouses with a small proportion being children (17%) or others (5%) such as friends. Most caregivers were unemployed (69%) and in good health (80%). They spent a mean of 7 hours a day (SD= 8.6) in direct caregiving contact with the Alzheimer subjects.

5.5.2 Comparability of the French and English Study Subjects

Since the French and English versions of the DAD were developed simultaneously, found to be content valid, and administered to both French and English subjects, the comparability of the groups was verified to determine if data could be pooled for analysis. Subjects were compared on age, gender, education, GDS stage, duration of the disease, MMSE and DAD scores. Table 9 shows the results from the analysis.

Table 8.

Characteristics of Alzheimer and Caregiver Subjects

Variables	Alzheimer subjects n		Caregivers n	
Age (yrs)				
mean ± SD	59	68.0 ± 8.2	59	61.3 ± 10.6
Gender (%)				
male	59	51%	59	32%
female		49%		68%
Language (%)				
French	59	41%	59	41%
English		59%		59%
Education (%)				
Primary	59	17%	59	7%
Second.		41%		46%
Post-Sec		42%		47%
Duration DAT[a](months)				
mean ± SD	59	23.7 ± 22.5		
GDS[b] **Stages** (%)				
3	58	10%		
4		39%		
5		44%		
6		7%		
MMSE[c] (max 30)				
mean ± SD	55	16.2 ± 8.3		

The slight variations in N are due to missing data

[a] Dementia of the Alzheimer's type

[b] Global Deterioration Scale

[c] Mini-Mental State Examination

Table 9.

Comparisons of Alzheimer Subjects' Characteristics and DAD Scores by Language.

Variables	FRENCH n	FRENCH	ENGLISH n	ENGLISH	Chi-square (df)
Gender(%)					
male	24	58%	35	46%	0.91(1)
female		42%		54%	
Education(%)					
primary	24	21%	35	14%	4.13 (2)
second.		25%		52%	
post-sec		54%		34%	
GDS[a] Stage(%					
3	24	13%	34	9%	3.60(3)
4		26%		47%	
5		57%		35%	
6		4%		9%	

Variables	FRENCH n	FRENCH	ENGLISH n	ENGLISH	Difference in means (95%CI[b])
Age (yrs)					
mean ± SD	24	67.5 ± 8.2	34	68.3 ± 8.4	-0.8 (-5.2, 3.6)
Duration DAT [c](Months)					
mean ± SD	24	27.6 ± 27.7	35	21.1 ± 18.0	6.5 (-5.5, 18.6)
MMSE[d] (max 30)					
mean ± SD	22	16.4 ± 8.3	32	16.0 ± 8.4	0.4 (-4.2, 5.1)
DAD [e]scale (max 100)	24	48.8±24.4	35	57.6±28.8	-8.73 (-23.3, 5.8)

Note: Results from the statistical tests were not significant (p>.05).
The slight variations in n are due to missing data
[a] Global Deterioration Scale
[b] Confidence intervals
[c] Dementia of the Alzheimer's type
[d] Mini-Mental State Examination
[e] Disability Assessment for Dementia

The groups were found to be similar on gender make up and somewhat different on educational profile. The English group had a higher number of subjects with a secondary education while the French group had a higher concentration of subjects with post-secondary degrees. These differences were not found to be statistically significant. In terms of stage of disease, both groups contained few subjects in stages 3 and 6. The English group had more subjects in stage 4 than 5 while in the French group this was reversed. The differences were not significant. However, several cells had expected counts less than five which may affect the validity of the test. To address this problem, subjects from stages 3 and 4 were regrouped to form an early stage category, while those in stages 5 and 6 were combined to form a late stage group.

Patients in stages 3 and 4 are often grouped like this in the literature (Baum et al., 1988; Flicker et al., 1984) Since there were very few subjects in stage 6 these were included with stage 5. As a result, the English group contained 56% of subjects in early stages and 44% in late stages while the French group had 39% in the early stages and 61% in the late stages. Although more French subjects were in later stages of the disease, the difference was not significant. The two groups were comparable on age, duration of disease, MMSE scores and DAD scores using a two-tailed Student t-test.

Since the MMSE has been found to be influenced by normal aging and education (Brayne & Calloway, 1990; Jagger et al., 1992; Kittner et al., 1986; Ylikoski et al., 1992), the relationship between these variables was investigated. In the present study, the sample was comparable in terms of age and educational level and the MMSE was found not to be significantly correlated with either age or educational status of the subjects ($p>.05$).

Since the English and French subjects were comparable on their characteristics and on DAD scores, the groups were pooled for all further analyses.

5.5.3 Item Reduction

The selection of items for the final version of the DAD Scale was done in consultation with a group of experts and based on results from tests of internal consistency (table 10), frequency of endorsement (table 11), unweighted kappa (table 12) and assessment of gender specificity for individual items. Face validity was also an important criterion for decision making regarding whether an item would be kept or deleted.

In general, when individual items were removed, the alpha for raw and standardized variables remained very high for all items and did not fluctuate markedly. The Pearson's item-total correlation coefficients were between .20 and .80 for all items. Only seven out of 46 items obtained a correlation coefficient under .40. The inter-item correlations, were moderate (.20-.80) for most items.

In terms of frequency of endorsement, 17 questions obtained either high or low frequencies or were non-applicable. The majority of items demonstrated substantial to perfect agreement with the unweighted kappa for test-retest and interrater reliability (table 12). Only one item for test-retest and two items for interrater reliability demonstrated fair agreement. No item showed slight or poor agreements. The decision making process for the specific items which did not meet the selection criteria that was done in consultation with the experts is now described.

Items 6, "brush his/her teeth or care for his/her denture appropriately", and 8, "undertake to dress himself/herself", which demonstrated frequencies of endorsement lower than .20 were kept in the scale. They were considered essential for face validity in a disability scale because they tap important basic activities of daily living. Items 12, "undertake to undress himself/herself", and 13, "undress himself/herself completely", also had low frequencies. In addition, they were highly correlated (r=.85). To avoid redundancy, and because these abilities are lost very late in the disease progression and are identified as less crucial than dressing in functional measures, only item 13, was kept. This decision

Table 10.

Cronbach's Alpha and Pearson's Item-total Correlations for Individual and Overall Items of the Disability Assessment for Dementia 3 Scale.

Items deleted	Cronbach Alpha		Pearson's item-total correlations	
	Raw	Standardized	Raw	Standardized
1	.959	.958	.713	.704
2	.959	.958	.616	.615
3	.959	.958	.641	.634
4	.958	.958	.797	.781
5	.959	.958	.673	.663
6	.960	.959	.569	.565
7	.959	.958	.771	.761
8	.960	.959	.504	.504
9	.959	.958	.663	.658
10	.959	.958	.632	.632
11	.959	.958	.626	.622
12	.960	.959	.526	.532
13	.960	.959	.500	.506
14	.961	.960	.241	.240
15	.961	.960	.288	.278
16	.960	.959	.526	.524
17	.960	.959	.573	.562
18	.960	.960	.346	.342
19	.961	.960	.252	.230
20	.959	.958	.675	.660
21	.959	.958	.719	.712
22	.959	.958	.727	.721
23	.959	.958	.677	.680
24	.958	.958	.782	.775
25	.960	.959	.565	.555
26	.959	.958	.601	.605
27	.959	.958	.713	.709
28	.959	.958	.680	.696
29	.959	.958	.670	.675
30	.959	.958	.706	.698
31	.960	.959	.376	.402
32	.959	.958	.641	.648
33	.959	.958	.642	.653
34	.959	.958	.606	.620
35	.960	.959	.529	.557
36	.960	.959	.458	.498
37	.959	.958	.612	.612
38	.960	.958	.570	.598
39	.960	.959	.475	.531
40	.960	.959	.390	.397
41	.959	.958	.598	.608
42	.961	.960	.364	.358
43	.960	.959	.465	.460
44	.961	.960	.385	.380
45	.960	.959	.485	.476
46	.959	.958	.659	.647
Overall	.960	.959		

Table 11.

Frequencies of Endorsement for Individual Items of the Disability Assessment for Dementia 3 Scale

Item	Frequencies of Endorsement (n=59)					
	NO		YES		N/A	
	f[a]	%	f	%	f	%
1	21	36	38	64	0	0
2	17	29	42	71	0	0
3	21	36	38	64	0	0
4	25	42	34	58	0	0
5	13	22	46	78	0	0
6	11	19	48	81	0	0
7	20	34	38	64	1	2
8	9	15	50	85	0	0
9	33	56	26	44	0	0
10	17	29	42	71	0	0
11	13	22	46	78	0	0
12	8	14	51	86	0	0
13	6	10	53	90	0	0
14	1	2	58	98	0	0
15	4	7	55	93	0	0
16	18	31	39	66	2	3
17	14	24	43	73	2	3
18	7	12	49	83	3	5
19	10	17	49	83	0	0
20	26	44	30	50	3	5
21	30	51	26	44	3	5
22	31	53	25	42	3	5
23	36	61	20	34	3	5
24	31	53	26	44	2	3
25	28	47	31	53	0	0
26	43	73	15	25	1	2
27	26	44	31	53	7	12
29	44	75	13	22	2	3
30	29	49	28	47	2	3
31	47	80	3	5	9	15
32	40	68	12	20	7	12
33	39	66	16	27	4	7
34	37	63	17	29	5	8
35	44	75	6	10	9	15
36	42	71	5	8	12	20
37	33	56	22	37	4	7
38	42	71	6	10	11	19
39	38	64	6	10	15	25
40	31	53	10	17	18	31
41	31	53	10	17	18	31
42	24	41	35	59	0	0
43	20	34	36	61	3	5
44	36	61	20	34	3	5
45	31	53	25	42	3	5
46	22	37	37	63	0	0

[a] Frequencies

Table 12.

Unweighted Kappa and Standard Deviations for Individual Items of the Disability Assessment for Dementia 3 Scale

Items	Test-retest (n=45)	Interrater (n=31)
1	.90 (.07)	.67 (.13)
2	.73 (.11)	.92 (.07)
3	.75 (.10)	.74 (.12)
4	.82 (.08)	.69 (.12)
5	.94 (.06)	.77 (.12)
6	.73 (.13)	.60 (.16)
7	.85 (.08)	.67 (.13)
8	.91 (.09)	.82 (.12)
9	.73 (.10)	.73 (.13)
10	.83 (.09)	.77 (.12)
11	.93 (.07)	.76 (.13)
12	.69 (.17)	.45 (.21)
13	.62 (.17)	.61 (.20)
14	.66 (.32)	1.00 (0)
15	.30 (.25)	.47 (.31)
16	.68 (.11)	.67 (.14)
17	.67 (.12)	.37 (.15)
18	.48 (.17)	.44 (.17)
19	.67 (.14)	.74 (.14)
20	.84 (.07)	.68 (.12)
21	.84 (.07)	.66 (.13)
22	.84 (.08)	.60 (.13)
23	.57 (.11)	.66 (.13)
24	.79 (.09)	.79 (.11)
25	.82 (.08)	.80 (.11)
26	.50 (.12)	.69 (.13)
27	.74 (.09)	.75 (.11)
28	.69 (.10)	.59 (.14)
29	.55 (.13)	.75 (.14)
30	.83 (.08)	.94 (.06)
31	.61 (.13)	.91 (.09)
32	.70 (.10)	.73 (.12)
33	.75 (.09)	.81 (.10)
34	.79 (.09)	.46 (.16)
35	.68 (.12)	.72 (.13)
36	.53 (.13)	.69 (.13)
37	.71 (.10)	.77 (.10)
38	.58 (.13)	.61 (.15)
39	.62 (.11)	.71 (.12)
40	.71 (.09)	.84 (.09)
41	.74 (.09)	.73 (.11)
42	.72 (.10)	.61 (.14)
43	.44 (.13)	.45 (.15)
44	.66 (.12)	.57 (.14)
45	.61 (.12)	.30 (.16)
46	.90 (.07)	.93 (.07)

respected the opinion of the expert panel which wanted to include "undressing" in the measure. Items 14, "decide to use the toilet at appropriate times", and 15, "use the toilet without accident", which demonstrated lower than .20 and higher than .90 frequencies of endorsement, item-total correlation coefficients under .40 and fair test-retest reliability, were also considered necessary for face validity. Low frequencies might have been obtained because these items may not be key indicators of disability with a community residing population as in this sample. However, if the scale is to be used with more severely disabled individuals, these items as part of the ADL subsection would be important determinants of disability.

Item 18, "eat his/her meal in the appropriate sequence", which showed a frequency below .20 and an item-total correlation under .40, was not considered to be important for face validity and thus was deleted. Item 19, "eat his/her meals at a normal pace and with appropriate manners", also had frequencies below .20 and low item-total correlation but when removed slightly improved the alpha and was kept for reasons of face validity. Items 28, "decide to use a mode of transportation", and 31, "go out and reach a non-familiar destination without getting lost", which had frequencies below .20 and a high number of N/A responses were deleted. In addition item 28 was highly correlated (r=.94) with item 32, "safely take the adequate mode of transportation", and thus may have been redundant. Item 31 added little to the scale as there are other early indicators of disability. Items 32, "safely take the adequate mode of transportation", 33, "return from the store with the appropriate items", and 34, "show an interest in his/her personal affairs", were kept for face validity even though they had a high number of N/A responses or a low frequency of endorsement.

Items 35, "organize his/her finance to pay his/her bills", 36, "adequately organize his/her correspondence", 38, "complete his/her financial transaction adequately", and 39, "answered his/her correspondence adequately", all demonstrated low frequencies and had a high number of N/A responses. Item 35 was highly correlated with item 38 (r=.81) while item 36 with 39 (r=.90). To avoid redundancy of items and because they were not considered important for face validity, items 38 and 39 were removed. Conversely, items 35 and 36 were kept for reasons of face validity.

Items 40, "decide to take his/her medications at the correct time", and 41, "take his/her medications as prescribed", showed low frequencies and a high number of N/A responses. This could be expected since not all patients take medications. The panel of experts, however, strongly advocated an item on medication in a scale for use with this population. The relationship between items 40 and 41 was examined to see if one was redundant. As the correlation coefficient was only moderate (r=.47) these items seemed to be addressing different aspects of medication use. Both were kept because of the importance of this activity.

Items 42, "show an interest in leisure activity(ies)", and 44, "plan and organize adequately household chores", were kept for face validity despite the fact their removal slightly improved the alpha. Item 46, "stay safely at home by himself/herself", was reworded because raters commented that the question was not readily understood by the caregivers. Caregivers had difficulty responding to this item because the time frame that subject would be left alone was missing. Thus the raters needed to clarify the time period with them during the interview so that they could answer properly. As a result, this item was changed to "stay safely at home by himself/herself for a reasonable period of time".

The items 19, "eat his/her meals at a normal pace and with appropriate manners", and 44, "plan and organize adequately household chores", which were found to be different for males and females were maintained to enhance face validity.

Items with high numbers of N/A responses were examined carefully to determine if other variables might influence this response choice. Inspection of the data did not reveal an impact of age, sex or stage. In addition, this response occurred across many subjects; 40 out of 59 individuals had answers ranging from 1 to 15 N/A answers. However there were more N/A responses found in English speaking subjects than French speaking subjects. Data were inspected to determine whether the N/A answers were found more in subjects who had been interviewed by a particular rater. This did not appear to be the case.

Of the 22 items, out of 46 scrutinized for removal, six items were eliminated and one was modified (table 13). As a result of this stage, the DAD scale became a 40 item questionnaire.

5.6 PROPERTIES OF THE FINAL VERSION OF THE DAD SCALE

5.6.1 Descriptive and Comparative Analyses on the DAD Scale

The mean obtained on the DAD for the total group of subjects was 56 (SD=28). Individual scores ranged from 5 to 100 %. The distribution (figure 2) was quite symmetrical with a median of 54 and a skewness of only -.09.

Distributions of scores when the scale was divided into self-care (ADL) and instrumental (IADL) subsections are presented in figure 3. As expected with this population, the distributions were not normal but approximated exponential configurations with marked negative skewness (-.85) for ADL and positive skewness (.42) for IADL. The median was 88 for the ADL and 35 for the IADL scores showing that the Alzheimer subjects in our sample scored high in self-care activities compared to instrumental activities where the ratings were low. Thus they were not very impaired on basic tasks but more markedly so on instrumental activities. The French and English groups of subjects did not differ significantly in their scores for each subsection.

Figure 4 shows the distributions of DAD, DADADL and DADIADL scores across the different stages of the disease for all subjects. These figures demonstrate that as the severity of the disease increases, the global score of the DAD decreases reflecting more disability. When looking at ADL scores across GDS stages, one can see that scores remain high in the early stages and start to decrease in stage 5 and continue to fall in stage 6.

Table 13.

List of Items from the DAD 3 Scale that Underwent Modification or Elimination

ITEMS	RATIONALE FOR MODIFICATION OR ELIMINATION
Eliminated:	
12. "Undertake to undress himself/herself"	.Low frequencies of endorsement (<.20) .High correlation with item 13 (r=.85) which also relates to undressing (redundant)
18."Eat his/her meal in the appropriate sequence"	.Low frequencies of endorsement (<.20) .Item-total correlation below .40 .Not important for face validity
28."Decide to use a mode of transportation"	.Low frequencies of endorsement (<.20) .High frequencies of non-applicable .High correlation with item 32 (r=.94) which also related to transportation use (redundant)
31."Go out and reach a non-familiar destination without getting lost"	.Low frequencies of endorsement (<.20) .High frequencies of non-applicable .Other early indicators of disability in the Scale
38."Complete his/her financial transaction adequately"	.Low frequencies of endorsement (<.20) .High frequencies of non-applicable .High correlation with item 35 (r=.81) (redundant)
39."Answered his/her correspondence adequately"	.Low frequencies of endorsement (<.20) .High frequencies of non-applicable .High correlation with item 36(r=.90) (redundant)
Modified:	
46."Stay safely at home by himself/herself"	.Not clearly understood by caregivers

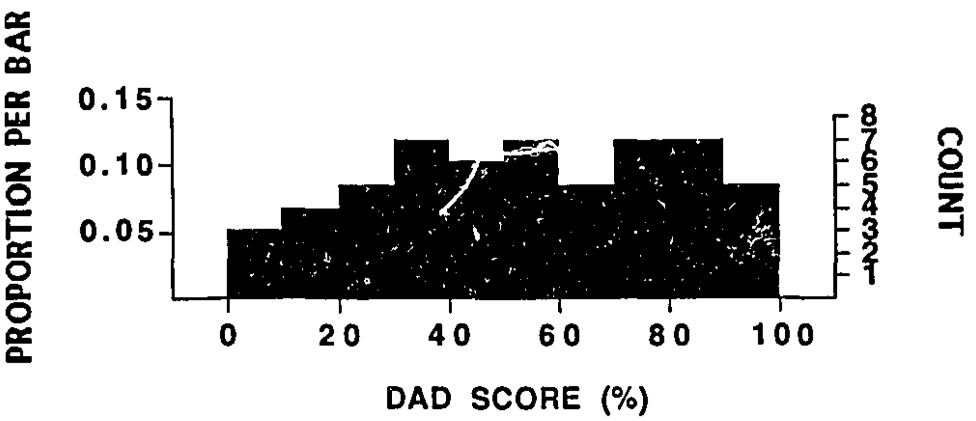

Figure 2. Distribution of Global Scores for the Disability Assessment for Dementia (DAD) Scale (n=59).

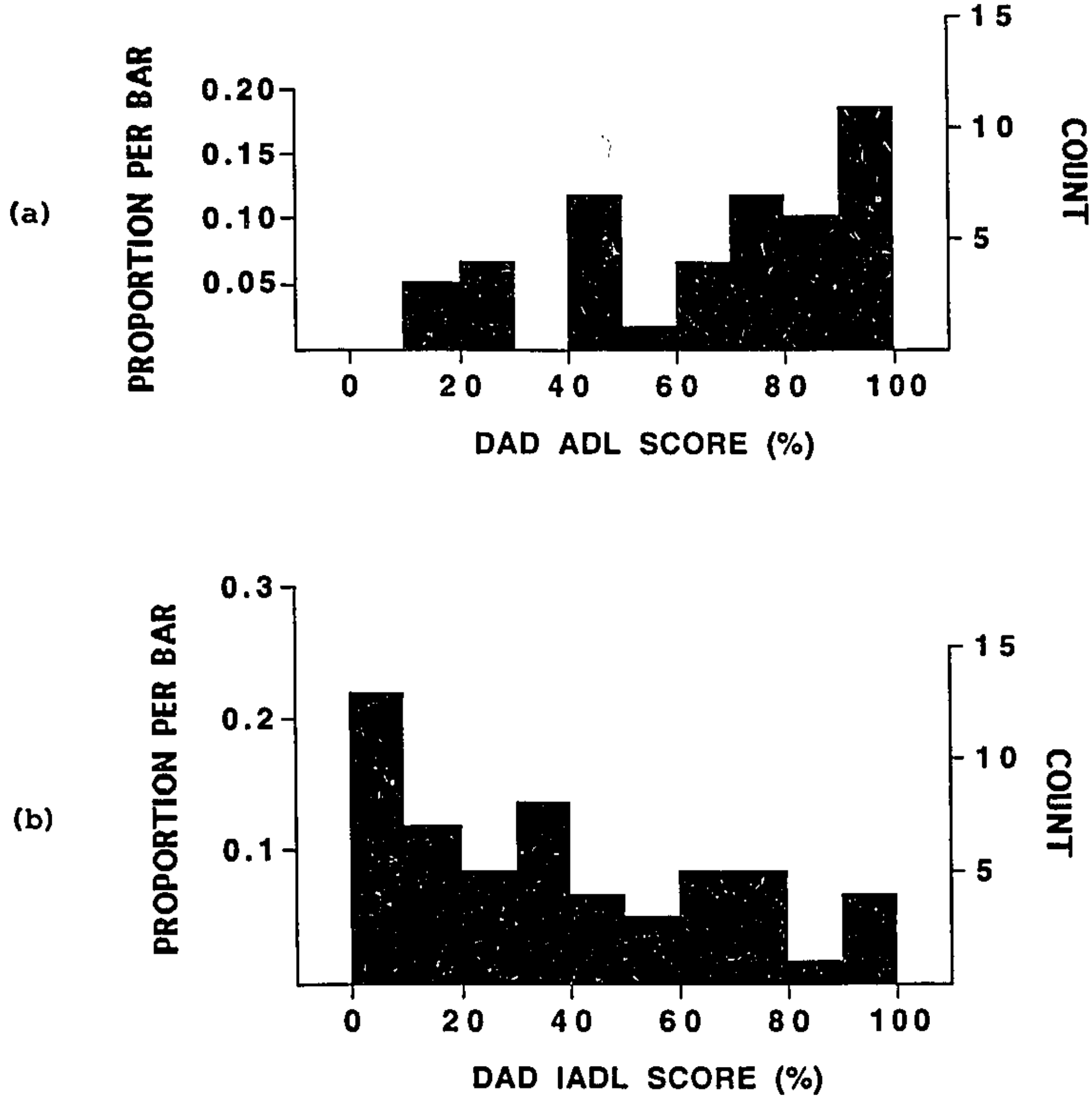

Figure 3. Distribution of Scores for the (a) Self-care (ADL) and (b) Instrumental (IADL) Subsections of the Disability Assessment for Dementia (DAD) Scale (n=59).

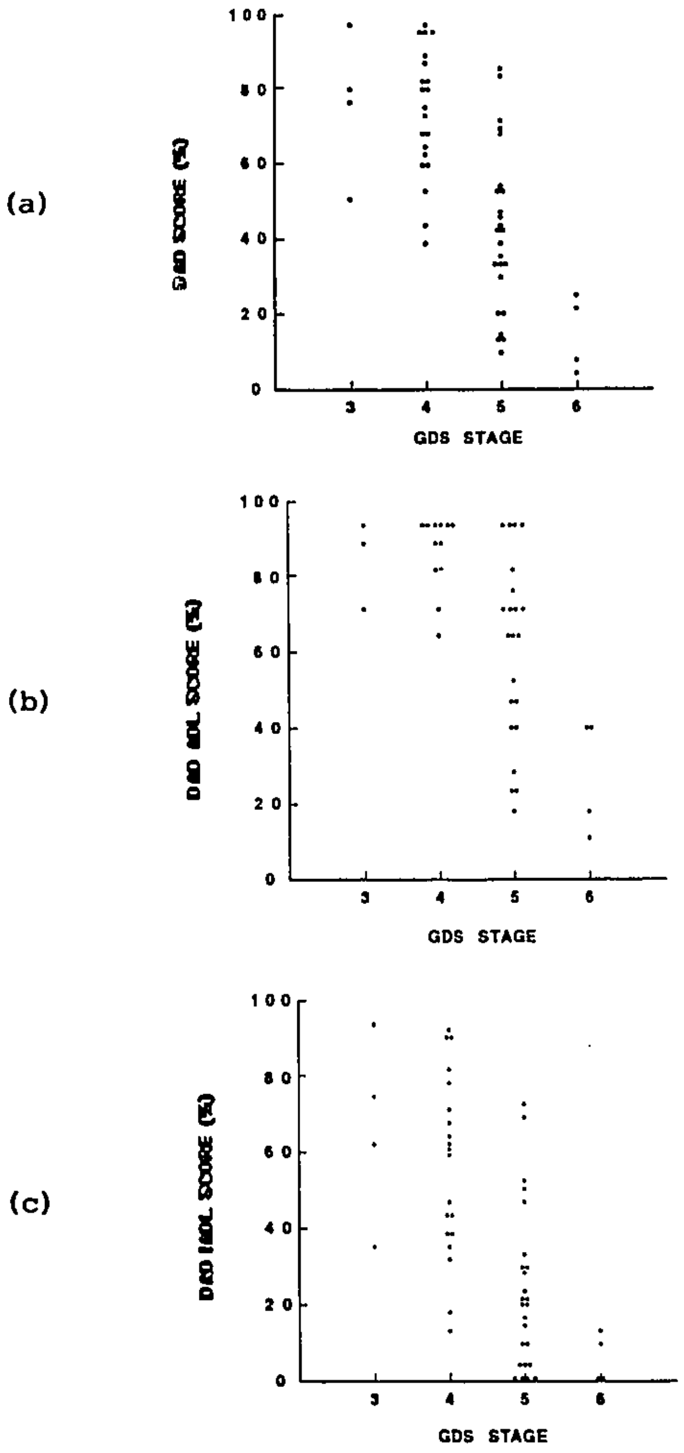

Figure 4. Distribution of (a) Global, (b) Self-care (ADL) and (c) Instrumental (IADL) Scores for the Disability Assessment for Dementia (DAD) Scale According to Stages of the Global Deterioration Scale (n= 59).

On the other hand, the IADL scores seem to decrease in stages 3 and 4, and are very low in stage 6.

The ADL and IADL subsections correlated well with each other (Spearman r=.83; Pearson r=.77, p<.0001). Figure 5 displays a plot of these two variables. Transformation of the instrumental scores as a square root did not greatly improve the linear relationship (Spearman r remained unchanged; Pearson r changed from.77 to .81) between the variables. The relationship between these variables does not appear to be linear but rather curvilinear. This was to be expected as the distribution of these variables have different shapes.

Visual inspection displayed linear relationships between the two variables in at least two sections of the graph. A cut off score between these two sections was chosen as 50 for IADL and the relationship was examined for scores at 50 and below as well as above. For scores in IADL at 50 and below, there was a significant relationship between the ADL and IADL subsections (F(1,36)=38.73, p<.0001). Scores in IADL explained 52% of the variance in ADL scores. The following model was obtained ADL= 37.4 + 1.2 IADL. This means that a unit change in IADL is associated with 1.2 unit changes in ADL for scores in IADL at or below 50 .

For scores in IADL above 50, there was no significant relationship between the variables (F (1, 19)=3.85, p>.05). Indeed for scores above 50, scores in ADL had reached a plateau (ceiling effect). It should be noted that a plateau was also observed visually for very low IADL scores (floor effect) while changes were still noted in ADL scores. In summary, the data indicated a significant relationship between ADL and IADL scores when functional disability in instrumental activities was more severe, for scores of 50 or below. Furthermore, there was no significant relationship between the scores when scores in IADL were above 50. These results suggest that disability in ADL started to occur when subjects were already quite severely disabled in IADL with scores at 50 and below. It also

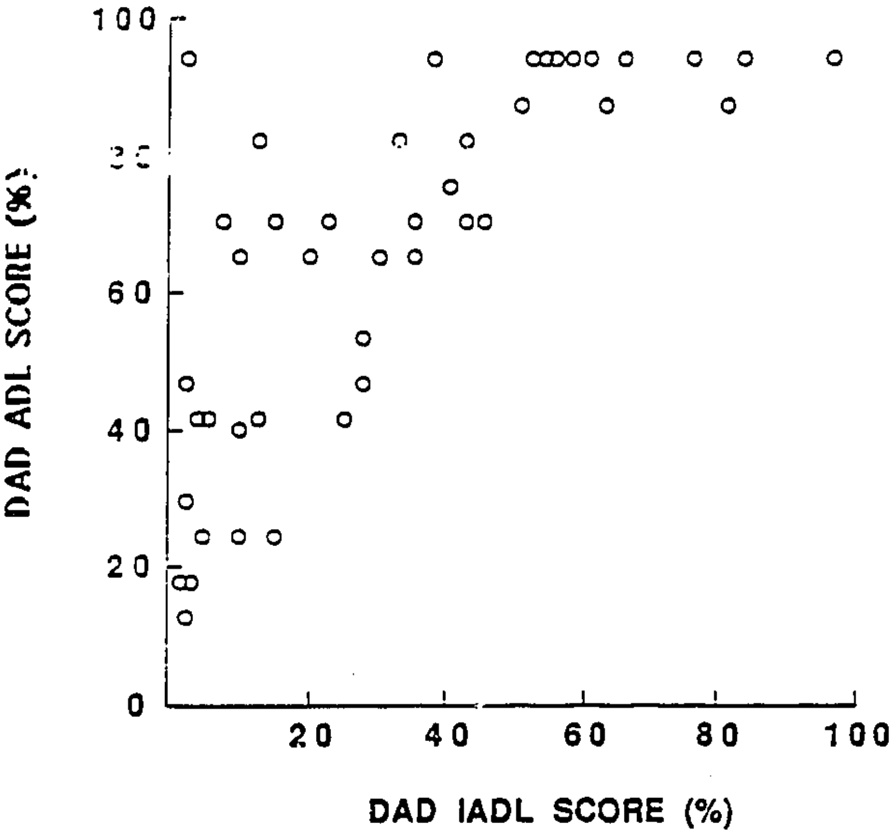

Figure 5. Scatter Diagram of Scores in Self-care (ADL) and Instrumental (IADL) Activities (n=59).

appears that when subjects were no longer able to perform IADL, they could still do some ADL although they were quite severely affected.

Distributions of scores on the three executive function subsections are presented in figure 6 and those across stages of the disease are presented in figure 7. The configuration of the planning and organization distribution looks almost exponential (skewness=.26). This seems less pronounced for the initiation (skewness=-.33) and effective performance (skewness=-.21) distributions which appear more symmetrical. For initiation (median=64) and effective performance (median=60), the majority of subjects obtained higher scores representing less disability while subjects scored worse (median=40) in planning and organization.

Distributions across GDS stages (figure 7) demonstrated a decrease in performance for all three subsections as severity of the disease increased. A slight difference in the pattern of deterioration between the three areas of performance was noted. Scores on the ability to initiate tasks were higher in the early stages and seemed to decrease in stages 5 and 6 while scores in ability to plan and organize appeared to be lost earlier in stages 3 and 4. Scores in the effectiveness subsection seemed to be deteriorating more rapidly than in initiation in the early stages but not as much as in planning and organization. The greatest loss appeared mostly in stages 5 and then 6. When these distributions were compared, similar patterns of deterioration across stages were found between ADL and initiation and between IADL and planning, organization and effective performance.

Correlations between the executive performance subsections were calculated using the Spearman correlation coefficient since scores were not normally distributed. Correlations were significant and high between these subsections (table 14). The scale was very quick to administer, it took an average of 13.8 minutes (SD=5.6).

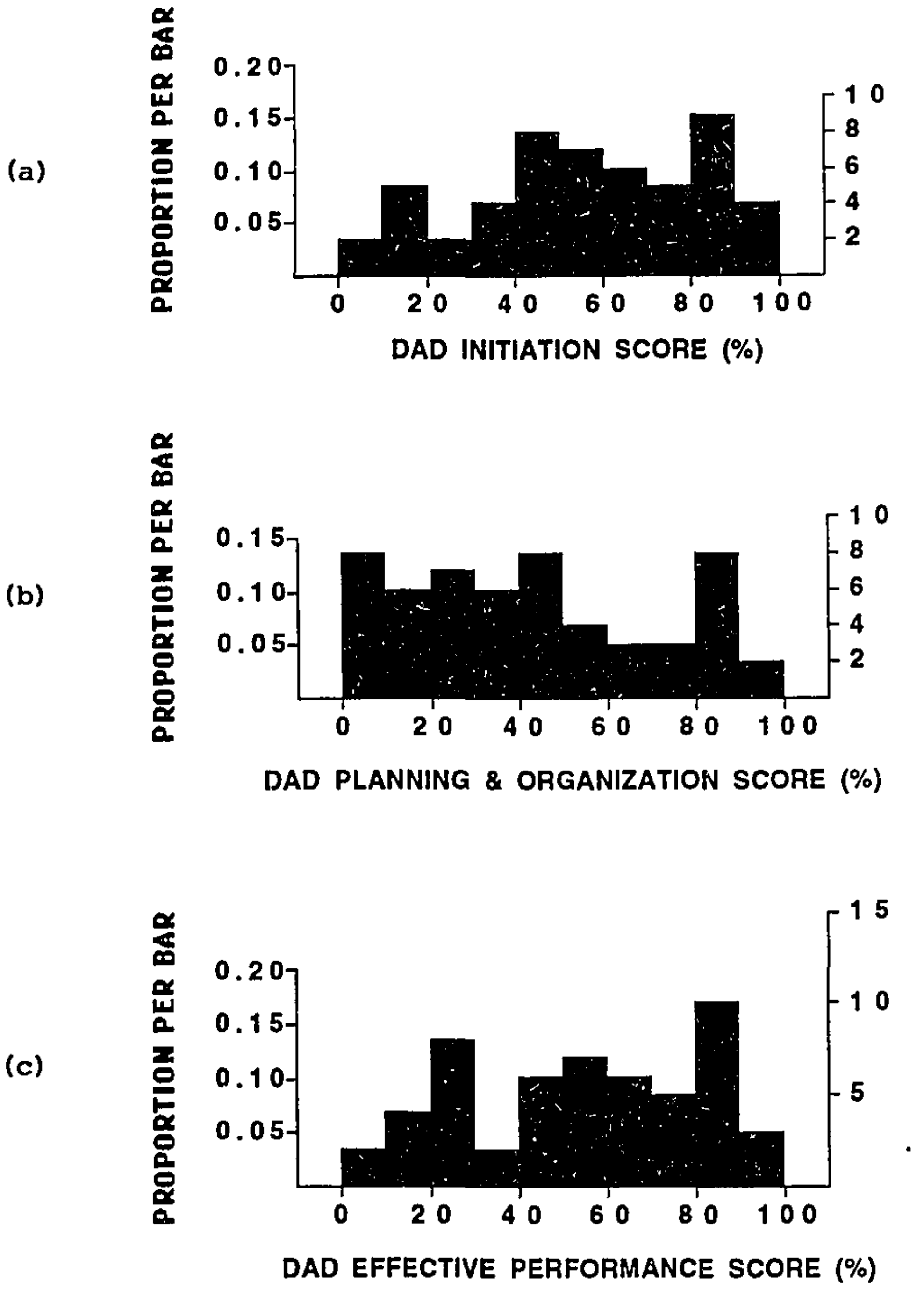

Figure 6. Distribution of Scores for the (a) Initiation, (b) Planning and Organization and (c) Effective Performance Subsections of the Disability Assessment for Dementia (DAD) Scale (n=59).

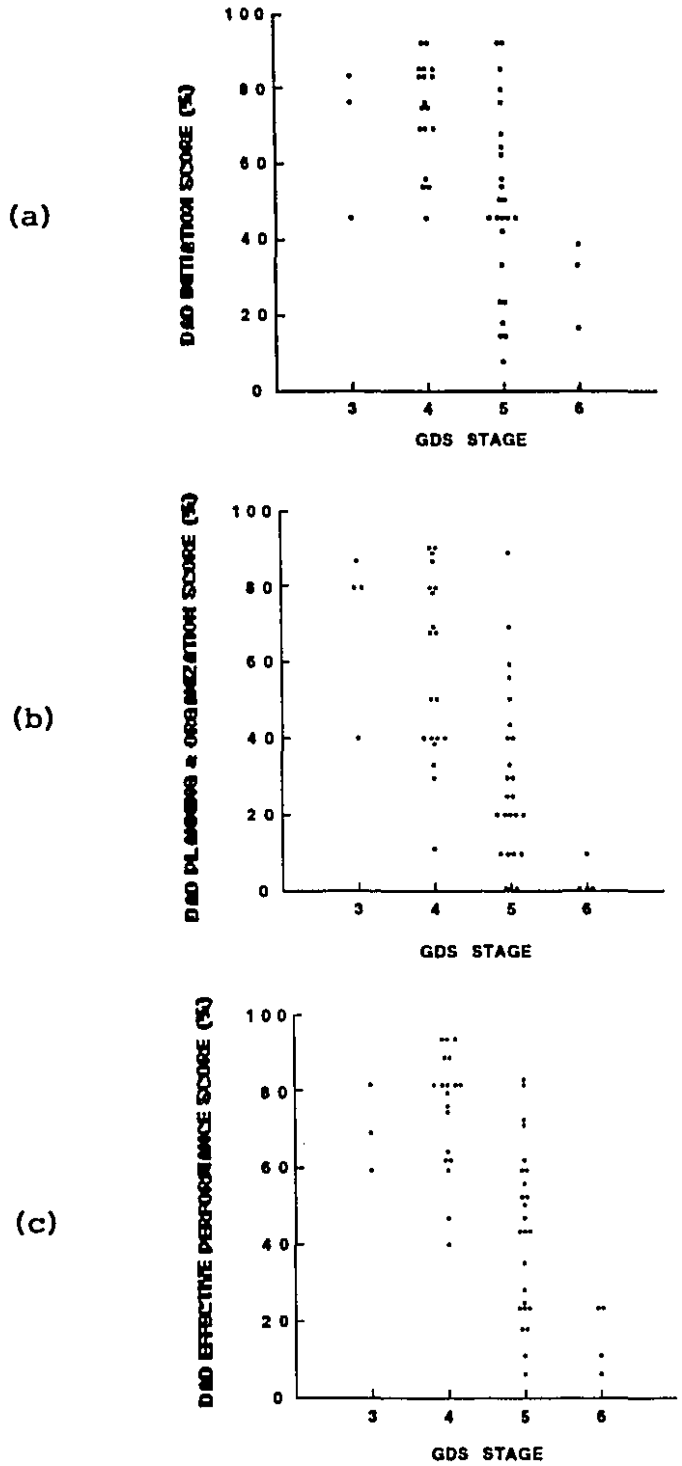

Figure 7. Distribution of (a) Initiation, (b) Planning and Organization and (c) Effective Performance scores for the Disability Assessment for Dementia (DAD) Scale According to Stages on the Global Deterioration Scale (n=59).

Table 14.

Correlation Matrix of the Executive Performance Subsections of the Disability Assessment for Dementia Scale

DAD Subsections	DAD Planning and Organization	DAD Effective Performance
DAD Initiation	.91*	.92*
DAD Planning and Organization	---	.92*

Note: n = 59
*p<.0001, Spearman' s correlation coefficient

5.6.2 Assessment of Gender Specificity on the DAD Scale

DAD was also investigated for gender bias by comparing global scores and frequencies on individual items for male and female subjects. The first step consisted of comparing groups on their characteristics (table 15) to identify any possible confounders.

Findings demonstrated a significant gender difference across the disease stages. The other variables were not significantly different in males and females. In terms of trends, the two groups were slightly different in educational level for secondary and post-secondary studies. Higher proportions of males were found to have post-secondary studies while higher proportions of females finished their education at the secondary level. Education was not, however, considered an important variable that could influence functional scores on the DAD Scale.

Because of the differences in severity of disease according to the GDS scale, global scores on the DAD were compared for males and females using an analysis of covariance controlling for the effect of stage. Before performing the analysis of covariance, a test of homogeneity of slopes was done to ensure that there was no interaction between gender and stage. The probability of stage by gender interaction was above the .50 value. The analysis of covariance demonstrated in a non-significant relationship (F=3.49, p>.05) between DAD score and gender when stages was controlled. Therefore males and females did not score differently on the DAD Scale.

5.6.3 Internal Consistency

Item-total correlations and Cronbach's alpha were recalculated with the 40 item scale (table 16). Item-total correlations remained in the moderate level with coefficients between .20 and .80. Only six items, considered important for face validity, showed correlations below .40. The overall alpha remained very high for raw (r=.957) and standardized (r=.956) variables. Therefore this modified version also demonstrated a high internal consistency.

Table 15.

Comparisons of Alzheimer Subjects Characteristics According to Gender.

	n	MALE	n	FEMALE	Chi-square (df)
Language (%)					
English	30	53%	29	66%	.91(1)
French		47%		34%	
Education (%)					
primary	30	13%	29	21%	5.13(2)
second.		30%		52%	
post-Sec		57%		27%	
GDS[a] Stage (%)					
3	30	17%	27	4%	8.41*(3)
4		46%		29%	
5		27%		63%	
6		10%		4%	

	n	MALE	n	FEMALE	Difference in means (95%CI[b])
Age (yrs)					
mean ± SD	30	66.8 ± 8.3	28	69.3 ± 8.1	-2.6 (-6.9, 1.8)
Duration DAT[c] (Months)					
mean ± SD	30	21.9 ± 25.1	29	25.6 ± 19.7	-3.7 (-15.5, 8.2)
MMSE[d] (Max 30)					
mean ± SD	28	17.6 ± 8.1	26	14.7 ± 8.5	2.9 (-1.7, 7.5)

slight variations in n are due to missing data

[a] Global Deterioration Scale

[b] Confidence interval

[c] Dementia of the Alzheimer 'sType

[d] Mini-Mental State Examination

* p<.05

Table 16.

Cronbach's Alpha and Pearson's Item-total Correlations for Individual and Overall Items of the Final Version of the Disability Assessment for Dementia Scale.

Items deleted	Cronbach Alpha		Pearson's item-total correlations	
	Raw	Standardized	Raw	Standardized
1	.955	.954	.721	.719
2	.956	.954	.620	.624
3	.956	.954	.642	.641
4	.955	.953	.814	.806
5	.956	.954	.691	.690
6	.956	.955	.583	.587
7	.955	.954	.771	.765
8	.957	.955	.500	.503
9	.956	.954	.661	.656
10	.956	.954	.638	.643
11	.956	.954	.632	.635
13	.957	.955	.498	.507
14	.958	.957	.234	.233
15	.957	.956	.300	.292
16	.957	.955	.518	.518
17	.956	.955	.583	.577
19	.958	.957	.263	.246
20	.956	.954	.686	.677
21	.955	.954	.712	.705
22	.955	.954	.720	.713
23	.956	.954	.681	.684
24	.955	.954	.779	.775
25	.956	.955	.572	.568
26	.956	.955	.599	.605
27	.955	.954	.713	.714
29	.956	.954	.654	.653
30	.955	.954	.703	.698
32	.956	.955	.610	.607
33	.956	.954	.626	.629
34	.956	.955	.582	.586
35	.957	.955	.497	.513
36	.957	.955	.427	.449
37	.956	.954	.612	.612
40	.957	.956	.369	.368
41	.956	.955	.585	.582
42	.957	.956	.381	.382
43	.957	.955	.470	.470
44	.957	.956	.391	.387
45	.957	.955	.501	.496
46	.956	.954	.670	.664
Overall	.957	.956		

5.6.4 Content Validity

Members from panel 4, who had also participated in stage III, were recontacted by mail with a structured questionnaire to determine if they agreed with the proposed modifications (Appendix M). One of the ten panel members, a neurologist, did not reply to the questionnaire or to a second attempt to contact him. Therefore two caregivers and seven health care professionals responded to the mailed validation questionnaire and provided data for the analysis. The a priori criterion agreement with the changes had to be achieved in order to keep the modifications. Six items, 12,18, 28, 31, 38, 39, were considered for removal. The a priori criterion (51%) for keeping the modifications was reached for all items.

Panel members were also asked if they agreed that question 13, related to undressing, be incorporated in the dressing section. They unanimously accepted the modification. In addition, they were consulted on the wording changes to item 46, "stay safely at home by himself/herself for a reasonable period of time", to make it more clear and precise for caregivers. The panel members agreed that it needed to be changed but did not unanimously concur with the proposed wording. They felt that the word "reasonable" was still ambiguous. They, however, gave some suggestions. The choice of "for several hours" was mentioned as well as giving a precise number of hours. In light of the comments from the panel members and since the intent of the item was not so much a matter of how long a person can stay alone at home but rather the ability to safely stay home for a period of time needed by the caregiver, the item was changed to "stay safely at home by himself/herself when needed".

As a result of this stage, the DAD scale was modified into version four, a 40 item scale (Appendix N).

5.6.5 Tests of Interrater and Test-retest Reliability

Forty-five subjects participated to the test-retest reliability study while 31 subjects were evaluated for the interrater reliability study. Table 17 displays the results of the tests of reliability using the intra-class correlation coefficient and the concordance correlation coefficient. As can be seen, the scale demonstrated very high stability over time as well as reproducibility between raters.

5.6.6 Factors that May Influence Results on the DAD Scale

The relationship between explanatory variables and the final version of the DAD was examined. Results from correlations between DAD version 4 and the explanatory variables are shown in table 18. The DAD score was found to be significantly correlated only with GDS stage and MMSE score ($p<.01$). Correlations with these variables were good for GDS stage and moderate for MMSE score. The DAD scale was not significantly correlated with age, marital status, education or duration of the disease. Amongst the explanatory variables, significant correlations were obtained only between GDS stage and MMSE score ($r=-.65$, $p<.001$). Other variables were not significantly correlated.

Multiple regression using the forward procedure was performed to determine which variables would best explain scores obtained on the DAD. The variables from table 18 were included in the model .

The first variable entered into the model was GDS stage. This variable explained 49 % of the variance (R^2) obtained in DAD score. When more variables were entered, the explained variance was not greatly increased. Moreover when all the variables were included in the model, GDS stage was the only one that significantly contributed to the prediction of DAD score (partial F (3, 40)=6.43, $p<.001$). Therefore, the one variable model including GDS stage was determined to be the model that best explained scores on the DAD: DAD score = 171.6 + -25.6 stage. This means that for one unit of change in GDS stage there was -25.6 change of unit in DAD score.

Table 17.

Tests of External Reliability for the Final Version of the Disability Assessment for Dementia scale.

	Test-retest (n=45)	Interrater (n=31)
Intraclass correlation coefficient (95% Confidence Interval)	.96 (.90, .97)	.95 (.90, .97)
Concordance correlation coefficient (95% Confidence Interval)	.96 (.93, .98)	.95 (.90, .97)

Table 18.

Correlation Matrix of the DAD Scale and Explanatory Variables

	1	2	3	4	5	6	7
1.DAD[a] Scale	—						
2.Age	.10 (59)	—					
3.Marital status	.09 (59)	.25 (59)	—				
4.Education	.01 (59)	-.18 (59)	-.24 (59)	—			
5.Duration of DAT[b]	-.42 (59)	.11 (59)	-.16 (59)	.03 (59)	—		
6.GDS[c] Stage	-.70** (58)	-.10 (58)	-.16 (58)	-.10 (58)	.44 (58)	—	
7.MMSE[d]	.54* (55)	.20 (55)	.08 (55)	.08 (55)	-.35 (55)	-.65** (55)	—

Note: Numbers in brackets indicate sample size.
[a] Disability Assessment for Dementia Scale version four
[b] Dementia of the Alzheimer's type
[c] Global Deterioration Scale
[d] Mini-Mental State Examination
Bonferroni probabilities significant at *p<.05, **p<.001, Pearson's product-moment correlation coefficients

CHAPTER 6

DISCUSSION

The intent of this study was to develop a French and English disability assessment for community residing individuals with dementia that would be valid as to content and that would demonstrate good reliability. It was also important to create an instrument which would have no gender bias and would be practical to use in clinical and research settings.

These objectives were reached in this study. A French and English, content valid, disability assessment for community dwelling Alzheimer's subjects was produced. The scale demonstrated strong internal consistency as well as very high stability over time and consistency amongst raters. It was found to be a quick and practical tool. These findings are further discussed in this chapter. Issues pertaining to the development of the scale and its psychometric properties are considered as well as factors which may influence the results obtained on the DAD Scale. Finally, findings on functional disability in dementia of the Alzheimer's type and the clinical implications of the scale as well as the limitations of the study are presented.

6.1 DEVELOPMENT OF THE DISABILITY ASSESSMENT FOR DEMENTIA SCALE

Before developing a new measure, it is important to search the literature to determine if adequate scales, which suit the desired purposes, exist. Therefore, as a first step in this study, an in depth search of the literature was performed. Existing measures were generally found to be unsatisfactory with regards to their content or psychometric properties. Suitable assessments for community residing individuals which provided information on how functional tasks are performed were especially scarce. A decision was thus taken to develop a new scale that would meet the desired purposes.

To adequately assess the complex concept of functional disability, it was important to operationally define it. It was also essential to base the definition on a well-established conceptual basis to provide a strong foundation for the measure. The definition of functional disability put forth by the World Health Organization (1980) was thus chosen. This model is well recognized and widely accepted (Granger, 1984; Hébert, 1982; Townsend et al., 1990).

Once the need to design a new scale has been established and the concept has been operationally defined, it then becomes important to determine which domains of functional disability should be included and to generate items reflective of these domains. Several steps were taken for the elaboration of the scale to ensure that it be suitable for use with the Alzheimer's. As stated by Spector (1992), the development of a scale is a multistep process. There are no standardized procedures that have been established to generate and assess the content of a new measure and therefore this process is usually left to the researcher (Thorn & Deitz, 1989). This scale was based on methods described by Spitzer and collaborators (1981). Similar procedures have been used by other researchers (Berg et al., 1989; Wood-Dauphinee et al., 1988) and have been described by Spector (1992) as constituting major steps in the development of a rating scale. The methodology proceeds through different stages; defining construct, formulating items, and pre-testing the scale to determining content validity. It is based on gathering information from various sources to ensure that all relevant domains and items are incorporated. The process facilitates the elaboration of a the scale that is useful clinically and can be used in research

The specific procedures in this study consisted of developing suitable items to assess functional disability with the Alzheimer population, pre-testing the scale to determine clarity and practicality, modifying the scale and determining content validity, testing it on a caregiver population, further modifying the scale, and finally testing content validity and reliability of the final version.

6.1.1 Content Development

6.1.1.1 Panel Composition

To ensure that the domains of functional disability were represented and that suitable items would be developed, different sources were utilized. These were information from the literature, previous research experience of the investigators and expert judgment from health care professionals and caregivers of Alzheimer subjects. Several of the functional scales found in the literature which provided information on their development, depended mostly on only one of these sources to gather information. Mahurin et al. (1991) and Moore et al. (1983) generated content based on information gathered from the literature. Carswell et al. (1992) and Skurla et al. (1988) relied on the use of panels of experts while Loewenstein et al. (1989) employed both information from the literature and from panels of experts.

Information from the literature and from research by Gauthier and collaborators (1990A, B, C, 1991A, B) was utilized to develop a preliminary version of the scale (DAD 1). Expert judgment was used in stage one to assess information included in DAD 1. Different experts were also consulted on items reflective of the domains of functional disability, specifically for dementia of the Alzheimer's type, based on their expertise and personal experience. In addition, they participated, during stage three, in the assessment of content validity of the scale. Because one purpose of the scale was to delineate which aspects of functional performance were problematic, expert judgment and information of the literature were used to determine impairments known to impact on functional performance.

The choice of experts was felt to be crucial to develop a scale that would be complete and content valid for the Alzheimer population. Fink et al. (1984) stated that the composition of panels has an important impact in terms of perceived credibility of the instrument developed. Therefore, the experts included in the panels had to have extensive experience in assessing or treating the functional disabilities of Alzheimer patients. They were selected from both clinical and research milieux as both settings can provide useful information for scale development. In addition, experts from various fields and different geographical areas were asked to participate to gain a broader understanding of disability. While it was not possible to have experts from several regions for all panels because of the costs, they were included whenever possible. Mailings were utilized to circumvent this problem and facilitated representation from a broader geographic area. It was, however, considered important to have direct on-site input for content validation and thus people from different parts of the country were brought to a meeting. The type of experts used for content development of functional instruments has varied from scale to scale, however, participants with divers backgrounds have often been chosen. Carswell et al. (1992) and Skurla et al. (1988) used experts with different backgrounds (medicine, nursing, occupational therapy), while the panel in the work of Loewenstein et al. (1989) was composed solely of geriatricians.

Caregivers of community residing Alzheimer subjects were also included in the panels as they can contribute invaluable information and insight gained from living with the patients. With the exception of Carswell et al. (1992), the functional scales which have reported using panels of experts have not employed caregivers. In relation to the development of a quality of life index for cancer patients, Spitzer et al. (1981) noted that for a scale to be utilized for clinical and research purposes it is critical that content reflects the views of the community and thus that patients, caregivers and health care professionals take part in identifying the domains. As the same concepts are valuable for functional scale development, inclusion of caregivers in the panels was felt to be essential.

Caregivers participated in all panels except for the one on impairments as it was felt that it would be difficult for them to contribute to this more specialized area. An attempt was made to have caregivers of subjects who were at different stages of the disease found in the community for each of the panels. Unfortunately, it was impossible to recruit caregivers of patients in the later stages. Nonetheless, the investigators are confident that important items for all stages were included by the panels because of the quality of the experts who participated. The health care professionals had extensive experience with subjects from all stages of the disease. They are also confident about the items generated as they are congruent with the information found in the literature.

6.1.1.2 Identification of Domains and Item Development

The content, developed through stages one to three, will now be discussed. The panel members identified five self-care items for the ADL domain, six items for the IADL domain and one item on leisure activities. Support for including these domains is found in the literature. Most of the existing functional disability scales assess either ADL, IADL or both. In fact, several studies support the use of these activities for the assessment of functional disability with the demented population. Barberger-Gateau et al. (1992), Green et al. (1993) and Hill et al. (1993) emphasized the importance of including both self-care and instrumental activities to have a scale that will assess the severity of disability with impaired populations. On the other hand, leisure activities are not usually included in these types of scales. They were found only in the Record of Independent Living from Weintraub (1986) as a general item. This may be due to the difficulty in assessing these types of activities which are extremely varied. This item was included in our scale because caregivers and health care professionals from different panels considered that it represented a crucial aspect of living. They noted that loss of the ability to participate in leisure activities is an indicator of change in functional abilities. Because the quality of performance may be difficult to judge for some activities, this item was evaluated in terms of the interest shown in leisure activities.

Hygiene, dressing, undressing, continence and eating were the self-care activities included in the scale. Dressing and hygiene activities were felt by panel members to be particularly important items to detect changes between stages. Apart from undressing, these activities are usually included in functional disability scales. Skurla et al. (1988) used only one self-care activity in their scale. Dressing was identified by their panel of experts as being essential to assess with the Alzheimer population to detect change in abilities.

Dressing as well as grooming and eating, were identified as being meaningful to include in a functional assessment by the panel of experts in the Loewenstein and collegues' (1989) study. Continence problems, present in the later stages of the disease, were also included in the DAD Scale to allow assessment of more severely disabled individuals.

Instrumental activities suggested by panel members were preparing meals, using the telephone, going on an outing, handling finances and correspondence, taking medication and performing household chores. Meal preparation, telephoning, and purchasing were identified by Skurla et al. (1988) as being significant activities to assess with Alzheimer patients. Loewenstein et al. (1989) also included financial abilities. Barberger-Gateau et al. (1993) found that telephoning, using transportation, taking medication and handling finances could detect dementia with a sensitivity of 94% and a specificity of 71%, thus demonstrating the importance of including these items in an evaluation of functional disability.

Disability in the DAD scale is assessed according to impairments in order to have a scale that would not only point out problematic activities but would also identify which aspects of performance are impaired. Impairments, named by the panel of experts, consisted of several cognitive dysfunctions notably difficulties in executive functions, memory, insight and flexibility. Problems in memory sequencing, judgment and executive functions were recognized by Skurla et al. (1988) as having an impact on the ability to complete functional activities. Impairments perceived by panel members were also similar to those identified in Carswell and collegues' study (1992) where panel members were asked to distinguish items which influence performance in Alzheimer's disease. Baum and Edwards (1993) associated problems in executive functions with cognitive processes that affect task performance and used them in their Kitchen Task Assessment. Impairments in executive functions were retained in the DAD scale as they are directly related to performance in activities of daily living (Lezak, 1983; Winegardner, 1993). They are also easier for the caregiver to observe than other cognitive abilities.

The development of content was carried out simultaneously in both French and English. Translating early versions of the scale had advantages over translating only the final version. It allowed consultations with both French and English individuals that incorporated cultural differences. It also permitted testing the properties of the French and English versions of the scale to ensure content validity and reliability.

6.1.2 Administration and Scoring

As defining content only represents one aspect of scale development, the method of administration as well as scaling format also needed to be determined. Information from the literature and consultations with experts were also used for these purposes. When asked about the preferred method of test administration with this population, health care professionals stated that both questionnaires for a proxy and direct observation should be employed as they provide different types of information. This is in accordance with findings from Myers et al. (1993) who assessed whether performance based measures of functional status were superior to self-assessment by questionnaire in the elderly. They found that, while one method was not superior to the other, each provided a different perspective and each had its own value. Conventionally, functional scales designed for the demented population employ either one of these methods of administration, however, the use of interview with a proxy seems to be more frequent (Blessed et al., 1968; Laberge, 1990; Moore et al., 1983; Reisberg et al., 1984; Weintraub, 1986). The proxy approach was favored for the DAD scale as it was considered to be the most reliable method of administration in a community setting with the Alzheimer population since lack of insight is a common manifestation of the disease (McGlynn & Kaszniak, 1991). Indeed, Kiyak et al. (1994) found that Alzheimer subjects did not identify the progressive deterioration in their daily performance over the years. These authors mentioned that Alzheimer patients' ability to report on their functional capacities is partially preserved in early to moderate stages of the disease but that this information should be complemented by the caregiver. Additionally, the use of proxy-respondent allows continuity over time particularly in later stages when patients can no longer respond. It is also less time consuming and often more practical. Indeed, because of constraints, it is not always possible to test the performance of the individual with dementia in its environment. However assessing the person in a clinical setting is not recommended since it was demonstrated that an individual should be tested in its environment to obtain information on true performance in activities of daily living (Nygard et al., 1994; Park et al, 1994) Finally, the use of interview with a proxy allows the assessment of a variety of activities which may not be easily observable due to time constraints and lack of appropriate resources. For instance, use of private or public transportation is a difficult item for inclusion in a performance based instrument.

The scaling format was selected through consultations with panel members, an advisory committee and the experience of the researchers. The purpose was to develop a good evaluative scale that could both discriminate and detect change over time. The health care professionals suggested that if specific questions were asked of proxies, their responses would be quite precise. Moreover, information from the literature revealed that fewer response choices as well as concrete and simple questions increase agreement between self- and informant-based questionnaires (Magaziner et al., 1988; Rubenstein et al., 1984). Kirshner and Guyatt (1985) recommended, for a good evaluative scale, the use of sufficient response options to allow detection of change in the condition. However they mentioned that there are no clear indications as to how many options are considered "sufficient" for items to be responsive.

A dichotomous scaling format was selected for scoring items in the DAD scale. This format has the advantage of diminishing the chance of variability in interpretation of the response choice by caregivers as opposed to when they have to choose from several options such as "very mild, mild, moderate, severe, very severe". Although Kirshner and Guyatt (1985) did not recommend this format for an evaluative instrument, the investigators are confident that using a dichotomous scale will still allow detection of disability over time or across different stages of the disease. Indeed, the content of the DAD scale is based on models of deterioration according to two spheres, functional performance in ADL and IADL and executive functions, which have shown hierarchical patterns of regression in DAT (Gauthier, 1988; Gauthier & Gauthier, 1990; Sclan & Reisberg, 1992; Stern et al., 1990). Moreover, results with the sample studied indicated a relationship between changes in GDS stages and scores on the DAD scale. The distribution of DAD scores across GDS stages also suggest differences in scores at the different stages. The DAD scale appears to be able to discriminate between various severity levels as measured by the GDS scale. Furthermore, panel members were in agreement with the use of a dichotomous scale considering that the content was based on a model of deterioration.

A non-applicable response choice was added to the scale after pre-testing and consulting with panels. This altered the initial scaling system which had used a response of YES when an activity was not performed. It had tended to inflate scores and might have distorted the results especially when comparing subjects. During pre-testing it became apparent that some of the activities, especially instrumental tasks, had never been performed by subjects or they did not have the chance of performing them in the time frame set for assessment. To insure that scores would be comparable among subjects or groups, the total score of all applicable items (excluding the N/A items) was converted into a percentage.

The time frame on which caregivers were asked to base their observations for performance was initially set at four weeks. This was changed to two weeks, however, as experts noted that caregivers had difficulty remembering daily events over such a long period of time. There was agreement that two weeks represented an adequate length of time.

The DAD scale, after passing through these stages, was found to be content valid by a panel of experts. It then was tested on a caregiver population to obtain information about psychometric properties and determine the need for further modifications.

6.1.3 Modification of the Instrument

Another important part of scale development relates to identifying items that may need to be removed or modified because they assess different constructs or do not add extra information to the instrument. This process involves looking at the results of several statistical analyses. Tests of internal consistency, frequency of endorsement, gender specificity and the reliability coefficients for individual items were used for this purpose. The decision making process concerning whether an item should be kept or removed was not based solely on the result of the statistical analyses. Face validity was considered an important criterion for keeping an item and prevailed over the statistical test. One must always be cautious about removing an item based solely on statistical performance.

In the statistical analyses, 22 items did not meet the criteria set for selection (table 4). Of these six were deleted and one was modified while the others were kept for face validity. The rationale for keeping, modifying or deleting these items will now be discussed.

Of the six items, four were removed because of low or high frequencies of endorsement and high correlation with other items. They were considered redundant and added little to the scale. These were item 12, "undertaking to undress", 28, "deciding to use a mode of transportation", 38, "complete financial transaction adequately", and 39, "answer correspondence adequately". Item 12 was highly correlated with item 13 which also inquired about the ability to undress oneself. As mentioned in the last chapter, undressing was not found to be an essential determinant of functional disability compared to dressing which was considered important by panel members to distinguish between stages of the disease. Difficulties in undressing are less consequential in daily life, and occur in late stages of the disease (DeAjuriaguerra et al., 1967). As such, they are not seen as often in the community resident. In fact, in the sample studied, it was rarely rated as being problematic and thus obtained a low frequency of endorsement on the NO response (not able to do it). However, as presented in the result section, one of the items was kept since undressing was proposed by panel members for inclusion in the scale. Moreover, item 13, which is related to the ability to effectively perform the activity, was considered more useful for clinical practice than the ability to initiate the activity as asked in question 12.

Items 28 and 32, which were highly correlated, both assessed the ability to use a mode of transportation. Item 28 was removed as it was also included in question 29 where subjects are assessed on their ability to adequately organize an outing with respect to transportation. Further, item 32 was kept because it incorporates a safety component which is often a concern for the caregiver especially if the person is still driving.

Items 38, "completing financial transactions adequately", and 35, "organizing finances to pay the bills", were also highly correlated, suggesting that both questions are assessing the same idea. This may have been due to the way the items were formulated which was not clear enough for caregivers. It may also imply that once finances to pay the bills are organized, subjects are able to complete the transaction. The latter was used as a rationale to determine the item to be deleted. The same thing occurred with items 36, "organizing correspondence", and 39, "answering correspondence adequately", which were highly correlated. Again they seem to be assessing the same things. Item 36 was kept while 39 was deleted. There was some incentive to remove the two items as frequencies of endorsement were low for both. The raters reported that subjects did not correspond as much as in past times but tended to use the phone more often. Nonetheless, because in certain cultures and geographic areas people do write each other and since it was identified as important by experts, one of the two items was kept.

The two other deleted items were numbers 18, "eat his/her meal in the appropriate sequence", and 31, "go out and reach a non-familiar destination without getting lost." The former was removed because of low frequency of endorsement and item-total correlation, and lack of face validity. Raters reported that caregivers did not find it important since in most homes each meal is served one course at the time. Alzheimer subjects, therefore, do not have to determine the appropriate eating sequence. Even if the whole meal would be served at once, this item was not considered a crucial indicator of disability since the impact of eating one part of the meal, such as the desert, before another, the main course, is minimal. Item 31 was removed because of the low frequency of endorsement and the high N/A response rate. It is possible that the N/A in this case really represented a NO. Since Alzheimer subjects have difficulty orienting themselves in unfamiliar environment and are thus unsafe on their own, caregivers might not let them go out alone. Although the ability to navigate in space is a very important determinant of disability in DAT (Liu, 1993; Reisberg, 1983), the capacity to move through a non-familiar environment seems to be lost so early that it is not helpful to determinate level of disability. On the other hand, the item related to ability to navigate in a familiar environment was kept as it is an important indicator of change in status (Liu et al., 1991; Reisberg, 1983).

Other items were retained even if they did not meet the set criteria because they were felt to be important for face validity. Notably, items 14 and 15 related to continence, which had low frequencies of endorsement, were kept. Item 15, "use the toilet without accidents", also obtained fair agreement for test-retest. This latter result was surprising since using the toilet is usually well preserved in Alzheimer patients who are still living in the community. Incontinence is usually a manifestation of later stages of the disease (Reisberg et al., 1984) and is, therefore, not often found in a community dwelling individual. Davidson et al. (1991) suggested that incontinence may appear in middle stages of the disease but that the prevalence increases with the severity of the disease. Moreover, the majority of individuals in the sample did not have any difficulty performing this task. Nonetheless, an item on continence would be important if the scale was to be used to monitor disease progression for the middle to late stages. Problems with continence are often a determinant for deciding to institutionalize an individual because of the burden on the caregiver.

Items pertaining to the use of medication were kept although they obtained a high rate of N/A responses. Panel members considered these items to be an essential component of a functional assessment for this population because of the possible danger of using medication inappropriately. Indeed, as previously mentioned, Barberger-Gateau et al. (1992) determined that ability to take medication along with telephoning, use of transportation and handling finances served in the detection of dementia. The high level of N/A responses obtained could be attributed to the fact that not all individuals with DAT are taking medication.

Items 17,"choose appropriate utensils and seasoning when eating", and 45," complete adequately household chores as he/she used to perform in the past", were also kept for face validity even if they showed fair interrater agreement. Obtaining only fair agreement on item 45 was less surprising because of the wide range of activities that fall under the rubric of household chores. Dissimilar answers may have resulted if the caregiver considered different activities in the two interviews.

Issues related to high levels of N/A responses for some of the items were explored to determine if they were caused by the influence of other variables. Neither age, gender nor stage of disease were found to have an impact. The N/A responses were, however, found to be more frequent in the English speaking group. Further investigation was done to determine if this occurred more frequently with a particular rater but the number of N/As were quite comparable across the English speaking raters. The difference in frequency may be due to dissimilarities in the training sessions. The English and French training sessions were conducted by two different investigators on separate occasions. It may well be that the N/A option was emphasized more during the English than the French training sessions. This might explain why English speaking caregivers tended to select that alternative more often. It would also suggest that instructions for administration should be reviewed to ensure that they are standardized.

6.2 PSYCHOMETRIC PROPERTIES OF THE DISABILITY ASSESSMENT FOR DEMENTIA SCALE

Content validity was reaffirmed and tests of reliability were undertaken for the final version of DAD Scale. These results are now discussed.

6.2.1 Study Sample

The sample of community dwelling Alzheimer subjects and caregivers recruited for participation in the study was for the most part consistent with demographic and epidemiologic information reported in the literature on this population.

In terms of age, the sample included individuals across the different age groups in which the disease occurs. They ranged from early onset cases younger than 65, to individuals in the 65 to 74 and 75 to 84 age groups, to a few subjects in the 85 and over group (Canadian Study of Health and Aging Working Group, 1994; Health & Welfare Canada, 1991; Rocca et al, 1986).

The sample, however, showed differences from epidemiologic data in terms of gender. According to these data there are more women than men affected by the disease (Canadian Study of Health and Aging Working Group, 1994; Rocca et al, 1986). Canadian studies have reported that for community-dwellers there are about twice as many women as man suffering from Alzheimer's Disease (Canadian Study of Health and Aging Working Group, 1994). The study sample included about equal numbers of males and females. This may have occurred due to the sampling technique. Subjects were not randomly selected from the population of community- dwelling Alzheimer subjects but were recruited on a volunteer basis. And since there is some evidence suggesting that women may volunteer more for health-related activities (Chambre,1984; Fischer et al., 1991; Romero, 1986), it may well be that women volunteered their Alzheimer spouses more often than men. Indeed, caregivers in the present study were predominantly wives.

Subjects in this study were moderately impaired and mostly in stages 4 and 5 of the Global Deterioration Scale. The sample appeared representative of the population we would expect to find in the community. Other studies, which have used larger demented samples randomly drawn from the community (Barberger-Gateau et al., 1992, n=666; Carswell & Eastwood ,1993, n=101), also obtained groups that were predominantly moderately cognitively impaired. As reflected in our sample, only a small number of stage 6 individuals should be expected in the community as these people are usually very disabled and often institutionalized. Our sample also included a small number of subjects in stage 3. These numbers might again be the results of the sampling technique. Since stage 3 subjects often present difficulties in demanding, complex, occupational or social tasks but have little difficulty with daily tasks, the spouse may not tend to volunteer. Another reason may be that subjects and caregivers are still denying or at least hiding the disease and therefore may not volunteer.

In summary, even though the sample was not randomly selected, it appears quite similar, apart from the sex ratio, to the larger DAT population living in the community.

6.2.2 Content Validity

The content of the DAD scale was verified by a panel of experts and caregivers in stage III and was reverified using the final version of DAD to ensure that the removal of items did not affect this psychometric property. The majority of panel members quite easily agreed on all items and accepted the proposed modifications, thus establishing content validity of the final version. This is not surprising as modifications were not based solely on statistical tests but also on face validity. Decisions were made according to the information from the literature and from the panels of experts. The content of the scale is congruent with information provided in the literature. Moreover, throughout the development of the scale, responses from panel members regarding content were very consistent . These facts are all good indicators of content validity.

Several published dementia scales assessing functional disability have described the processes utilized for development of content specifically for use with the Alzheimer population. However, very few of these scales have reported whether content validity was evaluated, although content validity is regarded as an important initial step in instrument development. Validation of content has been reported for the Psychogeriatric basic ADL scale (Laberge, 1990) and the FAST (Reisberg et al., 1984). Likewise, the DAD went through a rigorous test of content validity.

6.2.3 Internal Consistency

An aspect of reliability which needs to be established in multi-item scales is internal variability (Feinstein, 1987). This test evaluates the relationships among items and between the item and the total score to determine whether the scale is homogeneous. In other words, it addresses the question as to whether the scale assesses various aspects of one construct or different constructs. An indication of the former would be if the items are moderately correlated with the total score and with each other thus indicating that they are related but not redundant. Low correlations would indicate that the scale is measuring different constructs and high correlations would suggest item redundancy.

Item-total correlations and Cronbach's alpha were calculated to determine internal consistency. For item-total correlations, six of the items had low correlations (below .40) while none was above .80. These items were kept for face validity. Nonetheless, the scale demonstrated high internal consistency as Cronbach's alpha exceeded the .80 criterion which is considered satisfactory (Feinstein, 1987). It can therefore be summarized that the DAD measures various aspects of functional disability rather that different constructs.

In comparison, internal consistency was rarely reported as a psychometric property of other functional assessments for dementia. Moreover, it was mentioned only in the scale from Moore et al. (1983). Therefore, whether these other scales are tapping one or more constructs is not known from reports in the literature.

6.2.4 Test-retest and Interrater Reliability

The scale exceeded the established criteria of .80, as indicative of good reliability, for both test-retest and interrater reliability using the two reproducibility test statistics. The ICC and the concordance correlation coefficient yielded similar results. Lin (1989) demonstrated that these tests often give comparable results. However the ICC cannot distinguish bias from imprecision, how far observations depart from the best-fit line, as does the concordance correlation. Since the two coefficients were similar it can be speculated that this bias must have been minimal.

Good reliability is important if one wants to ensure that a scale is measuring functional disability in a reproducible and consistent manner. The type of reliability assessed will be determined by the purpose of the instrument (Kirshner & Guyatt, 1985). Most scales used to assess functional disability with Alzheimer's patients have been tested for at least one type of reliability. Several have demonstrated good interrater reliability (Loewenstein et al., 1989; Moore et al., 1983; Sclan & Reisberg, 1992). The Blessed Dementia Scale (Cole, 1990) is an exception. Others have shown good test-retest reliability (Laberge, 1990; Weintraub, 1986) and a few have been assessed on both types of reliability (Loewenstein et al., 1989; Mahurin et al, 1991; Moore et al., 1983). The DAD Scale seems to be reliable over time and across raters when considered either by individual item or by total score.

6.2.5 Gender Bias

Issues related to whether or not a scale has gender bias have not been reported for the functional scales for dementia. This is a matter of importance, particularly with the present generation of elderly individuals for whom gender specific activities are prevalent (Lawton & Brody, 1969). These activities are closely linked to learned gender roles and thus pertain mainly to instrumental activities of daily living. For example, it is not unusual to find an elderly man who cannot cook or an older woman who has never driven a car or taken care of finances. Lawton and Brody (1969) addressed this issue in their Physical Self-Care and Instrumental Activity of Daily Living Scales which were designed for the general elderly population. They circumvented the problem by designing two scoring systems, one for males and one for females; each excluded gender specific activities. Meal preparation, doing laundry and housekeeping were identified by these authors as female-linked items, while transportation and handling finance were more specific to males.

Revisions to the Lawton and Brody (1969) scales were made to avoid having two gender-specific scoring systems. These were included in the Older Americans Resources and Services Multi-Dimensional Functional Assessment Questionnaire (Older Americans Resources and Services, Duke University, 1978). Problems regarding gender specific items were solved by changing the scoring format. Whenever a person was unlikely to perform the task they were scored on whether they "could" perform the activity and thus were not penalized.

Since the DAD scale was to be free of gender bias and performance based, the strategies used in the Duke Study (1978) were not employed. Instead, care was taken to exclude gender specific questions and to formulate items so that gender bias would be avoided. For examples, housework and doing laundry were avoided; instead doing household chores was utilized. This latter term was more comprehensive and included activities for both men and women. Further, the items related to meal preparation were simplified so they evaluate the ability to prepare a light meal or a snack which most men can do. In addition, the inclusion of a non-applicable response choice and the conversion of the total score on a percentage prevented penalizing an individual who did not perform an activity. This process was successful as the scale was not found to have gender bias when considering either the global score and individual items (for 38 out of 40 items).

6.3 EXPLANATORY VARIABLES FOR THE DISABILITY ASSESSMENT FOR DEMENTIA SCALE

The influence of explanatory variables on scores obtained from the final version of the DAD scale were examined. The scale was found to correlate moderately with MMSE score and highly with GDS stages. It was not associated with other variables such as age or education. Moreover, a linear regression identified GDS stage as being the only factor influencing scores of the DAD scale. The fact that the other variables did not appear in the regression model was not surprising since they were not significantly correlated to the DAD.

The progressive loss of functional abilities in DAT according to a hierarchical pattern has been well demonstrated in longitudinal (Carswell & Eastwood, 1993; Gauthier & Gauthier, 1990; Green et al., 1993; Stern et al., 1990) and cross-sectional studies (Baum et al., 1993). Further, it has been established that the progressive deterioration in functional abilities followed the changes delineated in the Global Deterioration Scale (Sclan & Reisberg, 1992). Therefore the relationship between GDS stages and scores on the DAD scale indicates that scores on DAD scale change with stages of the disease allowing determination of patterns of regression in functional disability. Moreover, the scale should be useful in discriminating between individuals who are at different levels of disability.

Many studies have established a relationship between mental status scores (particularly scores on the MMSE) and functional performance in dementia (Aske, 1990; Carswell & Eastwood, 1993; Hershey et al., 1987; Reed et al., 1989; Teri et al., 1989; Teunisse et al., 1991; Warren et al., 1989). The reported strength of the relationship between these variables varies from low to high. Several studies, however, including this one, indicated a moderate association between these variables (Carswell & Eastwood, 1993; Hershey et al., 1987; Reed et al., 1989; Warren et al., 1989). The fact that only moderate correlations were obtained between the MMSE and the DAD score in this study, is congruent with increasing evidence in the literature showing that , although they are related, the course of deterioration between cognition and function is not parallel (Gauthier &

Gauthier, 1990; Reisberg, 1986; Weintraub,1982). The DAD scale appears able to capture these differences in deterioration. These results also indicate that the DAD scale assesses a different concept than cognitive tests. Other authors, taking into consideration the limitations of their studies, have also come to the same conclusion using different functional and cognitive tests (Hershey et al., 1987; Teunisse et al., 1991). Indeed, adequate performance in activities of daily living involves the ability to integrate many skills which are not evaluated by cognitive tests such as perception, executive functions and motivation.

Even though age and education have been identified as risk factors for the occurrence of DAT (Evans et al., 1991; Health & Welfare Canada, 1991; Hill et al., 1993; Katzman & Jackson, 1991; Rocca et al., 1986), they were not related to functional scores in the present study. This means that scores on the DAD were not influenced by either age or education. Reed et al. (1989) did not find age to be a significant predictor of functional status in demented individuals, however, in their study, the interaction of education with MMSE scores was a significant predictor of IADL scores. Contrary to these findings, Carswell and Eastwood (1993) determined that age was a significant predictor of scores obtained on the Instrumental and Self-Care Activities of Daily Living Scales (Lawton & Brody, 1969). These authors also found social function, marital status and duration of the disease to be prognostic of functional status with Alzheimer subjects.

6.4 FUNCTIONAL DISABILITY IN ALZHEIMER' DISEASE

Findings from this study provide information on functional disability in a community residing DAT population. In fact, the data are congruent with previous findings that have been reported in the literature.

In the sample studied, subjects, who were moderately cognitively impaired, scored higher on basic ADL and lower on IADL. In other words they still had ability to perform ADL activities while their capacity to accomplish IADL was markedly decreased. The fact that community dwelling DAT persons may be very impaired in instrumental tasks has serious clinical implications. These activities are very important for self-maintenance at home and will be determinant for an individual's ability to live alone. They, thus, will have a major impact on decisions regarding service delivery at home or the need for institutionalization.

When distributions of scores of DAD, DADADL and DADIADL across stages of the disease were examined, the findings mirrored trends reported in the literature (Baum et al., 1993; Carswell & Eastwood, 1993; Gauthier & Gauthier, 1990; Green et al., 1993; Sclan & Reisberg, 1992; Stern et al., 1990). The level of functional disability increased with severity of the disease as depicted by the GDS stages. In addition, the self-care activities seemed to deteriorate in later stages (starting in stage 5) while instrumental activities started to decline in early stages (3 and 4).

While the literature is abundant on the progression of DAT with regards to functional activities, there is very little on the progression in executive performance. In the present study, subjects were impaired on all executive functions. They appeared to experience more problems with planning, organization and effective performance than initiation. As for the ADL/IADL subsections, distributions of scores for the executive function subsections across stages of the disease suggested progressive deterioration in these skills with increasing severity. In addition, abilities in initiation seemed to decrease more markedly in stage 5 while planning and organization appeared to deteriorate as early as stage 3 and 4. Skills in effective performance also seemed to decline in early stages but this was not as apparent as in planning and organizational abilities.

Problems in executive functions similar to the ones reported in this study were noted to impact on functional abilities of DAT subjects by other authors (Gauthier, 1988, Laberge, 1990; Skurla et al., 1988). Moreover Laberge (1990) also found, in a moderately cognitively impaired DAT sample, that subjects experienced more difficulty in planning as compared to initiation or effective performance. On the other hand, the findings from the present study are in contrast to those reported by Gauthier (1988) in terms of observed patterns of deterioration in executive function in DAT. Deterioration in initiation was noted before the loss of the ability to plan and organize. Differences in sample size and design may account for the divergent results. Gauthier's study, for instance, was a multiple case study involving nine subjects with definite DAT determined by biopsy followed over nine months while the present study was cross-sectional and included 59 subjects.

Clearly, further studies need to be conducted with DAT subjects to draw solid conclusions on executive functions and their relationship to basic and instrumental activities of daily living.

6.5 CLINICAL IMPLICATIONS

Findings from this study have implications for the assessment of functional disability in dementia of the Alzheimer's type. Results support the use of both self-care and instrumental activities for adequate assessment of a community residing population with Alzheimer's disease. Both ADL and IADL subsections of the scale were identified as assessing components of the functional disability construct as opposed to representing different constructs. Findings also revealed limitations of the ADL subsection in the assessment of mildly impaired subjects while the IADL subsection had restricted abilities for severely impaired subjects. This reinforces the need to include both components in a functional disability measure with community dwelling Alzheimer's subjects. It is particularly important for community residing individuals, who are usually not severely impaired, to have a scale which includes instrumental activities. Similar findings, reported by Barberger-Gateau et al. (1993), Green et al. (1993), Hill et al. (1993) and Norstrom and Thorslund (1991) have led to similar conclusions.

The DAD scale in its present form fulfills many of the criteria previously described for good assessment of functional disability in Alzheimer's disease. It is based on a recognized conceptual definition from the World Health Organization. The content is valid for assessing functional disability with Alzheimer's patients and the scale has demonstrated high stability over time and consistency between raters. It also has shown a high degree of internal consistency.

The DAD scale should prove to be useful for clinical practice as it is very easy and short to administer, taking less than 15 minutes. In addition, it does not need to be used in a particular setting nor does it require any special equipment. It is, however, recommended to administer the scale to the caregiver alone, as the presence of the patient may influence the accuracy of answers. Another advantage of this scale is that it does not require any particular expertise or extensive training for administration. Care should be taken in the choice of the caregiver. Caregivers who have considerable contact with the person assessed should be selected to ensure that the individual answering the questionnaire has good knowledge of the subject's performance in functional activities.

Since it is suggested, to have a useful descriptive tool, that the content includes items that will allow comparison between individuals or groups and that the instrument shows stability over a short period of time and validity (Kirshner & Guyatt, 1985; Law & Letts, 1989), the DAD can be recommended for clinical use as a descriptive tool. Indeed it has demonstrated evidence of content validity to discriminate between subject or groups as well as test-retest and interrater reliability in the present study. Its concurrent and construct validity has been determined in a parallel cross-sectional study (McIntyre, 1994). To determine its ability as an evaluative tool to detect change over time, longitudinal studies need to be conducted. The scale, however, looks promising as it shows changes across different stages of the disease.

Assuming that the DAD will allow detection of change in abilities over time when tested in the near future, it will be a very attractive measure for research activities. The scale, as mentioned earlier, is practical to use in any setting and provides quantitative data on functional abilities which can be used for statistical analysis. In addition, it is available in both French and English thus allowing the conduct of study on larger samples including subjects from both language groups. The absence of psychometricaly sound French and English measures can often limit the recruitment of suitable subjects in studies especially in the province of Quebec. The existence of a French and English scale would also facilitate national or international research. Therefore, the DAD could be useful for descriptive studies on the functional characteristics of the DAT population and could serve as an outcome measure in intervention studies. The use of functional measures as outcome variables is now recognized as there is increasing evidence that cognitive status alone is not sufficient to provide a full picture of overall severity of the disease (Hershey et al., 1987; Reed et al., 1989; Teunisse et al., 1991)

The scale will also be useful for planning interventions or making decision with regards to support services or even the need for institutionalization with DAT patients and caregivers. The DAD assesses disability in a wide range of activities which are essential for independent living in a community setting. It also provides indications as to which aspects of performance are problematic.

6.6 LIMITATIONS OF THE STUDY

Limitations of this study pertain to the number and type of caregivers who participated in content development and the sampling procedure used for data collection. The impact of doing several interviews with the same subjects also warrants discussion.

Although the ideal number of caregivers needed for participation in panels for content development is unknown, the contribution of caregivers was minimal for one of the panels consulted. In addition, the investigators were unable to recruit caregivers of subjects from stage 5 of the GDS. It would have been preferable if caregivers of subjects from all stages found in the community would have been present to provide insight on several levels of functional disability. Fortunately, the high quality of experts and caregivers who provided information compensated for these factors. Moreover, the content generated was in concordance with the literature and was validated by another panel composed of experts and caregivers.

Another limitation relates to the sampling technique and the inclusion criteria utilized. The sampling technique was not random but based on volunteer participation and inclusion was limited to individuals with no physical disabilities that could interfere with the performance of ADL who were living in the Montreal area. As a result, the sample included only a small number of subjects from stages 3 and 6. This limited the analysis for comparison across stages. It should, however, be noted that there are few community residing individuals classified as stage 6 since these people are more disabled and are often institutionalized. On the other hand, a larger number of stage 3 subjects was expected in the sample since these individuals are less cognitively and functionally impaired and are for the most part still living at home. In consequence, the results obtained from the DAD Scale on the functional abilities of the study sample may not be generalizable to the larger DAT population. In addition, because data from the study sample were also used for taking decision regarding whether an item would be retained or discarded, there could be concerns as to whether the items selected (content) would be representative of the domains of functional disability for the larger community-dwelling DAT population. However because decisions regarding item reduction were not based solely on the statistical results but also on face validity and information from the experts, the investigators are confident that the items retained are representative of the larger DAT population. Moreover, the final version of the scale which underwent modifications was reassessed and found to be content valid by a panel of experts

Another issue which should be addressed is the number of interviews conducted on the same subject. Some participants were used for both the interrater and the test-retest reliability studies and as a result were interviewed as many as three times with the disability scale. A possible bias that could have occurred as a result of this procedure, is that caregivers may become more familiar with the scale and remember answers from one interview to the other. This would have the consequence of falsely increasing the correlation coefficient. However the fact that the scale contained many items (46) made it difficult for subjects to remember questions. Under-estimation of the correlation coefficient could also have occurred as a result of this situation since in some instance the third interview was done more than one week after the initial visit. Changes in the construct under study may have occurred because of the passage of time. To avoid these bias, separate groups of subjects could have been used for the two reliability studies. Only, this was not feasible with this population in the time period over which the study was conducted. Another solution might have been to use two raters during the second interview for the interrater reliability study. However bias may occur when this method is used as answers from one of the raters may be influenced by questions or clarifications asked by the other rater during the interview. Given the possible sources of bias, efforts were made to minimize them when scheduling interviews and during administration.

CHAPTER 7
CONCLUSION

This research project has made an original contribution by developing a content-valid, French and English instrument to assess functional disability in community-dwelling individuals with DAT through the use of a proxy respondent. It has demonstrated a high degree of reliability over time and across different raters. Further, the scale avoids gender bias and is very practical and easy to administer.

The scale is now ready for further testing of construct validity and responsiveness. The uniqueness of the instrument rests on the fact that this will be one of the only functional instrument for DAT available in French and English, thus facilitating multi-centered and international studies. It is also one of the few instruments with the DAT population which assesses not only which activities are problematic but also which aspects of performance are impaired.

This instrument will have a positive impact on geriatric rehabilitation, and on clinical and research activities with the DAT population. It will help clinicians and caregivers to make decisions regarding the choice of suitable interventions. Thus, it will allow the planning of treatment strategies that will take into account the patient's particular cognitive disabilities in relation to his or her daily functioning. It will also guide decision making with regards to the need for home care or institutionalization. As a research tool, it will be useful in describing the functional characteristics of DAT populations, the course of the disease and also as an outcome variable in intervention studies.

Findings from this study shed further light on functional disability in dementia of the Alzheimer type and on its relationship with executive functions. Indeed, there is very little literature on this topic and future work is warranted. Future research activities should also include longitudinal studies to better understand change in functional ability over time with the

DAT population and to test responsiveness of the instrument. Studies showing the usefulness of the scale for all types of dementia should also be instigated.

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APPENDICES

Appendix A: Measures of Functional Status Designed for Individuals with DAT

Name of the measure	Domains included	Type of Scale	Administration	Psychometric properties
Activities of Daily Living Situational Test (Skurla et al. 1988)	•Dressing (10 items) •Mealpreparation(9) •Telephoning (11) •Purchasing (8)	2 scores obtained for each items: •Performance score: rating on 4 point scale which reflects the level of assistance needed. O- "does not complete", 4- "complete independently". A raw score and percentage of raw score over highest possible score is obtained for each task and the total scale. •Time required to complete each task.	Direct observation with trained rater.	•Reliability is not reported. •Validity: the instrument correlated significantly with the Clinical Dementia Rating Scale (Hughes et al., 1982) (r=.59) and did not correlate significantly with the Short-Portable Mental Status Questionnaire (Pfieffer, 1975) (r=.40).
Dementia Scale (Blessed et al, 1968)	Functional performance: •everyday activity (IADL) •Changes in habits (BADL) •Changes in personality and interests Cognitive performance: •information-memory concentration test	The functional performance scale: rating for each item is done on either a 3 point-scale or a dichotomous scale. The total score ranges from 0 (fully preserved capacities) to 28 (extreme incapacity) The cognitive test: rating for each item is done either on a 3 point-scale or a dichotomous scale. The total score ranges from 0 (complete failure) to 32 (full mark).	Report from an informant on a questionnaire.	•Reliability: Interrater reliability was examined by Cole(1990) with 47 demented subjects and was found to be low (ICC, r=.297; Pearson's r=.59). •Validity: the functional performance scores and the cognitive scores were found to correlate significantly with senile plaques count in the cortex of 60 patients with varied diagnostic. r=.77 for functional performance r=.59 for cognitive tests.

Name of the measure	Domains included	Type of Scale	Administration	Psychometric properties
Direct Assessment of Functional Status (Loewenstein et al, 1989)	7 domains: •Time orientation (8 items) •Communication (17) •Transportation (13) •Financial skills (21) •Shopping skills (8) •Eating skills (5) •Dressing/grooming skills (13)	Points allocated on the basis that the item is performed correctly or not. The scale yields a composite functional score (excluding transportation which is optional) with a maximum of 93 points.	Direct observation with trained rater.	•Reliability: Interrater reliability assessed with 15 memory impaired patients (rs between .911 and 1.00) and 12 elderly controls (rs between .988 and 1.00). Test retest reliability assessed with 14 memory impaired patients (rs between .546 and .918) and 12 elderly controls (rs between .778 and 1.00) •Validity: Convergent validity obtained with 30 memory impaired subjects using the Blessed Dementia Rating Scale (Blessed t al, 1968) (r=-.588) and the modified Blessed scale (r=-.673).
Functional Assessment Staging (FAST) (Reisberg et al., 1984)	16 stages of deterioration in functional abilities	Items form an ordinal scale ranging from 1 to 7f. The score is the highest ordinal value obtained which reflects the highest level of function of the subject.	Report from an informant on a questionnaire	•Reliability: Interrater reliability assessed by Sclan & Reisberg (1992) with 16 demented subjects was found to be excellent (ICC, r=.86). •Validity: FAST was correlated with 10 independent psychometric tests (rs ranged from .59 to .73, p's<.001) and with independent clinical assessments (rs ranged from .83 to .94, p's<.001) in a study of 50 DAT (stages 2 through 6) and control subjects. FAST was also significantly correlated with the Mini-Mental State Examination (Folstein et al, 1975) with r=.87 in a study of 40 DAT and control subjects.

Na[illegible] the mea[illegible]re	Domains included	Type of Sc[illegible]	Administration	Psychometric pro[illegible]es
Functional Assessment Staging (FAST) (Reisberg et al., 1984)				Concurrent validity for 38 "probable" DAT subjects in GDS stage 6 to 8 was also established by Sclan & Reisberg (1992) using total OSPD score(Uzgiris & Hunt, 1975) (r=-.79) and OSPD subtests (rs ranged from -.60 to -.79). The validity of the progressive and hierarchical ordinality of FAST was ascertained by these authors with 56 "probable" DAT patients
Functional Dementia Scale (Moore et al, 1983)	20 items: •7 items on ADL •6 items on orientation •7 items on affect	Each item is rated on a 4 point-scale from 1 - "none or little of the time" to 4 - "most or all of the time". Total score ranges from 20 (less severely disabled) to 80 (severely disabled).	report from an informant on a questionnaire	•Reliability: Using 40 residents of nursing homes, good test-retest reliability (r=.88) and internal consistency (α=.90) were found. Agreement between raters for individual items ranged from 48 to 75 % . •Validity: The measure was found to be significantly correlated to the Short Portable Mental status Questionnaire (Pfeiffer, 1975) (r=.39) and the SET test (Isaaca and Akhtar, 1972) (r=.48)
The Psychogeriatric Basic ADL Scale (Laberge, 1990)	5 basic ADL: •Bathing (4 items) •Dressing (5) •Personal hygiene (9) •Continence (2) •Feeding (5)	Each item is rated on a 4 point-scale from 0 - "dependent" to 5 - "independent". Total score range from 0 (dependent) to 125 (independent)	Report from an informant on a questionnaire	•Reliability: In a study of 15 elderly control, 15 elderly depressed and 15 DAT subjects, the scale showed good test-retest (r=.98) reliability. •Validity: The scale was content validated. It also demonstrated good concurrent validity when compared to the Rapid disability Rating Scale-2 (Linn and Linn, 1982) [illegible]

Na[illegible] of the me[illegible]e	Domains included	Type of S[illegible]	Administration	Psychometric pr[illegible]es
Record of Independent Living (Veintraub, 1986)	3 domains: •Activities of daily living (17 items) •Communication (4) •Behavior (16)	Each item of the activity and communication section is rated on a 4 point-scale from 0-"no change when compared to prior competence" to 4-"no longer perform". Resulting score is a % representing severity of impairments which range from 0 (no impairments) to 100 (severely impaired). Each item of the behavior section is rated as being either "present" or "absent" on 2 occasions: before illness and at the time of the rating. Resulting score is a %, this score takes into account the behaviors that were present before the illness	Report from an informant on a questionnaire	•Reliability: Good test-retest reliability has been found for all sections: activity (r=.93), communication (r=.81), behavior (r=.95) •Validity: Each section of the scale was compared to the Dementia Rating Scale (Mattis, 1976). Significant relationships were found with the activity (r=-.49) and the communication sections (r=-.30).
Structured Assessment of Independent Living Skills (SAILS) (Mahurin et al., 1991)	10 subscales of 5 items each: •Fine motor skills* •Gross motor skills* •Dressing skills* •Eating skills* •Expressive language •Receptive language •Time & orientation •Money-related skills •Instrumental Activities •Social interaction	•Each item is scored on a three-point rating scale. The scale yields a maximum total score of 150. •Four items* are timed and yield a total motor time	Direct observation	•Reliability: Interrater reliability assessed with 10 DAT patients (r=.99 for both Total Score and Motor time). Test-retest reliability was obtained on 10 controls (r=.81 for Total Score and r=.97 for Motor time). It showed good internal consistency with an alpha of .90 . •Validity: The SAILS was significantly correlated with visuo-spatial, attention and visual memory tests (rs ranged from .50 to .88, p's<.05).It did not correlate significantly (p's>.05) with tests of verbal memory, degree of depression and praxis

Appendix B

DISABILITY ASSESSMENT FOR DEMENTIA (DAD)

Name:____________________________ File No____________________

Date:______________ MMS:_____ GDS:_______ DAD:__________

Respondant:________________________ Relationship:____________________

During the past four weeks, did (name)____________________,

	YES	NO
INITIATION		
1. Decide or ask to have a bath or shower	___	___
2. Dress alone or express the wish to dress	___	___
3. Take care of his/her hair (wash, comb) without prompting	___	___
4. Brush his/her teeth or care for his/her denture without prompting	___	___
5. Use the toilet by himself/herself without reminder	___	___
6. Express the desire to eat at appropriate times	___	___
7. Telephone someone by himself/herself	___	___
8. Decide to go shopping for something he/she needs	___	___
9. Decide to go out for a walk, a drive or to pay a visit	___	___
10. Decide he/she needs to go to the bank	___	___

INITIATION TOTAL ___ ON 10

	YES	NO
PLANNING AND ORGANIZATION		
11. Prepare the water, towels, and soap for his/her bath	___	___
12. Choose appropriate clothing (with regard to occasion, weather and color combination)	___	___
13. Dress himself/herself in the correct sequence (underwear, pant/dress, shoes)	___	___
14. Choose the appropriate utensils, or seasonings when eating	___	___
15. Eat his/her meal in the appropriate sequence (soup, main course, dessert)	___	___
16. Use the toilet at the appropriate moment/time	___	___
17. Adequately plan a meal/snack (ingredients, recipe, cookware)*	___	___
18. Plan a shopping trip effectively (means of transportation, money, shopping list, timing, required items)	___	___
19. Adequately organize an outing (means of transportation, timing, destination, weather conditions)	___	___
20. Prepare for a visit to the bank (timing, cheques, bankbook, bills)	___	___

PLANNING AND ORGANIZATION TOTAL ___ ON 10

	YES	NO
EFFECTIVE PERFORMANCE		
21. Completely wash and dry all parts of the body with safety	___	___
22. Completely dress and undress himself/herself	___	___
23. Properly put on a piece of clothing before putting on another	___	___
24. Eat most meals at a normal pace and with appropriate manners	___	___
25. Take care of all his/her bowel and bladder needs without "accidents"	___	___
26. Entirely prepare or cook a meal/snack *	___	___
27. Adequately hold and complete a telephone conversation	___	___
28. Return from shopping without missing items or money	___	___
29. Travel and reach a destination without losing his/her way	___	___
30. Successfully complete his/her banking transactions	___	___

EFFECTIVE PERFORMANCE TOTAL ___ ON 10

DISABILITY TOTAL ___ ON 30

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* If not applicable, score Yes

L. Gauthier, 1991.

EVALUATION DE L'INCAPACITE FONCTIONNELLE DANS LA DEMENCE (IFD)

NOM: ______________________ Numéro de dossier: ______________

Date: __________ M.1S: ______ GDS:______ IFD: ______

Répondant: ____________________ Degré de parenté ou autre: ______________

Au cours des quatres dernières semaines, est-ce que ____________________
nom

INITIATIVE

	OUI	NON
1. A décidé ou demandé à prendre un bain ou une douche?	___	___
2. S'est habillé/e seul/e ou en a exprimé le désir?	___	___
3. A pris soin de ses cheveux (laver, peigner) sans y être invité/e?	___	___
4. S'est brossé/e les dents ou a nettoyé sa prothèse dentaire sans y être invité/e?	___	___
5. Est allé/e aux toilettes seul/e, sans qu'on le lui rappelle?	___	___
6. A exprimé le désir de manger au moment approprié?	___	___
7. A, de lui-même/d'elle-même, téléphoné à quelqu'un?	___	___
8. A décidé d'aller magasiner pour se procurer une chose dont il/elle a besoin?	___	___
9. A décidé de sortir pour une randonnée à pied, en auto ou faire une visite?	___	___
10. A décidé qu'il/elle avait besoin d'aller à la banque?	___	___

INITIATIVE - TOTAL ___ SUR 10

PLANIFICATION ET ORGANISATION

	OUI	NON
11. A préparé l'eau, les serviettes, et le savon pour prendre son bain?	___	___
12. A choisi les vêtements appropriés (selon l'occasion, la température, l'agencement des couleurs)?	___	___
13. S'est habillé/e selon un ordre approprié (sous-vêtements, robe/pantalon, chaussures)?	___	___
14. A choisi les ustensiles ou assaisonnements appropriés en mangeant?	___	___
15. A mangé son repas selon un ordre approprié (soupe, entrée, dessert)?	___	___
16. Est allé/e aux toilettes au bon moment?	___	___
17. A correctement planifié un repas ou une collation (ingrédients, recette, ustensiles de cuisine)*?	___	___
18. S'est préparé/e à magasiner de façon efficace (mode de transport, argent, liste, heure, articles requis)?	___	___
19. A organisé une sortie adéquatement(mode de transport, heure, destination, température)?	___	___
20. S'est préparé/e à une visite à la banque (heure, chèques, carnet de banque, factures)?	___	___

PLANIFICATION ET ORGANISATION - TOTAL ___ SUR 10

ACTION EFFICACE

	OUI	NON
21. S'est lavé/e et séché/e complètement, toutes les parties du corps, en toute sécurité?	___	___
22. S'est habillé/e ou déshabillé/e complètement?	___	___
23. A endossé un vêtement de façon acceptable avant de commencer avec un autre?	___	___
24. A mangé ses repas à une vitesse normale et observé les bonnes manières?	___	___
25. A pris soin de tous ses besoins d'uriner et d'aller à la selle sans "accident"?	___	___
26. A entièrement préparé ou fait cuire un repas ou une collation?*	___	___
27. A tenu et complété adéquatement une conversation téléphonique?	___	___
28. Est revenu/e de magasiner sans qu'il lui manque des articles ou de l'argent?	___	___
29. Est sorti/e sans se perdre et s'est rendu/e à destination?	___	___
30. A complété ses opérations bancaires efficacement?	___	___

ACTION EFFICACE - TOTAL ___ SUR 10

INCAPACITE - TOTAL ___ SUR 30

* Si ne s'applique pas, indiquer Oui.

L. Gauthier, 1991.

Appendix C
CONTENT DEVELOPMENT OF THE DISABILITY ASSESSMENT FOR DEMENTIA (DAD)

Please read carefully the items listed on the Disability Assessment in Dementia before answering the following questions.

1. Would you agree that the total group of items assessed is reflective of the domains (ex. self-care or instrumental ADL) of functional disability in dementia ?

Strongly Agree ____ Agree ____ Disagree ____ Strongly Disagree ____ Unable to assess ____

Are there other domains that you feel are missing and should be added to the questionnaire?

____

____

2. Considering each item individually please answer the following questions with regard to appropriateness (suitability of using the item for the assessment of disability in dementia), importance (the ability of the item to detect a change in disability in persons with dementia i.e. improvement or deterioration) and frequency of occurrence (the number of times that the item is expected to take place in dementia).

EXAMPLE

Items	Is the item appropriate?		If yes, rate Importance VI=very imp. I=imp. NI=not imp.	Frequency VF=very freq. F=freq. NF=not freq.
During the past four weeks, did (name)__________	**YES**	**NO**	**Importance**	**Frequency**
1. Decide or ask to have a bath or shower	___	___	VI I NI	VF F NF

Items	Is the item appropriate?	If yes, rate

Importance	Frequency
VI=very imp.	VF=very freq.
I=imp.	F=freq.
NI=not imp.	NF=not freq.

During the past four weeks, did (name)__________

	YES	NO	Importance	Frequency
INITIATION				
1. Decide or ask to have a bath or shower	___	___	VI I NI	VF F NF
2. Dress alone or express the wish to dress	___	___	VI I NI	VF F NF
3. Take care of his/her hair (wash, comb) without prompting	___	___	VI I NI	VF F NF
4. Brush his/her teeth or care for his/her denture without prompting	___	___	VI I NI	VF F NF
5. Use the toilet by himself/herself without reminder	___	___	VI I NI	VF F NF
6. Express the desire to eat at appropriate times	___	___	VI I NI	VF F NF
7. Telephone someone by himself/herself	___	___	VI I NI	VF F NF
8. Decide to go shopping for something he/she needs	___	___	VI I NI	VF F NF
9. Decide to go out for a walk, a drive or to pay a visit	___	___	VI I NI	VF F NF
10. Decide he/she needs to go to the bank	___	___	VI I NI	VF F NF

Are there any comments you would like to make about the items?

____

____

____

Items	Is the item appropriate?		If yes, rate **Importance** VI=very imp. I=imp. NI=not imp.	**Frequency** VF=very freq. F=freq. NF=not freq.
During the past four weeks, did (name)__________	YES	NO	Importance	Frequency
PLANNING AND ORGANIZATION				
11. Prepare the water, towels, and soap for his/her bath	___	___	VI I NI	VF F NF
12. Choose appropriate clothing (with regard to occasion, weather, and color combination)	___	___	VI I NI	VF F NF
13. Dress himself/herself in the correct sequence(underwear, pant/dress, shoes)	___	___	VI I NI	VF F NF
14. Choose the appropriate utensils, or seasonings when eating	___	___	VI I NI	VF F NF
15. Eat his/her meal in the appropriate sequence (soup, main course, dessert)	___	___	VI I NI	VF F NF
16. Use the toilet at the appropriate moment/time	___	___	VI I NI	VF F NF
17. Adequately plan a meal/snack (ingredients, recipe, cookware)*	___	___	VI I NI	VF F NF
18. Plan a shopping trip effectively (means of transportation, money, shopping list, timing, required items)	___	___	VI I NI	VF F NF
19. Adequately organize an outing (means of transportation ,timing, destination, weather conditions)	___	___	VI I NI	VF F NF
20. Prepare for a visit to the bank (timing, cheques, bankbook, bills)	___	___	VI I NI	VF F NF

Are there any comments you would like to make about the items?

____

____

Items	Is the item appropriate?		If yes, rate	
			<u>Importance</u> VI=very imp. I=imp. NI=not imp.	<u>Frequency</u> VF=very freq. F=freq. NF=not freq.
During the past four weeks, did (name)__________				
	YES	NO	Importance	Frequency
EFFECTIVE PERFORMANCE				
21. Completely wash and dry all parts of the body with safety	___	___	VI I NI	VF F NF
22. Completely dress and undress himself/herself	___	___	VI I NI	VF F NF
23. Properly put on a piece of clothing before putting on another	___	___	VI I NI	VF F NF
24. Eat most meals at a normal pace and with appropriate manners	___	___	VI I NI	VF F NF
25. Take care of all his/her bowel and bladder needs without "accidents"	___	___	VI I NI	VF F NF
26. Entirely prepare or cook a meal/snack *	___	___	VI I NI	VF F NF
27. Adequately hold and complete a telephone conversation	___	___	VI I NI	VF F NF
28. Return from shopping without missing items or money	___	___	VI I NI	VF F NF
29. Travel and reach a destination without losing his/her way	___	___	VI I NI	VF F NF
30. Successfully complete his/her banking transactions	___	___	VI I NI	VF F NF

Are there any comments you would like to make about the items?

____

____

____

3. Are there other items that you feel are missing and should be added to the questionnaire?
Could you rate them in terms of their importance and frequency of occurence as you have done in the previous section?

____

____

____

____

____

4. Is the arrangement of items according to executive functions (ability to initiate, plan, organize or complete an activity) useful?
Yes ____ No ____ Unable to assess ____
If not, what other format would you prefer?

____

____

____

____

5. Do you agree with the scaling format used (Yes/No)?
Yes ____ No ____ Unable to assess ____
If not, which scaling format would you suggest ?

____

____

____

6. Would you agree that this assessment will show differences in functional disability between a group of healthy subjects and another with dementia of the Alzheimer's type?

Strongly Agree ____ Agree ____ Disagree ____ Strongly Disagree ____ Unable to assess ____

7. Would you agree that this assessment will show differences in functional disability between individuals with a dementia of the Alzheimer's type who are at different stages of the disease (early vs later stages)?

Strongly Agree ____ Agree ____ Disagree ____ Strongly Disagree ____ Unable to assess ____

8. Are there any other comments you would like to make?

____

____

____

____

9. Please indicate your profession:

____

______________________ ______________________
Signature Date

Thank you for your collaboration and time.
Please return this questionnaire in the self-addressed envelope.

Appendix C (Continued)

DEVELOPPEMENT DU CONTENU DE "L'EVALUATION DE L'INCAPACITE FONCTIONNELLE DANS LA DEMENCE"

Nous vous prions de lire attentivement les éléments de "l'Evaluation de l'Incapacité Fonctionnelle dans la Démence" avant de répondre aux questions suivantes.

1. Etes-vous d'accord que l'ensemble des éléments évaluées sont représentatifs des domaines (activités de base ou instrumentales) de l'incapacité fonctionnelle dans la démence?

Fortement en accord ____ En accord ____ En désaccord ____ Fortement en désaccord ____ Incapable de répondre ____

Y-a-t-il d'autres domaines que vous jugez manquants et qui devraient être ajoutés au questionnaire?

____

____

2. Considérant chaque élément individuellement, nous vous prions de répondre aux questions suivantes en ce qui concerne leur pertinence (la convenance d'utiliser l'élément pour évaluer l'incapacité fonctionnelle dans la démence), importance (l'habileté de l'élément à déceler un changement dans le statut fonctionnel chez un individu atteint de démence i.e. amélioration ou détérioration) et fréquence (le nombre de fois que l'élément peut se manifester chez des individus atteints de démence).

EXEMPLE

Eléments	L'élément est-il pertinent?		Si oui, évaluez	
			Importance TI= très imp. I= imp. PI= peu imp.	**Fréquence** TF= très fréq. F= fréq. PF= peu fréq.
Au cours des quatres dernières semaines, est-ce que (nom)________________				
	OUI	NON	Importance	Fréquence
1. A décidé ou demandé à prendre un bain ou une douche	___	___	TI I PI	TF F PF

Eléments

L'élément est-il pertinent?

Si oui, évaluez

Importance
TI= très imp.
I= imp.
PI= peu imp.

Fréquence
TF= très fréq.
F= fréq.
PF= peu fréq.

Au cours des quatres dernières semaines, est-ce que (nom)__________________

	OUI	NON	Importance	Fréquence
INITIATIVE				
1. A décidé ou demandé à prendre un bain ou une douche	___	___	TI I PI	TF F PF
2. S'est habillé/e seule/e et de façon appropriée, ou en a exprimé le désir	___	___	TI I PI	TF F PF
3. A pris soin de ses cheveux (laver, peigner) sans y être invité/e	___	___	TI I PI	TF F PF
4. S'est brossé/e les dents ou a nettoyé sa prothèse dentaire sans y être invité/e	___	___	TI I PI	TF F PF
5. Est allé/e aux toilettes seul/e, sans qu'on le lui rappelle	___	___	TI I PI	TF F PF
6. A exprimé le désir de manger au moment approprié	___	___	TI I PI	TF F PF
7. A, de lui-même/d'elle-même, téléphoné à quelqu'un	___	___	TI I PI	TF F PF
8. A décidé d'aller magasiner pour se procurer une chose dont il/elle a besoin	___	___	TI I PI	TF F PF
9. A décidé de sortir pour une randonnée à pied, en auto ou faire une visite	___	___	TI I PI	TF F PF
10. A décidé qu'il/elle avait besoin d'aller à la banque	___	___	TI I PI	TF F PF

Y-a-t-il d'autres commentaires que vous voudriez faire à propos des habiletés énumérées ci-haut?

____

____

____

Eléments	**L'élément est-il pertinent?**		**Si oui, évaluez**	
			Importance **TI= très imp.** **I= imp.** **PI= peu imp.**	**Fréquence** **TF= très fréq.** **F= fréq.** **PF= peu fréq.**
Au cours des quatres dernières semaines, est-ce que (nom)________________	**OUI**	**NON**	**Importance**	**Fréquence**
PLANIFICATION ET ORGANISATION				
11. A préparé l'eau, les serviettes, le savon pour prendre son bain	___	___	TI I PI	TF F PF
12. A choisi les vêtements appropriés (selon l'occasion, la température, l'agencement des couleurs)	___	___	TI I PI	TF F PF
13. S'est habillé/e selon un ordre approprié (sous-vêtments, robe/pantalon, chaussures)	___	___	TI I PI	TF F PF
14. A choisi les ustensiles ou assaisonnements appropriés en mangeant	___	___	TI I PI	TF F PF
15. A mangé son repas selon un ordre approprié (soupe, entrée, dessert)	___	___	TI I PI	TF F PF
16. Est allé/e aux toilettes au bon moment	___	___	TI I PI	TF F PF
17. A correctement planifié un repas ou une collation (ingrédients, recette, ustensiles de cuisine)	___	___	TI I PI	TF F PF
18. S'est préparé/e à magasiner de façon efficace (mode de transport, argent, liste, heure, articles requis)	___	___	TI I PI	TF F PF
19. A organisé une sortie adéquatement (mode de transport, heure, destination, température)	___	___	TI I PI	TF F PF
20. S'est préparé/e à une visite à la banque (heure de dépôt, carnet de banque, factures)	___	___	TI I PI	TF F PF

Y-a-t-il d'autres commentaires que vous voudriez faire à propos des habiletés énumérées ci-haut?

____

____

Eléments	**L'élément est-il pertinent?**	**Si oui, évaluez**	
		Importance **TI= très imp.** **I= imp.** **PI= peu imp.**	**Fréquence** **TF= très fréq.** **F= fréq.** **PF= peu fréq.**

Au cours des quatres dernières semaines, est-ce que (nom)__________________

ACTION EFFICACE	**OUI**	**NON**	**Importance**	**Fréquence**
21. S'est lavé/e et séché/e complètement, toutes les parties du corps, en toute sécurité	___	___	TI I PI	TF F PF
22. S'est habillé/e ou déshabillé/e complètement	___	___	TI I PI	TF F PF
23. A endossé un vêtement de façon acceptable avant de commencer avec un autre	___	___	TI I PI	TF F PF
24. A mangé ses repas à une vitesse normale et observé les bonnes manières	___	___	TI I PI	TF F PF
25. A pris soin de tous ses besoins d'uriner et d'aller à la selle sans "accident"	___	___	TI I PI	TF F PF
26. A entièrement préparé ou fait cuire un repas ou une collation	___	___	TI I PI	TF F PF
27. A tenu adéquatement une conversation téléphonique	___	___	TI I PI	TF F PF
28. Est revenu/e de magasiner sans qu'il lui manque des articles ou de l'argent	___	___	TI I PI	TF F PF
29. Est sorti/e sans se perdre et s'est rendu/e à destination	___	___	TI I PI	TF F PF
30. A complété ses opérations bancaires efficacement	___	___	TI I PI	TF F PF

Y-a-t-il d'autres commentaires que vous voudriez faire à propos des habiletés énumérées ci-haut?

____

____

____

3. Y-a-t-il d'autres éléments que vous jugez manquants et qui devraient être ajoutés au questionnaire?
Pouvez-vous les coter en fonction de leur importance et fréquence comme vous l'avez fait dans la section précédente?

4. Trouvez-vous la classification des éléments selon les fonctions exécutives (capacité d'initier, de planifier, d'organiser ou de compléter une activité) utile?
Oui ____ Non ____ Incapable de répondre ____
Si non, quel autre type de classification préfériez-vous?

5. Etes-vous en accord avec l'échelle de cotation utilisée(Oui/Non)?
Oui ____ Non ____ Incapable de répondre ____
Si non, quel autre échelle de cotation suggeriez-vous?

6. Etes-vous d'accord que cette évaluation montrera des différences dans les capacités fonctionnelles entre un groupe de sujets en santé et un groupe de sujets ayant une démence de type Alzheimer?

Fortement en accord ____ En accord ____ En désaccord ____ Fortement en désaccord ____ Incapable de répondre ____

7. Etes-vous d'accord que cette évaluation montrera des différences dans les capacités fonctionnelles entre des groupe de sujets ayant une démence de type Alzheimer qui se situent à différents stades de la maladie (stades initiaux vs stades avancés)?

Fortement en accord ____ En accord ____ En désaccord ____ Fortement en désaccord ____ Incapable de répondre ____

8. Commentaires additionnels.

____

____

____

____

9. Veuillez s'il-vous-plait indiquer votre profession:

____

____________________ Signature

____________________ Date

Nous tenons à vous remercier pour votre collaboration.
Veuillez s'il-vous-plait retourner ce questionnaire dans l'enveloppe pré-adressée.

Appendix D

DISABILITY ASSESSMENT FOR DEMENTIA (DAD)

Name:________________________ File No__________

Date:__________ MMS:______ GDS:______ DAD:______

Respondent:________________ Relationship:______________

Specify all motor and sensory disorders: ______________________

SCORING: YES=1 NO=0

During the past four weeks, did (name)__________,

	Initiation	Planning & Organization	Effective Performance
HYGIENE			
. Decide to have a bath or shower	☐		
. Prepare the water, towels, and soap for taking a bath or shower		☐	
. Completely wash and dry all parts of his/her body with safety			☐
DRESSING			
. Decide to dress himself/herself	☐		
. Choose appropriate clothing (with regard to occasion, cleanliness, weather and color combination)		☐	
. Dress himself/herself in the correct sequence (underwear, pant/dress, shoes)		☐	
. Completely dress and undress himself/herself			☐
CONTINENCE			
. Use the toilet by himself/herself without reminder	☐		
. Attend to his/her bowel and bladder needs without "accidents"			☐
EATING			
. Express the desire to eat	☐		
. Choose appropriate utensils, or seasonings while eating		☐	
. Eat his/her meal in the appropriate sequence (soup, main course, dessert)		☐	
. Eat most meals at a normal pace and with appropriate manners			☐
MEAL PREPARATION			
. Decide to prepare a light meal/snack	☐		
. Adequately plan a light meal/snack (ingredients, recipe, cookware)		☐	
. Prepare or cook an entire light meal/snack with safety			☐
TELEPHONING			
. Decide to telephone someone	☐		
. Adequately find and dial the telephone number		☐	
. Adequately hold and complete a telephone conversation			☐
. Adequately take a telephone message			☐
SHOPPING			
. Decide to go shopping for something he/she needs	☐		
. Plan a shopping trip effectively (means of transportation, money, shopping list, keys, required items)		☐	
. Return from shopping without missing articles or money			☐
GOING ON AN OUTING			
. Decide to go out for a walk	☐		
. Adequately organize an outing (means of transportation, keys, destination, weather conditions)		☐	
. Travel and reach a destination without losing his/her way			☐
FINANCE			
. Show an interest in his/her personal affairs such as his/her finance and correspondence	☐		
. Organize his/her finance to pay his/her bills (cheques, bankbook, bills)		☐	
. Adequately complete his/her financial transactions			☐
MEDICATIONS			
. Decide to take his/her medications	☐		
LEISURE AND HOUSEWORK			
. Show an interest in leisure activity (ies), friend (s) or housework	☐		
. Participate effectively in leisure and social activities such as hobbies, reading, watching T.V. or group activities.			☐
. Adequately plan and organize housework		☐	
. Adequately complete housework			☐
. Plan the above activities at the appropriate moment/time		☐	
. Stay at home by himself/herself safely*			☐
TOTAL	/11	/12	/13
DISABILITY TOTAL	/36		

---

* If not applicable, score Yes

L. Gauthier & I. Gélinas. 1992.

Appendix D (Continued)

EVALUATION DE L'INCAPACITÉ FONCTIONNELLE DANS LA DÉMENCE (IFD)

Nom:____________________ No. de dossier__________

Date:__________ MMS:______ GDS:______ IFD:________

Répondant:________________ Degré de parenté ou autre:____________

Préciser tout désordre du système moteur ou sensitif: ____________________

____

COTATION: OUI=1 NON=0

Au cours des quatres dernières semaines, est-ce que (nom)________,

	Initiative	Planification & Organisation	Action Efficace
HYGIÈNE			
.A décidé de prendre un bain ou une douche	☐	■	■
.A préparé l'eau, les serviettes, le savon pour prendre son bain ou sa douche	■	☐	■
.S'est lavé/e et séché/e complètment, toutes les parties du corps, en toute sécurité	■	■	☐
HABILLAGE			
.A décidé de s'habiller	☐	■	■
.A choisi des vêtements appropriés (selon l'occasion, la météo, la propreté, l'agencement des couleurs)	■	☐	■
.S'est habillé/e dans l'ordre approprié (sous-vêtements, robe/pantalon, chaussures*)	■	☐	■
.S'est habillé/e et déshabillé/e complètment	■	■	☐
CONTINENCE			
.A utilisé les toilettes seul/e, sans qu'on le lui rappelle	☐	■	■
.A vu à tous les besoins de sa vessie et ses intestins sans "accidents"	■	■	☐
ALIMENTATION			
.A exprimé le désir de manger	☐	■	■
.A choisi les ustensiles ou assaisonnements appropriés en mangeant	■	☐	■
.A mangé son repas dans l'ordre approprié (soupe, plat principal, dessert)	■	☐	■
.A mangé la plupart de ses repas à une vitesse normale et observé les bonnes manières	■	■	☐
PRÉPARATION DE REPAS			
.A décidé de préparer un repas léger ou une collation	☐	■	■
.A correctement planifié un repas léger ou une collation (ingrédients, recette, ustensiles de cuisine)	■	☐	■
.A entièrement préparé ou fait cuire un repas léger ou une collation, en toute sécurité	■	■	☐
UTILISATION DU TÉLÉPHONE			
.A décidé de téléphoner à quelqu'un	☐	■	■
.A correctement trouvé et composé un numéro de téléphone	■	☐	■
.A tenu et complété adéquatement une conversation téléphonique	■	■	☐
.A noté un message téléphonique de façon adéquate	■	■	☐
MAGASINAGE			
.A décidé d'aller magasiner pour se procurer un chose dont il/elle a besoin	☐	■	■
.A planifié son magasinage de façon efficace (mode de transport, argent, liste, clefs, articles requis)	■	☐	■
.Est revenu/e de magasiner sans qu'il lui manque des articles ou de l'argent	■	■	☐
DÉPLACEMENTS À L'EXTÉRIEUR			
.A décidé de sortir faire une promenade	☐	■	■
.A organisé une sortie adéquatement (mode de transport, clefs, destination, météo)	■	☐	■
.Est sorti/e sans se perdre et s'est rendu/e à destination	■	■	☐
FINANCES			
.A démontré de l'intérêt pour ses affaires personnelles, telles que ses finances et sa correspondance	☐	■	■
.A bien organisé ses finances afin de payer ses factures (chèques, carnet de banque, factures)	■	☐	■
.A complété adéquatement ses opérations financières	■	■	☐
MÉDICATION			
.A décidé de prendre ses médicaments	☐	■	■
LOISIRS ET ENTRETIEN DOMESTIQUE			
.A démontré de l'intérêt pour un passe-temps, un/e ami/e ou le travail domestique	☐	■	■
.A bien participé à des activités de loisirs ou sociales telles que: passe-temps, lecture, regarder la T.V., ou activités de groupe	■	■	☐
.A planifié et organisé adéquatement des tâches domestiques	■	☐	■
.A complété adéquatement des tâches ménagères	■	■	☐
.A planifié les activités précitées à l'heure et au moment appropriés	■	☐	■
.Est demeuré/e seul/e à la maison en toute sécurité	■	■	☐
TOTAL	/11	/12	/13
INCAPACITÉ-TOTAL	/36		

* Si ne s'applique pas, indiquer Oui

L. Gauthier & I. Gélinas, 1992.

Appendix E

McGill University
School of Physical and Occupational Therapy

CONSENT FORM

I have been informed that this is a research study undertaken by L. Gauthier, S. Wood-Dauphinee and S. Gauthier. I have also been informed that the purpose of this study is to develop an assessment of activities of daily living performance.

I understand that my primary caregiver (spouse, next of kin, friend) will complete a questionnaire concerning my functional abilities I have been told that no foreseeable risks are involved for me or my caregiver in this research study.

I realize that although the results from the study will be published, my identity will be held in confidence. I am aware that my participation in this study is on a volunteer basis and that I will not be paid.

I understand that I may withdraw from the study at any time without prejudice to my treatment.

____________________ ________________
Signature of Volunteer Date

I ____________________ caregiver of Mrs/Mr ________________
agree to answer a questionnaire.

____________________ ________________
Signature of Caregiver Date

I have explained to ____________________ the procedures of the study and I have informed him/her that he/she may withdraw from the study at any time.

____________________ ________________
Signature of Evaluator Date
(TEL: 398-4500)
or 398-4511

Appendix E (Continued)

McGill University
School of Physical and Occupational Therapy

FORMULE DE CONSENTEMENT

J'ai été informé(e) que cette étude est un projet de recherche accompli par L. Gauthier, S. Wood-Dauphinee et S. Gauthier. De plus, on m'a informé que le but de cette étude est de développer une évaluation des habiletés dans les activités de la vie de tous les jours.

Je comprend que mon accompagnateur (conjoint, parent, ami) complétera un questionnaire concernant mes habiletés fonctionnelles dans la vie de tous les jours. On m'a expliqué qu'il n'y a aucun risque pour moi ou mon accompagnateur prévisible au cours de cette étude.

On m'a dit que toutes les informations obtenues demeuront confidentielles.

Je réalise que ma participation à cette étude est volontaire et que je ne serai pas payé(e).

Je comprends que je peux retirer mon consentement et me retirer de l'étude en tout temps sans aucun préjudice envers mes autres traitements.

Signature du volontaire	Date

Je ____________________ accompagnateur de Mme/M.______________ accepte de répondre à un questionnaire.

Signature de l'accompagnateur	Date

J'ai expliqué à ________________________ les diverses procédures de l'étude et je l'ai informé qu'il/elle peut se retirer de l'étude en tout temps.

Signature de l'examinateur (TEL: 398-4500) ou 398-4511	Date

Appendix F

General Information: Subject

Date of interview ____/____/____ File # __________

Last Name ________________________ First Name ________________________

Gender: Male ___ Female ___

Address ____
Street Apt. City Province

Telephone number ________________________

Date of birth ____/____/____ Age ____ (years)

Marital status Single ___ Married ___ Common Law ___ Divorced ___ Widowed ___

Languages spoken and written English ___ French ___ Other __________

Education level Primary ___ Secondary ___ Post-secondary ___ (years)

Does Subject Wear Corrective Lenses ____ Does Subject Wear Hearing Aid ____

Past Medical history ____

____

Date of first diagnosis of DAT ____/____/____ Duration of DAT ___________

Current Medication ____________________ Stage of GDS ___________

Name of Referring Neurologist or Institution ____

==

MMSE Score ________

DAD Score ________ DAD Scoring Time ________

Inter-rater Score DAD ________ Intra-rater Score DAD ________

RDRS.2 Score _____________ Burden of Care Score ________

Appendix F (Continued)

General Information: Primary Caregiver

Date of interview ___/___/___ File # ________

Last name ____________________ First name _______________

Relationship to the subject __________ Gender: Male ___ Female ___

Address ____
Street Apt. City Province

Number of Persons Living at the Above Adddress _____

Telephone number __________________

Date of birth ___/___/___ Age ___ (years)

Marital status Single ___ Married ___ Common Law ___ Divorced ___ Widowed ___

Languages spoken and written English ___ French ___ Other ________

Education level Primary ___ Secondary ___ Post-secondary ___ (years)

Corrective lenses required Yes ___ No ___

Outside help required Yes ___ No ___

Hours of outside help required Daily ___ Weekly ___

Type of outside help required by another relative ___ Other (Specify) ___

Is payment required for outside help Yes ___ No ___

Amount of caregiver contact with the subject ___ (hrs/day) ___ (hrs/week)

Does the subject participate in community programmes Yes ___ No ___

If Yes: Type of involvement _____________ Frequency ____ (hrs/week)

Is caregiver currently employed Yes ___ No ___
If yes, Fulltime ___ Part time ___ Casual ___

Does caregiver have any health problems? Yes ___ No ___ Type ___

Appendix F (Continued)

Information Générale: Sujet

Date de l'entrevue ____/____/____ # Dossier:__________

Nom de famille ____________________ Prénom ____________________

Sexe: Masculin ___ Féminin ___

Adresse ____

Rue Apt. Ville Province

Numéro de téléphone ____________________

Date de naissance ____/____/____ Age ____ (années)

Statut civil Célibataire ___ Marié(e) ___ Union libre ___ Divorcé(e) ___

Langue parlée et écrite Anglais ___ Francais ___ Autre __________

Niveau d'éducation Primaire ___ Secondaire ___ Post-secondaire ___ (années)

Est-ce que le sujet porte des lunettes ____ Est-ce que le sujet porte un appareille auditif ____

Histoire médicale passée ____

Date du premier diagnotic de la MA ____/____/____ Durée de la MA __________

Médication courante ____________________ Stage du GDS __________

Nom du Neurologue ou institution ______________________________

==

MMSE Score ________

DAD Score ________ DAD Scoring Time ________

Inter-rater Score DAD ________ Intra-rater Score DAD ________

RDRS.2 Score ____________ Burden of Care Score ________

Appendix F (Continued)

Information Générale: Donneur de soins principal

Date de l'entrevue ____/____/____ # Dossier __________

Nom de famille _________________________ Prénom _______________________

Relation avec le sujet ______________ Sexe: Masculin ____ Féminin ____

Adresse ____
Rue Apt. Ville Province

Nombre de Personnes vivant à l'adresse ______

Numéro de téléphone ________________________

Date de naissance ____/____/____ Age ____ (années)

Statut civil Célibataire ___ Marié(e) ___ Union libre ___ Divorcé(e) ___

Langue parlée et écrite Anglais ___ Francais ___ Autre __________

Niveau d'éducation Primaire ___ Secondaire ___ Post-secondaire ___ (années)

Verres correcteurs / lunettes nécessaires Oui ___ Non ___

Une aide extérieure est-elle nécessaire Oui ___ Non ___

Heures d'aide supplémentaire requise Quotidienne ____ Hebdomadaire ____

Type d'aide supplémentaire requise Par un membre de la famille ___ Autre (indiquer) ________

Paiement requis pour l'aide supplémentaire Oui ___ Non ___

Contact avec le sujet (par le donneur de soins) ____ (hrs/jour) ____ (hrs/semaine)

Est-ce que le sujet participe à un programme communautaire Oui ___ Non ___

Si oui, Type de participation _____________________ Fréquence ____ (hrs/semaine)

Est-ce que vous êtes couramment employé(e) Oui ___ Non ___
Si oui, À plein temps ___ Temps partiel ___ À l'occasion ___

Est-ce que vous avez des problèmes de santé Oui ___ Non ___ Type ___________

Appendix G

CONTENT VALIDATION OF THE DISABILITY ASSESSMENT FOR DEMENTIA (DAD)

Please read carefully the items listed on the Disability Assessment for Dementia before answering the following questions.

1. Does the total group of items assessed adequately cover the domains (self-care or instrumental ADL) of functional disability in community residing individuals with dementia ?

Yes ____ No ____ Unable to assess ____

2. Is the assessment of functional disability according to executive functions (ability to initiate, plan, organize or complete an activity) appropriate and useful for use in a population with dementia?

Yes ____ No ____ Unable to assess ____

If not, what other format would you prefer?

____

____

3. Considering each item individually please answer the following questions with regard to the **importance** of including the item in the instrument to detect a change in disability i.e. improvement or deterioration, the **clarity** and the **completeness** of the item.

EXAMPLE

Items	**Is the item important?**		**Is the item clear and complete?**		**Comments**
During the past four weeks, did (name)___________	**YES**	**NO**	**YES**	**NO**	
1. Decide to have a bath or shower	_X_	___	_X_	___	

Items	Is the item important?		Is the item clear and complete?		Comments
During the past four weeks, did (name)__________	**YES**	**NO**	**YES**	**NO**	
INITIATION Decide to have a bath or shower	___	___	___	___	
Decide to dress himself/herself	___	___	___	___	
Use the toilet by himself/herself without reminder	___	___	___	___	
Express the desire to eat	___	___	___	___	
Decide to prepare a light meal/snack	___	___	___	___	
Decide to telephone someone	___	___	___	___	
Decide to go shopping for something he/she needs	___	___	___	___	
Decide to go out for a walk	___	___	___	___	
Show an interest in his/her personal affairs such as his/her finance or correspondence	___	___	___	___	
Decide to take his/her medications	___	___	___	___	
Show an interest in leisure activity(ies), friend(s), or housework	___	___	___	___	
PLANNING AND ORGANIZATION Prepare the water, towels, and soap for taking a bath or shower	___	___	___	___	
Choose appropriate clothing (with regard to occasion, cleanliness, weather, and color combination)	___	___	___	___	
Dress himself/herself in the correct sequence(underwear, pant/dress, shoes)	___	___	___	___	
Choose the appropriate utensils, or seasonings while eating	___	___	___	___	

Items	**Is the item important?**		**Is the item clear and complete?**		**Comments**
During the past four weeks, did (name)___________	**YES**	**NO**	**YES**	**NO**	
PLANNING AND ORGANIZATION					
Eat his/her meal in the appropriate sequence (soup, main course, dessert)	___	___	___	___	
Adequately plan a light meal/snack (ingredients, recipe, cookware)	___	___	___	___	
Adequately find and dial a telephone number	___	___	___	___	
Plan a shopping trip effectively (means of transportation, money, shopping list, keys, required items)	___	___	___	___	
Adequately organize an outing (means of transportation ,keys, destination, weather conditions)	___	___	___	___	
Organize his/her finance to pay his/her bills (cheques, bankbook, bills)	___	___	___	___	
Adequately plan and organize housework	___	___	___	___	
Plan the above activities at the appropriate moment/time	___	___	___	___	
EFFECTIVE PERFORMANCE					
Completely wash and dry all parts of his/her body with safety	___	___	___	___	
Completely dress and undress himself/herself	___	___	___	___	
Attend to his/her bowel and bladder needs without "accidents"	___	___	___	___	
Eat most meals at a normal pace and with appropriate manners	___	___	___	___	
Prepare or cook a entire light meal/snack with safety	___	___	___	___	
Adequately hold and complete a telephone conversation	___	___	___	___	
Adequately take a telephone message	___	___	___	___	

Items	Is the item important?		Is the item clear and complete?		Comments
	YES	NO	YES	NO	
During the past four weeks, did (name)__________					
EFFECTIVE PERFORMANCE					
Return from shopping without missing articles or money	___	___	___	___	
Travel and reach a destination without losing his/her way	___	___	___	___	
Adequately complete his/her financial transactions	___	___	___	___	
Take his/her medications as prescribed	___	___	___	___	
Participate effectively in leisure and social activities such as hobbies, reading, watching T.V. or group activities	___	___	___	___	
Adequately complete housework	___	___	___	___	
Stay at home by himself/herself safely	___	___	___	___	

4. Are there important items missing in the questionnaire?
Yes ____ No ____ Unable to assess ____
If yes, which items would you add ?

5. Is the scaling format used (Yes/No) appropriate?
Yes ____ No ____ Unable to assess ____
If not, which scaling format would you suggest ?

____

____

____

6. Is the use of a report from a significant informant an appropriate method for the assessment of functional disability in a population with dementia?
Yes ____ No ____ Unable to assess ____
If not, which method would you suggest ?

____

____

____

7. Would you agree that this assessment will show differences in functional disability between a group of healthy subjects and another with dementia of the Alzheimer's type?

Strongly Agree ____ Agree ____ Disagree ____ Strongly Disagree ____ Unable to assess ____

8. Would you agree that this assessment will show differences in functional disability between individuals with a dementia of the Alzheimer's type who are at different stages of the disease (early vs later stages)?

Strongly Agree ____ Agree ____ Disagree ____ Strongly Disagree ____ Unable to assess ____

9. Are there any other comments you would like to make?

____

____

____

____

10. Please indicate your profession:

____

____________________ Signature

____________________ Date

Thank you for your collaboration and time.
Please bring this questionnaire to the meeting on July 24, 1992 at the school of Physical and Occupational Therapy, McGill University (Davis House, 3654 Drummond St), Room 2, 3:00 PM.

Appendix H

DISABILITY ASSESSMENT FOR DEMENTIA (DAD)

Name:____________________ File No__________

Date:________ MMS:______ GDS:______ DAD:______

Respondent:________________ Relationship:________________

Specify all motor and sensory disorders: __________________________

SCORING: YES=1 NO=0 Not Applicable=N/A

During the past two weeks, did (name)__________, without help or reminder

	Initiation	Planning & Organization	Effective
HYGIENE			
. Undertake to wash himself/herself or to take a bath or a shower	☐	■	■
. Undertake to brush his/her teeth or care for his/her dentures	☐	■	■
. Decide to care for his/her hair (wash and comb)	☐	■	■
. Prepare the water, towels, and soap for washing,taking a bath or a shower	■	☐	■
. Wash and dry completely all parts of his/her body safely	■	■	☐
. Brush his/her teeth or care for his/her dentures appropriately	■	■	☐
. Care for his/her hair (wash and comb)	■	■	☐
DRESSING			
. Undertake to dress himself/herself	☐	■	■
. Choose appropriate clothing (with regard to the occasion, neatness, the weather and color combination)	■	☐	■
. Dress himself/herself in the appropriate order (undergarments, pant/dress, shoes)	■	☐	■
. Dress himself/herself completely	■	■	☐
UNDRESSING			
. Undertake to undress himself/herself	☐	■	■
. Undress himself/herself completely	■	■	☐
CONTINENCE			
. Decide to use the toilet at appropriate times	☐	■	■
. Use the toilet without "accidents"	■	■	☐
EATING			
. Decide that he/she needs to eat	☐	■	■
. Choose appropriate utensils and seasonings when eating	■	☐	■
. Eat his/her meal in the appropriate sequence	■	☐	■
. Eat his/her meals at a normal pace and with appropriate manners	■	■	☐
MEAL PREPARATION			
. Undertake to prepare a light meal or snack for himself/herself	☐	■	■
. Adequately plan a light meal or snack (ingredients, cookware)	■	☐	■
. Prepare or cook a light meal or a snack safely	■	■	☐
TELEPHONING			
. Attempt to telephone someone at a suitable time	☐	■	■
. Find and dial a telephone number correctly	■	☐	■
. Carry out an appropriate telephone conversation	■	■	☐
. Write and convey a telephone message adequately	■	■	☐

SCORING: YES=1 NO=0 Not Applicable=N/A

During the past two weeks, did (name)_______________, without help or reminder

	Initiation	Planning & Organization	Effective Performa
GOING ON AN OUTING			
. Undertake to go out (walk, visit, shop) at an appropriate time		■	■
. Decide to use a mode of transportation (car, bus, taxi)		■	■
. Adequately organize an outing with respect to transportation, keys, destination, weather, necessary money, shopping list	■		■
. Go out and reach a familiar destination without getting lost	■	■	
. Go out and reach a non-familiar destination without getting lost	■	■	
. Safely take the adequate mode of transportation (car, bus, taxi)	■	■	
. Return from the store with the appropriate items	■	■	
FINANCE & CORRESPONDENCE			
. Show an interest in his/her personal affairs such as his/her finances and written correspondence		■	■
. Organize his/her finance to pay his/her bills (cheques, bankbook, bills)	■		■
. Adequately organize his/her correspondence with respect to stationery, address, stamps	■		■
. Handle adequately his/her money (make change)	■	■	
. Complete his/her financial transactions adequately	■	■	
. Answer his/her correspondence adequately	■	■	
MEDICATIONS			
. Decide to take his/her medications at the correct time		■	■
. Take his/her medications as prescribed (according to the right dosage)	■	■	
LEISURE AND HOUSEWORK			
. Show an interest in leisure activity (ies)		■	■
. Take an interest in household chores that he/she used to perform in the past		■	■
. Plan and organize adequately household chores that he/she used to perform in the past	■		■
. Complete household chores adequately as he/she used to perform in the past	■	■	
. Stay safely at home by himself/herself	■	■	
TOTAL	/15	/11	/20
DAD TOTAL	/46		

TIME: ____________

RATER: ________________________

EVALUATION DE L'INCAPACITÉ FONCTIONNELLE DANS LA DÉMENCE (IFD)

Nom:______________________ No. de dossier______________

Date:__________ MMS:________ GDS:________ IFD:__________

Répondant:__________________ Degré de parenté ou autre:______________

Préciser tout désordre du système moteur ou sensitif: ______________________

____

COTATION: OUI=1 NON=0 Non Applicable=N/A

Au cours des deux dernières semaines, est-ce que (nom)__________,sans aide ou rappel,

	Initiative	Planification& Organisation	Action Effi
HYGIÈNE			
.A entrepris de se laver ou de prendre un bain ou une douche	☐	■	■
.A entrepris de se brosser les dents ou de nettoyer sa prothèse dentaire	☐	■	■
.A décidé de prendre soin de ses cheveux (laver et peigner)	☐	■	■
.A préparé l'eau, les serviettes, le savon pour se laver ou prendre un bain ou une douche	■	☐	■
.S'est lavé/e et séché/e complètement, toutes les parties du corps, de façon sécuritaire	■	■	☐
.S'est brossé/e les dents ou a nettoyé sa prothèse dentaire adéquatement	■	■	☐
.A pris soin de ses cheveux (laver et peigner)	■	■	☐
HABILLAGE			
.A entrepris de s'habiller	☐	■	■
.A choisi des vêtements appropriés (selon l'occasion, la météo,l'état de propreté et l'agencement des couleurs)	■	☐	■
.S'est habillé/e dans l'ordre approprié(sous-vêtments,robe/pantalon, chaussures)	■	☐	■
.S'est habillé/e complètement	■	■	☐
DÉSHABILLAGE			
.A entrepris de se déshabiller	☐	■	■
.S'est déshabillé/e complètement	■	■	☐
CONTINENCE			
.A décidé d'utiliser les toilettes au moment opportun	☐	■	■
.A utilisé les toilettes sans "accidents"	■	■	☐
ALIMENTATION			
.A décidé qu'il/elle avait besoin de manger	☐	■	■
.A choisi les ustensiles ou assaisonnements appropriés en mangeant	■	☐	■
.A mangé son repas dans l'ordre approprié	■	☐	■
.A mangé ses repas à une vitesse normale et observé les bonnes manières	■	■	☐
PRÉPARATION DE REPAS			
.A entrepris de se préparer un repas léger ou une collation	☐	■	■
.A correctement planifié un repas léger ou une collation (ingrédients, ustensiles de cuisine)	■	☐	■
.A préparé ou fait cuire un repas léger ou une collation de façon sécuritaire	■	■	☐
UTILISATION DU TÉLÉPHONE			
.A entrepris de téléphoner à quelqu'un de précis à un moment convenable	☐	■	■
.A correctement trouvé et composé un numéro de téléphone	■	☐	■
.A tenu et complété adéquatement une conversation téléphonique	■	■	☐
.A noté et transmis adéquatement un message téléphonique	■	■	☐

COTATION: OUI=1 NON=0 Non Applicable=N/A

Au cours des deux dernières semaines, est-ce que (nom)__________,sans aide ou rappel,

DÉPLACEMENTS À L'EXTÉRIEUR

	Initiative	Planification& Organisation	Action Efficace
.A entrepris de sortir à l'extérieur (marche, visite, magasinage) à un temps approprié		▨	▨
.A décidé d'utiliser un moyen de transport (auto, autobus, taxi)		▨	▨
.A organisé une sortie adéquatement tel que le mode de transport, clefs, destination, météo, argent nécessaire et liste d'achat(s)	▨		▨
.Est sorti/e et s'est rendu/e à une destination famillière sans se perdre	▨	▨	
.Est sorti/e et s'est rendu/e à une destination non-famillière sans se perdre	▨	▨	
.A utilisé de façon sécuritaire un moyen de transport (auto, autobus, taxi) approprié	▨	▨	
.Est revenu/e de magasiner avec les articles appropriés	▨	▨	

FINANCES

	Initiative	Planification& Organisation	Action Efficace
.A démontré de l'intérêt pour ses affaires personnelles,telles que ses finances ou sa correspondance écrite		▨	▨
.A organisé ses finances pour payer ses factures (chèques, carnet de banque, factures)	▨		▨
.A organisé sa correspondance adéquatement tel que le papier à lettres, les adresses, les timbres	▨		▨
.A manipulé adéquatement son argent (faire de la monnaie)	▨	▨	
.A complété adéquatement ses opérations financières	▨	▨	
.A répondu adéquatement à sa correspondance	▨	▨	

MÉDICATION

	Initiative	Planification& Organisation	Action Efficace
.A décidé de prendre ses médicaments au bon moment		▨	▨
.A pris ses médicaments tels que prescrits (selon la bonne dose)	▨	▨	

LOISIRS ET ENTRETIEN DOMESTIQUE

	Initiative	Planification& Organisation	Action Efficace
.A démontré de l'intérêt dans une/des activité(s) de loisir		▨	▨
.A démontré de l'intérêt dans les travaux domestiques qu'il/elle avait l'habitude d'effectuer dans le passé		▨	▨
.A planifié et organisé adéquatement des tâches domestiques qu'il/elle avait l'habitude d'effectuer dans le passé	▨		▨
.A complété adéquatement des tâches domestiques qu'il/elle avait l'habitude d'effectuer dans le passé	▨	▨	
.Est demeuré/e seul/e à la maison en toute sécurité	▨	▨	
TOTAL	/15	/11	/20
FD-TOTAL	/46		

DURÉE: __________

EXAMINATEUR: ____________________

Appendix I

STANDARDIZED MINI-MENTAL STATE EXAMINATION (SMMSE)

NAME:________________________________ DATE:____________

FILE #:____________

I am going to ask you some questions and give you some problems to solve. Please try to answer as best as you can.

1. (Allow 10 seconds for each reply)	POINTS	MAX SCORE
a) WHAT YEAR IS THIS?	____	(1)
b) WHAT SEASON IS THIS?	____	(1)
c) WHAT MONTH OF THE YEAR IS THIS?	____	(1)
d) WHAT IS TODAY'S DATE?	____	(1)
e) WHAT DAY OF THE WEEK IS THIS?	____	(1)
2. (Allow 10 seconds for each reply)		
a) WHAT COUNTRY ARE WE IN?	____	(1)
b) WHAT PROVINCE ARE WE IN?	____	(1)
c) WHAT CITY ARE WE IN?	____	(1)
d) WHAT IS THE NAME OF THIS HOSPITAL?	1	(1)
e) WHAT FLOOR OF THE BUILDING ARE WE ON?	____	(1)

3. I AM GOING TO NAME THREE OBJECTS. AFTER I HAVE SAID ALL THREE OBJECTS, I WANT YOU TO REPEAT THEM. REMEMBER WHAT THEY ARE BECAUSE I AM GOING TO ASK YOU TO NAME THEM AGAIN IN A FEW MINUTES.

REPEAT THE FOLLOWING WORDS:

BALL CAR MAN	____	(3)

FILE #:__________

4. SPELL THE WORD "WORLD". (you may help the subject to spell it correctly) NOW SPELL IT BACKWARDS (or, beginning at 100, count backwards by 7.Stop after 5 subtractions.) (93, 86, 79, 72, 65.)

_____ (5)

5. WHAT ARE THE THREE WORDS THAT I ASKED YOU TO REMEMBER?

_____ (3)

6. WHAT IS THIS CALLED? (Show a watch) _____ (1)

7. WHAT IS THIS CALLED? (Show a pencil) _____ (1)

8. REPEAT THE FOLLOWING PHRASE:
"NO IFS, ANDS OR BUTS." _____ (1)

9. READ THE WORDS ON THIS PAPER AND DO WHAT IT SAYS:
"CLOSE YOUR EYES."

_____ (1)

10. ARE YOU RIGHT OR LEFT-HANDED? TAKE THIS PAPER IN YOUR RIGHT/LEFT HAND, FOLD IT IN HALF ONCE, WITH BOTH HANDS AND PUT IT ON THE FLOOR.

_____ (3)

12. WRITE ANY COMPLETE SENTENCE ON THIS PAGE.

_____ (1)

11.COPY THIS DESIGN. _____ (1)

TOTAL:____/30

TIME:______

Appendix I (Continued)

EXAMEN DE L'ÉTAT MENTAL STANDARDISÉ

NOM:________________________________DATE:____________

DOSSIER:____________

Je vais vous demander quelques questions et vous donner quelques problèmes à résoudre.

1. (Laissez 10 secondes pour répondre)	POINTS	MAXIMUM
a) QUELLE ANNÉE SOMMES-NOUS?	_____	(1)
b) QUELLE SAISON SOMMES-NOUS?	_____	(1)
c) QUEL MOIS SOMMES-NOUS?	_____	(1)
d) QUELLE EST LA DATE AUJOURD'HUI?	_____	(1)
e) QUEL JOUR DE LA SEMAINE SOMMES-NOUS?	_____	(1)

2. (Laissez 10 secondes pour répondre)		
a) DANS QUEL PAYS SOMMES-NOUS?	_____	(1)
b) DANS QUELLE PROVINCE SOMMES-NOUS?	_____	(1)
c) DANS QUELLE VILLE SOMMES-NOUS?	_____	(1)
d) QUEL EST LE NOM DE CET HÔPITAL?	__1__	(1)
e) À QUEL ÉTAGE SOMMES-NOUS?	_____	(1)

3. Je vais vous nommer 3 objets. Je veux que vous répétiez les 3 objets quand j'aurai fini de les nommer.Ne les oubliez pas car je vais vous demander de les nommer encore dans quelques minutes.

RÉPÉTEZ LES TROIS MOTS SUIVANTS:	____	(3)

BALLE AUTO HOMME

DOSSIER #:____________

4. ÉPELEZ LE MOT "MONDE".
MAINTENANT ÉPELEZ LE MOT "MONDE" EN SENS INVERSE

_____ (5)

(ou soustraire 7 de 100 et ainsi de suite. Arrêtez après 5 réponses.)
(93, 86, 79, 72, 65.)

5. VOUS SOUVENEZ-VOUS DES TROIS MOTS QUE VOUS AVEZ RÉPÉTÉ TOUT À L'HEURE? _____ (3)

6. NOMMEZ CET OBJET? (Montrez une montre) _____ (1)

7. NOMMEZ CET OBJET? (Montrez un crayon) _____ (1)

8. RÉPÉTEZ LA PHRASE SUIVANTE:
"PAS DE SI NI DE MAIS." _____ (1)

9. LISEZ ET FAITES CE QU'IL Y A D'ÉCRIT:
"FERMEZ VOS YEUX."
_____ (1)

10. ÊTES-VOUS DROITIER OU GAUCHER?
PRENEZ CETTE FEUILLE DE PAPIER AVEC LA
MAIN DROITE / GAUCHE, PLIER-LA EN DEUX
AVEC LES DEUX MAINS ET POSEZ-LA PAR TERRE. _____ (3)

11. ÉCRIVEZ UNE PHRASE COMPLÈTE SUR CETTE FEUILLE. _____ (1)

12. COPIEZ CE DESSIN. _____ (1)

TOTAL:_____/30

DURÉE:_______

Appendix J

McGill University
School of Physical and Occupational Therapy

Consent Form

I have been informed that this is a research study undertaken by L. Gauthier, S. Wood Dauphinee and S. Gauthier. I have also been informed that the purpose of this study is to develop an assessment of the activities of daily living performance. I understand that I might be asked to answer a short test on orientation, attention, and language skills. I have been told that my referring physician may need to be contacted in order to confirm my medical diagnosis.

I understand that my caregiver (spouse, next of kin, friend) will complete two questionnaires concerning abilities, and will also be asked questions about their involvement in taking care of me. I have been told that no risk to me or to my caregiver are involved in participating in this research study.

I realize that although the results from this study will be published, my identity will be held in confidance. I am aware that my participation in this study is voluntary and that I will not be paid.

I realize that I may withdraw from this study at any time without prejudice to my treatment nor to my caregiver.

Signature of the volunteer: ______________________ Date:___/___/___

I.______________________, caregiver of Mr./Mrs. ______________________, agree to answer the questionaires.

Signature of primary caregiver: ______________________ Date:___/___/___

I have explained to ______________________ the procedures of the study and I have informed him/her that he/she may withdraw from the study at any time.

Signature of the Evaluator______________________ Date:___/___/___

My inquiries concerning the study will be answered by the above mentionned researchers, who may be reached at the School of Physical and Occupational Therapy, 3654 Drummond St.
Telephone number: (514) 398-4500 or (514) 398-4511

Appendix J (Continued)

Université McGill
L'École de physiothérapie et d'ergothérapie

Formule de consentement

J'ai été informé(e) que cette étude est un projet de recherche accompli par L.Gauthier, S. Wood-Dauphinee et S.Gauthier. De plus, on m'a aussi informé que le but de cette étude est de développer une évaluation des habiletés dans les activités de la vie quotidienne. Je comprends que l'on pourrait me demander de répondre à des questions d'orientation, de langage et d'attention. Aussi, on m'a informé que mon docteur pourrait être contacté pour confirmer mon diagnostic médical.

Je comprends que mon soignant (conjoint, fils/fille, ami) complétera deux questionnaires concernant mes habiletés fonctionnelles dans la vie de tous les jours et des questions concernant son rôle de soignant lui seront posées. On m'a expliqué qu'il n'y a aucun risque pour moi ou mon soignant au cours de cette étude .

On m'a dit que toutes les informations obtenues demeuront confidentielles. Je réalise que ma participation à cette étude est volontaire et que je ne serai pas payé(e).

Je comprends que je peux me retirer de l'étude en tout temps sans aucun préjudice envers mes autres traitements ou mon soignant.

Signature du volontaire: ____________________ Date:___/___/___

Je,________________, soignant de Mr./Mme.________________, accepte de répondre aux questionnaires.

Signature du soignant: ____________________ Date:___/___/___

J'ai expliqué à ____________________ les diverses procédures de l'étude et je l'ai averti qu'il/elle peut se retirer de l'étude en tout temps.

Signature de l'Évaluateur: ____________________ Date:___/___/___

Toutes mes questions en relation avec l'étude seront répondues par les chercheurs. Il est possible de les contacter à L'École de physiothérapie et d'ergothérapie.
Université McGill, 3654, rue Drummond, Montréal.
Numéro de Téléphone: (514) 398-4500 ou (514) 398-4511

Appendix K

Dear Dr. ,

Please answer the following necessary questions to confirm the medical diagnosis:

Is Mrs.currently a patient of yours?:

____ YES ____ NO

Has Mrs.been diagnosed of Probable Dementia of the Alzheimer Type according to the DSM-IIIR and the NINCDS-ADRDA?

____ YES ____ NO

If YES, place a check besides Mrs.'s present stage of dementia according to Reisberg's Global Deterioration Scale?

___ 2 ___ 3 ___4 ___ 5 ____6 ___7

* *

Your efforts to complete this optional section would be greatly appreciated.

When was Mrs.first diagnosed with Dementia of the Alzheimer type? ____

Does Mrs.have other known neurological condition(s)? ___ YES ____ NO

If YES, specify: ______________________________

Does Mrs.have other known psychiatric condition(s)? ___ YES ____ NO

If YES, specify: ______________________________

Completed by Dr.____________________ Date ________________

Thank you for your time.

Appendix K (Continued)

Cher Dr. ,

<u>Veuillez s'il-vous-plaît répondre aux questions suivantes afin de confirmer le diagnostic médical</u>:

Est-ce que Mme. est présentement une de vos patientes ?:

____ OUI ____ NON

Est ce que Mme. a été diagnostiquée avec une démence probable de type Alzheimer selon le DSM-IIIR et le NINCDS-ADR

____ OUI ____ NON

si OUI, veuillez mettre un crochet auprès du stade de la maladie d'Alzheimer de Mme., selon le "Global Deterioration Scale" de Reisberg?

___ 2 ___ 3 ___4 ___ 5 ____6 ___7

* *

<u>Votre effort à compléter cette section faculative sera grandement apprecié</u>.

Quand Mme. a-t-elle été diagnostiquée avec la démence de type Alzheimer?

____

Mme. présente-t-elle d'autres condition(s) neurologique(s) ? ___ OUI ____ NON

si OUI , spécifier: ____________________________________

Mme. présente-t-elle une condition psychiatrique ? ___ OUI ____ NON

si OUI , spécifier: ____________________________________

Completé par le Dr.______________________ Date_______________

Merci pour votre temps.

Appendix L

Project DAD: Coding

Subject

File number: ___ ___ ___
1 2 3

Gender: Male 1
Female 2
___
4

Age: ___ ___
5 6

Marital Status: Single 1
Married 2
Common Law 3
Divorced 4
Widowed 5
___
7

Languages Spoken: English 1
French 2
Other 3
___
8

Education Level: Primary 1
Secondary 2
Post-secondary 3
___
9

Corrective Lenses: Yes 1
No 2
___
10

Hearing Aid: Yes 1
No 2
___
11

Duration of DAT: Years ___ ___
12 13

Stage of GDS: ___
14

==

MMSE Score: ___ ___
15 16

DAD Score (100%): ___ ___ ___
17 18 19

DAD Scoring Time: Minutes ___ ___
20 21

Inter-rater Score DAD (100%): ___ ___ ___
22 23 24

Intra-rater Score DAD (100%): ___ ___ ___
25 26 27

RDRS. 2 Score: ADL subtotal ___ ___
28 29

RDRS. 2 Score: ADL subtotal (100%) ___ ___ ___
30 31 32

RDRS. 2 Score: Total ___ ___
33 34

RDRS. 2 Score: Total (100%) ___ ___ ___
35 36 37

Burden of Care Score: ___ ___
38 39

Burden of Care Score (100%): ___ ___ ___
40 41 42

Primary Caregiver

Relationship to Subject:	Spouse 1 Child 2 Other 3	___ 43
Gender:	Male 1 Female 2	___ 44
Number of Persons Living at Address:		___ ___ 45 46
Age:		___ ___ 47 48
Languages Spoken:	English 1 French 2 Other 3	___ 49
Education Level:	Primary 1 Secondary 2 Post-secondary 3	___ 50
Corrective lenses:	Yes 1 No 2	___ 51
Outside help required:	Yes 1 No 2	___ 52
Hours of outside help required:	Daily	___ ___ 53 54
	Weekly	___ ___ 55 56

Type of outside help required: By another relative 1
Other 2
___ 57

Payment required for outside help: Yes 1
No 2
___ 58

Amount of caregiver contact with subject: Hrs/Day
___ ___ 59 60

Hrs/Week
___ ___ ___ 61 62 63

Subject participation in community programs: Yes 1
No 2
___ 64

Frequency: Hrs/Week
___ ___ 65 66

Caregiver currently employed: **If yes:** Fulltime 1
Part-time 2
Casual 3
If no: 4
___ 67

Caregiver health problems: Yes 1
No 2
___ 68

DAD ADL Score (100%)
___ ___ ___ 69 70 71

DAD IADL Score (100%)
___ ___ ___ 72 73 74

Burden of care Personal strain score(100%)
___ ___ ___ 75 76 77

Burden of care Role strain score(100%)
___ ___ ___ 78 79 80

Dad Initiation (100%)
___ ___ ___ 81 82 83

Dad Planning & Organization (100%)
___ ___ ___ 84 85 86

Dad Effective Performance (100%)
___ ___ ___ 87 88 89

Appendix M

To: Louise Gauthier or Isabelle Gélinas
FAX: 514-398-6360

CONTENT VALIDATION OF THE DISABILITY ASSESSMENT FOR DEMENTIA

Please refer to the appropriate question on the *Disability Assessment for Dementia (DAD)* and the justification sheet before answering each question.

For each question indicate whether you agree or disagree with the proposed modification to the DAD.

1. Removal of Question #12 Agree ____ Disagree ____
2. Moving Question #13 in the **DRESSING** section Agree ____ Disagree ____
3. Removal of Question #18 Agree ____ Disagree ____
4. Removal of Question #28 Agree ____ Disagree ____
5. Removal of Question #31 Agree ____ Disagree ____
6. Removal of Question #38 Agree ____ Disagree ____
7. Removal of Question #39 Agree ____ Disagree ____
8. Modification of Question #46 to:
"Stay safely at home by himself/herself for a reasonable period of time"
Agree ____ Disagree ____

If you disagree, please indicate why: ______________________________

____

______________________ ______________________
Signature Date

Thank you for your collaboration and time.
Please return this questionnaire by mail or FAX.

Appendix N

DISABILITY ASSESSMENT FOR DEMENTIA (DAD)

Name:______________________________ File No________________

Date:______________ MMS:________ GDS:________ DAD:__________

Respondent:______________________ Relationship:______________________

Specify all motor and sensory disorders: ____

____

SCORING: YES=1 NO=0 Not Applicable=N/A

During the past two weeks, did (name)______________, without help or reminder

	Initiation	Planning & Organization	Effective Performance
HYGIENE			
. Undertake to wash himself/herself or to take a bath or a shower	☐		
. Undertake to brush his/her teeth or care for his/her dentures	☐		
. Decide to care for his/her hair (wash and comb)	☐		
. Prepare the water, towels, and soap for washing,taking a bath or a shower		☐	
. Wash and dry completely all parts of his/her body safely			☐
. Brush his/her teeth or care for his/her dentures appropriately			☐
. Care for his/her hair (wash and comb)			☐
DRESSING			
. Undertake to dress himself/herself	☐		
. Choose appropriate clothing (with regard to the occasion, neatness, the weather and color combination)		☐	
. Dress himself/herself in the appropriate order (undergarments, pant/dress, shoes)		☐	
. Dress himself/herself completely			☐
. Undress himself/herself completely			☐
CONTINENCE			
. Decide to use the toilet at appropriate times	☐		
. Use the toilet without "accidents"			☐
EATING			
. Decide that he/she needs to eat	☐		
. Choose appropriate utensils and seasonings when eating		☐	
. Eat his/her meals at a normal pace and with appropriate manners			☐
MEAL PREPARATION			
. Undertake to prepare a light meal or snack for himself/herself	☐		
. Adequately plan a light meal or snack (ingredients, cookware)		☐	
. Prepare or cook a light meal or a snack safely			☐
TELEPHONING			
. Attempt to telephone someone at a suitable time	☐		
. Find and dial a telephone number correctly		☐	
. Carry out an appropriate telephone conversation			☐
. Write and convey a telephone message adequately			☐

SCORING: YES=1 NO=0 Not Applicable=N/A

[illegible]ring the past two weeks, did (name)________________, without help or reminder

GOING ON AN OUTING

	Initiation	Planning & Organization	Effective Performance
. Undertake to go out (walk, visit, shop) at an appropriate time	☐		
. Adequately organize an outing with respect to transportation, keys, destination, weather, necessary money, shopping list		☐	
. Go out and reach a familiar destination without getting lost			☐
. Safely take the adequate mode of transportation (car, bus, taxi)			☐
. Return from the store with the appropriate items			☐

FINANCE & CORRESPONDENCE

. Show an interest in his/her personal affairs such as his/her finances and written correspondence	☐		
. Organize his/her finance to pay his/her bills (cheques, bankbook, bills)		☐	
. Adequately organize his/her correspondence with respect to stationery, address, stamps		☐	
. Handle adequately his/her money (make change)			☐

MEDICATIONS

. Decide to take his/her medications at the correct time	☐		
. Take his/her medications as prescribed (according to the right dosage)			☐

LEISURE AND HOUSEWORK

. Show an interest in leisure activity (ies)	☐		
. Take an interest in household chores that he/she used to perform in the past	☐		
. Plan and organize adequately household chores that he/she used to perform in the past		☐	
. Complete household chores adequately as he/she used to perform in the past			☐
. Stay safely at home by himself/herself when needed			☐
TOTAL	/13	/10	/17
DAD TOTAL	/40		

TIME: ____________

RATER: ______________________________

Appendix N (Continued)

EVALUATION DE L'INCAPACITÉ FONCTIONNELLE DANS LA DÉMENCE (IFD)

Nom:________________________ No. de dossier______________

[illegible]te:__________ MMS:________ GDS:________ IFD:__________

Répondant:________________________ Degré de parenté ou autre:______________

Préciser tout désordre du système moteur ou sensitif: ______________________

____

COTATION: OUI=1 NON=0 Non Applicable=N/A

Au cours des deux dernières semaines, est-ce que (nom)__________,sans aide ou rappel,

	Initiative	Planification& Organisation	Action Efficace
HYGIÈNE			
.A entrepris de se laver ou de prendre un bain ou une douche	☐	■	■
.A entrepris de se brosser les dents ou de nettoyer sa prothèse dentaire	☐	■	■
.A décidé de prendre soin de ses cheveux (laver et peigner)	☐	■	■
.A préparé l'eau, les serviettes, le savon pour se laver ou prendre un bain ou une douche	■	☐	■
.S'est lavé/e et séché/e complètement, toutes les parties du corps, de façon sécuritaire	■	■	☐
.S'est brossé/e les dents ou a nettoyé sa prothèse dentaire adéquatement	■	■	☐
.A pris soin de ses cheveux (laver et peigner)	■	■	☐
HABILLAGE			
.A entrepris de s'habiller	☐	■	■
.A choisi des vêtements appropriés (selon l'occasion, la météo,l'état de propreté et l'agencement des couleurs)	■	☐	■
.S'est habillé/e dans l'ordre approprié(sous-vêtments,robe/pantalon, chaussures)	■	☐	■
.S'est habillé/e complètement	■	■	☐
.S'est déshabillé/e complètement	■	■	☐
CONTINENCE			
.A décidé d'utiliser les toilettes au moment opportun	☐	■	■
.A utilisé les toilettes sans "accidents"	■	■	☐
ALIMENTATION			
.A décidé qu'il/elle avait besoin de manger	☐	■	■
.A choisi les ustensiles ou assaisonnements appropriés en mangeant	■	☐	■
.A mangé ses repas à une vitesse normale et observé les bonnes manières	■	■	☐
PRÉPARATION DE REPAS			
.A entrepris de se préparer un repas léger ou une collation	☐	■	■
.A correctement planifié un repas léger ou une collation (ingrédients, ustensiles de cuisine)	■	☐	■
.A préparé ou fait cuire un repas léger ou une collation de façon sécuritaire	■	■	☐
UTILISATION DU TÉLÉPHONE			
.A entrepris de téléphoner à quelqu'un de précis à un moment convenable	☐	■	■
.A correctement trouvé et composé un numéro de téléphone	■	☐	■
.A tenu et complété adéquatement une conversation téléphonique	■	■	☐
.A noté et transmis adéquatement un message téléphonique	■	■	☐

COTATION: OUI=1 NON=0 Non Applicable=N/A

Au cours des deux dernières semaines, est-ce que (nom)___________,sans aide ou rappel,

	Initiative	Planification& Organisation	Action Efficace
DÉPLACEMENTS À L'EXTÉRIEUR			
.A entrepris de sortir à l'extérieur (marche, visite, magasinage) à un temps approprié	☐		
.A organisé une sortie adéquatement tel que le mode de transport, clefs, destination, météo, argent nécessaire et liste d'achat(s)		☐	
.Est sorti/e et s'est rendu/e à une destination famillière sans se perdre			☐
.A utilisé de façon sécuritaire un moyen de transport (auto, autobus, taxi) approprié			☐
.Est revenu/e de magasiner avec les articles appropriés			☐
FINANCES			
.A démontré de l'intérêt pour ses affaires personnelles,telles que ses finances ou sa correspondance écrite	☐		
.A organisé ses finances pour payer ses factures (chèques, carnet de banque, factures)		☐	
.A organisé sa correspondance adéquatement tel que le papier à lettres, les adresses, les timbres		☐	
.A manipulé adéquatement son argent (faire de la monnaie)			☐
MÉDICATION			
.A décidé de prendre ses médicaments au bon moment	☐		
.A pris ses médicaments tels que prescrits (selon la bonne dose)			☐
LOISIRS ET ENTRETIEN DOMESTIQUE			
.A démontré de l'intérêt dans une/des activité(s) de loisir	☐		
.A démontré de l'intérêt dans les travaux domestiques qu'il/elle avait l'habitude d'effectuer dans le passé	☐		
.A planifié et organisé adéquatement des tâches domestiques qu'il/elle avait l'habitude d'effectuer dans le passé		☐	
.A complété adéquatement des tâches domestiques qu'il/elle avait l'habitude d'effectuer dans le passé			☐
.Est demeuré/e seul/e à la maison en toute sécurité au besoin			☐
TOTAL	/13	/10	/17
FD-TOTAL	/40		

DURÉE: __________

EXAMINATEUR: __________________